

Copyright is owned by the Author of the thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. The thesis may not be reproduced elsewhere without the permission of the Author.

*Action Research, Power and Responsibility:
the predicament and potential of New Zealand
community groups.*

*A thesis presented in partial fulfilment of the requirements for the
degree of Doctor of Philosophy.*

Massey University, Albany, Auckland, New Zealand.

Carmel Frances Cervin

2001

Abstract

This thesis tells the story of the action research projects of three community groups: The West Auckland Women's Centre, Homebuilders Family/Whanau Support Scheme, and the Autistic Association of New Zealand Inc., Auckland Branch. The projects focused on addressing specific injustices identified by each community group.

Through participating in three concurrent projects, significant insights into the process, context, and key themes of action research are presented. The methodology discussion integrates the literature review with practical examples drawn from these projects. This enables critical observations on action research to be identified and explored in a grounded substantive manner. Key themes include: ethical implications of an academic researcher working with community groups, particularly in terms of power dynamics; recognition and validation of the expertise shared within the groups; and the necessity of trusting in the evolving nature of the action research process. Comparisons between the groups are written sensitively, honouring each group and their processes.

The West Auckland Women's Centre project consisted of qualitative research exploring retirement income and issues around unpaid work for women. The project was undertaken as part of the Women's Centre's role as an advocate on issues affecting women.

Homebuilders began with a story-telling project that sought to address a lack of understanding about their work in their community. However their focus shifted to a new project on Rural Living Standards following concerns raised by Homebuilders workers regarding the difficulties faced by families they were working with. The project developed in to a comprehensive survey on family household living standards, using a participatory process with the involvement of a large number of interested people from the community. The results of this survey are being fed back into the community to raise awareness regarding the spread of living standards and income issues in the local community.

The Autistic Association project consisted of a comprehensive survey of all Auckland branch members to identify needs and gaps in services for families with a family member with Autism or Aspergers. The survey was then used, and continues to be used, to lobby and educate funding providers and government agencies regarding the services needed. The National Autistic Association is, at the time of completing this thesis, running the survey nationally.

Finally this thesis explored the predicament of community groups acting as advocates for families in a context where funding providers set all the rules for 'negotiation' and highlighted the potential of community group action research projects for power reversals and enhancing democracy.

Acknowledgments

There are many people I wish to thank for contributing to and making this thesis possible.

Firstly and most importantly, my heartfelt thanks to everyone at the West Auckland Women's Centre, Homebuilders Family Support Agency and the Autistic Association Auckland Branch. Your support, encouragement, enthusiasm, time, energy, work and commitment gifted me with joy, meaning and motivation to make this thesis real. I am immensely grateful for the space you all gave me within your groups, for all that we learnt together, for the wisdom you shared with me and for allowing me to use the projects as part of my thesis.

I would like to say an extra special thanks to my friends Sharon from the West Auckland Women's Centre and Irene from Homebuilders, for suggesting the possibility and inviting me to meet with your groups. Your invitations were a surprise and delight and I feel very lucky to have friends open such wonderful doors to me. I would also like to say a special thank you to Deborah Cox from the Autistic Association for her warmth, guidance and support when I first approached the association.

To my supervisors, Mike O'Brien and Marilyn Waring, a deep thank you for always being there. Your guidance, questions, listening ears, support, laughter and ideas have helped me grow in confidence and relish the challenge of this thesis.

Also a thank you to Massey University, Albany for the award of a scholarship, an important financial support to my thesis.

A special thank you to Cybele Locke for being a fantastic friend and flatmate and for being one step ahead of me on the thesis journey. You helped me realise that a thesis was achievable, and you shone a light for me on the track ahead.

To Malcolm Beggs, Yvonne, Brian, Marilyn and Diane a special thanks for treasured memories and love.

I would also like to thank Shirley and Colette for your support and friendship through the ups and the downs.

A special thank you to Barbara Grant and all the women from the Tauhara Writing Retreats. Our times together were always an inspiration and an invaluable productive space for writing. Also a thank you to all my sailing friends, for support and fun, fresh air and time out.

To all my friends and flatmates who have put up with me going on about this thesis, thanks for your patience and support. A very special thanks to Ian Ashton for all your love and support.

Prior to even beginning this thesis there were many special people who helped shape my passion for community and social justice and I would particularly like to acknowledge Terry Dibble and St Clairs, Ewen Derrick, Neil Darragh and Manaaki.

Finally a huge thank you to my family – Naomi, Liam, Seamus, Brendan and Siobhan for all your love and support, to Elva Lynch for inspiring me with your passion for history and research and finally to my mum and dad, Anne-Marie and Maurice Cervin. You gave me high expectations, endless support, resources, took a real interest in my study, proofed my thesis, and were always there for me. Thank you.

Dedication

This thesis is dedicated to Anne-Marie and Maurice Cervin.

Table of Contents

Chapter 1: Introduction	1
<i>Introducing Myself</i>	3
<i>Introducing the Groups</i>	5
<i>The West Auckland Women' s Centre</i>	5
<i>Homebuilders Family/Whanau Support Scheme</i>	5
<i>The Autistic Association of New Zealand Inc., Auckland Branch</i>	8
<i>The Structure of this Thesis</i>	9
<i>Organisation of Appendices</i>	10
Chapter 2: Methodology	11
Action Research	11
<i>History and Major Strands of Action Research</i>	11
<i>Key Aspects of Action Research</i>	13
<i>Process of Action Research</i>	13
<i>Social Change Focus</i>	13
<i>Improving and Transforming</i>	13
<i>Future Orientation</i>	14
<i>Evolving Nature of Action Research and Ethical Implications</i>	14
<i>Importance of Process in Action Research</i>	15
<i>Role of Dialogue</i>	16
<i>Action Research in New Zealand</i>	17
<i>Community and Action Research</i>	17
<i>Community Ownership of Problem Definition</i>	17
<i>Collective Participation</i>	18
<i>Collective Knowledge Creation</i>	19
<i>Collective Ownership</i>	20
<i>Collective Reflection</i>	21
<i>Researcher Role & Relationship to Groups</i>	23
<i>Working with Existing Communities</i>	26
<i>Being Physically Present and Building and Maintaining a</i>	
<i>Relationship</i>	28
<i>Working with Group Timeframes</i>	28
<i>Validity, Objectivity, Reliability and Partiality</i>	29
<i>Dilemmas in the Process</i>	31
<i>The Group may not stick to the Process – It May Decide</i>	
<i>Not to take Action</i>	31

<i>Macro Change and Action Research</i>	32
<i>Time Issue</i>	33
<i>Triangulation</i>	34
<i>Ethics</i>	36
<i>Feminist Research and Social Change</i>	37
<i>Pakeha Research</i>	37
<i>Research Concepts</i>	37
<i>The Beginning Steps</i>	37
<i>Time-line of Group Projects</i>	39
Chapter 3: West Auckland Women's Centre Action Research Project	45
<i>The Beginning</i>	45
<i>Exploring Possibilities</i>	45
<i>Issue of Retirement Provision Emerges</i>	46
<i>Literature Review on Recent Superannuation Debates</i>	46
<i>Choosing Our Method</i>	47
<i>Preparing Pilot Interviews and Group Discussion</i>	48
<i>Drawing on Principles of Feminist Research</i>	49
<i>Values</i>	50
<i>Politics</i>	50
<i>Ethics</i>	51
<i>Research Concepts</i>	52
<i>Contacting Women to be Interviewed</i>	52
<i>Interviewing</i>	53
<i>Drawing Out Strands from the Interviews</i>	53
<i>Validity</i>	54
<i>Follow-up Calls</i>	54
<i>Feedback to Participants and Focus Group Session</i>	55
<i>Further Discussion on Use of Research Material</i>	55
<i>Meeting with the Older Women's Group in West Auckland</i>	55
<i>Changes at the West Auckland Women's Centre</i>	56
<i>Dialogue with the Ministry of Women's Affairs and the Retirement Commissioner</i>	56
<i>Preparation of the Research Report</i>	56
<i>Future Steps</i>	57
<i>Concluding Comments</i>	57
<i>Appendices</i>	
Appendix 3.1 Superannuation Review	58
Appendix 3.2 My Information Sheet	66

Appendix 3.3	Letter to Participants	67
Appendix 3.4	Consent Form for Participants	69
Appendix 3.5	Transcriber Confidentiality Form	70
Appendix 3.6	Invitation to Feedback Meeting	71
Appendix 3.7	Covering Letter on Overview for Participants	72
Appendix 3.8	Overview – Sent to Participants and Summary for the West Auckland Older Women’s Network	73
Appendix 3.9	Letter to the Retirement Commissioner	77
Appendix 3.10	Letter to the Ministry of Women’s Affairs	78
Appendix 3.11	Article sent to the Retirement Commissioner and the Ministry of Women’s Affairs	79
Appendix 3.12	Flyer for Women’s Book Festival	103
Chapter 4:	Homebuilders Action Research Project	105
	<i>Initial Contact and Building a Relationship</i>	105
	<i>Storytelling</i>	107
	<i>Difficulty Finding Issue Clarity</i>	110
	<i>The Code of Social Responsibility and Homebuilder’s Response</i>	111
	<i>Reflection on Awareness/Funding Issue</i>	111
	<i>Beginning of Participatory Living Standards Project</i>	113
	<i>Values</i>	115
	<i>Politics</i>	115
	<i>Ethics</i>	115
	<i>Questionnaire Development</i>	116
	<i>Research Concepts</i>	116
	<i>Piloting the Questionnaire</i>	117
	<i>Selecting the Sample</i>	117
	<i>Organising Funding</i>	118
	<i>Hannah’s Role</i>	118
	<i>Asking Interviewers</i>	119
	<i>Preparing the Surveying Process</i>	119
	<i>Replacement System</i>	119
	<i>Call-back System</i>	119
	<i>Training Interviewers</i>	120
	<i>Media Work</i>	120
	<i>Starting Interviewing – Discoveries</i>	120
	<i>Surveying in Snells Beach – Where are all the families?</i>	122
	<i>Supporting Volunteer Interviewers</i>	122
	<i>Benefits for Volunteers</i>	122
	<i>Community Response</i>	122

<i>Setting up Data-entry Database</i>	123
<i>Data-entry Training</i>	123
<i>Analysis of Results</i>	123
<i>Future of the Rural Section of the Survey</i>	123
<i>Concluding Comments</i>	124
<i>Appendices</i>	
Appendix 4.1 Story Letter	125
Appendix 4.2 Story Consent Form	126
Appendix 4.3 Survey Information Sheet	127
Appendix 4.4 Survey Form	129
Appendix 4.5 Survey Feedback Form	153
Appendix 4.6 Survey Tracking Sheet	154
Appendix 4.7 Instructions for Interviewers	155
Appendix 4.8 Survey Call-back Note	156
Appendix 4.9 Newspaper Articles on Survey	157
Appendix 4.10 Survey Results	160
Chapter 5: Autistic Association of New Zealand Inc., Auckland Branch Action Research Project	191
<i>Initial Contact and Building a Relationship</i>	191
<i>Project Issue Identified</i>	192
<i>Media Attention</i>	193
<i>Discussion of Literature Review and Parents' Views</i>	194
<i>Needs Survey Initiated</i>	195
<i>Relevant Reports Released</i>	195
<i>Classroom Survey</i>	196
<i>Autism Action Committee and Looking for a Building</i>	196
<i>Personal Advocacy Trust</i>	196
<i>Needs Survey Develops</i>	197
<i>Research Concepts</i>	197
<i>Piloting the Survey</i>	199
<i>Values</i>	199
<i>Politics</i>	199
<i>Ethics</i>	200
<i>Discussion of Ethical Issues</i>	200
<i>Training and Beginning Interviewing</i>	201
<i>Discoveries When Interviewing</i>	202
<i>Survey Feedback</i>	203
<i>Searching for More Interviewers</i>	203
<i>Survey Sample</i>	204

<i>Major Changes in the Auckland Branch</i>	205
<i>Interviewing Continues and Data Entry Begins</i>	205
<i>Analysis and Brainstorming</i>	205
<i>Submission to Special Education 2000 (SE2000) Policy Review</i>	206
<i>Analysis of Survey for the Committee</i>	206
<i>Survey Results in the Newsletter</i>	206
<i>Identifying the Next Survey Steps</i>	207
<i>National Association Begins Survey</i>	207
<i>New Committee</i>	208
<i>Ongoing Use of Survey</i>	208
<i>Concluding Comments</i>	208
<i>Appendices</i>	
Appendix 5.1 My Information Sheet	209
Appendix 5.2 Interest Form for Parents	210
Appendix 5.3 Issue Article in Newsletter	211
Appendix 5.4 Newspaper Article re Eady Family	212
Appendix 5.5 Selection of Media Articles	213
Appendix 5.6 Autism Literature Review Summary	218
Appendix 5.7 New Classroom Newspaper Article	220
Appendix 5.8 Personal Advocacy Trust Article in Newsletter	221
Appendix 5.9 Letter to Members re Survey	222
Appendix 5.9a Newsletter Article About Survey	223
Appendix 5.10 Survey Form	224
Appendix 5.11 Tips for Interviewers	249
Appendix 5.12 Sample Interviewer Tracking Sheet	250
Appendix 5.13 Volunteer Interviewers Poster	251
Appendix 5.14 Volunteer Interviewers Confidentiality Form	252
Appendix 5.15 Special Education Service Submission	253
Appendix 5.16 Initial Analysis of Full Survey	263
Appendix 5.17 Newsletter Articles on Survey Findings	297
Chapter 6: Conclusion	301
<i>Action Research and Retaining My Own Analysis</i>	301
<i>What to Conclude?</i>	302
<i>Two Key Themes: Funding and Responsibility</i>	302
<i>The Funding Environment as an Inadequate Forum for Negotiating Responsibility</i>	304
<i>Community Groups as 'Piggy in the Middle' of Responsibility Debates</i>	306
<i>Impact of Public Responsibility Debates</i>	307
<i>The Power to Define Legitimate Need and Responsibility</i>	309

<i>Questioning the Distribution of Power and Responsibility</i>	313
<i>Importance of Reversing Power Relationships</i>	313
<i>Power Reversals and Democracy</i>	317
<i>Postscript</i>	318
Bibliography	319

Chapter 1: Introduction

This thesis focuses on addressing specific injustices identified by three groups, each using the action research methodology. The three groups are:

The West Auckland Women's Centre
Homebuilders Family/Whanau Support Scheme
The Autistic Association of New Zealand Inc, Auckland Branch.

A second focus of this study is a comparison of the action research process between the three groups.

I began this thesis with the following questions:

With a focus on specific areas, what injustices arise from unpaid work in New Zealand?

How should these specific areas be addressed within New Zealand in terms of possible state responses (for example: legislation, policies)?

Given the direction of desirable specific changes to address injustices arising from unpaid work, what vision do these changes suggest for broad structural change in the relationship between paid and unpaid work?

The 'specific areas' in the first and second questions refer to the areas identified as appropriate with a particular group/community in the context of action research. The emphasis is on structural explanations and solutions rather than on only individual responsibility within the existing structures. The third question is important because it reinforces that it is not only the unpaid work environment that needs to change. The actual relationship between paid and unpaid work needs to be questioned. There are two sides to this relationship and a relationship can never be examined by looking at only one side. This is necessary to prevent a misleading picture of who or what needs to change to solve which problems. As the project evolved the above questions became further refined and developed.

The above three questions were my own frame of reference at the beginning, as distinct from the specific issues each group identified.

Following are some of my reflections when I began this study:

Throughout my education I have been keenly aware of the need to equip myself for a 'career' to ensure my personal financial independence and security. However as my knowledge of the position of women in paid work grew, along with my own experiences in paid work and my observations of the experiences of women around me, I have become increasingly conscious of the continuous tension and struggle involved in trying to juggle unpaid and paid work. Rather than seeing this ability to juggle as a measure of personal success I question the whole structural framework in which the odds are stacked against so many women.

Our discourse and choices seem framed by structures that fail to recognise unpaid work and particularly the gendered inequities stemming from women predominantly being responsible for unpaid work. Sometimes there is the implicit assumption that in the 1990s, when the 1980s slogan of 'girls can do anything' is taken for granted, that no one will personally and explicitly block a woman from following the paid work path of her choice. And yet we are surrounded by basic structures that are still not only limiting women's choices but also defining them.

At the beginning of this study my focus was on perceiving injustice through the division of paid and unpaid work. As I began working with the groups, they chose the actual issues to focus on and I had to let the paid/unpaid focus and the standpoint of my original questions shift to the background. Over time I began to see the issues the groups chose, not so much as issues of injustice stemming from the division of paid/unpaid work, as injustices stemming from an imbalance in the distribution of responsibility, particularly for unpaid caring work, between individuals, families, communities and government. All three projects involved questioning who should be responsible for providing specific social services to meet identified needs. Each project was also influenced by vigorous public debates regarding responsibility in their respective issue areas. In the conclusion I have explored the commonalities in themes and context that are shared by all three projects.

In the project chapters I have told the story of each project, the issues and injustices the groups sought to address and the project appendices contain some of the analysis and findings of the research. Because the exploration of specific issues occurred within a context of action research, the resulting analysis of the problem and search for solutions was not my own individual work, but rather a collective process owned by each group. The process of making sense of the findings is also still continuing to varying degrees in the groups. As a result this thesis does not contain a complete/final analysis of the research findings for each project.

A second key focus that emerged during my study, but was not one of my original questions, was a comparison of the action research process between the three groups. Within my methodology chapter I have explored the commonalities and differences

between the three projects and also reflected on the projects in relation to other literature on action research. Participating in three projects at the same time gave me a unique opportunity to compare the processes and be immersed in action research.

In my conclusion I have presented my own analysis of two common themes across the three projects, funding and responsibility, and reflected on the context of the three projects. I have explored how the distribution of power is central to negotiating responsibility and then drawn on the lessons learnt from action research to advocate for a reversing of power relationships between 'normal professionals' and community groups. Finally I have highlighted the potential of action research and power reversals to enhance democracy. My conclusion in part reflects my original third question, identifying broad structural changes, but focusing on responsibility, power and action research rather than the paid-unpaid work relationship. Thus the issues chosen by the groups and the way the projects evolved led me to shift from my initial focus on paid and unpaid work to power issues concerning the distribution of responsibility for meeting identified needs.

Introducing Myself

Some background to my values and myself is important to the context of this thesis, to provide some understanding of why I chose the action research method, my personal background when I began working with the groups, and a significant event in my life that occurred part way through the projects.

I am a young Pakeha New Zealand woman. I am the oldest of a family of six, with a very strong awareness of the importance of making time for family and of the commitment and responsibilities involved in actively caring about family.

A strong part of my upbringing has been to question and challenge injustice, whether through the Springbok protests, anti-nuclear campaigns, or questioning church structures and injustices. My commitment to seeking social justice has shaped my interests and questioning.

I am also committed to a belief in community, both as a source of identity and as the means of challenging injustice. Community is a key source of empowerment for both question and action. My interest in action research reflects my concern and commitment to community.

I began work on my thesis in March 1997. At the end of August 1999 Malcolm Beggs, my boyfriend, was murdered by his flatmate Lachlan Jones, who then committed suicide. Lachlan was a mental health patient of Waitemata Health. Malcolm's death had huge ramifications for me personally and for my study. The initial impact was that I went into

shock as I struggled to comprehend what had happened and untangle the mess that had led to Malcolm's death. Officially I took a two month break on my thesis, unofficially I went into a holding pattern on all the projects, doing only what I had to do to keep them progressing and putting whatever I could on hold.

As time went by and information slowly leaked out of Waitemata Health, Malcolm's family, friend's and myself gradually uncovered what had happened. Malcolm's death was no innocent accident of community mental health care. It was both a very foreseeable and preventable disaster. His death highlighted many inadequacies in the provision of mental health services.

One effect was to bring home to me personally how wrong things can turn when government at all levels, from the individual nurses through to Health Ministers, fails to take responsibility for delivering essential services. Malcolm, without his knowledge, consent, any information, support, or someone to turn to when he was afraid, was left to care for a very psychotic mentally ill stranger, his new flatmate, Lachlan Jones. Although Malcolm raised his concerns to family, friends and myself, none of us realised how serious the situation was for Malcolm and so we were unable to help him.

Waitemata Health failed abysmally in its responsibility to care for Lachlan Jones. Malcolm, through being asked to pass on Lachlan's medication, was used as a de facto caregiver, but given no rights whatsoever. Malcolm was murdered because his flatmate did not receive the care he needed, and Malcolm, although he was afraid and knew that his flatmate was 'nuts', had no information regarding what he could or should do. Malcolm's situation was a worst case scenario of what can happen when the government fails in its caring responsibilities and an innocent uninformed member of the public is left to bear the consequences.

For me, I couldn't help but see the parallels in my study. The parents of children severely affected by Autism were also innocent random victims left to struggle on their own, by a government that refused to recognise or deliver on its responsibilities. Malcolm's death personalised and magnified the issue of imbalance in responsibility in a way I could never have dreamed of. There was no public accountability for Malcolm's death.

Malcolm's death was undoubtedly the most significant influence on my perspective of the overall issues involved in this study during the last year.

I am very grateful for all the support I received from the three groups following Malcolm's tragic death.

Introducing the Groups

Following is a brief introduction to the three groups.

The West Auckland Women's Centre

The West Auckland Women's Centre (WAWC) began in November 1993. It is based in McLeod Rd, Henderson and provides a wide range of services to West Auckland Women. Services provided by the WAWC include drop in and phone support, a health check programme, counselling, a legal service, massage and a library. The centre also runs a number of groups, courses and workshops. The WAWC has been active in political issues and conducted a major research project, 'Feeling Stretched', in 1994. The report of the project provided this description of WAWC's work:

We have a belief that women know best about themselves, but they often do not have the information, skills and support they need to make changes in their lives. The Centre supports and assists the development of women's self help initiatives and educational opportunities. We are involved in working with women for change, at a local, regional and national level. With members of all sections of the community in which we work we explore ways of making information and skills available while ensuring that any solutions remain the property of the community. Our method of working is developmental or community empowering. (The West Auckland Women's Centre, 1994, p. 10)

The WAWC chose to do a research project on women and retirement income. I worked particularly closely with two members of the WAWC, Sharon Milne and Verle Cahill, on the WAWC research project.

Homebuilders Family/Whanau Support Scheme

Homebuilders Family Support is based in Warkworth and provides services in the Rodney District, from Puhoi to Mangawhai. Homebuilders were set up in 1989 as part of a pilot programme.

Historical background to Homebuilders in NZ

The Department of Social Welfare (DSW) launched the Homebuilders Programme in late 1988.

The intention was that there would be national provision of Homebuilders programmes for families under stress through the DSW entering into 'partnership' with locally-based community organisations through contracting for services. These

organisations were to deliver preventive social services in a 'responsive' and 'flexible' way, yet remain within parameters set by the DSW. (de Haan, 1998, p. 27)

Unfortunately the Homebuilders programme was short-lived and its funding was absorbed into the new Community Funding Agency's budget.

While the DSW in the form of the CFA continued to contribute to the funding of family support services working according to the Homebuilders model, the contracting system developed by the CFA allowed for only part-funding of such services, and certainly allowed for no developmental work to nurture, develop, support and improve services in the ways promised at the Homebuilders Conference. (de Haan, 1998, p. 28)

Following are some of the key aspects of Homebuilders family support work:

- A close link exists between the assumptions of family support work and the 'Homebuilders Programme Guidelines';
- Homebuilders draws on an ecological perspective, seeing the family as a whole rather than working with only individual members, helps families to deal with all the issues they face, arising from both personal and environmental factors (de Haan, 1998, p. 29);
- Encourages linking families with sources of support and promotes concepts of interdependence and reciprocity – encouraging families to 'give back' eg through supporting other families, lay helpers, and by valuing the contribution of families to bringing up children;
- Linking families with their local community encourages a community development function;
- Strong preventative focus – helping families at an early stage of their difficulties – assisted by an emphasis on availability and ease of access;
- Also able to intervene and help with crises;
- "While the model promotes families' self-determination, this does not preclude the giving of advice, information and education, or training in social skills, often by modeling and reinforcing such skills." (de Haan, 1998, p. 30);
- Working with families in their homes – " 'workers are more able to develop close relationships with the family and an understanding of the needs of the family'. (Munford et al, 1996:13)" (de Haan, 1998, p. 31).

Another key aspect of the Homebuilders model is a significant change in the relationship between workers and families.

'The assumptions upon which family support is built have dramatically altered the traditional professional's role'. (Weissbourd, 1987:256) This alteration recognises the concepts of self-determination and of a 'non-deficit' approach to working with

families, and involves a shift from the conventional professional 'expert and client' approach, to one of a partnership between worker and family where the family is the expert or specialist about their own situation, and the worker is the resource person or 'generalist' (Weissbourd, 1987, Wolcott, 1989). (de Haan, 1998, p. 31)

From Homebuilder's pamphlet:

"We support families to create change by walking with them through hard times, and by

- identifying problems
- and building on strengths
- to find solutions and develop opportunities."

Homebuilders runs the following services:

- The Family Centre: open 9-12 weekdays for information on their services and the opportunity to talk with a support worker;
- Family Support: Family support workers with a wide range of skills, including advocacy, parenting and counselling, go to people's homes to help them work through a wide range of difficulties (eg relationship issues, communication difficulties, parenting issues, support person for meetings at schools, income support etc.). There is no charge for a family support worker;
- Help Desk: Provides practical, immediate help and information on a wide range of issues eg. paperwork, links to other services, accommodation, dealing with agencies and budget advice;
- Disability Information Service: Provides information, practical support and advocacy for those with intellectual or physical disabilities. Also arranges needs assessments;
- Youth Programmes: Group activities for teenagers, designed to improve communication and enhance self-esteem and confidence. One to one counselling support and weekend programmes also available;
- Chrysalis Children's Programme: A programme of play and creativity for children aged 6-12 years, whose behaviour is hard to handle. It is run with parent involvement;
- Post-natal Support: 10 week programmes offering women a safe and confidential group setting to share their experience of motherhood and post-natal distress;
- Op Shop: open Monday to Friday, 10 am to 1 pm;
- Bag of Tricks: a practical parenting course;
- Young Mums' Groups: For younger women up to the age of 24 years. For friendship, support, parenting and skills development;
- 'Living Well On Your Income' Groups: For learning practical skills to make your money stretch further in a fun and sociable way.

The first research project chosen by Homebuilders was the story-telling project and a number of Homebuilders staff were actively involved in this project, particularly Irene de Haan, Pat Curtis, Madhuri Ball, and Terry Healey.

Homebuilders also undertook a second research project on rural living standards. The membership of the second project extended well beyond Homebuilders, with a wide range of people from local communities becoming actively involved. As a result the second project was owned by this wider group.

The Autistic Association of New Zealand Inc., Auckland Branch

The Auckland Branch of the Autistic Association of NZ Inc is a parent support group. It aims to provide support, information and guidance to parents. The Branch is also active in providing information to professionals and the general public. The Association is a non-profit organisation, relying on funding from donations, contracts with funding bodies and one-off grants. The Branch committee consists of parent and professional volunteers.

Services include (but are not limited to):

- Telephone support. This includes supporting parents who need input into the difficulties children with Autistic Spectrum Disorder (ASD) may have, liaising with professionals regarding particular families and being on call for their clients;
- Providing initial contact with new families. When approached by a new family the Branch sends out information and the Auckland Co-ordinator visits the family to answer questions and provide practical verbal information and also the opportunity for the family to talk to another parent;
- A free library utilised by all members wishing to take out books, audio-tapes and videos;
- Providing referrals to community agencies and follow-ups to ensure that the family is getting support. Liaises with agencies in order to establish the level of support the family is entitled to and is receiving;
- Providing advocacy for parents at Individual Development Plans (I.D.P's for children under five years old) and Individual Education Plans (I.E.P's for children five years and over) and/or attending any other meetings where their clients feel they need support;
- The Auckland Branch also employs a programme developer. She is available to visit families and assist in putting together home programmes;
- Branch newsletters that outline support activities and lots of useful information regarding ASD;
- Providing support activities, including a playgroup at Lollipops, Aspergers Coffee Group, North Shore Group and more.

Many people from the Auckland branch were involved in the survey project over time. Some of the key people involved were Deborah Cox (branch worker), Wendy Duff (committee member), Joanie Panting (committee member), Christina Birkin and Priya Sahni (branch workers).

Following is a brief outline of Autistic Spectrum Disorder (ASD) to provide some understanding of the challenges faced by people with ASD and their families. The term ASD is used to encompass the severity and manifestations of Autism and Asperger Syndrome (Aspergers is a form of autism at the higher functioning end of the spectrum). Features of the disorder can vary widely from one person to another. All those affected by the disorder have impairments in social interaction, social communication and imagination. Typical autistic spectrum traits include difficulty mixing with children, no fear of real dangers, not cuddly, no eye contact, spins objects – sustains ‘odd’ play, marked physical over activity or extreme passivity, echolalia (echoing words or phrases), and apparent insensitivity to pain. People with Asperger syndrome often have difficulty reading body language, facial expression and gesture, display indifference to social norms and have difficulty interacting with peers. ASD is a lifelong developmental disability but early diagnosis and appropriate intervention early in life can help maximise skills and achieve full potential in adulthood.

The Structure of this Thesis

My thesis is structured into six chapters. Following this initial chapter, the second chapter presents the methodology for this thesis, with a substantial focus on action research. Within the methodology chapter I have drawn my reflections on the three group projects and literature together, commenting on commonalities and differences between the projects and in relation to the literature. The method detail of each project is discussed within the project chapters. The methodology chapter ends with an outline of the process I used to find community groups I could work with and a time-line of the three group projects.

Following my methodology chapter are three chapters, one on each research project. The project chapters tell the story of each group’s project. All of the projects were still continuing at the time of finishing this thesis and as a consequence none of the stories are complete. The story of each project includes the process and conveys to some extent the character of each project. However the depth, focus and vibrancy of each story is very dependent on the story-teller, me, and in this instance my medium, this academic thesis. Although the version of the stories presented here has the consent of each group, if each story was told in a different context and by the groups themselves, different aspects would be highlighted and in a different style. The version of the stories in this thesis is my version, from my perspective and for the purpose and audience of my thesis.

Each of the project chapters follows a similar story structure. Within the story of each chapter I have deliberately woven in discussion of issues and aspects of action research as they arose. Through telling each project as a story I have tried to convey the evolving nature of the projects, how they unfolded and changed direction along the way.

Throughout the life of each project both memories and a paper trail accumulated. It is difficult to convey the atmosphere of different meetings and events over time, when energy was high and when energy was low, when lots of people were involved and when a handful were drawing the projects on, when the projects were a source of pride and accomplishment and when the outlook of getting through a stage looked bleak. In an attempt to convey some sense of the life of each project and my feelings at different points in time, I have included a number of my own reflections made at various points during each project. These are my own rather than group reflections and I have indented and italicised these.

A significant paper trail did accumulate for each project. The trail ranged from meeting notes, to survey forms, literature reviews, letters, consent forms, posters, interview transcripts, interviewer instructions, survey messages and tracking sheets, faxes, newspaper articles, research findings and initial analysis, submissions, funding applications, group brainstorms, newsletter articles and more. I have chosen to include as much of this paper trail as possible as appendices, within some space confines, as it contains a lot of the substance and flavour of each project.

The concluding chapter is my reflection on some of the overall themes across the three group projects and some commonalities in the context of the three projects. The two key themes I chose to reflect on were funding and responsibility. Following this are some concluding thoughts on action research. In the conclusion I move from the 'how to' and nuts and bolts aspects of action research, covered in the methodology and through the project chapters, to a more general reflection on the contribution of action research, particularly for power reversals and democracy.

Organisation of Appendices

Directly following each project chapter is their set of appendices. I have located the appendices after each project because the appendix material was intrinsic to each research project and contains a lot of the substance of each project – particularly in regard to research findings and the process of each project. The order of the appendices follows the chapter text and is basically the order in which pieces occurred. There are a number of pieces in the paper trail that I have not included – such as faxes from other organisations that have privacy statements on them. I have also omitted funding applications, partly for privacy reasons and because I was not directly involved in most funding applications. It is important to note that all of the appendix material is included in its original form as it was used by the groups and I have not reformatted it or changed its content or presentation for this thesis. This is because it was important to present the material as it occurred within the process. References are made to appendices within the project chapters and I have avoided repeating the content of each reference within the chapter text.

Chapter 2: Methodology

Action research is the main methodology I have chosen for this thesis. Following is my analysis of this methodology and a comparison of how it applied to the three research projects. Participating in three concurrent projects was a unique opportunity to reflect on and explore action research within the context of New Zealand community groups. Some additional methodology issues, in relation to my thesis as a whole, are addressed following my analysis of action research. The method detail of each project is discussed within the project chapters. This chapter ends with an outline of the process I used to find community groups I could work with and a time-line of the three group projects.

Action Research

History and Major Strands of Action Research

Action research has been given a variety of definitions, in part reflecting the differing emphasis of traditions that have developed action research. The origins of action research lie in social psychology, the natural sciences, organised science and social planning. "Its intellectual roots are likewise diverse; action research has been linked to Moreno (1956), Freire (1974), and the critical theory associated with Habermas (1979) and the Frankfurt school." (Stringer, 1996, p. xvi).

Sarantakos draws on Burns's definition of action research, defining it as "the application of fact finding to practical problem solving in a social situation with a view to improving the quality of action within it, involving the collaboration and co-operation of researchers, practitioners and laymen." (Burns quoted in Sarantakos, 1993, p. 8). This definition reflects action research projects in a business/professional organisational context more than the form used with oppressed/community groups. This is because the focus on 'improving the quality of action within a social situation' reflects a desire to improve a practice rather than to transform the situation. "Historically, action research has been most often associated with private industry and organisational development." (Small, 1995, p. 942) The form of action research applied in business contexts differs markedly from the form of action research being used with community groups.

The different strands of action research developed largely independently of each other as their political and economic contexts were completely different. The terms 'participatory research' and 'participatory action research' have been used to differentiate action research directed by and extensively involving oppressed groups from action research in a business/professional context. Brown argues that the differences in ideology and in the political economy of two strands, action research and participatory research, have shaped

their interaction. Although the strands share similar values, they “focus on different levels of analysis, use conceptual tools from different disciplines, hold fundamentally different assumptions about the nature of society, and attend to different central problems.”(Brown & Tandon, 1983, p. 283) One fundamental difference between these two strands is that traditional action research is allied with organisation authorities, whereas participatory action research is allied with oppressed groups.

Elizabeth Hart and Meg Bond have developed a typology of action research which identifies the key criteria of action research, as distinct from other forms of research, and locates the different traditions of action research within four broad types of action research. Their aim was to make sense “of what otherwise might appear as diverse and disconnected ways of applying action research to a range of different problems and settings.” (Hart & Bond, 1995, p. 37). The four types of action research Hart and Bond have identified are ‘experimental’, ‘organisational’, ‘professionalising’ and ‘empowering’.

These four types of action research which Hart & Bond identified, rest on a continuum between a consensus and rational social management model of society on the left and a conflict/structural change model of society to the right. Left to right represents a developmental process over time as action research has shifted from a scientific approach to social change, to a more qualitative and social constructionist methodology. Experimental action research sits within a rational social management model of society and empowering action research is at the other end of the continuum with a conflict/structural model of society. Professionalising action research can be located closer to empowering action research if the research relationship is based on professionals doing research ‘with’ a client/community group rather than ‘on’. These alternative models of society are based on different locations and ways of using power. Hart & Bond’s typology encompasses the spectrum of projects which have been labelled action research over the years. Thus earlier and more traditional forms of action research, usually within a private business context, fit into the experimental or organisational type, and research within a community group context usually fits within the empowering type.

This typology fits with Brown’s (Brown & Tandon, 1983) analysis of the differences between traditional action research, beginning from the 1940s, and participatory action research, which has developed from the 1960s. Other writers, such as McTaggart (McTaggart, 1991), Mies (Mies, 1993), and Carr and Kemmis (Carr & Kemmis, 1986), show a strong preference for projects that rest predominantly on a conflict/structural change model of society, locating power in oppressed groups and using power in a “power for” rather than “power over” manner. This corresponds most with the empowering type of action research. Empowering action research, the fourth type, is associated with community development approaches. It is characterised by an explicit anti-oppressive stance to working with vulnerable groups in society.

Action research also has much in common with a range of other traditions, including practitioner research, action inquiry, action science, and community development (Stringer, 1996).

Key Aspects of Action Research

Process of Action Research

The process of action research is commonly described as a spiral of planning, action, observing and reflecting. Action research is also viewed as a means to bridge the gap between theory and practice.

The definition of action research that I have used is that it is a process of working with a community group on a problem they have identified and working together to find ways of addressing the problem. The process of addressing the problem involves cycles of reflecting, planning and acting.

Social Change Focus

One key defining feature of action research is that "the intention to affect social practice stands shoulder to shoulder with the intention to understand it." (Kemmis quoted in McTaggart, 1991, p. 7). This stands in stark contrast to traditional positivist researchers who "do not expect to alter the way their respondents see and live their lives" (Graham quoted in Hart & Bond, 1995, p. 68). The emphasis in action research on changing the status quo can be summed up in the motto "'If you want to know a thing, you must change it.' ('If you want to know the taste of a pear, you must change it, i.e. you must chew it in your mouth', Mao Tse-Tung, 1968)" (Mies, 1983, p. 125).

The three groups I have been working with all chose their own focus for social change. The West Auckland Women's Centre focused on changing the debates on retirement income to include a broader perspective reflecting the experience of some West Auckland women. The Autistic Association Auckland branch focused on changing a range of government policies that effected the care of people with autism. Homebuilders focused on highlighting the living standards of people in their rural community, Rodney District. For all three groups generating change in their respective interest areas was as important as furthering their understanding.

Improving and Transforming

Carr & Kemmis (1986, p. 163-164) argue that three important characteristics of action research are its democratic impulse, participatory character, and simultaneous contribution to social science and social change. Carr & Kemmis (1986, p. 165) also point to the essential aims of action research as to improve and to involve. The three levels of improving they identify are improving a practice, improving the understanding of a practice,

and improving the situation in which a practice takes place. The concept of improving is more narrowly defined in the context of experimental and organisational types of action research, where the scope of what might be improved is not fully open for negotiation. Within participatory action research with community groups the focus is more on transforming a situation than on improving a specific practice within it. Empowering action research involves a process of 'conscientisation' for all involved in the research process.

People have been involved in many ways in each project and a number of people commented on how they found participating in the project empowering. This was particularly the case for volunteer interviewers in both the Homebuilder's and Autistic Association projects. Volunteer interviewers frequently remarked how they were learning a lot of information that was relevant for their own situation and that the people they were interviewing were also finding the opportunity to reflect on questions useful and enlightening.

Future Orientation

Another difference between action research and mainstream, positivist social science is that action research is future directed. "Mainstream social science, in contrast, is concerned with describing 'what is', not with proposing what 'should be' (Babbie, 1986)." (Small, 1995, p. 949) Action-oriented researchers acknowledge that science is not value-free and believe that judging proposed solutions to social problems cannot be avoided. (Small, 1995, p. 949)

Being future orientated was a key aspect of all three projects. The topics chosen by the West Auckland Centre and the Autistic Association were both concerned with preparing for the future. All three projects also focused around suggesting positive changes in their respective areas for the future.

Evolving Nature of Action Research and Ethical Implications

"A unique aspect of action research is that both the research focus and the methodology may change as the inquiry proceeds." (Small, 1995, p. 942) This is because action research takes its direction from participants and their circumstances may change the focus or direction over time during the process. As Patton (1990) notes, in such circumstances "research methods tend to be less systematic, more informal and quite specific to the problem and organisation for which the research is undertaken' (p. 157)" (Ballard, Bray, Watson, Burrows, & MacArthur, 1992, p. 8)

In the early stages of working with the groups I became very aware of some important ethical implications of the evolving nature of action research. The following are my reflections at that time:

At this stage, even though I am approaching and beginning to meet with groups, I cannot formulate a consent form. This is because I do not yet know what groups may wish to consent to. It is likely that for groups who wish to initiate work in this interest area some process will be necessary for them to identify which specific issue is most relevant and appropriate to them. When using the action research method the planning, acting and reflecting is determined by the groups themselves and my role within this is on the terms decided by each group. I am also aware that how a group decides to go about addressing a specific issue may change over time, and the specific issue itself may also change. Given this ongoing developmental nature of the research formulating a consent form is ethically challenging.

Thus in terms of the major ethical principles (informed consent, confidentiality, minimising of harm, truthfulness and social sensitivity) the application of each principle to a considerable extent needs to be determined by each group I begin working with. It is possible that what they consent to may change over time and that their position on confidentiality may also change over time. The main difference in approaching groups using an action research method from other methods, such as surveys and interviewing, is that I cannot predetermine what each group may wish to do and hence what they may wish to consent to. I am also aware that for each group the application of consent and confidentiality in relation to individuals within the group may be different from the application of these principles to the group, and that this may also change over time.

The West Auckland Women's Centre has expressed very strong interest in working with other groups that have an interest in their specific issue. This raises questions of confidentiality, in that in order for linkages to occur across groups I need to state what other groups I have approached that share an interest area, or even in actually approaching groups state that a joint approach across groups could be a possibility if they were interested.

In practice I found that at different times in each project either members of the group or I asked questions regarding ethical principles as they became relevant. Sometimes this was in relation to the interviewing or surveying for the project and at other times it was in relation to my role as a student working on a thesis and the group. It was very important that ethical concerns were revisited as the projects developed and that the discussion on how best to meet ethical concerns was open and forthright.

Importance of Process in Action Research

Within action research projects the process of the project often becomes very significant. As Elden and Chisholm note, "... for many action-oriented researchers, the actual process of

conducting research is considered as important as any knowledge derived from the research itself (Elden & Chisholm, 1993).”(Small, 1995, p. 949) For the three projects I was involved in, the importance of the process in each group became more noticeable as the projects developed. Paying attention to the process was critical to ensuring the integrity of the research and was one key to the projects being meaningful for the groups. Following the action research process enabled collective reflection to be developed adding depth and validity to the projects. For me, following the process was also important as it was part of honouring the time the groups were giving.

Maguire's concluding comments reflect the importance of the open-ended and transforming character of the process.

However, transformation, social and personal, is not an event. It is a process that we are living through, creating as we go. It's dangerous to compare our modest beginnings and exhausting middles to the successful, documented endings of others' work. For we never know when we begin where the work will take us and those involved. ... The point is to learn and grow from doing, and to celebrate the doing, no matter how flawed, small-scale, or less than ideal. (Maguire, 1993, p. 176)

Role of Dialogue

Park views dialogue as one means of bringing about transformation at a personal and possibly social level.

Through dialogue people come together and participate in all crucial aspects of investigation and collective action. ... As a tool of research, dialogue produces not just factual knowledge but also interpersonal and critical knowledge, which defines humans as autonomous social beings. This is an essential reason for the people's participation in research. It is not just so they can reveal private facts that are hidden from others but really so they may know themselves better as individuals and as a community.(Park, 1993, p. 12-13)

I have also found ongoing dialogue to be a key ingredient to working through each step in the action research process. There were two periods where this ongoing dialogue was particularly crucial. The first was at the initial exploration of whether working together on a project was desirable and then secondly through the ongoing definition of the research problem. With all of the groups the initial exploration of whether a project was desirable required a number of discussions. Discussion of the research problem also returned again and again, as different facets were explored and small different steps identified both to find out more about the problem and to try and address specific angles. Maintaining the momentum of all the projects also relied heavily on ongoing dialogue, in the form of regular

brief updates of where things were at and more in-depth discussions exploring particular aspects or issues within the process.

Action Research in New Zealand

A lot of existing overseas literature on action research in communities focuses on action research in the context of 'oppressed' communities, particularly action research projects in Latin America, Africa and Asia (Smith & Willms, 1997). There are difficulties in using the language of 'oppressed' in a context where we are all part of the same social milieu. The groups themselves do not talk so much in terms of being oppressed as difficulties in getting their perspectives' heard and addressed within the current political structure. Their situation may be similar to oppression – but it is not quite the same as there is no clear body of oppressors and the community itself does not see itself as being oppressed – they see it more as specific problems or needs that are not being recognised.

There are also significant differences between doing action research with 'oppressed groups' which are of a different culture, class, specific form of oppression and in a different society from the researchers' and a researcher doing action research within their own society and culture. The three groups I was working with were all predominantly middle-class Pakeha community groups and so I did not have to deal with major cross-cultural issues.

Community and Action Research

Community Ownership of Problem Definition

Sandra Harding notes that "reflection on how social phenomena get defined as problems in need of explanation in the first place quickly reveals that there is no such thing as a problem without a person (or groups of them) who have this problem: a problem is always a problem for someone or other."(Harding, 1987, p. 6)

A key feature of action research is that the community itself, rather than the researcher, identifies and defines the problem that needs to be addressed. Thus "... the sense of the problem arises from the people who are affected by it and whose interest demands that it be solved. And the problem addressed is social in nature and calls for a collective solution; otherwise, there is no participatory exigency."(Park, 1993,p. 8)

The problem definition for the West Auckland Women's Centre was originally defined through a series of wide ranging brainstorming discussions with a subgroup and occasional discussions with the full collective. As the material from the interviews was collated there was ongoing discussion about the emerging themes and this further developed the problem definition. The Autistic Association decided on their problem definition through

brainstorming at a committee meeting one evening. This was then incorporated into a far broader survey to be used in addressing a whole raft of problems faced by association members.

The problem definition for Homebuilders was the most difficult due to it being very multifaceted and outside influences constantly shifting the most pressing concerns faced by Homebuilders. Initially the problem focused on making the nature of Homebuilders' work more visible. Then, as a result of changes in the way welfare benefits were being administered, the focus shifted to the needs of Homebuilders' clients, to highlight the issue of poor living standards in their rural community.

Collective Participation

Following on from identifying and defining the problem, action research also involves members of the community participating throughout the research process. However the roles and level of involvement of community members in the research changes over time. The Otago Family Network action research project found that:

Where participants in a project choose to be involved in a way that best suits them there will be different partnership perspectives, a division of labour and a variety of roles. To require that every parent be a reflective researcher would take away their power of choice. Also, the degree of involvement in such activities may not reflect the level of interest or commitment. (Ballard et al., 1992, p. 228)

Thus it is possible for collective commitment to the project to continue even though an individual's level of involvement and participation may change over time depending on their circumstances.

Action research relies on a collective commitment to the action research process. The membership of all three groups changed during their respective projects. In the case of two of the groups key co-ordinating people in the groups left and were replaced by other people who had to pick up some of the commitment to the research projects. This change in key membership was a concern for me, as I couldn't take the commitment of people new to the project for granted. However in all cases new people who joined the groups also took on board the collective commitment of the groups to the projects and thus there was no real discontinuity in the process for the projects. However it did have the effect of making my role as one of the people who had been involved in the project from the beginning more marked. Individuals' involvement in each project also varied over the duration of the projects, largely depending on changes in people's personal circumstances and on the differing activities during the project. For instance many people were very involved in the interviewing but not as involved in meeting for discussing and analysing the data. This was

partly a result of changes in availability or being more able to assist at home than attend group meetings.

The ongoing energy a group has for the project and the speed at which it progresses was very dependent on how directly the problem impacted on the group. Another key variable affecting a group's energy on the project was what else was happening for the group and for the individuals involved, particularly in terms of external pressures. Other time pressures were extremely significant for all three groups. Two of the groups had major accommodation issues during the project period. The Autistic Association Auckland branch shifted premises and Homebuilders continued to illegally occupy their building through a period of major council upheaval (the Rodney District Council was replaced by a temporary government appointed Commissioner) and intense public debate on the action of the group.

Collective Knowledge Creation

Through actively involving the community as participants in the research process “an immediate objective... is to return to the people the legitimacy of the knowledge they are capable of producing through their own verification system, as fully scientific, and the right to use this knowledge, but not be dictated by it – as a guide in their own action (Rahman 1991, 15)”(Hall, 1993, p. xv)

I often heard comments from various group members querying whether what they were doing in the ordinary course of their group activities could ‘count’ as real research. This was sometimes pitched in the form of asking me whether what they were doing had any value for my study. I responded by saying that the process and information did ‘count’ academically, that what the groups were highlighting and the process they followed was valid and useful, particularly for their own purposes. Lather notes that if participants are fully involved in shaping the research, then the resulting theory becomes a collaborative effort and the “theory will be an expression of politically progressive popular feeling, not a theory which is imposed on experience by intellectuals.”(Lather, 1986, p. 447)

Supporting knowledge generation by the community may involve selecting methods and measures that have a high degree of face validity and practical utility (Small, 1995), and both quantitative and qualitative approaches can be used (Park, 1993, p. 13). It is also important that research material is presented in a form which is accessible, meaningful and appropriate for the people it is meant to serve. The criteria of research being presented in an accessible and appropriate form for the people it should serve is paralleled in Evelyn Stokes discussion on Maori research(Stokes, 1985). The groups did choose both quantitative and qualitative methods and have benefited from a degree of face validity. This was linked to making the research accessible and meaningful to the group members and other participants in the research.

"The path from knowledge generation to knowledge utilization is direct in participatory research, since the same actors are involved in both activities. There is no middle-person scientist/researcher."(Park, 1993, p. 3) To some extent I felt I was a bit of a middle person because I took a strong role in the data analysis in all three projects, as I could offer the computer skills and time to do this work. However I constantly feedback the raw data material and basic analysis to enable others to participate in guiding and using the data.

Evelyn Stokes (1985) comments that the concepts of wairau and tapu raise issues of 'private' or 'community' knowledge versus 'public' knowledge. This is particularly the case where ethical concerns of safety exist. The issue of community versus public knowledge was not an important concern or problem with any of the groups as they all had very clear guidelines around protecting the privacy of individuals they worked with. Thus there was already a strong sensitivity about knowledge that was not for public disclosure.

Collective Ownership

When a commitment to community participation can be expressed in collective ownership there is a strong basis for stimulating more active involvement. The West Auckland Women's Centre very explicitly took full ownership of their project. This was highlighted when the information sheets for the interviews were being prepared and they decided to use only the Women's Centre letterhead and not to include the University letterhead.

A major difference between these research projects and other literature examples is that although I came from the university environment I was not bringing university resources to the groups (although Mike O'Brien was able to contribute some resources from Massey University to Homebuilders Living Standards Project). The only resource I had to offer the groups was myself. This was in contrast to major action research projects where the university invests considerable resources into the process – for instance the Otago Family Network project which involved a number of university staff (and possibly access to university resources). Overseas examples have also involved money and other resources from universities. Sometimes the resources have come from action research centres that are set up with the sole purpose of providing resources and support for groups to do action research.

Because the input of outside resources into these projects was minimal, it meant that the groups had to make a far greater contribution to maintaining the action research process. One positive effect of this, was that when the group invested substantially in the process it could also have a far greater sense of complete ownership of the research, than if a significant proportion of resources were coming from outside the group. The difficulty was that it left all the responsibility and pressure on the group to find sufficient resources within its current budgets and time limitations. Another implication of a project being owned and resourced by a community group is that when the research does result in new knowledge

and positive effects for the wider community, it is primarily the group itself which has had to find a way of funding and bearing the costs of the project.

Although I didn't have any strong anxieties about the success of the research projects some writers have highlighted this issue as a concern.

Another feature was the amount of anxiety about the success of the research. One of the defining features of a partnership is that it is joint, and the research produced by it is a joint product. This means that what is produced is not under the control of any one individual. ... Cathy Banwell suggested that because no one is in control of the outcome, partnerships may give rise to a greater collection of concerns and anxieties than 'solo' research. (Park, 1992, p. 590).

I agree that there is less certainty and control over the outcome of projects owned by groups, and this was one of the reasons I chose three projects instead of one. With no one individual able to make all the major decisions regarding a project at the start, as in more traditional research methodologies, there is an ongoing sense of fluidity regarding the direction and timeframes of the project. In reality this fluidity is very necessary for the groups as the pressures and time constraints they are working under change. Changes in the group memberships may also have significant effects on the outcome and hence the reality of membership changes further decreases certainty about the project outcome.

Collective Reflection

Another key characteristic of action research is that planning and reflection must be collective activities in action research. The reflection aspect of action research involves re-thinking the theories and values that inform actions, particularly unexamined, traditional, customary, habitual, intuitive and impulsive ways of behaving. Reflexivity also involves reflecting upon and critically examining the nature of the research process. Flowing on from the reflection aspect of the process of action research is the recognition that activism without reflection is not action research.

Reflection was a very ongoing activity with all three groups. With the WAWC we had numerous discussions leading up to the interviews, identifying the issues and reflecting on what was happening politically at that time. Following the interviewing we had another lengthy reflection period as I worked on drafts of the findings and we explored and reflected on the many strands that emerged from the interviews. With the Autistic Association the development of the survey took numerous meetings over a year, as a group of parents and other members of the association struggled to find the time to further refine and identify the questions that needed to be asked. Homebuilders spent some time reflecting on the issues and difficulties they faced and the process to be used for the story-telling, however there was not a lengthy reflection period following the story-telling sessions. With the shift in focus

to the Living Standards project there was considerable ongoing reflection as that project developed.

Reflexivity is also an important aspect in feminist research. "Feminist researchers tend to identify their own values and to consider their own feminist presuppositions in a highly self-reflexive manner."(Eichler, 1997, p. 18) Small notes that reflexivity also extends to the research participants (in the case of the three projects this would include people interviewed and surveyed) and it is related to consciousness raising (Small, 1995, p. 947). Again the idea of the research leading to raising people's consciousness or awareness of issues is a strong aspect of the action research process.

Small also notes that "Some aspects of the feminist model that are given more emphasis than in other action-oriented research approaches are its concern with ethics, the role of reflexivity, and the attention given to emotional aspects of the inquiry process."(Small, 1995, p. 947) I found that ethical issues were a concern at various times to all three groups and concerns over the emotional aspects of the inquiry process were also expressed in all three projects. For the Autistic Association it became obvious that some families found the interview upsetting because it gave them a clearer picture of the range of support services they were missing out on and the extent of the gaps in services. This response and the emotions it stirred up for both the interviewers and families led to some discussion, reflection and ideas about what practical response interviewers could give when this situation arose. In the West Auckland Women's Centre project sharing reflections with the group during the interviewing stage was an important part of the process and there was some discussion about the more emotional aspects and effects of the interviews. I am unsure whether the importance attached to ethical concerns and emotional aspects is in part a reflection of the influence of feminist methodology within the group projects. However given the context of the research projects I think it was highly likely that ethical and emotional concerns would have arisen regardless of whether feminist methodology was consciously drawn upon.

McTaggart suggests community may be seen as critical when participants regard their values as historically determined and as objects for examination, interpretation, critique and reconstruction through discourse and practice. (McTaggart, 1991, p. 55). Values of action research are problematised in action research practice. McTaggart argues that action researchers must expect to experience resistance from within themselves as they question their customary ways of doing things, and from other social actors in their contexts (McTaggart, 1991, p. 48). Jan McPherson notes that if the research process is challenging and changing the status quo, then it is likely to be uncomfortable and some measure of conflict or resistance may be an important part of the process itself (McPherson, 1994, p. 84). This reinforces the importance of community in providing the context for working

through conflict, strengthening the identity of a community and providing the support and collective commitment to finding a constructive resolution for conflict.

The issue of conflict over values did not noticeably arise with the three groups. It may be that conflicts arising from self-critiquing are more applicable to action research within a professional context eg teaching or nursing, where the action research is focused on improving the practice of professionals themselves rather than on seeking change at a broader social context level. I was aware of the potential for conflict to arise during the projects. However I found that all the groups were focused on the goal of being able to use the research and thus the groups kept themselves on track, resolving any difficult areas and keeping the momentum of the projects going.

Researcher Role and Relationship to Groups

The relationship between the researcher and other participants is an issue of the location of power in any research study. Empowering action research emphasises the need for the researcher to take a non-elitist role and the power of the group/community to decide on the terms and extent of the researcher's involvement in the project. A refuge project in Germany is an example of where the women social scientists who joined the group had to give up their status of uninvolved, neutral experts, and instead participate actively on a equal footing with non-academic women in all the work (Mies, 1983, p. 131). McTaggart argues that in action research as it has been re-conceptualised, groups are there to be joined, not facilitated (McTaggart, 1991, p. 45).

The way each group fitted me in varied. With Homebuilders I was coopted as a community representative so I could formally be part of their Scheme meetings. With the Autistic Association I attended their monthly committee meetings along with other interested people and formally elected committee members, becoming involved in other activities as appropriate. With the West Auckland Women's Centre I mainly met with a subgroup of the centre to work only on the research project.

I found that the relationship between myself and other group participants was subtly shifting and being renegotiated at various points during the projects. This was related to the degree to which I was dependent on members of the groups to make the next steps (eg. working with parents in the Autistic Association to design the survey meant fitting in with when they could spare time and I was relying on them to identify the questions that needed to be asked), to whether we were working on a equal footing (eg being just one of a number of interviewers helping with the Homebuilders survey), or when I was responsible for certain steps (eg organising the data entry for the Autistic Association survey). The groups all explicitly identified to varying degrees the terms and extent of my involvement in the research project. The degree to which the project tasks were shared evenly within each

group varied, depending on the resources of each group. Both the Autistic Association and Homebuilders were very keen to give group members and volunteers the opportunity to develop skills through being involved in various steps of the project. The WAWC were happy for me to have most of the responsibility for doing the work for some tasks (eg interviewing and transcribing), but all decisions, reflection and organising was worked on together.

There were some differences in terms of skills in each group and this influenced both individual roles and the pace of the projects. I found with the Autistic Association that to some extent I was outlining the research steps, but their knowledge was the content of those steps in terms of the questions to ask and the way to go about working with the families in a way that was constructive for the relationship they already had with them. In contrast some members of the West Auckland Women's Centre seemed more familiar with the mechanics of research steps. The WAWC had undertaken research projects before, and so the initiative for research steps was more evenly distributed. The participatory process in the Living Standards project with Homebuilders meant that all the people involved contributed what they knew, and that the process was one of gathering together all the pieces of information so that the project steps came from the group itself.

Near the beginning of my work with the groups I had a stark reminder of the power of the groups to make decisions regarding the direction of the project.

At one point discussion wandered over into another area. A woman Verle knows was keen for her to do a workshop on what happens to older women when their partner dies. I made a comment that I wasn't as interested in that topic. Sharon came back with the really important point that if the issue does go off in a direction that is not as relevant to me that I would have to live with that. The point she was making is very important for me to bear in mind in the future with all the groups I'm working with, basically the idea of not controlling and not saying oh we're only gonna talk about this area and not go on off in this direction.

This occurred in an early brainstorming session, surprising me and making me realise just how conscious and alert I always needed to be in regard to not controlling or to strongly influencing the direction a group may take.

Linda Smith notes that the knowledge she does have access to comes with responsibilities to the group (Smith, 1986, p. 10). Again this reinforces the role of the researcher as operating on the terms of the group and being explicitly accountable to the group. There were times in each project where I also felt a powerful sense of responsibility and obligation to honour the knowledge being shared in each project, strengthening my commitment to the group projects.

There were a number of differences in the power dynamic operating in these projects from some other action research projects. As a student working with New Zealand community groups I was very dependent on them. Instead of the group relying on me for guidance, the groups were more concerned with their own reality and existence than with meeting the needs of a researcher. Another difference that placed me in a weaker power position in relation to the groups was the fact that I was younger than almost all the members of the groups and I did not have experience in their actual work area. Hence although I gained some understanding of the work of group members I was not qualified in that work area and hence had no status based on experience.

Although I was not experienced in the field of work of the groups, in the case of two of the groups I did come from similar social networks and my point of access into the groups was a friend within each group. Connecting with a group through a friend did give some sense of equality and welcoming into the group and an assumption of shared social values, networks and interests. Thus although I was not seen as a full member of the group, I could be identified as a researcher sharing similar values and understandings and coming from similar networks. With all three groups I knew people who the group also knew and these connections were identified along the way. This situation is likely to be in contrast with many of the literature examples where the researcher, although having an interest in the issue area of the group, does not have any prior connection to the group, coming in as a stranger and an expert with resources and knowledge to offer.

Another significant factor in my relationship with the groups was a sense of unbalance in the degree of reciprocation between what I could offer the groups and what they were giving, particularly in terms of time for the projects. At times I felt I was in the situation of relying on more from the group than I could reciprocate. The fact that I could only give my own time and skills to the project, but that the group may have to give considerably more resources to maintain the project further reinforced my dependency on the group for the existence of the project. It also heightened my awareness of my inability at certain times to maintain a more even balance between what I could offer the group and what the group was offering. This issue was a particular concern to me as I was very conscious that I was using these projects for my doctorate and therefore it was very important that the projects were as beneficial as possible for the groups and that I gave as much back as possible in return for how they were helping me.

Maguire also used action research for her doctorate, articulating slightly different issues in the relationship between herself and the group.

When we eventually got a support group rolling, I did play the major motivating role. Yet I felt uneasy with it, which may have been complicated by the fact that I was doing this in part as my doctoral research. For example, by working hard to motivate

women to become active and regular group participants, was I trying to make the project, also incidentally part of my dissertation, a success? Was this 'contamination' of a true participatory research paradigm. Was that fear itself a holdover from the old research paradigm? Since ultimately project control was a key issue, I knew I should increasingly step back and see what happened as I relinquish the organizer/motivator role and some of the women took it up. I did try, by fits and starts, to step out of the organizer role over the year the group worked together. Yet none of the women followed through or apparently wanted this role. (Maguire, 1993, p. 162)

I think one main difference between our situations was that she set up a group whereas I worked with existing groups. Another difference is that by choosing to work with more than one group I was endeavouring to provide the success of my thesis with insurance. I was trying to limit my dependence on one project for my thesis, making the group's control of the research less problematic for my thesis. If one group decided to not continue with the project it didn't mean the end of my thesis. I was also fortunate that different members of the groups I worked with were prepared to share organising and motivating roles in each project.

In the case of all three groups I felt very privileged to be welcomed into the group and with all three groups there were public occasions where I would be with members of the group and identified as having a connection with the group. Thus my relationship with each group was a public one in various ways.

Working with Existing Communities

Shumsky considered action research as a way of regenerating community life.

An action research movement is potentially a grass roots approach to the solution of community problems. It means activating the social and spiritual life of a community in a continuous search for self-improvement. It means providing a social setting where people can work together, dream together of a better community, and try to translate their dreams into the language of action and evaluation. (Shumsky (1956) quoted in (McTaggart, 1991, p. 17).

However Maria Mies in her reflection on research projects with rural women in India does not share the same degree of optimism regarding the role of action research in stimulating community. Instead she highlights the importance of a research project linking up with existing local groups. These local groups "constitute a permanent base for conscientization, mobilisation and action" (Mies, 1983, p. 137), and without them any

research project is more likely to be only an episode in the lives of people, unable to develop its emancipatory potential (Mies, 1983, p. 137).

In her research project Patricia Maguire realised that although she initiated a new group by bringing together women who were battered, working with the group who provided services to these women may have been a more effective avenue for creating change. "Sometimes the seemingly 'reformist' approach might eventually lead to the most significant change, for clearly participatory research takes an organizational base of some kind to implement and sustain change."(Maguire, 1993, p. 168) The women involved in the group Maguire initiated were reluctant to take on active leadership roles. "They were also saying that because control and participation take time, the benefits have to be weighed against the time costs."(Maguire, 1993, p. 171)

In conclusion Patricia Maguire suggests being very prudent about the setting chosen for action research. In particular she highlights that when looking for groups "don't overlook the organizations, groups, or agencies in which you are already involved, regardless of how 'reformist' you may initially assess them. You will inevitably make choices based on time constraints."(Maguire, 1993, p. 175)

The three groups I worked with were all well established. Homebuilders and WAWC had both been in existence for over 10 years. The Auckland branch of the Autistic association had been in existence for over thirty years and is the largest and one of the most active branches in the country. Both the Autistic Association and the WAWC went through a major change in their internal structure during the time I was working with them. Fortunately these changes, although significant for the groups, did not have a significant impact on the research projects. The organisational base of the three groups was a very significant resource for all three projects, especially in terms of the groups community networks. The issue of time costs was very real for the members of all the groups I worked with. At various stages this did slow the process down but different members of each group were prepared and able to take active leadership roles at different stages and when some members stepped out there were other members prepared to become more involved. Thus group members were weighing the benefits against the time costs and there were sufficient benefits for people to want to become involved in different ways.

Another difference to many examples of action research in the literature, is that for the groups I was working with the action research project was additional to their own everyday work activities and their ordinary functions and jobs came first. Thus although the issue was of central concern to each group, it was not the reason for the existence of any group and nor was it their sole or even primary focus. This is in contrast to many case examples where the action research project becomes the primary and sometimes exclusive focus of the group. For work on the group's action research project to proceed, other scarce resources,

such as time and sometimes money for other activities, had to be sacrificed and it actually encroached on their everyday work. This meant that there was a continual balancing act between continuing working on the action research project and fitting it in within the more immediate and pressing demands of everyday work.

Being Physically Present and Building and Maintaining a Relationship

An important key to working with a group is to be physically present, to be with them. This was particularly important in the early stages of working with the groups, when my focus was on building a relationship with group members and on gaining some understanding of how the groups worked and the issues they faced. Being physically present was particularly important with Homebuilders and the Autistic Association. Because Homebuilders was based up in Warkworth the only way I could overcome the physical distance and work with the group was to go up there regularly. As I had no knowledge or experience of Autism prior to working with the Autistic Association, the best way for me to learn about all the issues the association faced was to help in the office, go to some of the playgroups and picnics, attend committee meetings and assist with association activities where appropriate. I found with both groups that the only way opportunities to work with them on other activities could arise was through being around at the time.

Building a relationship with group members took time and meant getting involved and working with them on other activities, not necessarily directly related to the research project, whenever opportunities arose. Taking the time to build relationships was extremely important. I spent several months gradually building a relationship with Homebuilders and the Autistic Association. With Homebuilders this involved spending time helping them with their accounts and participating in their scheme meetings. With the Autistic Association it meant helping in the office with their membership database, participating in their committee meetings and other activities.

Working with Group Timeframes

Park has identified that the researcher may have an organiser or mobiliser role to begin the action research process, however the degree of organising or mobilising will vary greatly depending on the type of organisation which is involved in the project. (Maguire, 1993, p. 161) "This initial organizing phase of the project can require considerable time and effort. Its success will depend on how acutely the problem is felt by the community and how motivated its members are to do something about it."(Park, 1993, p. 10) For all three groups the offer I made of working with them on a project provided the catalyst for the beginning of each project (except for Homebuilders' Living Standard project). However I found that after initial agreement to do a project it was not appropriate for me to rush in to suggest various topics or push for things to happen faster. Instead I found myself adjusting to the pace of each group.

Part and parcel of the groups owning the projects is that they also set the timeframes for working on the project. This meant that when other things took priority it was a case of being patient and waiting till they had the space and time available to focus on the project again. Other than the everyday work of the groups, funding applications were noticeable as the main overriding priority for all three groups that resulted in the projects being temporarily put on hold or slowed down.

Enabling group members to fully participate in the projects also meant not putting pressure on them to get on with the next step. For instance with the Autistic Association it took a good year to develop the survey questions as we could only meet as people were available. If a short time deadline had been placed on developing the survey I think this would have limited the amount of parent input into designing the survey and thus substantially limited its usefulness.

Working within the groups' timeframes also meant that it could take considerable time for the actual project issue to emerge. This was the case for both Homebuilders and the Autistic Association. The key was to be patient and to have ongoing dialogue with the groups around clarifying the issues they faced.

Validity, Objectivity, Reliability and Partiality.

Action research is focused around addressing an issue of a specific community. Depending on the nature of the problem, this may have implications for the type of knowledge generated and the role and use of theory in the research process. Rather than the researcher identifying a research question from a theory context and then going into the field to put it into practice in some form, action research reverses this sequence because the question comes from the experience of the community and theory is usually drawn on selectively at points further down the research process.

Thus, the usual theory to practice sequence for formulating research is reversed. And 'theory' here might be the cause-and-effect explanations of participants in a given context or what has been termed 'tacit knowledge' and 'local theory' rather than 'general knowledge' or 'scientific theory'. (Elden & Chishom, 1993, p. 127)

The reversal of the normal theory to field sequence had major implications for this thesis. Although I started with some very general theory reviews it quickly became evident that I was dependent on the groups to identify the focus of the research and hence restrict the theory to areas that were relevant. It also meant that I have been reluctant to read up on theory for the sake of theory and that my energy in exploring theories has been directly related to how relevant the theory was to the group's purpose. Another issue has been a awareness that sometimes I have needed to translate the language of a theory into

language which is more appropriate and succinct for a busy group that includes members who are not from an academic background.

Whereas conventional academic social scientists have tended to study well-structured problems, action-oriented researchers tend to focus on 'ill-structured' problems. ... ill-structured problems are ones that do not have well-defined or reliable methods of determining a problem or its solution. The problem definition may vary as a function of the particular situational circumstances and the stakeholder's perspective. The relationship of research knowledge to action is not assumed to be reliable across encounters with the problem. Ill-structured problems require regular but differing solutions depending on where and when they are encountered (Tolan, Chertok, Keys, & Jason, 1990 quoted in Small, 1995, p. 948-949)

Ill structured problems were most clearly in evidence in the Homebuilders project. The repercussion of grappling with a very ill structured problem was that more time for reflection was required and it took a lot longer to work out the next steps. Having an ill structured problem also made it more difficult for all the group members to have a strong ownership of the problem. These difficulties contributed to the initial project using stories being effectively aborted when a new more clearly defined problem emerged from the group (see chapter 4 for a fuller explanation of the change in project). The Autistic Association was faced not so much with ill structured problems as a limitless list of problems. The issue chosen for the research project was just one of many areas where there was concern about an unaddressed need. The issue of who will care for their children when the parents no longer can was therefore fitted into the survey as one issue amongst numerous issues that the association knew needed to be addressed.

All researchers bring their own perspective to their research. The key difference is in how conscious a researcher is of their own bias and how explicitly this bias is dealt with in the course of the research. There is a real need for all research to be recognised as "socially constructed, historically embedded and valuationally based."(Lather, 1986, p. 439) The social construction and identification of shared values was intrinsic to all three projects through collective reflection during the research process. With regard to validity, Evelyn Stokes states that "Neither the source of motivation for research, nor cultural framework or methodology in which it is undertaken, is necessarily an impediment or a reflection on the quality of research."(Stokes, 1985, p. 5)

Lather suggests four strategies to establish 'data-trustworthiness'. Firstly triangulation; secondly systematised reflexivity, by this she means the researcher explaining their thoughts prior to the research and then the ways the research modified their ideas; thirdly face validity, presenting participants with emerging data and interpretations for their

scrutiny; and fourthly catalytic validity, by this she means the extent to which the research process was a catalyst bringing the participants greater knowledge about the topic and determination to change the situation (Lather, 1986, p. 450-452). The project chapters illustrate how the action research process did enable Lather's four strategies to occur in the three action research projects.

Oakley argues that the mystification of the researcher and researched as objective instruments of data production needs to be replaced by the recognition that personal involvement is more than dangerous bias, "it is the condition under which people come to know each other and to admit others into their lives." (Oakley, 1981, p. 58). Through all the research projects it was obvious that there were times when the people being interviewed expected some sort of feedback or discussion of some issues that were being raised. All the interviewers were made aware of the trade-off between expressing our own views and possibly influencing responses versus not being open and therefore reinforcing an hierarchical relationship to the person being interviewed and not allowing the information flow to go both ways. The reality was that in a number of instances not to branch into discussion, for example on where a family could go for services in the Autism interviews when they were asking, would have been unethical. Our main practical concern with branching into other discussions was trying to ensure that the interview could be completed in a reasonable timeframe.

There are many issues that can be raised in relation to validity, objectivity, reliability and partiality. I chose to identify some of the aspects I found most pertinent to the action research projects I participated in. The reversing of the normal theory-to-field sequence was particularly significant in shaping this thesis and also reflected the importance of the groups controlling the direction of the research projects. The ill-structured nature of some of the problems faced by the groups reflected the nature of community work and the multifaceted nature of communities and people. Recognising the shifts in the role of theory and the importance of ill structured problems was one key to the research having validity and real meaning to all the research participants. Ongoing reflection and dialogue within the groups enabled perspectives and values to be identified and the impact of personal involvement to be explored, all contributing to a deeper understanding of objectivity and partiality.

Dilemmas in the Process

The Group may not stick to the Process – It May Decide Not to take Action

"Yet we live within the very structures and relationships we seek to transform. It is not a neat intellectual exercise. Collective work is messy and time-consuming. People may decide not to take action."(Maguire, 1993, p. 176) There were times, particularly in the beginning stages, when shaping the projects did feel messy. I was particularly conscious of this with Homebuilders as we grappled with very ill structured problems and struggled to see a clear

path of action that could address the structural problems they faced. In terms of developing the story-telling sessions, Homebuilders did not stick to the process, it was effectively aborted and a new project was begun. During the West Auckland Women's Centre's project both some of the women being interviewed and members of the Women's Centre raised the issue of people deciding not to take action as being a problematic aspect of action research and perhaps a flaw of action research. Thus I was very conscious that the groups always held the choice of deciding not to take an action or any further action. I think that because all three groups chose issues that were important to them this provided the best basis and motivation for them to continue the projects, following through the process to the best of their ability. The commitment was always there to taking both action and reflection steps. Once the initial steps of each project had begun the most likely threat to the continuance of the projects was the impact of external pressures on the groups – such as continuance of funding sources.

Macro Change and Action Research

Another major issue within empowering action research is to what extent local initiatives can promote fundamental socio-economic change at a national level that might be necessary to overcome identified problems. Acker notes that an emancipatory intent is no guarantee of an emancipatory outcome (quoted in McPherson, 1994, p. 24). For all three projects the issue of how small community groups could find ways of generating change on a macro level was very real. At various times there was a sense in all three groups of feeling very daunted about how they could address the issues they had chosen and generate the change that was needed. Given the potential size and macro nature of some of the problems that needed to be addressed it was possible that the groups could have 'given in' and decided the task was too big or that they were not in a position to influence the macro level. However all three groups did find different ways to overcome the daunted feeling and to at least try and generate changes at a macro level.

The West Auckland Women's Centre drew on their past experience of both in depth qualitative research and lobbying government. They saw these activities as part of their function and hence through their past experience were able to overcome concerns that they may not have much influence, believing that such projects were worthwhile and necessary anyway.

When I first began working with the Autistic Association they were very much in the same boat as all other small special needs interest groups. The likelihood of anyone listening to their needs and concerns was remote. However the situation of the association changed dramatically when front page stories of families struggling with Autistic family members hit the media. The stories in the media, from March 1998 on (see Appendix 5.4 and 5.5), suddenly threw the spotlight on the plight of families with members with Autism and the Association quickly realised that there was a new willingness from politicians and education

and health services to find ways of meeting their needs. This dramatically changed the whole perspective of the Association in regard to what it could ask for and expect in response from government. When I started working with the Association there was very little optimism and a great deal of realism about what they could achieve. However since then, there has been a real growth of energy and expectation. I think this was partly behind the decision to undertake such an ambitious survey.

For Homebuilders the issue of how to generate macro change was also a real question. In the end the impetus for putting the spotlight on the issues they identified came from people within their community. When the idea of doing a survey on rural living standards was first mooted a wide range of people from the local community expressed an interest in being involved and started coming along to meetings to plan the project. Local community members and later more volunteer interviewers and even many of the people interviewed for the survey all gave positive feedback to Homebuilders about the value of the project in terms of raising awareness in the community. This community support behind the research was essential in providing the momentum for it to happen regardless of concerns about how effective it may be in influencing changes in government policy.

Time Issue

The centrality of time as an issue in all three research projects became obvious early in the projects. Following is my reflections from when I first identified this issue.

A key issue in negotiating the actual process used by each group is time. Once a group has said yes we are interested and would like to pursue a particular issue the importance of finding the time and of juggling this into each person's life and the time resources of a group collectively immediately becomes a real difficulty. The shortage of time is a direct reflection of the myriad of difficulties many people face in juggling paid and unpaid work. To then ask people to stretch their limited time even further to address a particular issue that is often in part a cause of the time pressure can be a difficult bridge to cross at a practical level (for instance parents of children with Autism trying to find more time to work on a research project that can be used to lobby for better services for them). It highlights the difference not only between intentions and practice but also between the desired reality and the actual, present oppressing reality. Acknowledging the very real time cost of pursuing an issue also means choosing to make the current reality an even harder juggling act purely in the hope that at some indefinite future time the difficulty of juggling paid and unpaid work will be eased.

Following is another early reflection on this theme:

Although a collective commitment to the project may be strong, the ability of individuals to find time for working on the project is a completely different matter. Within New Zealand Pakeha society there seems to be a very strong awareness of how limited and overstretched each person's time is. I think this is particularly the case for women – who are the majority of participants in all the action research projects. Most of the women involved are juggling paid work, family caring responsibilities and a wide range of voluntary, unpaid work responsibilities. This contributes to making them very protective and cautious of overcommitting their time. Alongside this very strong discourse of being too busy and not having enough time, there is also another reality that sits in contradiction – the desire and valuing of spending time catching up with people and of stretching time when people personally recognise and value the opportunity to participate in a discussion that they find meaningful. Thus the issue has drawn the women in because of its importance and meaning in their lives but at the same time they are still torn by other demands and so find themselves juggling the everyday pressures with a desire to find ways of creating changes which may make the everyday juggling more manageable.

Triangulation

Triangulation is the use of multiple research methods, investigators, data sources and theoretical perspectives in the process of research. It is a way of partially overcoming the weakness of one method or data source. There are four basic types of triangulation:

1. Data triangulation - this has three subtypes; time, space and person. Person analysis also has three levels; aggregate, interactive and collective;
2. Investigator triangulation;
3. Theory triangulation;
4. Methodological triangulation.

Through my focus on action research this study used a number of forms of data triangulation, including collectivity person analysis. For example, the WAWC project, through the use of follow-up phone calls incorporated changes over time. It is important to note that "data triangulation seldom yields a single, coherent, consistent picture of the situation being studied."(Denzin, 1989, p. 239) Instead the "situated character of action" (Silverman, 1985 : 105)"(Denzin, 1989, p. 239) means data triangulation is always indefinite and open-ended. This highlights the importance of incorporating other forms of triangulation into a study.

Investigator triangulation refers to multiple as opposed to single observers being employed. In the context of research undertaken with a community, the members of the community itself, in certain situations, constitute the multiple observers. In all three action research projects members of each group were involved in analysing and reflecting on the data gathered.

Theory triangulation refers to "approaching empirical materials with multiple perspectives and interpretations in mind."(Denzin, 1989, p. 239) It "minimises the likelihood that the investigator will present to himself and the work a prematurely coherent set of propositions in which contradictory propositions, however plausible, are ignored."(Denzin, 1989, Westie quoted in Denzin p. 242) Again, through having collective reflection with each group, there was greater potential for theory triangulation as the differing experiences of group members led to different questions and theories being applied to the data.

The final type of triangulation is methodological triangulation. This can be in two forms, either 'within-method' or 'between-method'. In the within-method triangulating multiple strategies within one method are used to examine data. Within the action research method used for this study a range of other research strategies were used as each group chose its own research method. Denzin argues for between-method triangulation because "the flaws of one method are often the strengths of another; and by combining methods, observers can achieve the best of each while overcoming their unique deficiencies." (Denzin, 1989, p. 244) Usually one dominant method is stressed with combinations of other methods giving additional dimensions.

Forms of triangulation applied within each action research project, and, for my analysis of action research and my own research questions, across the three research projects. For my original questions working with three groups means three different data sets and different methods within each group. Thus working with multiple groups has provided triangulation of data sources for my original research questions. However, within each project there was limited use of different data sources and one main method was used. Thus the individual projects did not use method triangulation and had limited data triangulation. However through using the action research methodology they did use investigator and theory triangulation.

The use of triangulation was not a major focus in the group projects, and given the enormity of the research tasks, particularly for the surveys, I am unsure whether the groups would have had sufficient resources to undertake data and method triangulation. Because the projects are to varying degrees still continuing, it is possible that a group may decide on doing further research and this may provide some triangulation. For instance, the National Autistic Association is now running the Auckland branch survey nationally.

Ethics

An ethical question arose in relation to my role with each group when I gave them drafts of the methodology and project sections of my thesis. Giving the groups and individuals, both past and present, in each group an opportunity to see the drafts, make comments and give consent was a very important part of the process.

One question I was asked was whether I should have given the groups more information about the action research process at the beginning. I had considered this issue in relation to consent forms when I first began working with the groups. At the beginning I highlighted only the key points of action research with the groups as I didn't want to impose theories of what was required on the groups or influence the ways each group worked or the issues they chose. In relation to consent forms I decided it was inappropriate to use consent forms at the beginning as I could not determine or say what the groups were consenting to.

Another significant influence on my actions at the beginning was that my focus was on the issues the groups chose more than the action research process. It was only over time that my interest shifted to also focusing on a comparison of the action research process in each group. As a consequence of this shift in focus my thesis has included a lot more information regarding the research process and workings of each group. Because I have ended up studying the groups themselves, as well as the issues they chose, I think I should have been more explicit about this aspect of my study at the beginning.

As I realised my shift, I began to emphasise to the groups that I was interested in the research process as much as the issue areas. However my seeking consent regarding what I wrote about the process and each group had to occur towards the end of the projects, in the form of showing the groups the drafts. This was because at the beginning the groups would not have known what they were consenting to, as the process was still to unfold.

Thus in hindsight the consent I could have asked for at the beginning was not around the content of the projects but around reflecting and writing about the process used by each group. In giving the drafts to the groups I was seeking that consent at the end rather than the beginning.

When I began working with the groups I didn't want to tell them how to do action research because I didn't see that fitting with the relationship I sought to create with each group. However I think the comparative analysis I now have of how action research within community groups can work in New Zealand, would be very useful background information for any other groups looking to begin an action research project.

Feminist Research and Social Change

Action research and feminist research both share an orientation to social change, with feminist research being particularly focused on research that will benefit rather than oppress women. "The concern with change, like the call for research that does no harm, is shared by researchers working in other critical traditions. What makes practice distinctively feminist is its relevance to change in women's lives or in the systems of social organization that control women."(DeVault, 1996, p. 33-34) The West Auckland Women's Centre project drew strongly on feminist research principles.

Elizabeth Gross argues that feminist theory "must recognise its own perspective, that it is being written from a particular point of view with partisan aims, and must therefore be seen not as an attempt to produce new universal or objective truths, but as a political intervention."(Crowley & Himmelweit, 1992, p. 337) Similarly, Evelyn Stokes highlights the Maori attitude that research for the sake of knowing is pointless. Instead there should be more specific aims and objects directed at helping people in their daily lives (Stokes, 1985, p. 3). The idea of research being directly linked to political intervention was central to the West Auckland Women's Centre project and was also important in the other two projects.

Pakeha Research

When I was looking for groups to work with, I did not limit my search to only Pakeha community groups. However, in hindsight, I was pleased that the three groups I ended up working with were predominantly Pakeha community groups as this meant that I did not have major cross cultural issues in my relationship with the groups. I do not speak any languages other than English and I have only a limited knowledge of some norms of Maori culture. Thus I would have been ill-equipped and significantly challenged if I had ended up working with a non-Pakeha community group.

Research Concepts

The research concepts used for this thesis were defined within the context of each project, hence they are addressed in the discussion of each project.

The Beginning Steps

I began this study in March 1997 and for the first year I spent a considerable amount of time looking for groups to work with. At the beginning I was very open regarding the type of groups I could work with and I approached a very wide range of possible groups. I also considered and discussed the idea of setting up a group by drawing people together around a particular issue. Possible areas were parent helpers at primary school or

caregivers of people previously in an institution. However I decided against this idea as I could see a number of ethical and organisational difficulties in setting up a group, for instance some of the difficulties identified by Patricia Maguire in her research project (Maguire, 1993) such as issues around ownership and control of a project. Instead I decided to look for a minimum of two established groups and possibly more depending on the groups and the issues chosen.

I prepared an information sheet to give to groups and people that I contacted. The information sheet outlined the research I was interested in and gave some personal background (Appendix 3.2 and 5.1 are the two versions I used).

During the first year I also worked on a general literature review. However, I realised that to make a literature review more useful, I needed to begin with the groups first to define the scope and purpose of any literature reviews. As a result, I prepared the Superannuation Review for the West Auckland Women's Centre, and later on I worked on a literature review for the Autistic Association focusing on the issue they had identified.

There were a number of clear steps I followed in contacting different groups. I contacted groups through people I knew in a particular group, by just choosing a particular group that looked interesting and through snowballing - where someone suggested someone who suggested someone else.

My first step in contacting a group was to phone up and have an initial conversation indicating what I was interested in and then asking whether it was okay for me to send a background information sheet. In most cases there was a fairly positive response at that point, only one group responded with a flat not interested in the first conversation. After I sent out a background information sheet, I usually waited a week or so. Most people asked me to phone them back as they may not take the initiative in contacting me. On the second phone call, I usually gained a clear indication of whether or not the group was interested in exploring any possibilities. If they were interested then I would suggest I meet with them at a time that was convenient for the group - or sometimes just the contact person in the group. Often there was some delay before the contact person was available to meet and a number of meetings were rescheduled to a later date.

When I did finally meet with a group, there was an interesting discussion to explore what were possible issues for the group, and for them to understand what I was looking for. From that meeting I usually received a clear indication of whether the possibility of working together was still open, or if not, some of the groups reasons for deciding working together would not be appropriate. Even if the possibility of working together was still open, there was usually no definite decision at the meeting to go ahead, and nor was there any decision on a beginning process. The lack of definite decisions was usually because I was

meeting with a subgroup that needed to go away and talk to other people, and because the group itself would like an opportunity to reflect. Thus if a group was still interested the next step was to arrange another meeting, sometimes with the full group.

At the second meeting a loose decision was made as to whether the group saw some value in committing to the idea of working together. If the group did decide in favour of working together, then depending on the nature of the group, its structures, and particularly time constraints, the first steps in a process of working together could be identified. With the West Auckland Women's Centre the first steps in the actual process of working together were simply to continue meeting and exploring ideas, gradually identifying small concrete steps as they emerged from brainstorming sessions.

During this first year I had many meetings with different possible groups and contact people within the groups. I used the snowballing technique extensively and I also spent time hunting for lists of groups from a wide range of sources, eg council offices, notices in local papers, Citizen's Advice Bureaus and North Shore Community Houses.

By August 1997 I became concerned about initiating contact with too many groups. I wanted to only approach groups that I felt I could follow through with. Therefore I decided to hold off contacting any further groups until an outcome was reached with the groups I had already approached. This meant waiting a few weeks before looking for more groups again, but I decided this was a safer option as I did not want to be in a situation of having too many groups agreeing and wanting to work with me. By this time Homebuilders and the WAWC were definite and there was a number of other groups that I had made initial contact with. It was a few months later, and following another round of contacting potential groups that I met with the Autistic Association and then began working with them.

Time-line of Group Projects

Following is a time-line of the three group projects. This provides an overview of the project activities and how they were developing alongside each other. The detail of each project is then explored in their respective chapters.

Action Research Projects Time-line

Date	West Auckland Women's Centre	Autistic Association	Homebuilders
1997			
June–July	<ul style="list-style-type: none"> ● Initial contact & relationship building 		
August–October	<ul style="list-style-type: none"> ● Exploring possibilities ● Background superannuation review ● Deciding on project form 		<ul style="list-style-type: none"> ● Initial contact & building relationship
November	<ul style="list-style-type: none"> ● Pilots 	<ul style="list-style-type: none"> ● Initial contact with association 	<ul style="list-style-type: none"> ● Preparation for story-telling sessions
December	<ul style="list-style-type: none"> ● Ideas from collective ● Transcribing Pilots 		
1998			
January–March	<ul style="list-style-type: none"> ● Interviews ● Transcribing 	<ul style="list-style-type: none"> ● Building relationship 	<ul style="list-style-type: none"> ● Two stories and transcribing completed ● March - Reflection on other literature
April–May	<ul style="list-style-type: none"> ● Sending transcripts back to the women to edit and review 	<ul style="list-style-type: none"> ● Issue chosen 	<ul style="list-style-type: none"> ● Stories continuing
June	<ul style="list-style-type: none"> ● Working on drafts – looking at themes and structure 	<ul style="list-style-type: none"> ● Literature review & reflection 	<ul style="list-style-type: none"> ● Transcribing of two more stories completed
July–August	<ul style="list-style-type: none"> ● Continue working on drafts 	<ul style="list-style-type: none"> ● Survey begins – developing questions 	<ul style="list-style-type: none"> ● Workshops and sessions identifying issues & strategies for Homebuilders ● August – idea for Living Standards Project
September	<ul style="list-style-type: none"> ● Follow-up calls 	<ul style="list-style-type: none"> ● Survey preparation continues 	<ul style="list-style-type: none"> ● First Living Standard project meetings

October–November		<ul style="list-style-type: none"> • Survey preparation continues 	<ul style="list-style-type: none"> • Forming of Living Standard project group
1999			
January–February	<ul style="list-style-type: none"> • Preparation for reflection 	<ul style="list-style-type: none"> • Assisted with classroom survey 	<ul style="list-style-type: none"> • Questionnaire development
March	<ul style="list-style-type: none"> • Reflection with women interviewed • Discussion of ways to use research findings • Mail-out of overview of themes • Phone around to check re participation 	<ul style="list-style-type: none"> • Survey preparation continues 	<ul style="list-style-type: none"> • Questionnaire development continues
April–May	<ul style="list-style-type: none"> • Feedback session with collective • Pack of information for Older Women's Group 	<ul style="list-style-type: none"> • Article about Personal Advocacy Trust in newsletter 	<ul style="list-style-type: none"> • Formatting survey • Identifying and selecting sample
June–July	<ul style="list-style-type: none"> • Meeting with Older Women's group - feedback session and discussion 	<ul style="list-style-type: none"> • Piloting survey • Ethical discussions 	<ul style="list-style-type: none"> • Pilot survey • Media work • Finding volunteers • Working out details of surveying process
August	<ul style="list-style-type: none"> • Sharon and Verle leave the centre • Meeting with collective on final stages and catch up 	<ul style="list-style-type: none"> • Final changes to survey • Begin training volunteers for interviewing 	<ul style="list-style-type: none"> • Training volunteers for interviewing • Media work

September		<ul style="list-style-type: none"> Organising and training interviewers 	<ul style="list-style-type: none"> Begin surveying in Snells Beach area
October–December	<ul style="list-style-type: none"> Lull in project 	<ul style="list-style-type: none"> Interviewing continues Setting up database for data entry of surveys 	<ul style="list-style-type: none"> Interviewing continues Setting up database for data entry of surveys Supporting volunteers
2000			
January–February	<ul style="list-style-type: none"> Lull in project 	<ul style="list-style-type: none"> Data entry of survey begins Update sample from revised membership list Organise second round of volunteer interviewers Major changes in Auckland branch and shifting office 	<ul style="list-style-type: none"> Finish surveying Snells Beach Continue surveying Wellsford area Begin data entry of survey
March	<ul style="list-style-type: none"> Letters to the Ministry of Women's Affairs & the Retirement Commissioner 	<ul style="list-style-type: none"> Interviewing continues Data entry continues 	<ul style="list-style-type: none"> Surveying in Wellsford completed Discussion of next steps Data entry continues
April		<ul style="list-style-type: none"> Brainstorm of how to use survey Interviewing & data entry continues 	<ul style="list-style-type: none"> Data entry continues
May	<ul style="list-style-type: none"> Article sent to Retirement Commissioner 	<ul style="list-style-type: none"> Interviewing completed Data entry completed Analysis of data begins 	<ul style="list-style-type: none"> Data entry completed

June	<ul style="list-style-type: none"> • Same article sent to the Ministry of Women's Affairs 	<ul style="list-style-type: none"> • SES submission prepared drawing on survey analysis 	
July–August	<ul style="list-style-type: none"> • Discussion of next steps 	<ul style="list-style-type: none"> • Initial analysis of survey for committee prepared 	
September	<ul style="list-style-type: none"> • Meeting with WAWC and Sharon to identify ideas and networks for disseminating findings 	<ul style="list-style-type: none"> • Copy of Auckland branch findings given to National Association • National body decides to run survey nationally • Work with national to modify Auckland branch survey form, model, and data-entry database for national survey 	<ul style="list-style-type: none"> • Survey analysis begins
October	<ul style="list-style-type: none"> • Meeting with WAWC and Verle to work on revised report form for disseminating findings • Flyer prepared for the Women's Book Festival 	<ul style="list-style-type: none"> • First instalment of survey results in newsletter • Identifying next survey steps • National association begins surveying and data-entry • New Auckland branch committee elected and is updated on survey 	<ul style="list-style-type: none"> • Survey analysis completed and initial feedback to Homebuilders
November–December	<ul style="list-style-type: none"> • Identifying and contacting possible funding sources for printing report 	<ul style="list-style-type: none"> • Second instalment of survey results in newsletter • Initially analysis of national survey combined with Auckland survey prepared for a meeting with the Ministry of Education 	<ul style="list-style-type: none"> • Begin planning next steps

Chapter 3: West Auckland Women's Centre Action Research Project

The Beginning

Sharon Milne, a member of the West Auckland Women's Centre (WAWC) and a good friend, suggested to me that the centre may be interested in working together on a project. Following this I sent Sharon a copy of the information sheet about myself and what I was looking for (Appendix 3.2) and Sharon raised the idea of my working with the Centre at a collective meeting. There was a positive response and this led to a first meeting with a subgroup of the collective and myself. This first meeting took place in June 1997 and we had an initial discussion exploring the possibility of working together.

Exploring Possibilities

Following the initial meeting, I continued to meet with Sharon and Verle, a subgroup from the centre, and we had a series of brainstorming sessions to identify an issue area that interested the WAWC. The collective operated with a number of subgroups and they discussed the idea of structuring working with me in this way at the beginning. The subgroup was formed for working on the project, with other WAWC members stepping in as appropriate.

One of the aims of the collective was to exercise its voice at a national level on relevant issues. Verle also expressed the need for ongoing political challenging of the collective itself in order to prevent it from becoming buried as just another 'service provider'.

An idea that emerged early in our brainstorming sessions was that the collective was very keen to work with other groups in some form of flexible joint project. This was a model that the WAWC had used before and found attractive. Although the idea of a joint project was attractive to the WAWC, joining up with another group did not eventuate. None of the other groups I contacted expressed an interest in the issue area chosen by the WAWC.

We had a number of very interesting initial discussions, exploring a range of possible research topics and issues. We discussed doing a project across time, for example over two years and possibly picking up strands from the WAWC's Feeling Stretched project (The West Auckland Women's Centre, 1994). We also discussed a range of different possible research methods and the point that the issues may change/evolve over time. As the discussions continued our ideas became more focused. The nature of the project gradually emerged and developed with each discussion. At this time I was meeting with the WAWC fortnightly. Following is a reflection from these early discussions:

Lots of different possibilities exist and it is good that we are talking about building on things done in the past. Personally I'm interested in highlighting the expectations of older women but Verle is making it clear she doesn't see it limited to that age group, Sharon agreed. Lots of discussion about how to put together a really rich picture, and then we can focus down on strands and say this is the one we want to explore, and I suspect that will be the approach we take here. Start with a picture with a lot of depth and then focusing down on the angles we want to pursue.

I really enjoyed another brainstorming session today. We didn't decide concrete steps ahead because we're not ready to do that yet but it will come easily out of this sort of brainstorming session. Verle was expressing a really keen desire to have a project she can get her teeth stuck into, a good omen for things developing. Both Verle and Sharon are interested and on board at this stage although what shape the project takes is still open. However it is starting to take on some sort of shape and we are putting some of the key ideas in place.

Issue of Retirement Provision Emerges

In 1997, leading up to the referendum on superannuation, there was a lot of debate around superannuation policy, particularly around the future cost of superannuation for government. As well as providing a number of services to women, the WAWC saw engaging in political debate as an important part of its function and activities. Over time and through discussion a strong interest emerged in engaging in the public debate on superannuation. There was particular concern about the limited nature of the public debate about superannuation at the time. There did not appear to be much consideration of the reality of the lives of many women in relation to their ability to save for their own retirement.

At one stage the WAWC asked to put our regular meetings on hold as they were in the midst of all their funding applications. This meant only a slight delay and we continued meeting again in August.

Literature Review on Recent Superannuation Debates

During August – September 1997 I prepared a specific literature review for the West Auckland Women's Centre, reviewing the recent debates over retirement income and in particular the implications for women and unpaid work concerns. The literature review was used to further refine our ideas about the direction to take with the project and it was helpful in informing our discussions.

The literature review occurred in the lead-up to the referendum on the compulsory Retirement Saving Scheme (RSS) being proposed by Winston Peters. The RSS would

have made it compulsory for all people earning an income to choose a retirement savings fund and pay a proportion of their income into it until the age of 65. At the time there was extensive debate on the viability of continuing with the current system of New Zealand Superannuation (NZS), and a range of alternatives, other than RSS, were being proposed. The literature review examined the main arguments for and against RSS, and then, presuming the referendum would be against RSS, the review examined the alternative options being presented by participants in the debate. Participants proposing alternatives included The Ministry of Women's Affairs, the Todd Periodic Review Group, and Jenny Shipley. Following this, two key issues for future debates were identified. Firstly the need to focus not just on affordability, but on the distribution of goods and services available at a point in time between all members of the population. The second key issue for future debates, identified by Susan St John (1996, p. 34), was whether the state pension would continue as a universal pension or become a targeted welfare benefit. The literature review and discussions helped shape our perspective on the issue and the questions we were interested in. I have included the literature review in its original form as Appendix 3.1.

Following the literature review we continued exploring the issue of retirement income and began developing questions to ask and our method. We were interested in finding ways of concretising the issue of retirement income in the actual situation of some women's lives and how their situation changes over time, and then using this as a basis for furthering public debate on the issue of retirement provision and government policy. We were considering doing interviewing or possibly using focus groups. There was also the possibility of going back to some of the people involved in the Feeling Stretched project. We were interested in covering all age groups and not limiting the interviews to one age group.

Choosing Our Method

After further discussion we decided to interview a number of women for a small qualitative study, including some from the Feeling Stretched project (this included some questions on retirement provision). We discussed how many women to interview, deciding on under twenty to keep the project manageable. The Women's Centre identified 15 women to interview, drawing on their networks, snowballing and some of the women involved in the Feeling Stretched project. The women were all from the predominantly suburban area of West Auckland, reflecting the geographical area covered by the WAWC. The women also reflected a wide socio-economic range, age range, family situations, and paid and unpaid work situations. The WAWC deliberately chose to interview only Pakeha women, as they felt this was more appropriate for a predominantly Pakeha organisation. The view was that aspects of the process and the membership of the group of researchers would need to change for the research process to be inclusive and appropriate for other cultural groups.

We discussed what level of participation to ask for from the women, deciding on doing interviews in the first instance and then to have some catch up phone calls over the next year. The follow up phone calls were to discuss any significant events that occurred in regard to retirement income and to be snapshots of changes in the women's situations. We also decided to ask the women regarding their level of participation at various points during the project. We wanted the women to be able to have some input into saying how involved they wanted to be.

We decided to leave decisions regarding how to use the material from the research until after it had been collated and reflected on. There was also a commitment to consultation with the participants before publication.

We discussed method and theory as well, particularly about action research and how open that needed to be. The collective was keen to build on previous research done by the WAWC, particularly the Feeling Stretched project. We also spent some time reflecting on what had worked with other WAWC projects. Another activity was checking with other sources, such as the Ministry of Women Affairs and the Department of Statistics for relevant information and progress on the time use study.

Preparing Pilot Interviews & Group Discussion

From October 1997 on, the nature of our meetings began to change from general discussions and reflections to more focused planning and organising of the actual research steps. Following is one of my reflections from a planning meeting.

It was quite a short meeting dealing with practicalities. We are progressing along smoothly at the moment in terms of setting up the interviews. I had changed my background information sheet and they had changed the letter and so we were checking both of those over and they seem ok. I've got to put my sheet on letterhead and send it back to them, they will then let me know as to when it suits people to have the interviews, starting with the pilots from the Women's Centre. There may be a group session, and then the actual interviews. They will also make a phone call before the sheets/letter are sent out to people to interview. Again I'm pleased with how that is ticking along.

Sharon and Verle checked with the collective regarding three members of the collective being interviewed for the pilot and also having a group discussion with the collective prior to beginning the interviews. Drawing on the collective for these steps reflected the collective's role as an ongoing resource for the project.

Following are the key themes we identified for the pilot interviews:

1. Current work situation – paid, unpaid, and family situation;
2. Steps toward retirement – what steps have they taken and what steps would they like to take;
3. Retirement expectations - ideal, images (examples from people they know inside/outside family, negative or positive), when, what doing/ how they perceive their retirement;
4. Government policies - what they would like to see.

We ended up doing two pilots rather than three as two plus a group discussion was sufficient preparation for the interviews. I transcribed the pilots and these were used as the basis of a group discussion to finalise the areas and approach to be taken in the interviews. The discussion with the full collective occurred in early December 1997.

Drawing on Principles of Feminist Research

Following the principles of feminist research was central to the research project. Early on we discussed how there was no one feminist methodology but that we would follow key guidelines for feminist research and these were reflected in many of the method decisions.

Some of the guidelines for feminist research drawn on include:

- Feminist research aims to create social change (Reinharz, 1992:240);
- Replaces 'value free research' with conscious partiality (Mies 1983 : 122-123). Intellectual commitments not to truth, objectivity and neutrality, but to theoretical positions openly acknowledged as observer and context specific. "Rather than deny its spatio-temporal conditions and limits, feminist theory accepts and affirms them, for they are its *raison d'être*."(Gross, 1992, p. 365);
- Can use a multiplicity of research methods (Reinharz, 1992:240);
- Feminist research is guided by feminist theory (Reinharz, 1992:240);
- Frequently includes the researcher as a person;
- Research is an interactive process without the artificial object/subject split between researcher and researched (Duelli Klein, 1983, p. 95);
- "Another theme emerging in feminist epistemology involves shifting the focus from individual knowers to the perspectives of groups or communities. This shift in focus should perhaps represent a reminder rather than a new idea, since the 'experience' so valued in early feminist consciousness raising was in fact a collective construction."(DeVault, 1996, p. 42)

Our research sought to value women as a legitimate target of study and explore research questions that were relevant to women's lives. We wanted to make visible the ordinary context and reality of their lives and how this was shaping their actual retirement provision, their hopes for retirement and their views on government policy for retirement.

Values

It is important that what and whose values underpinning any research project are explicit as they shape the whole orientation of a project and define what is ideal and what is perceived as good versus bad. In this research project values were drawn from the WAWC, the women interviewed and myself. Everyone who had input into the project played a role in articulating values the project should reflect. The starting point from the WAWC and myself was recognising the value of unpaid work and its implications for saving for retirement, and valuing the experience and views of the women interviewed. The women interviewed expressed a range of values but a common value they all shared was the importance of a pension/benefit to prevent poverty and to enable belonging and participation.

Other values that shaped the orientation of the project were:

- An explicit questioning of shifts in the balance of individual, family and government provision for retirement;
- A view that the issue of retirement provision should involve more than an exclusive focus on affordability;
- Examining the issue of pension versus benefit – deliberately drawing out the opinions of the women interviewed.

Politics

Linda Smith identifies five central questions focusing around power, which all research should address. She locates the questions in a cross-cultural context, however they are equally valid in other contexts. The questions are:

1. Who has helped define the research problem?
2. For whom is this study worthy and relevant? Who says so?
3. Which cultural group will be the one to gain new knowledge from this study?
4. To whom is the research accountable?
5. Who will gain most from this study? (Smith, 1986, p. 9)

In relation to this project the research problem was defined by the WAWC. The study was relevant to the women interviewed and to the WAWC in their role of advocating for better government policies for women. I say the study was relevant to the women interviewed because they all chose to participate in it in part due to having an interest in improving and reflecting on their own retirement provision. The study was focused on the experience of West Auckland pakeha women and the WAWC will gain new knowledge from the study, however the findings of the project will be disseminated, both back into the local community and at a national level. The research was accountable to the full WAWC collective and to the women interviewed, as the process included seeking consultation with everyone before

publication. The people most likely to gain most from this study were the WAWC in terms of being able to further their advocating role and myself as it forms part of my doctorate.

During the project I was conscious of a balancing act between using a process that was in the interests of the women interviewed while not demanding too much from them. The process of specifically asking the women regarding their level of involvement, at points along the project, was important, as it gave them the control to become more or less involved in the project as it progressed.

Another power issue was how to represent the diverging opinions expressed by the women, to ensure everyone's opinion was respected and heard. In drafting up the findings I was very conscious of the power I had to include or exclude specific voices and ideas. I needed to be very careful not to abuse the power I had and to be very conscious of it. Group reflections were very important in drawing out the issues involved and appropriate responses.

I was the interviewer for all the interviews, a Pakeha woman and younger than most of the women interviewed. All the interviews were in English and none of the women interviewed spoke English as a second language. The interviews were an hour in length and involved me asking a number of open ended questions. Whenever I was asked questions I responded as openly as possible, answering to the best of my knowledge. The interviews were all friendly and I did the best I could to minimise any hierarchical relationship.

Ethics

Informed consent was sought from all the women prior to being interviewed. They were given an information sheet explaining the project (Appendix 3.3), introducing me and my role, and a consent form to sign (Appendix 3.4). The consent form also gave them options regarding what they would like to happen to the interview tape. The participants also had the right to decline at any stage.

We guaranteed confidentiality and anonymity for all the women interviewed. Where necessary some minor details were changed in the quotes to ensure this. We respected an obligation to maintain honesty between the researchers (the WAWC and myself) and the women interviewed. The women were all phoned prior to being sent their transcripts. The information gained from the interviews was used only as agreed on the original consent form.

Research Concepts

We had a number of discussions and also did two pilot interviews to clarify and refine the themes we wanted to examine. Because we were using a qualitative method, interviews with open-ended questions, we chose to leave the themes broad and open for the women to influence. Our final set of themes to examine was similar to the pilot themes, with the addition of an awareness of contradictions in individual and family expectations for retirement and care provision and adding the theme of what do elderly expect to provide to their family (reciprocal obligations). We were interested in exploring the contradictions: in terms of what people would like for their retirement (expectations), what provision they were making for themselves, what provision they may make for elderly people within their own family, and what they saw as reciprocal family obligations of elderly people to their families (for instance, inheritance).

In regard to what steps the women were making towards their own retirement, this question was left open so that the women could define for themselves what counted as steps for retirement. This enabled more than just financial steps to be discussed; other areas raised included health and children.

When asking about retirement expectations, I deliberately questioned the women regarding their preferences for care provision and accommodation in retirement. This enabled us to explore the importance of reciprocal relationships within families in defining what was ideal in different scenarios in retirement (for instance what was the ideal when they were healthy and how did this change when they were sick and needed care). By also asking about expectations in relation to providing care for elderly family members, we could make the connection between supporting an elderly parent and the repercussions this has on a women's ability to provide for her own retirement.

Finally we wanted to give the women an opportunity to give their own views on the balance of responsibility of government/individuals to provide for their own retirement. We also sought their views on superannuation being a pension versus a benefit.

During the interviews the women raised a wide range of ideas and issues associated with the four broad theme areas. As a result, our research concepts – what we examined, was further developed after the interviews as common themes and unusual ideas emerged.

Contacting Women to be Interviewed

Sharon and Verle decided to contact the women by phone first – before the letter was sent out. They thought a personal approach first would be more appropriate. After an initial phone contact a letter inviting them to participate in the project, explaining what was

involved, and also explaining my involvement in the project, was sent to each woman (Appendix 3.3). The letter also gave options regarding the interview tapes being returned or destroyed. The plan was to contact the women in February 1998 to make interview times.

Interviewing

In early 1998 I meet with Sharon and Verle before beginning interviewing and then we continued to meet during the interviewing period. This was a useful opportunity to feedback initial impressions and reflections from the interviews and to monitor progress with the interviews.

The interviews took a little over a month to complete. Some were held at the West Auckland Women's Centre and the rest took place wherever was most convenient for the women, usually their own house.

After the interviews were completed, the next stage was a lot of transcribing and then sending the transcripts back to the women to edit and review. The transcribing was done in March-April 1998. When I was about half-way through the transcribing I decided to seek some help with all the typing (I had a history of Occupational Overuse Syndrome and I was concerned that this may return). After discussing this with the Women's Centre, I prepared a confidentiality form (Appendix 3.5) and approached a typist to help me. We worked out a method of transcribing that was very efficient. I listened to the transcribing machine, speaking it aloud at her typing speed. This method was very fast and it also meant that where the tape was difficult to hear I could use my knowledge of the interview to understand what was being said.

During April and May I sent the transcripts back to the women to edit and review. I also asked them to choose a name for themselves.

Drawing out Strands from the Interviews

June, July, August 1998

After the transcripts had been finalised, we began drawing out all the threads from the interviews. During the period June to August 1998 I prepared a number of draft findings from the interviews. At regular intervals I meet with Sharon and Verle and we discussed the drafts and shared ideas on important themes, structure and areas to develop further. Although I was doing the actual writing these discussions were a very important source of feedback and input for developing the drafts. I divided the drafts into four separate sections, reflecting the main topic areas of the interviews. We also discussed the next steps in relation to the interview group and we decided to give an open invitation for the women to meet to discuss some of the themes emerging from the interviews.

I deliberately chose to interweave what the women said with other sources and research studies. This enabled the linkages between the experience of the women interviewed and other sources to be developed. As Maynard argues, the connecting of the experience of women with other research and theories, develops understanding and analysis.

Also at issue here is that, although women's experience may constitute a starting point for the production of feminist knowledge, it is not sufficient for understanding the processes and practices through which this is organized. ... To repeat and describe what women might have to say, while important, can lead to individuation and fragmentation, instead of analysis. Feminism has an obligation to go beyond citing experience in order to make connections which may not be visible from the purely experiential level alone. ... as Maureen Cain argues, we need 'to take our own theory seriously' and 'use the theory to make sense of ... the experience'. This is an interpretive and synthesising process which connects experience to understanding. (Maynard, 1994, p. 23-24)

Validity

Collective reflection on the themes emerging from the interviews was a very important aspect of validity in developing the research findings.

Those writers in this book who address the question of validity in feminist research seem to agree that reaching conclusions is a social process and that interpretation is a political, contested and unstable activity. ... as Holland and Ramazanoglu suggest, feminist researchers can only try to explain the grounds on which selective interpretations have been made by making explicit the process of decision-making which produces the interpretation, and the logic of the method on which these decisions are based. (Maynard & Purvis, 1994, p. 7).

By discussing and teasing through the themes together we were able to challenge and question each other regarding possible interpretations of the themes and hence our decision-making process was more explicit and thorough.

Follow-up Calls

In September 1998 I did a round of follow-up phone calls, a step mentioned in the information sheet on the project. The follow-up calls were used to pick up any changes in the situation of the women and to briefly explore two follow-up question areas – inheritance and housing. This gave the women an opportunity to bring up anything else that had occurred to them around retirement provision (eg some discussion of the media

campaigns). It was also an opportunity to gauge any interest and preferred times for a group meeting to look at themes emerging from the interviews.

The end of 1998 was a quiet period on the research project, although towards the end of the year we did begin to explore forums and ways in which the research findings could be used.

Feedback to Participants and Focus Group Session

In 1999 I continued to meet regularly with Sharon and Verle. In early March we organised a focus group session for those interested from the group interviewed (Invitation included as Appendix 3.6). This session was used to feedback some of the material from the project and to develop ideas around some key questions that we had identified. Unfortunately the turnout to this meeting was very poor (only 1 of 7 likely's and 3 maybes actually made it) and thus we had a very interesting but more informal discussion.

Following the meeting I prepared a mail out to everyone with an overview of themes emerging from the project and a handful of quotes (Appendix 3.7 is the covering letter and Appendix 3.8 is the overview). I also signalled that I would do a phone around to check in with everyone and find out the degree to which they would like to continue participating in the project.

Further Discussion on Use of Research Material

We continued exploring options for using the research material. (eg. West Auckland District Council of Social Services, the Older Women's Group in West Auckland, Probus). Verle suggested that the Older Women's Group would be interested in the project. I prepared a pack of information explaining the project and the overview material for Verle to take to their next meeting (Appendix 3.8 – the same overview material as was sent to the women interviewed).

Meeting with the Older Women's Group in West Auckland

In mid 1999 the Women's Centre and I meet with the Older Women's Group in West Auckland to discuss the research we had been doing on women and retirement provision. The meeting with the Older Women's Group in West Auckland went well. It was basically a feedback session of some of the findings from the research project and a lively discussion of key themes.

In mid 1999 we also had a feedback session with the WAWC collective as a whole. This was important for keeping the collective informed about progress on the project and the key themes that had emerged.

Changes at the West Auckland Women's Centre

By August 1999 both Sharon and Verle, the main people I had been working with on the project, had officially left the Women's Centre. They had both been with the centre for many years and were ready to move onto new things. It also signalled a time of change for the Women's Centre. Over a number of months the collective went through a process of reshaping itself, with changes to its internal structure and new members.

The project was in a lull through the end of 1999 and the beginning of 2000 for a number of reasons. One reason was that this was election time and I thought it was better for the new government to settle in before approaching relevant ministers and departments with the research findings. The other main reason was that I was in a holding mode on the projects at the end of 1999, doing only what needed to happen to keep them going, and taking some time out for myself. This was also the period of substantial change for the Women's Centre and they were happy for me to initiate the next steps when I was ready.

Dialogue with the Ministry of Women's Affairs and the Retirement Commissioner

In March 2000 I contacted the Retirement Commissioner and the Ministry of Women's Affairs regarding the WAWC project (Appendix 3.9 and Appendix 3.10). They were very interested in the research and as a result I prepared a summarised article of the project for both agencies (Appendix 3.11). There was a possibility that findings from the research could be include in a bi-monthly publication of the Retirement Commissioner, Future Focus, but this did not eventuate. Instead the office of the retirement commissioner were keen to use the research material for their strategic planning, particularly for a communication strategy for women in Jan-March 2001.

Preparation of the Research Report

Following sending the article on the research project to the Retirement Commissioner and the Ministry of Women's Affairs, we considered how the project could be further disseminated. The WAWC invited Sharon to a meeting on ideas and networks that would be interested in the project, as the Women's Centre recognised and valued her knowledge and experience (particularly from the Feeling Stretched project) in this stage of the project. We identified a wide range of groups that may be interested in the project – focusing on relevant community groups, rather than just government agencies and politicians.

We also decided to change the form of the findings and began exploring possibilities to publish it as a report. We identified a handful of agencies we could approach for funding for printing and distributing the report. We were keen to make it as accessible and reader-friendly as possible (the initial article was not an appropriate form for the main dissemination of the report) and so we looked at a range of possible presentations, identifying another

report that we could use as a model. We have now applied for funding and our scope for distributing will depend on the outcome of the funding applications. We prepared a flyer advertising the report for the Women's Book Festival and this was available throughout the festival (Appendix 3.12).

We had a group discussion on the form and content of the report, Verle was also invited to this meeting. The discussion was useful and I am preparing another draft in the revised format.

Future Steps

At the time of finishing my thesis the WAWC project is still continuing. A number of future steps have been identified. These include: finalising the format of the report and consulting with participants regarding quotes, printing and distributing the report, and publicising and presenting the report to interested groups. I will continue to be involved in all these steps as appropriate.

Concluding Comments

Working with the West Auckland Women's Centre on this project has been a pleasure. I am looking forward to the full dissemination of the project findings and I found the process of working together very supportive and the discussions along the way very stimulating.

Of the three group projects, I found the WAWC project the most manageable and straightforward. I think this was largely due to their being no major changes to the direction of the project and not having to deal with the issues of a large survey. The WAWC's past experience with major research projects was also valuable for the smooth running of the project.

Appendix 3.1

Carmel Cervin

12 September 1997

Super Review

This review seeks to outline the current field of debate between the Retirement Saving Scheme (RSS) and New Zealand Superannuation (NZS), and to look at where the debate is heading after the referendum.

Winston Peters and Jim Bolger have put forward three main arguments for RSS:

- firstly that the current system of New Zealand Superannuation is unsustainable
- secondly that the current system is too prone to political interference
- and thirdly that New Zealanders have a poor savings record.¹

Each of the above three arguments have been critiqued, e.g. the Todd Periodic Review Group reported that NZS could be sustainable with some changes, a number of opponents of RSS have pointed out that the legislation for RSS does not prevent further political changes in the future, and the Consumer magazine has come out with a strong critique of the view that New Zealanders have a poor savings record.

The arguments against RSS have come from across the political spectrum. The next section identifies some of the key arguments against RSS from various sources.

Consumer magazine, in its August 1997 issue argues against RSS using twelve reasons. In summary form these are:

1. NZ Superannuation works and with modifications is expected to remain sustainable in the first half of next century.
2. Long-term retirement planning should be subject to ongoing multi-partisan review.
3. RSS would not be free from political interference.
4. Will compulsory privatisation of retirement incomes lead to the same thing in other welfare areas, such as health care?
5. NZers already have a reasonable savings record.
6. RSS will cost more to run.
7. RSS is based on means-testing, like the surcharge.
8. RSS represents broken promises by both coalition partners.

¹ Consumer, No. 362, August 1997, p. 4.

9. RSS will allow fund managers to make poor investments, knowing that the government will provide a top-up for anyone not reaching the target.
10. RSS may cost mortgage-holders and other debtors in the long-term.
11. With the tax cuts and RSS, which current areas of government expenditure will be cut to fund the tax cuts?
12. The referendum process is itself unsatisfactory.

The Ministry of Women's Affairs has developed six principles that were to assist the RSS design team to develop a scheme that would not disadvantage women. The six principles were:

1. The compulsory scheme is integrated with NZS, or other form of state provided pension, in a way which ensures that everyone has an adequate income in old age.
2. The scheme does not significantly diminish paid work incentives.
3. The scheme, in tandem with adjustments to tax and social assistance policies, does not reduce the disposable income of those on the lowest incomes.
4. The scheme should ensure voluntary contributions from employers, and voluntary schemes that are counted as compulsory savings, do not discriminate against women.
5. Annuities are unisex, rather than gender rated.
6. The scheme in tandem with adjustments to tax, social assistance and NZS policies, should not lead to a deterioration in the relative income position of women as compared to men.²

The Ministry of Women's Affairs paper on RSS focuses on assessing RSS in relation to the six principles outlined above. Thus it outlines some areas where the scheme does not fully support the above principles and other areas for which the design still needs to be completed. Through the provision of a government top-up of savings to the level required to purchase an annuity the first principle is met. With regard to the second principle, not significantly diminishing paid work incentives, the impact of the scheme on the effective marginal tax rates faced by different income groups is assessed. There is the possibility that the scheme may act as a disincentive for beneficiaries considering taking up low paid employment and for people close to retirement in paid work who assess that they will require some form of top-up. These possibilities do not support the principle of not diminishing paid work incentives. The third principle, concerning not reducing the disposable income of those on the lowest incomes, is not supported by the scheme. It is not certain whether the scheme will support the fourth principle. For principle five, the government top-up for all women will have the same effect as unisex annuities, although there is also some discussion of future issues that may arise in this area. With regard to principle six, a list of the main differential impacts of the RSS on

² Hon Chris Fletcher, Office of the Minister of Women's Affairs, Retirement Savings Scheme paper, 11 July 1997, p. 1.

Appendix 3.1

men and women is given, and it is noted that it is “difficult to quantify the overall impacts of the scheme on the relative position of women compared with men.”³

Jenny Shipley has spoken out strongly against RSS. Her speeches clearly outline the main reasons for her opposition as well as a multitude of subsidiary supporting reasons. Her main reasons for opposition are:

- Women and people on a low income will continue to be disadvantaged by the compulsory retirement savings scheme.
- All New Zealanders personal savings choices will be limited by the compulsory retirement savings scheme.
- Concerns about the economic impact of RSS⁴

The NZ Council of Trade Unions has critiqued RSS from four angles: is it enough, is it secure, is it fair, and is it efficient. Ken Douglas sums up the NZ Council of Trade Unions opposition to RSS with “RSS is the wrong answer looking for a problem that doesn’t exist.”⁵

In looking ahead to the possible direction of the debate after the referendum, and presuming an outcome against RSS, it is useful to look at the broad alternative options being presented by participants in the debate.

The Ministry of Women’s Affairs paper goes on to make a second comparison of how women would fare relative to men if the current regime were to continue. Three main options are given for adjusting NZS provisions prior to the escalation of costs predicted in around 20 years time. The options given are firstly reducing the level of NZS, secondly raising the age of eligibility for NZS, and thirdly targeting of NZS against other income. The third option is identified as the most equitable of the three alternatives.⁶

The terms of reference for the Todd Periodic Review Group were:

- describe trends and likely future developments that will affect or will be likely to affect retirement income policies
- comment on whether emerging trends of public and private provision of retirement income are adequate, efficient, equitable, and sustainable

³ Hon Chris Fletcher, Office of the Minister of Women’s Affairs, Retirement Savings Scheme paper, 11 July 1997, p. 6

⁴ Hon Jenny Shipley, There’s Nothing Super about Compulsion, Address to Auckland Executive Club, Auckland, 14 July 1997, pp. 2-6.

⁵ Ken Douglas, editorial in New Zealand Council of Trade Unions paper on RSS.

⁶ Office of the Minister of Women’s Affairs, Retirement Savings Scheme paper, 11 July 1997, p. 6.

- identify areas of risk or unsatisfactory performance in relation to the provision of retirement income
- suggest modifications to retirement income policies, where desirable.⁷

The Periodic Review Group presented a number of options for adjusting NZS. These included:

- gradually raising the age of eligibility;
- adjusting NZS rates by a mixture of price and wage movements;
- reducing the net amount provided from public funds for a retired person as that person's total income increases (income testing/ targeting).⁸

Jenny Shipley states that changes will be necessary and that there are "only three ways to achieve this:

- to privatise superannuation with some public top-up as the compulsory retirement savings scheme proposes;
- to retain full NZS as we currently know it, with no change, but with significant tax increases;
- or to retain some form of NZS with private voluntary savings top-ups and tighter income testing."⁹

Shipley argues that the second option is unrealistic and that the third option is the direction to take. "I believe New Zealanders need to agree what percentage of GDP we can realistically hope to spend on retirement savings now and in the future."¹⁰ She suggests that the alterations to NZS "could be through a universal element being available to all and a tightly income tested top-up for those who have no other sources of income."¹¹

In an earlier address to the National Council of Women Northern Regional Seminar on 10 May 1997, Jenny Shipley comments that "Over the last 25 years New Zealanders have struggled to understand that the welfare state was never intended for the middle class. ... We should not perpetuate the myth that New Zealand historically has been able to afford a universal

⁷ Jeff Todd, Address to The Super Seminar, New Zealand Federation of University Women, 16 August 1997, p. 3.

⁸ Jeff Todd, Address to The Super Seminar, New Zealand Federation of University Women, 16 August 1997, p. 4.

⁹Hon Jenny Shipley, There s Nothing Super about Compulsion , Address to Auckland Executive Club, Auckland, 14 July 1997, p. 9.

¹⁰ Hon Jenny Shipley, There s Nothing Super about Compulsion , Address to Auckland Executive Club, Auckland, 14 July 1997, p. 11.

¹¹ Hon Jenny Shipley, There s Nothing Super about Compulsion , Address to Auckland Executive Club, Auckland, 14 July 1997, p. 11.

Appendix 3.1

retirement scheme, nor should we pretend this is possible right through the period of the aging population from 2020 onward.”¹²

When looking ahead to the options after the referendum the unity with which voices across the political spectrum are speaking against RSS breaks up and traditional ideological political differences become more visible again. There is basic agreement over the options, that is higher taxes, targeting NZS, raising the age of eligibility, and reducing the rate of NZS. These areas are likely to be the main terrain of future debate. The basic issue is still seen within the lens of affordability, but the different ideological perspectives differ in the mix of options they see as preferable.

Susan St John argues that “We have to ask why it is that there is support from all shades of the political spectrum for the current regime. Is it that people see the role of the state pensions differently? I believe a critical fight will be over the nature of the state pension.”¹³ The fight over the nature of the state pension which Susan St John is referring to, is about whether the state pension continues as a form of citizenship right, based on residency in New Zealand, or whether it is redefined more narrowly as a targeted welfare benefit for people unable to support themselves.

Gareth Morgan has clearly expressed the targeted welfare benefit view of the nature of the state pension: “So what should government policy on superannuation provision be? Simplicity, minimal intervention and addressing real need is the only rationale for state payouts. This means leave it to self provision but then provide a superannuation annuity of last resort to those who fall short of the means to provide for themselves. Most importantly this safety net should be slung so low that nobody would aspire to such a measly income. If it is not set that low the hazard of people deliberately seeking to qualify for the state pension will boost the burden on the rest of us taxpayers unnecessarily. Further, to qualify the applicant must be both income and asset tested.”¹⁴

There is one other major line of argument in the current debate which is against not just RSS but is basically saying the focus on the affordability aspect of whatever superannuation policies we have should not be the main issue. Prue Hyman says the issue of affordability is a red herring altogether. She argues that both the government’s ability to pay pension and the

¹² Hon Jenny Shipley, *Superannuation and Compulsion*, Address to National Council of Women Northern Regional Seminar, 10 May 1997, p. 7.

¹³ Susan St John, *Compulsory Superannuation. Social Policy Planning Point of View*, Address to The Super Seminar, New Zealand Federation of University Women, 16 August 1997, p. 4.

¹⁴ Gareth Morgan, *NZ Herald*, 5 August 1997.

performance of private super funds will be dependent on various economic factors.¹⁵ The various economic factors she is referring to is around the importance of what is sometimes referred to as 'the size of the cake', the overall level of goods and services available in our society at a point in time to be distributed between all members of the population. The living standards of people of all ages will be determined by the real goods and services available to them.

When the definition of the problem is turned in this direction, away from a narrow focus on affordability, and toward a focus on how the goods and services (including all aspects of physical care) are to be distributed between workers and retired people, the terrain of the debate is opened right up. When the focus is on only affordability then the issue for women is seen primarily in terms of the need to maximise their time and income in the paid workforce in order to minimise their reliance on a meagre state pension. But when the focus shifts to this broader terrain, then the very real demands women face on their time to provide care for both elderly and young people can be recognised within the public debate as part of a public choice on how we wish to distribute not only the income in our society but also aspects of physical care. Below are some quotes from Susan St John which very clearly express this line of argument.

"The enjoyment of a fulfilling retirement is inextricably linked to issues of physical security, mental, physical, economic and social health, the distribution of income and wealth, and sustainability of the earth. To confine the discussion to monetary accumulation is to buy into the illusion that money is all that matters."¹⁶

"The dependence on the next generation of workers cannot be avoided. Those workers must provide most of the personal labour intensive services for the older generation so that the skill, caring and ethical responsibility of that workforce is critical. ... Women in their 40s and 50s and younger retired women will find increasing demands on their time and energy for monitoring, visiting, supporting, providing friendship, helping with taxes, acting as trustees and executors, arranging funerals, nursing, shopping, and driving to appointments and other caregiving."¹⁷

"On the male model of employment, one's highest earning capacity should be achieved in later years along with the greatest ability to set money aside as parental responsibilities lessen. Many women not only do not enjoy the advantages of high earnings in later life but

¹⁵ Consumer, No. 362, August 1997, p. 6.

¹⁶ Susan St John, Keynote Speech at Retirement Income and Women Conference, June 1996, pp. 27-28.

¹⁷ Susan St John, Keynote Speech at Retirement Income and Women Conference, June 1996, p. 31.

Appendix 3.1

with the pressures of aging neighbours, relatives, and older friends many may have less, not more opportunity to participate in paid employment in those critical years.”¹⁸

Unfortunately Susan St John’s very clear and crucial line of argument for women is existing largely on the periphery of current debates as affordability remains centre stage. Even the Ministry of Women’s Affairs background paper titled *Women and Retirement Income: Current Issues*, does not adequately, specifically and with sufficient detail, examine the significance of this unpaid caring work. The document identifies a number of reasons that make retirement income is an important issue for women:

- Women live longer than men
- Women earn less than men
- Women are more likely to have part-time employment or have long periods out of the workforce
- Women are more likely to live alone in older age
- Women are less likely to have private superannuation or to belong to employment based schemes
- Women contribute to communities and households

For each of the above reasons the paper gives background statistics and some general discussion. With regard to the fact that women are more likely to live alone in older age it is noted that “While women will provide care for their spouses during their final years, they often do not have a primary unpaid carer able to provide them with the same level of care. They will therefore need to purchase these services or move into residential care.”¹⁹

The final reason, that women contribute to communities and households, is the only one for which no statistics were given - as none exist. The general discussion only states that women are major contributors to community work and unpaid care of children, older spouses and other family members. It does not draw out fully or clearly the significance of this reality for women and retirement income. The concluding comment notes that “As many women have husbands who are older they are more likely to be in the position of providing care for their partner in their older age. If women were unable to provide this care, it is likely there would be an increase in the number of older people requiring residential care.”²⁰

¹⁸ Susan St John, Keynote Speech at Retirement Income and Women Conference, June 1996, pp. 31-32.

¹⁹ Office of the Minister of Women s Affairs, *Women and Retirement Income: Current Issues*, A Background Paper, 11 July 1997, p. 2.

²⁰ Office of the Minister of Women s Affairs, *Women and Retirement Income: Current Issues*, A Background Paper, 11 July 1997, p. 3.

The problem with the debate when it is seen primarily in terms of an issue of affordability, is that the solution is seen in terms of increasing the significance of paid work as the means for everyone to save their own nest egg for retirement in order to avoid being dependent on a meagre government pension. Inevitably this has huge disadvantages for women as it increases the pressure for them to place priority on paid work careers, and completely misses the point that the demands for their unpaid work are also going to significantly increase.

In the question and answer session of the The Super Seminar held by the New Zealand Federation of University Women, a key question was raised:

“Question 7: Will the proposed scheme have a detrimental effect on women as mothers and caregivers as there will be huge pressure for women to go into the workforce to save?” Anne Batten and Susan St John gave the only two responses to this question. Anne Batten responded with “In a political context, with the unpaid work time-use survey - we will be able to quantify what the value of unpaid work in the home and community really is, and that will reduce the pressure for women to go out and work because they will feel ok about their role at home, so there will be no more pressure than there is now. Also, for women, if she were to die, her contribution can be left to her family.” Susan St John commented that “I worry that the tax cuts will not match the contributions, so that women on low incomes who face the RSS contribution will have an additional disincentive to work because it is a tax. It is very important for women to have additional savings which they get from being in the workforce, so there are very good reasons for women to keep a toe in the labour market.”²¹ Thus the current debate is already reinforcing the message that it will be essential to have our own savings from our own paid work.

Susan St John has commented that “The political debate will be on whether the state pension is a pension or a welfare benefit. This is critical.” Whether it will be possible to shift the debate away from primarily affordability to a broader debate over the distribution of goods and services is very much an open question. The recognition of the necessity and value of unpaid caring work will probably be key to arguing for a continuation of the pension rather than shifting NZS to a welfare benefit.

²¹ Susan St John, response to question at The Super Seminar, New Zealand Federation of University Women, 16 August 1997.



MASSEY
UNIVERSITY

A L B A N Y

20 May 1997

FACULTY OF SOCIAL SCIENCES
DEPARTMENT OF SOCIAL POLICY & SOCIAL WORK

Background Information Sheet

Personal Background

- My name is Carmel Cervin and I am starting a PhD at Massey University, Albany campus.
- My area of interest is injustices in the relationship between paid and unpaid work in New Zealand and ways these should be addressed.
- Marilyn Waring and Mike O'Brien are my supervisors.
- My undergraduate degree was a BA/BCom at Auckland University, in NZ history and computers.
- Over last summer I worked on a research project, co-ordinated by Mike O'Brien, looking at Social Service needs and responses in Auckland.
- I have been a member of the consultative group of Catholic Family and Community Services for the past couple of years.
- I am a young Pakeha women, the oldest of a family of six.
- A strong part of my upbringing has been to question and challenge injustice, whether through the Springbok protests, anti-nuclear campaigns, or questioning church structures and injustices. Thus this motivation for social justice shapes my interests and questioning.
- I am rooted in a belief in community, both as a source of identity and as the means of challenging injustice. Community is a key source of empowerment for both question and action.

Key Starting Points

1. Use of Action Research Method
 - Collectively planning, acting and reflecting.
 - Not exclude the use of other methods where and when appropriate.
 - Action research as a way of orienting relevance and use of study towards social change.
2. Explicit political agenda of clarifying specific structural changes (most likely in terms of state responses) needed to address injustices arising from relationship between paid and unpaid work. That is a focus of identifying specific social injustices and then looking at how these could be addressed, finding appropriate ways of working towards social change.
3. I am open in regard to what specific issue might be chosen. The specific issue must be what is most relevant and appropriate to the group.
4. My hope is to work with more than one group, and for my role to be on the terms decided by each group.



Retirement income and unpaid work

Dear

In 1994 the West Auckland Women's Centre conducted a Health Research Council funded research project called "Feeling Stretched" which examined the impact of economic and social policy changes since 1990 on the health and well-being of West Auckland women with dependents under the age of 25.

As an extension of this research, and with the current focus on superannuation, we are interested in exploring with you, as part of a small qualitative project, your ideas on retirement income and issues around unpaid work and how these might impact on you at different stages in your life. We believe it is important to document New Zealand women's experiences as any changes to retirement policy will have a significant impact.

To help us with this task, we are working with Carmel Cervin (see attached profile) who is a PhD student from Massey University, Albany. Her thesis is concerned with injustices in the relationship between paid and unpaid work in New Zealand and ways these should be addressed. She will be the person who, with our support, will make contact and conduct the interviews.

We invite you to be part of this project and whatever input you are able to make would be a valuable contribution. This is a 2 year project and our initial contact would be to meet at a mutually agreed place for an interview which will take approximately one hour. There after contact will be made every 3 months or so by telephone or in whatever way is most convenient to you. At the completion of this study, we would like to seek permission for further occasional contact. The tapes from all interviews will be returned to you if you wish or destroyed at the end of the research period.

We have identified a number of key issues to assist with prioritising what you perceive are the main areas for discussion.

- Are you doing paid work? What is your current situation?
- What is the range of your unpaid work? - school committees, sports, caring for older relatives etc.

111 McLeod Road
Henderson, Auckland
Aotearoa (New Zealand)
P.O. Box 69-116 Glendene
E-mail address:
wawc@cybernet.co.nz
Tel 09-838-6381
Fax 09-836-2470

- How do you envisage your retirement?
- Is there anyone either within or without your family who you see as having a successful retirement?
- Is there an image of retirement which raises negative feelings for you? Do you know anyone whose retirement has turned out badly for them?
- What steps have you taken towards your retirement?
- Given ideal circumstances what steps would you take to secure a satisfactory retirement?
- What would you see as an ideal retirement policy for women?

Part of the Women's Centre's role is as an advocate on issues affecting women and making recommendations to policymakers in government is an integral part of our work and therefore we would, with your permission, utilise the information for this purpose. The results of this research will form part of Carmel's PhD thesis and all participating women will receive a summary of the research results and conclusions. All information given will be treated as confidential and your consent will be sought with regard to any additional input. You may leave the project at any time and participate to whatever level suits your needs.

We intend to begin this research in February 1998 and we will contact you closer to that time to arrange a suitable meeting time. Thank you for your participation.

Yours sincerely

A handwritten signature in cursive script, appearing to read 'Nerle', with a long horizontal flourish extending to the right.



West Auckland Women's Centre Consent Form for Retirement Income and Unpaid Work Project

I have read the Information Sheet and have had the details of the retirement income project explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand I have the right to withdraw from the study at any time and to decline to answer any particular questions.

I agree to provide information to the West Auckland Women's Centre and Carmel Cervin on the understanding that confidentiality and anonymity will be preserved.

The information will be used only for this project and publications arising from this project and for Carmel Cervin's PhD thesis. I understand that I will have the opportunity to edit or delete any information before it is used.

I *agree / do not agree* to the interview being audio taped.

I understand that I have the right to ask for the audio tape to be turned off at any time during the interview.

At the end of the project I would like the tape to be
returned to me / destroyed.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signed:

Name:

Date:



A L B A N Y

COLLEGE OF HUMANITIES AND SOCIAL SCIENCES

DEPARTMENT OF SOCIAL POLICY & SOCIAL WORK

West Auckland Women's Centre Confidentiality Form for Retirement Income and Unpaid Work Project

I agree to keep all details that I have heard on tapes for the Retirement Income and Unpaid Work Project confidential. I will not discuss information regarding this project with anyone. I understand that this is to ensure that I preserve the anonymity and confidentiality of project participants.

I also agree to erase any files in my possession relating to this project.

Signed:

Name:

Date:



18 February 1999

Dear

As discussed by telephone, the West Auckland Women's Centre is inviting you to a meeting:

Where: 111 McLeod Rd, Henderson – Cnr TeAtatu & McLeod Rd

When: 2 March 1999, Tuesday evening

6.45 – 8.45pm

Light refreshments will be provided

This meeting will be an opportunity to update the research and discuss a section of the final data coming out of the interviews.

A wide range of themes have emerged from the interviews. One theme is how providing care to children and parents has a significant impact on a woman's ability to save for retirement. The current government policy debate around superannuation is shifting to whether super should be a universal pension or a targeted benefit. The area that we think would be interesting to discuss is:

- *Why superannuation should remain as a pension rather than a benefit ?*
- *What the pension recognises and how should it be measured ?*

The Women's Centre supports a process of consultation and participation and this meeting will enable you to have a say in the direction of this research project.

Yours sincerely

Carmel Cervin

111 McLeod Road
Henderson, Auckland
Aotearoa (New Zealand)
P.O. Box 69-116 Glendene
E-mail address:
wawc@cybernet.co.nz
Tel 09-838-6381
Fax 09-836-2470



16 March 1999

Dear

Enclosed is an overview of themes emerging from the women and retirement income project so far. This overview is to inform you and give an indication of the material that's come out of the interviews. The range of themes show the breadth of the project and the handful of quotes give a indication of the vividness of everyone's reflections.

A number of these themes were further explored at the meeting at the West Auckland Women's Centre in early March. Many thanks to those who were able to attend the meeting, some interesting discussion was generated.

Within the next week I will do a phone around to establish the degree to which you are able to continue to participate in the project. This could range from no further involvement, to wanting to be kept informed as to how the project is developing, to acting in some form of advisory capacity around how the research material could be used, or any other role suggestions.

Looking forward to catching up and many thanks for your participation.

Yours sincerely

Carmel Cervin

111 McLeod Road
Henderson, Auckland
Aotearoa (New Zealand)
P.O. Box 69-116 Glendene
E-mail address:
wawc@cybernet.co.nz
Tel 09-838-6381
Fax 09-836-2470

Retirement Income and Unpaid Work Overview

This overview is a brief outline of the material emerging from the retirement income and unpaid work project. One of the limitations identified in the current debate on superannuation is a strong focus on the funding of superannuation leading to an emphasis on individual saving. Focusing only on funding issues misses many significant issues for women and retirement income. This project has sought to draw in the wider issues of unpaid work and provision of family care to understand how they impact on the issue of women and retirement income.

The overview is divided into three sections. The first section is the starting questions and aim used for the interviews. The second section is a brief point outline of themes emerging from the interviews and the third section is a handful of quotes to give a more direct sense of the experience and reflections of the women interviewed. The interviews occurred in the first half of 1998 and fifteen women from West Auckland were interviewed.

1. Interview Questions:

Aim: To explore the contradictions in terms of what people would like for their retirement, what provision they have/are making for themselves and related issues, and what provision they may make for elderly people within their own family and what they see as reciprocal family obligations of elderly people.

Questions:

1. What do people expect in retirement (common ideals), in terms of:
 - independence
 - choices
 - financial security
 - living arrangements
 - care provision
2. What provision for retirement do people expect to make (feasible steps towards retirement - individual provision)
3. What do people expect to provide for elderly family members (family provision), in terms of:
 - physical care
 - financial
 - accommodation
 - keeping an eye
 - NB: interacts with ability to make feasible steps
4. What do elderly expect to provide to their family (reciprocal obligations) in terms of:
 - grandchildren
 - inheritance
 - financial assistance
5. What should government responsibility be, in terms of:
 - financial security
 - accommodation
 - care provision

2. Interview Themes

Retirement expectations

- financial security and control - not relying on partner or solely on state
- ability to make choices - requires sufficient resources, freedom from the norm, making choices before health deteriorates

Appendix 3.8

- views on living and being cared for by children - for/ against, living close, depending on health, not wanting to be a burden, paying for care from family, only if family have time
- family care vs rest-home care

Steps towards retirement

- being prepared/ in control
- paying off the mortgage/ housing as focus
- pooling resources with friends
- health - living healthy and insurance
- other steps – owning a business
- continuing to work, putting off retiring
- inheritance as a backup to steps
- partners - disappointment in not getting a share of a partners scheme, issues around sharing a scheme, having a partner who has taken responsibility, significance of partnerships
- not using work schemes
- attempts to prepare/responding to expectations - on and off again, subject to changes in situation, unforeseen crumbling plans, having a small subsistence scheme
- not feasible to prepare financially
- token schemes as a response to pressure
- media and other reasons for starting a scheme - relating to changes in life situation, withdrawing more from paid work and recognising inherent risk for future
- feeling the pressure but not able to make any provision - leading into conflicting expectations
- family first, maybe make steps later

Family provision expect to provide/ currently providing

- primary caregiving - preventing need to move into rest home for the time being
- past experiences, in the house caregiving and support when live close by, travelling to stay when live further away
- support and possibility of increase in caring needs in immediate future
- Mixed feelings on extended family - not sure if can handle providing care in home
- Negotiating family responsibilities - women picking it up
- Being perceived to be available
- being chosen
- providing support but setting limits - past experience & future scenarios
- not picking it up
- can't rely on family provision – spouse most likely
- rationing of services – those without family have first access – pressure on families and means-testing
- increase demand for rest-home private care at expense of inheritance
- housing assumptions

What do elderly expect to provide to family

- currently actively providing care for grandchildren
- grand-parenting kids have access to
- happy with/not wanting primary backstop caregiving role
- providing financial support

What should/could be a better balance of provision

basic provision due to uncertainty/life circumstances

- necessity of an income for those who can't save
- not relying on partners
- conflicting expectations - saving and being a primary caregiver to children
- caring by choice
- wealthy don't need super - means test? - but cut off must be reasonable
- concern over adequacy of super (follows means testing)
- govt. priorities (against meanstesting)
- part of the whole picture of provision for elderly people
- a time and a season

provision that recognises life/caring work

super as entitlement/ as of right

- shouldn't feel lucky, is entitlement
- recognising working class role in country
- Pension as of right
- right due to paying taxes

pensions vs benefits

- not trust governments agenda, against labeling people, unrealistic savings goals
- against as reducing women's independence, having to be grateful, assumptions about access to family wealth
- against stigma associated with benefit
- individual vs collective responsibility, against deserving and undeserving, rights based as recognising different contributions, means-testing as degrading
- role of tax incentives rather than penalising through low benefit
- life work justifying entitlement

pension and women's independence

- having your own money
- recognising work women do

super recognising caregiving

- remembering family benefit
- difficulties in measuring unpaid work
- need to recognise directly unpaid work

not fair to penalise those picking up unpaid work - recognising role of parents

funding superannuation provision

paying for superannuation through taxes

- pay more tax and be guaranteed security, easier way of providing
- separate super fund, not part of consolidated fund, hard to trust govt., need some govt. guarantees
- govt. needs to use taxes to manage redistribution within elderly group, going back to previous scenario but not raising taxes

progressive taxation - mixed feelings

- cynical about progressive tax
- favour progressive tax over regressive taxation

role of private schemes

role of tax incentives to save

- linking tax incentives to broader picture

3. Interview Reflections & Experience

Doreen: Yeah, I wouldn't like to be without extra income over and above the superannuation. I wouldn't like to be scraping through, I think that's really tough. Somebody said 'old age is not for cowards', and it's hard enough being elderly, with all these aches and pains and slowing downs and the world closing in without having to worry about am I going to have enough money to buy some of my food with this week. I think that's terrible. So that's my negative image of old age.

Janet: No I'd like to be in a position to make choices about myself. I think that's a time when I really deserve those choices and if I felt like travelling I'd like to be able to travel, to have something put aside to um travel and just live a really full life.

Carmel: Ok, so a degree of financial independence enough to have those choices.

Janet: It's about choices for me really, if I choose to do something I want to be able to do it at that time because there's no way I can actually be saving towards something I don't think, it's gonna have to be there already and I can't rely on my kids. I don't assume they're going to be doing too much, I'm hoping that they'll be supportive but I don't expect them to . . .

Amy: At the moment I've got this voice inside of me saying do something, do something, do something, but then my wallets saying you can't, you can't, you can't, you know what I mean, so yeah, at the moment I've got no, I've not made any arrangements for my retirement at all.

Michelle: Like society's really changing in that yes we've got an aging population. And I mean I have no intention of retiring at 60 or 65. I mean I look forward to being able to work in some capacity and earn fairly well but on a part time basis, well past 60 or 65 or whenever it is you're supposed to stop doing what you're doing. And I think that that will be, I mean most people my age, how old am I, I'm mid thirties, you know most people my age, I don't think any of us have got any intention of stopping doing what we're doing or not. The thought of not earning an income is just not, I mean you just know that you're going to have to earn an income. I certainly don't imagine that there'll be anything there to provide for me. So I just imagine that I will work and that my main asset is my home, so something will work out.

Megan: It's really interesting cos my mother's just coming up to the stage where she's entitled to the pension and she's, I mean... Like my parents are well off but she is so excited about getting money, her own money that doesn't have to, you know that's totally hers to do with what she wants. Like I think that what the pensions done is that for many women it's created their own income, it hasn't been something they've had to ask for, you know, it hasn't been linked to their husbands ...

Rebecca: It's a tricky one because so often retirement income is totally linked to income during your working years so women are very disadvantaged. I think my ideal would be that, you know where there are, there have been benefits, family benefits based on how many children you have, my ideal would be that there'd be a retirement benefit that would start to accumulate that would somehow acknowledge women or men for that matter, the caregivers who are actually homebased, who have children at home or who are or who are working shorter hours because because they're the caregivers. So it strikes me that it's not untenable that to actually do that because the government is very aware of who the children are and which house they're living in and in the same way that there has been ... an allowance that's accumulative for people who are fulltime caregivers ... cos there needs to be something that balances the fact that there have been superannuation schemes that come out of your income ...



24 March 2000

Liz Read
Communications Manager
Office of the Retirement Commissioner
PO Box 12148
Wellington

Dear Liz Read

Following on from our discussion last week, attached is a brief outline of the Retirement Income and Unpaid Work research project by the West Auckland Women's Centre.

As you can see from the outline, the research covered a wide range of issues relating to women and retirement income. I would be very happy to discuss which aspects of the research are of interest to you, in order to provide you with relevant material from the research project and to tailor it for your bi-monthly publication 'Future Focus'.

The West Auckland Women's Centre is also interested in any work that you may be doing on women and retirement income at present.

Please feel free to phone me at home on 09 376 3662. I look forward to discussing this further with you.

Yours sincerely

Carmel Cervin
West Auckland Women's Centre

111 McLeod Road
Henderson, Auckland
Aotearoa (New Zealand)
Tel 09-838-6381
Fax 09-836-2470



27 March 2000

Judy Lawrence
Chief Executive Officer
Ministry of Women's Affairs
PO Box 10049
WELLINGTON

Dear Judy Lawrence

Please find attached a brief outline of the Retirement Income and Unpaid Work research project by the West Auckland Women's Centre.

As you can see from the outline, the research covered a wide range of issues relating to women and retirement income. We would be very happy to discuss any aspects of the research which are of interest to you. We are also interested in any work that you may be doing on women and retirement income at present.

If you would like to discuss this research further or perhaps exchange information, please phone Carmel Cervin from the Women's Centre on 09 376 3662.

Yours sincerely



Carmel Cervin
West Auckland Women's Centre

111 McLeod Road
Henderson, Auckland
Aotearoa (New Zealand)
P.O. Box 69-116 Glendene
E-mail address:
wawc@cybernet.co.nz
Tel 09-838-6381
Fax 09-836-2470

Retirement Income and Unpaid Work

Recent debates around New Zealand Superannuation have focused heavily on questions of its future affordability and the role of government provision in relation to individual private savings for retirement. Although at the time of the superannuation referendum there was a lot of discussion about how a compulsory savings scheme would disadvantage women, following the referendum there has been far less discussion of the implications of future directions of superannuation for women. The debate on affordability has continued with the focus shifting to whether government should provide a pension (universal right to a retirement income) or a highly targeted means tested benefit (for those with inadequate individual provision). However the shift from a pension to a means tested benefit signals a fundamental shift in the balance of individual, family and government provision for retirement. It is important that the questioning of this balance of provision should be shaped by broader issues than just affordability.

Given that in New Zealand society women bear the brunt of all caregiving responsibilities, the shift from a pension to a means tested benefit has huge implications for women. This article seeks to reflect on the balance between individual, family and government responsibility for retirement provision based on the life experience of fifteen women living in Auckland. The reality of their lives highlights contradictions in individual and family retirement expectations. Key issues for retirement provision which these women identify are maintaining independence (adequate individual resources) and of not being a burden on family when reciprocal relationships breakdown. Location of care when elderly and no longer able to live independently is very problematic, as neither resthome care or care within the family is ideal when individual resources are insufficient and reciprocal relationships within the family have broken down.

This reflection begins by looking at the degree of financial security, independence and choices, and type of living arrangements and care provision these women would ideally like in their own retirement. This sets out some of the range of ideals these women would like, often based on their reflections of friends and older family members retirement experiences. Following on from this is an overview of the actual steps they have taken to provide for their own retirement (or lack thereof). The next section briefly looks at how expectations vary in relation to the care to provide to elderly family members. The section also highlights the repercussions supporting an elderly parent has on a women's ability to provide for her own retirement. This broad ranging reflection will assist in making visible where gaps are for women in providing for retirement and what happens in reality to fill these gaps - and the subsequent repercussions. Finally the women suggest where should/could changes in the balance of responsibility occur.

Retirement Ideals

Financial Security

An ideal which a number of women highlighted as being important to them was having their own financial security, control, and the ability to make choices in retirement and not having to rely on a partner or solely on the state.

Rose: My mother ... she was always able to earn money while we were at home but then her eye sight started failing and so she found it increasingly difficult to do her sewing. And so she ended up... in a situation where she was in her mid-50s with all of us having gone away from home and she had no earning power at all. And you know my father and my mothers relationship with money and all that sort of thing was quite traditional and they had all sorts of issues come up between them because she had no access to the money and no control over the money. They weren't short of assets, in fact their assets were quite good but she had no choices, was not allowed to make any choices, decisions around those assets and consequently ended up you know really scraping and I thought shit that's never ever going to happen to me. So that's the sort of thing I'm really avoiding ...

Appendix 3.11

The experience of Rose's mother highlights that although a couple may have a comfortable household income it cannot be assumed that the women has financial security and control. Robin Fleming has explored the allocation of money within family households in New Zealand. She found that "more women than men were involved in managing the family money, and more men than women had overall control." (Fleming, 1997, p. 54) Money management was defined as buying food and other consumer goods on behalf of the family and paying the regular bills such as the mortgage or rent, power and telephone. 'Controlling the money' was defined as setting the limits on spending and saving, having the major say in big spending decisions, and feeling able to spend money on one's own account without having to negotiate or justify the purchase to a partner. (Fleming, 1997, p. 54) She also found that in respect to Pakeha women: "Women who earned little or no income ... were often involved in day-to-day management, but not in the major financial decisions. These women were also the most hesitant about spending family money on themselves. I concluded that contributing a major share of the family income was one of the most important factors in Pakeha women's access to family money." (Fleming, 1997, p. 64) With regard to financial security for Pakeha women in retirement this implies that their ability to control money, if still in a relationship, may be influenced by their past participation in paid employment and the share of family income they contributed over time. Rose's reflection on the key differences in her mother and mother in law's situation supports Fleming's findings.

Rose: ... My mother in law is an excellent role model for me because she and her husband, they had an incredible relationship in that she was incredibly adventurous and he was very much a stay at home person ... and she always had her own house as well so they had the family house and then she wanted a bach and he didn't so she said 'well I'm going to go and buy one' and he said 'hey fine, excellent' so she bought one, so she's over there half the time ... and they're both absolutely accepted how each other was and I just think that's so rare, that freedom. I mean my parents wouldn't do that really ... I mean my mother in law's family had the financial wherewithal to be able to do that. She had started working when both her children were quite young so I guess they were different from my parents in that way because she had the financial independence and complete control over her share and you know and then the family share was kind of mutually democratically worked out. So I'm so glad that I've been exposed to that because there is a different way and I like it better.

Another twist to financial security is highlighted in Alice Day's study of expectations about care and varieties of family support among people 75 years and over in Sydney. She found that "housing tenure was also seen to be a crucial element affecting older people's own assessment of their bargaining position. A number in this study expressed the view that, as long as one owned and held onto his or her home, one had both the economic resources and rights to private domain necessary to negotiate a position of independence from children or next of kin who might find some other arrangement for the old person more to their liking." (Day, 1985, p. 53) Thus financial security and control is shaped not only by spouse relationships but also by the relationships with children or other kin and having direct control of assets may be necessary to retain choices.

A number of women talked about the living standard they ideally expected in retirement. A real concern was to be in a situation where money was not a constant worry.

Doreen: Yeah, I wouldn't like to be without extra income over and above the superannuation. I wouldn't like to be scraping through, I think that's really tough. Somebody said 'old age is not for cowards', and it's hard enough being elderly, with all these aches and pains and slowing downs and the world closing in without having to worry about am I going to have enough money to buy some of my food with this week. I think that's terrible. So that's my negative image of old age. ... Being financially strapped would be the main one and that doesn't mean being financially rich. It means being able to have enough food and to be able pay the rates and to be able to live in a safe area.

Ability to Make Choices

The ability to make choices in retirement was another important ideal a number of women discussed, and financial security was seen as a key basis to provide choices. Trish saw choices in retirement as something she would have already earned.

Trish: No I'd like to be in a position to make choices about myself. I think that's a time when I really deserve those choices and if I felt like travelling I'd like to be able to travel, to have something put aside to travel and just live a really full life. It's about choices for me really, if I choose to do something I want to be able to do it at that time because there's no way I can actually be saving towards something I don't think. It's gonna have to be there already and I can't rely on my kids. I don't assume they're going to be doing too much, I'm hoping that they'll be supportive but I don't expect them to . . .

Linda saw it as important to make choices before her health deteriorated.

Linda: I would like to be in a position where I had a choice and I would like to think that I would be smart enough to make the choice before the decision had to be made for me. . . . I've always had this discussion with my grandmother that I'll support her in whatever she decides to do but I would rather she makes the decision to move from her house rather than us having to make it for her. Because then she's got a say in where she goes, when if she's not capable of making that decision we may end up putting her somewhere she's not happy. I would like to think that I'd be smart enough to make the decision that I wasn't coping or I was going to need care and put in place the steps to provide that for myself before the decision had to be made for me.

Views on Living with Children

There was a wide range of views between these women on the issue of whether they would like to live with their children when they are elderly. A number of women talked about needing to know who their children were as adults before they could decide whether it would work. Other question areas were in relation to their children's partners and whether they would still be in the same country. It was also a possibility some of the women had not considered.

Rose: It's hard to know because they're not adults yet, but I guess that would depend on how their family situation is, if they've got partners and if they are in NZ. I mean there's no guarantee nowadays is there really, no guarantee at all really, they might bugger off overseas, leave their poor darling mother here like half of my brothers and sisters did. So yeah I haven't even contemplated that possibility . . . I had them pretty young . . . so they'll be well into adulthood by the time I get old and frail . . . I hadn't actually, it's the first time I even thought of that.

Another common response was the suggestion of living very close to their children, possibly on the same property but not in the same house.

Trish: I really like the concept of, not just for my own selfish reasons, but of a grandparent or a parent staying on the same property with their family as some other cultures do. . . . On the same property probably not in the same house, yeah. I think it's a really valuable exercise for the grandchildren for everybody. It's happened actually my neighbours did it just down the road. They had their mum, they've just moved away but their mum lived there, they built a house especially with one wing at the end, it's quite separate but it's still slightly attached and granny was always there. It worked really beautifully, I was very envious of their setup because it worked so well.

Melissa continued this theme of wanting to live close to family but suggests that this is only desirable if the family has time for the grandparent.

Appendix 3.11

Melissa: My boyfriends grandmother, sometimes she comes to stay... and she's lovely, ... and I feel sorry for her because all she does is go to house cause that's her only social outlet, because everyone's too busy to do anything with her or take her anywhere and she virtually gets shoved from house to house to house, depends who can be bothered looking after her.

Interviewer: she doesn't have her own place?

Melissa: No. She used to, she used to live very close to her daughter and son in law but then she had an intruder or something so they moved her out. Moved her in with them and I think she lived with them for about five or six years but got quite sick because she was being neglected. Like, I think as she got older people just didn't realise that like she needed more help and she needed more taking care of, and everyone's lives got busier and busier and she got more and more neglected and then got quite sick. So as a result of that she's gone and lived with the other sister who is at home all the time and can take care of her and she's a lot happier there. ... I wouldn't like to be in that situation. I'd rather be somewhere where I could be taken care of all the time than be at home and be left alone or forgotten about because everyone's too busy doing their own thing, I don't see the point of living with a family, you know.

Not Wanting to be a Burden

An underlying assumption of the living close scenario is good health. When the possibility of not being entirely healthy is raised then a concern emerges in the interviews over not wanting to be a burden on their children.

Melissa: My grandfather is quite sick at the moment and my grandmother died a couple of years ago and he's very stubborn. He lives on his own, right out so its sort of miles for anyone to go and he can't really take care of himself but he refuses to be cared for. Now having said that my parents wouldn't go to a retirement home, its funny because I think he should be in a home, you know, but he won't go. So looking at his situation I'd like to think that if that was the best thing for everybody, I'd like to think that perhaps I'd do that, I'd go to a home. If my health was bad and I couldn't take care of myself like he can't, cause of his health, I'd like to think that I wouldn't be so stubborn, and say 'oh a home, no, you know, nobody will come and see me, no' and this and that like he is. I'd like to think that I would just go to a place where I can be cared for full time and not put that burden on the children. ... Because they are too young to be taking care of him full time, they are very busy with their lives and their other, you know aspects of their life that they can't take care of him full-time, they'd virtually have to give up their jobs and they, they can't cause they've got houses to pay for, you know all that sort of thing, so yeah. And then I've seen a good experience of going into a home with a mother in-law, when she was very ill, and she was the same, she didn't want to leave her home. She was in the home by herself and thought she could take care of herself but went to a home and really thrived in it and stayed there for quite a few years before she died. Personally I'd like to think that I'd be okay to do that and have the children come and visit, but if I was well and healthy I'd quite like to live with my children or live very close to them.

Ambivalence About Care Links to Reluctance to Plan

A number of the women talked about the possibility of being sick leading to a catch twenty-two, not wanting to be a burden on women in the family but also seeing shifting to a rest-home as less than ideal. The usual scenario seems to be not to think about poor health, often leaving family to make choices when a crisis occurs.

This ambivalence about the main options for care when health is deteriorating may be an important factor in a lack of planning for future care provision. A New Zealand study by Judith Davey comparing a group using home equity release schemes and a control group not participating in such a scheme found that although people thought some preparation should be made (83% clients, 87% controls), a majority had not settled on a plan. The majority said "... that this is a family concern, although some insisted that the final decision should be with the person involved, if possible. Despite this, very few

respondents had settled on a plan; 67% of clients, 53% of controls had not talked to their families about what would happen if they needed a high level of care." (Davey, 1995, p. 21)

Alice Day in her typology identified as a distinct group elderly people who had not made plans for care provision. She named this group 'procrastinators'. "In short, these are all people who eschewed making contingency plans for custodial care because they were ambivalent about the main alternatives: move in with children or go to an institution for the aged. Since neither alternative presented a clear choice, they were reluctant to make a move in the direction of either." (Day, 1985, p. 117) The historical origins of institutional care in Britain were the poor houses which were notoriously unpopular. Negative attitudes towards rest homes today may in part stem from the undesirable reputation of past forms of institutional care.

Following is an example of the dilemma of not wanting to be institutionalised but also recognising that being cared for by family may not be ideal either.

Trish: My husband's grandmother was put into a rest home. Her husband died many years before her and she lived very independently, she's quite a stropky older woman, she's a real uppity sort of older woman, she's great. And I think it was Alzheimer's, she just became very forgetful and would leave elements on and was physically in danger. So she was taken against her will out of her house and put into a fairly upmarket rest home actually, it was horrible. They all ate at the same time, she had her own beautiful room and everything but she was so used to her independence. It was really sad and in her lucid moments she was aware of where she was and she was very unhappy. That was only sort of 20% of the time. But there were no children there. We used to see the visitors book and there were probably 50 residents and hardly any visitors signed in because it was mainly an Alzheimer's home. With that sort of focus and everything was locked, you had to get a code to get in and out. It was horrible, it was very upsetting for everybody. She died you know, didn't last too long and on the other hand my grandfather ... his wife died and he, eventually my mother bought the house behind her, just a little house and he moved in there. And he became very psychiatrically sick and he just, basically he died in his own home but he was drinking scotch and it was horrible you know, so that didn't work either. And she tried that and she ran herself ragged looking after him because he was running off and you know just doing these really bizarre things and so she wanted him to be in his own home but maybe that wasn't the best place for him, very difficult ...

Paying Family for Care to Maintain Independence

Linda continues this theme of not wanting to be a burden but also talks about wanting to pay family for any care they do provide. This would have the effect of commodifying care within the family as a way of the elderly person trying to maintain their independence in their relationship to other family members.

Linda: By my children - I expect them to do it and to love it (laugh). If it was for a short period of time that would be fine, I would expect to pay for that care. If in reality it was going to be a long period of time, then I would prefer to pay for my own care and leave them to do what they need to do with their lives. And I would hope that financially I was in a position to be able to do that. ... I also think that there's ways of caring for your parents that don't necessarily involve you putting your life on hold or providing unpaid care for it I think, and especially if financially your parents are in a position to be able to do that, to pay for somebody to come in. Fine it may be that I live in their house but pay somebody to come in and look after me, so that you don't feel like you're leaning on them. ... But I can't see me wanting to be cared for by my kids. I'd expect them to come wherever I was, I'd expect them to come and visit me all the time but to actually expect them to be my primary caregivers, I think that isn't an expectation I have of them, yeah, that may change.

Appendix 3.11

The Beyond a Dollar Value, Informal Care and the Northern Region Case Management Study, includes some comments from both carers and the cared for person reiterating the theme of payment to family members for the care they are providing as being desirable from a range of different perspectives.

- “However, some carers felt that some recognition should be given for the work undertaken: ‘I felt at that stage the government were getting a quite a good deal from our family.’ (Daughter, tape 30.)
- Some believed that the older person would find it empowering to pay their carer for the work undertaken. Instances were reported of older people telling their carer that they ‘felt like a burden’.
- ‘I wouldn’t want it from my point of view (payment), but for the person concerned it may be important. Mum would say you are doing all this running around. Why don’t you buy yourself something. She wants to see that she is not a burden.’ (Daughter, tape 25.) (Belgrave & Brown, 1997, p. 47)

Preference for Care by Family

In contrast to some of the views expressed above, Rebecca suggested that it is precisely when her health is poor that she would prefer to be cared for by her family.

Rebecca: But I think for me living as an independent adult in retirement would be a huge priority rather than living with offspring. I think if I was unwell and needed to be living with other people because of that then offspring would probably be a good option. But I would personally find that a really tough decision because I feel struggling with not wanting to be dependent on others but I’m realistic that there will come a time in my life when I’m going to have to be dependent on others for health reasons. I’d probably be more happy with my own family.

Preference Against Care by Family

A couple of women were strongly against being cared for by their children, but from contrasting perspectives. Laura saw it from the perspective of the elderly person being vulnerable, due to a lack of independence, whereas Doreen saw it from the offspring’s perspective suggesting that the demands of most elderly people would be unfair to place on younger people.

C: ... how would you feel about living with your children, any thoughts
Laura: Oh yes, I don’t want to, (laugh) but again its something I don’t rule out. I’ve seen a lot of people experience difficulties with that and I would be very wary of that situation unless I had some independence within it, yeah.

Doreen: I wouldn’t want that, that would be the last thing in the world I’d want. Older relatives become so demanding. The world narrows down and you became very much centered on your own needs, to get through each day. I think those elderly people who are not like that are really quite remarkable and they’re wonderful to be with but they are an exception. For most people, everything narrows down to your own comforts and how to get through each day and that’s not fair on younger people. I wouldn’t want to live with my kids.

Retirement Provision Steps

This section on steps towards retirement provision is divided into six major themes. These themes are explored by weaving together the experiences of the west Auckland women and the findings of recent statistical studies on retirement provision in New Zealand. The six themes explored are:

- Being prepared and the key ingredients;
- Issues in collective provision;
- Other key forms of provision;
- Pressure and attempts to respond;
- Other ideas about how to survive in retirement; and
- Reasons not feasible to prepare financially.

There are two major statistical surveys on retirement provision that are discussed. Firstly data from the 1992 Survey of Retirement Provision carried out by the Department of Statistics for the Department of Social Welfare. The survey was conducted in conjunction with the Household Labour Force Survey and interviews took place between January to March 1992. The achieved sample size was 1268 individuals, with people over 60 and under 15 excluded. People retired under the age of 60 were also excluded.

Secondly a nationwide survey of 3000 women entitled NZ Women: Family, Employment, Education, (NZW:FEE). This survey was on family formation, family structures, work, education, and other factors, and included a question on retirement provision. The survey was conducted in October – November 1995, including women aged 20-59 years and a separate Maori analysis. “There were four categories regarding saving: women could respond that no provision was being made, that she herself was making financial provision, that someone was making provision on her behalf, or that her saving was a combination of self provision and provision by another party.”(Dickson, Fish, Marsault, Pool, & Martin, 1997, p. 2) The emphasis of most previous surveys has been on the propensity to save and attitudes surrounding this, but this survey looks at how demographic factors might affect saving profiles. The survey was conducted by the Population Studies Centre, Waikato University.

Being Prepared and the Key Ingredients

Some women are fortunate enough to be in a situation where their preparation for retirement is not being significantly constrained in some way by their circumstances. Thus they are in a position of ‘being prepared’ as they are fully in control of the steps they are taking for their retirement, are basically carrying out their ideal steps at the moment, and not at some distant future point in time, and are fully in a mindset of ‘being prepared’. Linda describes her reasoning for being prepared.

Interviewer: I was just curious regarding what made you decide at such an early age to start a retirement scheme going

Linda: Well the finance training we had you see. A lot of it would be the financial training that we do to get doing the degree, puts it more in your mind more than anything. I could see that like my parents generation they contributed to the national superannuation and in those days in fact a certain percentage of their tax went into the national superannuation fund, and when that got all pulled into the consolidated fund it was fairly obvious that it was going to be used for everything and sundry and there wasn't going to be enough to pay out to everybody in years to come. So from my point of view I kind of felt that although when I started I wasn't on a huge wage I really started with a minor amount going away but just to get me in the routine of doing it and in the pattern of doing it and that just increased with my salary over time. I think a lot of it was the training side of it more than, but I think also seeing my grandparents surviving on just the superannuation and yet knowing how hard they worked during their lifetime and I kept thinking I don't want to work till I'm sixty five. And for somebody like my father who does manual building work, realistically physically he cannot work to the level that he was till he's sixty-five, and there's nothing for him until he attains that age so I spose its really a precaution thing from my point of view. I just sort of felt that I didn't want to be bound by the government rules and that I'd do something for myself.

Miriam, a woman closer to retirement age, describes how she has now reached a point of being prepared.

Miriam: When I look back I wonder how the hell I managed it but I suppose maybe its fifteen years ago, I did start putting some money away in a fund. And although it was only a small amount nearly you know fifteen or so years later its its looking quite nicely. And then later on when I felt I could afford it I started up another retirement fund, so I mean at the end of the day I'm not gonna come out with a fortune, I mean I'll be lucky if I come out with two years wages, but I think well I've got my house as a asset and for me I want to get out of Auckland.

Appendix 3.11

Alice Day, in her study in Australia entitled 'We Can Manage', looks at expectations about care and varieties of family support among people 75 years and over. She develops a model of orientation of frail aged towards contingency planning, identifying four groups: planners, procrastinators, fatalists, and counters on family support. The characteristics of 'planners' identified by Alice Day are consistent with/shared by the women who were planners/in control in this group. Planners are distinguished "by the fact that they had made an independent decision about arrangements for their future care, and by the fact that they were not ambivalent about the type of care they wanted." (Day, 1985, p. 115) It is particularly interesting to note Alice Day's observation of the importance of the relationship with their families for 'planners' and how their planning was part of continuing that relationship. "Four of the five had made plans to go into a hostel or nursing home. ... The distinguishing feature was that all four had unequivocally ruled out relying on children when the time came that they needed more personal care. Their reasons were varied ... Rejection of custodial care from family did not, however, appear related to the quality of past bonds with children. In fact, it seemed that those who were closest to their children and placed most value on the parent-child relationship, were often the ones most reluctant to put that relationship to the test by living under one roof." (Day, 1985, p. 115) 'Planners' have two key points in their favour. Firstly and very significantly they have the resources to plan for their retirement. Secondly they also have a very clear idea of the retirement they are planning, they have identified where they want to live, the lifestyle they expect and how they expect to relate to other family members.

The NZ Women: Family, Employment, Education survey highlights the significance of income level and job category in relation to women's propensity to save for retirement. "It is perhaps not surprising to see that women whose individual income is \$25000 or more, have the highest capacity to save for retirement in each age group. ... It is worth noting that a high percentage of non-Maori women aged 50-54 who earned over \$25,000 were saving for retirement (80 percent)." (Dickson, Fish, Marsault, Pool, & Martin, 1997, p. 8) And women in households with higher gross household incomes showed a greater propensity to save for retirement. (Dickson et al., 1997, p. 8) Related to this is how the job category women are in can affect their ability to save. "The results for all women and non-Maori women show two very general trends. First, those women whose current job was categorized under 'associate professional' showed a propensity towards earlier saving for retirement. For Scientific/Professionals, of course, savings will have been delayed because of prolonged study, a finding which raises questions about the life-course effects of the current tertiary loans scheme as it affects women. Second, in general, women working in personal services and sales related jobs at the time of the NZWFEE survey, showed lower levels of saving for retirement over each age group." (Dickson et al., 1997, p. 6.) Employment stability is also likely to affect the ability of women to save for retirement.

The 1992 Survey of Retirement Provision found that "those working full-time, either self-employed or for wages or salary, express a significantly higher level of confidence than do those working part-time, unemployed or not in the work force: only about one-fifth of those with 'other' employment status are confident, compared with two-fifths of those in the two groups in full-time employment." (Department of Statistics, 1992, p. 44) "Significantly more people on high incomes express confidence (about two-fifths) than do those on low incomes (about one-fifth)." (Department of Statistics, 1992, p. 45)

Issues in Collective Provision

Women's retirement provision is also influenced by whether they are in a partnership or are single, whether they divorce and the number of partnerships they may have had over time. The 1992 Survey of Retirement Provision found that "females who have never married appear less confident than married females or males who have never married, but again this difference is not statistically significant." (Department of Statistics, 1992, p. 43) The NZW:FEE survey notes that "in general women who were legally married showed a higher propensity towards saving for retirement than women in any other type of marital union. This was true for all women, non-Maori women and Maori women, with one exception. The exception was among all women aged 35-39 years, where the percentage saving for retirement, who were currently in a de facto union, was at the same level as for those women who were legally married. At the older ages, where

divorced women contribute a major category, those women who were divorced showed significantly lower percentages saving for retirement.” (Dickson et al., 1997, p. 5)

Rebecca’s situation highlights the complexity some women face in negotiating for their own retirement provision when they have to rely on their partner’s income.

Rebecca: Yes it’s something um my husband and I first talked about probably about five years ago when we were almost approaching mid-30s and thinking oh we’ve really done not a lot and he decided that he could become part of the government superannuation scheme through work. But then there was the question of well that’s great for one income and what about me and the challenge has been that my income has been the least stable of ours because I’ve chopped and changed jobs because of family commitments and other things you know. And we looked seriously at trying to take on a second mortgage and buy another property, whether a piece of land or as an investment for retirement and that felt too scary. So we decided about 2 years ago we took out a retirement fund and we decided that it would be in both of our names, it’s interesting. So my husband’s one’s in his name and my one is in both of our names but it’s just grey. His couldn’t be in both of our names because it was through work and I’m not employed by them. So we have a scheme that will cover me but the income comes out of his bank account because mine’s just not stable enough.

Doreen is in the situation of having a partner who has taken responsibility for her retirement savings.

Doreen: Well, I personally haven’t taken any, but that’s because I’ve got a husband who likes to play with money, he moves it from one account to another or he invests a bit here and a bit there and we have targets, I know about this, he tells me what he’s doing every now and again would you sign this form because this money’s coming due and I’m gonna reinvest it and so I just sign ... I could chose to not sign and so I have a choice, but I’ve basically left it up to him.

Robin Fleming also noted some interesting points about how couples organised their superannuation saving. “In eighteen of the Pakeha couples, the man but not the woman belonged to a superannuation scheme. These couples followed the traditional pattern of the man being the one who saves for the future because he is the main earner. Superannuation schemes were often based on this expectation that the man will invest during his working life and his wife will share the cover, some of which will extend to her on his death. This traditional pattern has its advantages. Employment-based schemes and employer contributions are more likely to be available to men than to women, and men are more likely than women to have an uninterrupted career and a high income. However, this arrangement leaves women dependent on their husbands investment decisions and on the continuation of their marriage.” (Fleming, 1997, p. 147) She notes that it was not uncommon for the women not to know what preparation their husband was making and that where the women are earning they may still be putting family needs first. “Among the eighteen couples who relied on the man’s superannuation, there were several with low-paid or non-earning wives who did not know what preparation their husband was making for their future. At least two of the earning wives were putting their income towards their children’s education rather than saving for their own old age.”(Fleming, 1997, p. 147)

However the NZW:FEE survey did find that among non-Maori women the key saver is themselves (rather than their partner or someone else). “Indeed alone, or through joint saving, women are playing an instrumental and majority role in saving; only a minority overall are reliant completely on someone else. At 45-49 and 50-54 years, over 50 percent of the total non-Maori women are instrumental in part or in full for their own savings, and at 35-44 and 55-59 it is more than 40 percent.”(Dickson et al., 1997)

Laura was in the unfortunate situation of supporting her partner in the implicit agreement that she would share his retirement provision. When she divorced a number of years ago she encountered difficulties accessing her partners scheme.

Appendix 3.11

Laura: Well I've never really been in a position to do so. When I was married and my marriage ended ... sometime ago now, my husband had a superannuation fund and I never gave it much thought to be honest. But he died four years into his retirement so I mean it seems, you know, well all those forty odd years plus contributing to a super fund and its gone. And when we split, the financial arrangement we came to didn't include me having any part of that superannuation so, no I have never actively made provision for retirement. ...

Joy's situation highlights how even when both partners have their own retirement plan, an unanticipated change in the situation of one partner can adversely affect both retirement plans. This is because Joy's individual plan is heavily influenced by their collective situation. It would be interesting to know how many people are affected by their plans being thwarted towards the end of their working life. It would also be interesting to know whether caregiving responsibilities are more likely to thwart women's plans and ill health more likely to thwart men's plans.

Joy: Well my current work situation is I work full-time ... I guess I probably wouldn't have expected now to be probably working these hours a few years ago I thought that probably come about 50 I'd be starting to slow down and that doesn't seem to have happened ... it's getting harder. Part of that is a change in government, I mean I have to work till I'm 65 until I retire for superannuation. Secondly though we have private superannuation that is all linked in to supplementing our income at the time when we will retire ... or slow down a bit I suppose. But I think the thing that made the biggest impact for me was my husband got sick so that changed our financial plan that we had in place at that time. I think it's very hard you know, when you plan you think you have planned for a point in your life and planned well and some people don't, and you actually have sat down and thought through a responsible plan. But you can never plan for events that just come out of the blue and government policies have changed part way along that's caught us, we're in that age group ... Like the situation that I had with my husband was he's unemployed and he had just come back from overseas and he had actually had a tumour. So he's well and he's certainly very fortunate ... and we were very lucky with that but it meant that he won't go back in the work force again ... So because of our assets and because I was working he was not entitled to anything for that amount of time the only income is mine. ... and he'd always had sickness insurance being self employed but when you get to a certain age they cut it, they won't continue it and that's just even if you want to they won't even if you've been so very well that insurance is cut and it's no good going anywhere else because its just that is the thing you get to... so there was no renewal so that insurance as a back up was no longer there and the other thing is he's a builder our house that we live in is huge... you know we'll move and to a point where you'd sort of go to the effort perhaps a couple of units or a smaller place or something like that we have that as a chunk of our superannuation ah ... but he certainly won't build another house he won't build another unit ... so when we do sell we'll probably get something small but smaller and certainly it's still been a good investment for us but probably not ... it would have been done in a certain way .. getting something out so that changed everything.

Other Key Forms of Provision

Paying off the Mortgage

For a number of women paying off their mortgage is seen as a key step towards preparing for their retirement. Often other steps, such as contributing to a scheme, are seen as a possibility only after the mortgage is paid off.

Assumptions About How Housing can be Used in Retirement.

A number of women talked about how their house was part of their retirement provision. However there are a number of issues with assuming that their house can be used as a form of retirement provision.

Miriam: Oh well ultimately I'd like to move out of Auckland and so the theory of it is that I can afford to buy a cheaper home and so to a degree my home is part of my superannuation, my investment.

Miriam was well aware that there are a few problems with her plan of selling down. One issue is that there may be unknown future changes in the housing market that lessen the value of a house and hence make it harder to sell down and still have a reasonable amount left for retirement income. Another potential problem is around finding somewhere to shift that is appropriate in terms of still being close to family or other necessary services. Hence even though many elderly own their house mortgage free, the market value of their house and the availability of suitable housing stock in their local area has a direct impact on their ability to afford housing changes and hence use their house as a basis for retirement income. The use of housing to pay for rest home care is also problematic as it is likely that a substantial amount of housing would be inadequate to pay for longterm care needs.

Family Business

For Trish, working part-time and the main caregiver at home, the family business is her key form of retirement provision. However because it is not just her business, this form of provision is collective and hence to some extent reliant on staying with her partner.

Interviewer: Have you ever thought about taking out a retirement scheme?

Trish: Well the only person I've worked for the last ten years full-time has been [work name] and they did have a super scheme that I didn't join a long time ago. Just wasn't something I thought about then and because I've only been part time in the last 4 or 5 years when super has become a major national issue I haven't thought about contributing part of that meagre amount into a super. And we've been concentrating on building up the business so really that's our major super scheme at the moment until I'm working.

A Small Scheme

Several women talked about only having a small scheme. They saw their lack of provision as a risk and will very aware that they would be heavily reliant on government support.

Rebecca: But there's not a lot we can do about it, its just the risk we take. I guess we both we're very aware that we're likely to be on our own and without a lot of government support by then, that's a scary thought. So we haven't done anything else really I mean in terms of financial funding, other than those two retirement schemes which would help but wouldn't be enough to keep us going in retirement not other than at subsistence.

This very limited provision links to a lack of confidence in their retirement provision. "Predictably, people with nothing or little in the way of retirement provision are the least confident: only about one-fifth of this group express confidence compared with about two-fifths of those with either kind of superannuation and/or investments."(Department of Statistics, 1992, p. 46)

Pressure & Attempts to Respond

Jill is in the unenviable position of having only a small scheme as a response to government, media and friend pressure. She is well aware that in reality it is only a token scheme.

Jill: So I thought about retirement. And then the Government started really going on in the media about 'you've got to save for your own retirement because we're not going to be able to sustain it, there's more elderly now and there's not enough people working to sustain it'. When the unemployment situation was sky high and they were saying there's no way we can sustain it, there's not enough people working to sustain it and and I thought very carefully about it, wondering

Appendix 3.11

how much of a propaganda story it was. Because I don't understand how we can't afford to pay for superannuation when the population hasn't grown all that much since the fifties and sixties compared to Asia or America. There are more people in the workforce than ever before and I realise that there are more elderly because we don't die as young as we used to, and more moneys been generated by huge corporations and I thought the answer is more the people who are paying taxes, we ought to be paying more instead of less and not having tax cuts. I can't really understand why the governments saying its unsustainable when it has been sustainable for years and years and years and years and years. I don't understand how it works, I'm not economically minded. ...I thought well I've got to do something, I'll have to start doing something for myself because maybe its true, maybe what they're saying is true. I got hold of my insurance company and said what can I do, I'm on this sort of income, its pretty low. I ought to do just what I can afford to do and if that's the best I can do well that's the best I can do. So I have got a superannuation scheme, its just small, its not going to be anything like the sort of levels you should be saving at and I thought there's no way even if I was working ninety hours a week I'd ever be able to save that much and I thought well I better save what I can out of my disposable income after everything else has been paid for, so that's what I've done. Its not very much, its pathetic really, I mean it would be like a drop in the bucket and it won't pay very much in the end and they'll have to top me up. So I have got my own scheme going which is only pathetically small. I feel it actually won't do anything, monetarily-wise. It won't do a thing. At least I can say I'm doing my bit you know, at least I'm not relying on the government for everything.

Jill is on a benefit, she has a chronic illness, and is also caring for her elderly mother at home. To feel obliged to save in the situation she is in says a lot about the pressure being exerted through the media. Is it fair to be placing pressure and expectations to save on people who are in a situation like Jill?

Rebecca highlights the role of the media and a number of other factors which provided the impetus for her to look at retirement schemes.

Rebecca: I think for my scheme I must admit that the media did help get me thinking about it. By then there were the government funded ads on television so I was certainly challenged and something to think about that was one. And getting older you know sort of heading towards 35 and realising that you know I was likely to live to 70 and I'm halfway there so that was there. And I think the other big catalyst was being pregnant again or I don't know if we were probably at that stage looking at a second pregnancy and so we started talking about life insurance which ... for the sake of the kids and retirement fund and also realising I suppose the other impetus for me was recognising that we were beginning to make choices where I who had been the larger income earner early on in our married relationship would have dropped my income significantly and looked like I probably won't go back to full-time work for many years if I ever do and that was a scary thought. That there wasn't going to be a lot of extra money coming in, that the money that we were earning was comfortable for us to live on but in terms of putting it away we would have to really discipline ourselves, so that was the thing that I was thinking about.

Other Ideas About How to Survive in Retirement

Continuing to Work

Michelle assumes that she won't be able to retire because she will have to rely on herself and continue earning her own income.

Michelle: Like society's really changing in that yes we've got an ageing population and I mean I have no intention of retiring at 60 or 65, I mean I look forward to being able to work in some capacity and earn fairly well but on a part time basis, well past 60 or 65 or whenever it is you're supposed to stop doing

what you're doing. And I think that that will be, I mean most people my age, how old am I? I'm mid thirties, you know most people my age I don't think any of us have got any intention of stopping doing what we're doing or not. The thought of not earning an income is just not, I mean you just know that you're going to have to earn an income. I certainly don't imagine that there'll be anything there to provide for me, so I just imagine that I will work and that my main asset is my home, so something will work out.

Pooling Resources

A few women pointed to the possibility of pooling resources with friends to make some form of joint retirement provision. This was very much at the 'still an idea' stage, possibly a future form of provision, rather than a step towards retirement that they could take at present. It also relies on more than just individual provision as it involves other people participating in the same form of provision.

Kate: Well I see paying off the mortgage as a really essential step towards being quite secure in my housing situation in the future and I've had a number, I mean with friends, had a number of discussions about the kind of lives we might lead in the future. Where we might, you know most of my friends are now in a position where they have got their own houses and maybe in the future selling our houses and buying some joint establishment and employing someone to look after us. And so really I like the idea of having some kind of collective lifestyle as I get older I suppose. I don't want to be living by myself or you know in a isolated situation so I think that quite possibly, that some of those ideas of living in a flatting situation or buying property with some other people or establishing something like that. I like the idea of not just being isolated as an older person but also creating a kind of wider sort of extended family in the broader sense you know having contact . . . I suppose a lot depends, I think that probably we spend a lot of time talking about different ideas and not in a really tangible and planned ways saying that in 10 years this is what we'll do, but I think that as we get to the stage where we pay off our mortgages then I think that it opens up a whole chunk of options ...

Laura: I've discussed the idea with a friend of maybe further down the track pooling our resources and possibly buying some land and building a house that would suit both of us. Where we'd both have our private separate areas plus a joint communal type living kitchen ... and that's quite a creative option because we're both women on our own, both the same age both have some kind of house, and recognise the need or beginning to recognise that further down the line that may not be as easy as it is now. Just beginning to explore those issues in terms of supportive housing, you know, that we can be creative and do something like that. So those ideas are all being talked about.

Health steps

In relation to health the main retirement preparation steps were living a healthy lifestyle and debates over whether to have health insurance. Joy raises some key concerns around health insurance, highlighting how changes in the public health system have increased the reliance on having private health insurance.

Joy: Well we have health insurance and... because I think that's going to be much more of a problem for people as we get older and not having access to a public health system. So and yes that's a change because we didn't have that, you know we had access to a health system that you didn't think you had to buy, we would have thought that if we were paying for something it was because we chose to have this operation and not wait but now you would never get one done in the public system. So you really have to look at the idea of health needs in the future.

For most of the women who did not have private health insurance, the reason came down to cost. However Rebecca had rejected health insurance on political grounds as

Appendix 3.11

she saw it as further undermining the public health system, and Jill found that because of her chronic illness she was not eligible for health insurance.

Inheritance

Kate highlighted the significance of knowing she had a sizeable inheritance at some point in the future as providing her with an underlying sense of security about her future.

Kate: I think the other thing that makes the relevance of how you see your life in the future is also the kind of social economic group that you come from. Because my parents are both quite well off so I think I have an inbuilt, although I don't think of it, I think that I'm responsible for myself, I also think there's security knowing that at some point I will have access to some kind of inheritance unless laws change or unless circumstances change in what happens to them in old age. But I realistically can think that I'll probably have some kind of inheritance and I think that really creates a buffer against, you know, I think that reality really creates a security for me in the future. So whereas for other people if they don't have access to inheritance or any of that kind of stuff it's a lot tougher. So I think that those things really impact on how you see the future and how you feel about it ... and I think it also influences the choices that you do make even in your present life. ... I do have a sense that if anything really drastic happened to me they wouldn't let me fend for myself. ... That support is there in a sort of passive way, I find it part of my reality in how I view the future. Whereas if I was totally totally dependent only on myself and my own resources how I thought about the future might be really totally different.

Reasons Not Feasible to Prepare Financially

Financial Reasons

A number of the women interviewed were in a situation where it is just not possible for them to be preparing financially for their retirement. Laura talks about being in a situation where she feels powerless to save and is also finding that as time goes by the assets and resources she does have are being whittled away. She has tried self-employment but that didn't work out and being near retirement age there is very little she can do now to change her situation.

Laura: I had thought about it for some time but I'm in a position financially where I actually can't make provision for my retirement. So I actually decided not to worry about it, there's no point worrying about something I can't, no I don't feel that I can radically change and at such a low income I'm not in a position to put money away. So I've basically made no practical steps. ... I've become aware of the, especially over the last few years, that while I have a little bit of money invested that amount of money is dwindling and when I get large unexpected bills, something going wrong with the car or something like that, I sometimes have to draw on that and that's a worry in terms of the future. The question is what will I choose to do when I reach the end of that resource but it's not a question I can actually answer at this point because I haven't got there yet, and it's not something I'm going to attempt to answer or worry about.

The NZW:FEE study notes that "What is immediately noticeable .. is the very low percentage of women, in each age group and ethnic group, whose individual income was from a 'non-market' source (mainly benefits) and who were saving. In comparison, for women whose type of individual income was from personal earnings, the percentages of saving provision were substantially higher."(Dickson et al., 1997, p. 7). This highlights the negative impact being on a low income or a benefit has on the ability of women to save for retirement.

In line with the quantitative studies above, Robin Fleming also found in her study that saving for retirement was related to gender and income level. "In seventeen of the 59 Pakeha case studies, people said they had no plans yet for their old age. Thirteen of these were couples in the low-income group (less than \$35,000 a year), or at the lower

end of the medium-income group (between \$35,000 and \$45,000 a year). Three had cashed in their superannuation to deal with a crisis such as an illness, business decline or redundancy. Some said they were trying to pay off their home mortgage before starting any savings scheme, and two were putting their hopes for future security into building up a successful business.” (Fleming, 1997, p. 146-147)

A number of the women had the experience of not using work based superannuation schemes. The impact of their future expectations regarding paid work and the value they placed on their participation in paid work was important in shaping their view of how feasible it was to commit to a scheme. Often there was no expectation of long-term paid work security, especially when caring responsibilities were considered. Another issue was not being adequately informed about the schemes employers were running.

Interviewer: You mentioned moving in and out of paid work over time, have any of those jobs that you've been in had a superannuation scheme attached to them?

Melissa: Yeah they did, but I never, like Telecom, but I was quite young when I worked for them and the last thing I was thinking of was retirement. And I really wasn't interested, after Telecom the next major job was Inland Revenue and I'm sure they probably did have one but I again I wasn't aware of it, and working at a school there's the teachers one, knowing that it was only temporary I didn't ever take steps towards it either, but I certainly will be once I start teaching because apparently it's a really good one.

Interviewer: Did you ever have a superannuation scheme through your work?

Ann: No I didn't, I should have done, I was really, really stupid because [my work] actually had a very generous superannuation scheme but when I joined you had to be there two years before you could join it and then it became very unclear who could join it and who couldn't ... so I wasn't clear for a while which staff could and which staff couldn't ... And then I thought 'oh I'll never stay here long enough', you know you have to stay in it for five years or something to make it worthwhile, 'oh I'll never be there that long', and in the end I was, and should have done and didn't basically. And every time I thought 'oh well, I will now' I thought 'oh no, no I won't be there that long' .. and also it's very difficult to know how much, I mean what I have is pathetic in terms of what I would need to maintain the standard of living that we have now, but it's very difficult to know what one should be doing in order to do that, because I mean life over the last year for me has changed dramatically and it's so difficult to know what you're going to be doing next year, leaving alone age 60+.

Family First

Another key reason for women putting off their own retirement provision was giving priority to other family needs and seeing retirement saving as having to wait till later.

Interviewer: Have you given retirement any thought?

Esther: Well we have actually and I suppose that's one of the things why really I have to keep working now because apart from my family needs ... my husband changed his job last year ... and there's a lot less money coming in ... now he's got a set income um and so there's been quite an adjustment with that. So a bit tight and now and again I think ... wait till later ... providing for our retirement .. things are very tight and very stressful.

Rose: In terms of money for retirement and savings funds, I mean we haven't got, neither of us have got anything and we haven't got any savings of any sort. In fact it's been real survival stuff up until now. This is the first time we've ever actually had two you know decent incomes and yeah we've purposely kept our mortgage and that quite small. And we haven't had overseas trips and that sort of thing because we didn't want our debts to get to huge. So the plan is to pay off the mortgage and then look at saving fund or I don't know...

Robin Fleming examined various ways in which control was exercised over women's spending. She found that "the strongest control over women's spending was that

Appendix 3.11

exercised by the women themselves. Women were at pains to tell us how little they spent on themselves, how frugal they were, and how little they really needed. ... The women who were most insistent on this issue were those who were not themselves earning.”(Fleming, 1997, p. 61) Consistent with other studies on how families in poverty managed she found that “in families with low incomes, women did not use the money for their own personal needs until they had met the needs of the rest of the family, and particularly those of their children. The belief that ‘family comes first’ had a strong influence on women’s use of family money. However, the key to understanding access to money in the Pakeha families was the belief that the control of family money was associated with earning it.”(Fleming, 1997, p. 65)

Caregiving Responsibilities

Caregiving responsibilities also have a significant role in limiting the ability of some women to save for retirement, particularly when they start having a family at a young age.

Melissa: When I first started working because I had no responsibilities, I was paying fifty dollars a week at home, I was busing to work. When I think about the money I wasted from sixteen to say nineteen, I cringe because I was on really good money. I just happened to get a good wage at Telecom and I just think of the money I wasted. That’s the time that I could have saved a lot of money. And then I started having children from nineteen, so perhaps it would have been more difficult, but just from those three years I think I could of saved thousands of dollars, if I had of been in that frame of mind, if I had of...

The NZ Women: Family, Employment, Education survey found that: “Generally those women who had their first birth at a later age had a higher propensity to save for retirement. what is perhaps most noticeable is that in almost all age groups, women who had their first birth when aged 15-19 years show lower percentages saving. This is, however, somewhat different at older ages where those who started childbearing very late had also lower propensity towards saving, as might be expected.” (Dickson et al., 1997, p. 5) The survey also found that “... among non-Maori women the percentage saving in which there is no young person usually resident in the household, is generally higher in comparison to households where one or more young person is resident.”(Dickson et al., 1997, p. 7)

Caregiving responsibilities for elderly family members is also significant in limiting the ability of women to save. “... A relatively systematic pattern were for women in those households with an elderly person present (aged 65 years or over) to have a lower capacity to save.” (Dickson et al., 1997, p. 7) This leads into the next section looking at what families expect to provide to elderly family members and what the elderly expect to provide in return.

Expectations to Provide for Elderly Family Members & Repercussions

There was a spectrum of experience regarding providing care to elderly family members among the women interviewed. Some were in a primary caregiving role with their parent living with them, preventing the need to move into a resthome for the time being. Another common scenario was providing support and an awareness of a possible increase in caring needs in the immediate future. Another experience was of travelling to stay and assist on a regular basis when parents live some distance away.

Finch and Mason’s Family Obligation survey is useful in understanding the wide range of views and experience among the west Auckland women. Finch and Mason found that there is widespread agreement that children have a responsibility to do something to help parents if this is needed. However what children should do is dependent on the commitments that have built up over time rather than a sense of fixed obligation (Finch, 1995, p. 53). Finch and Mason found that commitments are built up over time through a process of reciprocity – accepting help and then giving something in return. Because the situation of families varies, the commitments that are built up also vary and hence the expectations of how children should support their parents also varies between families.

There are many factors that can influence a families situation in regard to providing care to elderly family members. Finch and Mason found that inheritance and divorce tend to strengthen the significance of the family of origin for people, enhancing the likelihood that children develop the kinds of commitments to their parents which would result in the offer to provide care (Finch, 1995, p. 61).

In their study on family responsibilities, Finch and Mason found that employment is the most common reason given for being unable to provide support to other family members (Finch & Mason, 1993, p. 103). Sara Arber and Jay Ginn have done a statistical analysis looking at three kinds of impact that providing informal care has on paid employment. The three kinds of impact focused on were firstly work accommodation, secondly seeking part-time work, and thirdly giving up paid work. They found that for the majority of carers, their caring role leads to work accommodation rather than influencing them to withdraw from the labour force.(Ginn & Arber, 1995, p. 468). The different commitments built up in families means that only certain daughters will face a real conflict between employment and providing care for their parents. Only daughters who have developed the kind of commitments to their parents in which direct provision of care looks like a natural consequence. For the rest the question is more likely to be how these daughters can provide some kind of help, which falls short of a direct involvement which they will see as in appropriate (Finch, 1995, p. 60.)

Linda: I'm the only daughter, so realistically if my parents got to the stage where they couldn't care for themselves, in reality my brothers are hopeless. So to a certain extent the responsibility would fall on me. The other side of that though is both my parents are very independent and wouldn't like that, so to a certain extent they would take control of things and get themselves put in a situation where I think they'd pay for their care, which they would be in a position to do. So yeah I can't see it, it might happen for a short period of time but there's absolutely no way either of them could stand for being cared for by one of their own kids. I think they would much rather pay strangers to do it than to have the responsibility and the other thing, the other reality is that I am quite career oriented so for me to give up work to look after somebody would actually be a big thing for me to do. I've worked quite hard to get where I am, I'll pay somebody else to do it, I have no qualms about doing that, but in terms of me doing it personally, yeah for my sanity I don't think it would be the best thing at all, its not my nature, so its not something I believe I'd be good at, and I think my parents would probably vouch for that(laugh), so yeah

A number of the west Auckland women discussed how responsibilities were being negotiated within their family. Some of the women reflected on how they were perceived to be available and one of the women talked about 'being chosen' by her mother, and several mentioned the remoteness of their brothers taking any responsibility, especially given that a daughter existed. For some the negotiation meant providing support but being clear about setting limits.

Interviewer: What about your father, any possibility that you'd care for him?

Michelle: No I don't like my father and no my father he doesn't have good health. So no I wouldn't, but then again I mean, when he ended up in hospital, you know like a few years ago, it was me that went down to make sure that Mum was OK. ... so it falls on me, the responsibility falls on me. I could pick that up more fully, I simply choose not to.

Interviewer: Ok and are you able to pass that onto your brothers?

Michelle: I certainly am fairly proactive in reminding them of their responsibilities around that. They are not so proactive about picking that up, yeah but one of them has a wife now and I've noticed that she's stepping into that role fairly nicely, which means that my brother will continue to relinquish his responsibilities.

Another factor influencing the need for family care and support is the availability of support services. The demand for home support services for elderly people has grown, without a corresponding increase in resources. This has effectively resulted in home support having to be rationed. "The demand for home support services has continued to grow as the numbers of older people have increased, however resource allocation

Appendix 3.11

has failed to keep pace. Increasingly RHAs have responded by narrowing the eligibility criteria for these services, and encouraging cost-cutting by service providers in a competitive environment. The outcomes of these measures have been negative for older people.”(Age Concern New Zealand Incorporated, 1997, p. 7). The substantial minority of older people who have no immediate family have always had priority in the ‘eligibility’ queue for services. As services become more rationed the perceived availability of family carers influences the support services which can be accessed. “The extent to which family care is needed depends to a large extent on the extent to which older people in need of care can gain access to support services, and conversely, the extent to which older people can gain access to support services usually depends considerably on the availability of family care.”(Allen & Perkins, 1995, p. 222) Thus the effect of increased rationing of services in conjunction with the perceived availability of family is to increase the pressure on families to provide care in some form.

Allen and Perkins suggest that as the trend towards means-testing community care continues there will be an increase in the demand for nursing home care – at the expense of the family inheritance (Allen & Perkins, 1995, p. 233). “We would suggest that all the signs are that the demand for family care will rise for reasons related to a relative decrease in the supply of universally available formal health and social care services. ... Even if most older owner-occupiers tap into the capital resources tied up in their property, the relatively low average values of these properties will soon be used up if residential or nursing home care is needed, and there can be little doubt that expensive packages of community care will soon be subjected to much more rigorous means-testing than usually found at present.”(Allen & Perkins, 1995, p. 232)

The subtle shifting in responsibility of care for the elderly places families and particularly women in a difficult position. The more responsibility daughters take on for providing care to their parents the less able they are to make their own provision for retirement. However if a parent can no longer manage on their own and instead of providing direct care the decision is to go into a rest home or residential care then this could be at the expense of the family inheritance.

Generally elderly people prefer to maintain independence in their own home, possibly close to family, for as long as possible. “In 1995 the National Health and Disability Committee acknowledged the importance of enabling older people to live in their own home for as long as possible. It also recognised that New Zealand research confirmed that older people generally shared this view. This concept is simply known as ‘ageing in place’ and is supported widely by health and social policy makers in New Zealand.” (Age Concern New Zealand Incorporated, 1997, p. 6).

Given the preference of most elderly to maintain their independence and live in their own home and the repercussions for usually daughters if they pick up the responsibility for providing care and support, increasing the resource allocation for a more universal home support service is an important and long-term strategy for government to improve the ability of women to provide for their own retirement.

Views on Government Responsibility for Retirement Income

The final area of discussion in the interviews was the views of the west Auckland women regarding government retirement policies. A number of common themes emerged as well as differences in opinion. Following is an outline of some of the key themes.

A first key theme mentioned by all the women interviewed was that there will always be a necessity for government support for those who can't save.

Linda: I believe the reality is there is always going to be a body of people that is never ever going to be able to provide for their own superannuation. There is always going to have to be some form of government superannuation in place. But I cannot see how they will ever in a million years be able to say there will never be, like there will be no government superannuation. Just not feasible, you're always going to get people in the lower income bracket who no matter

how hard they try are never ever going to be able to put aside enough money for superannuation, they have enough trouble feeding their kids, so there will always have to be a government superannuation.

The second main area of discussion was over whether superannuation should be income tested or not. Here there was considerable divergence in opinion, with a number of women thinking it should be and others thinking it should not be. The main reason for income testing was that those on high incomes did not actually need support from the government.

Ann: I just think its absolutely totally ludicrous that we have a comprehensive universal superannuation scheme. I just think its crazy. I think for somebody like my partner's parents who have not huge independent resources but enough to live on for all their needs, for them to get superannuation as well is ridiculous, so I think that we need to means test superannuation, that's what I would do.

Linda: So I actually personally don't have a problem with income testing of the national superannuation apart from the fact that ... I know someone who is worth millions of dollars but everything's in a family trust, they legally could apply for superannuation but they refuse. They find it obscene that they would be entitled to receive nine and a half thousand dollars each a year when they earn income of over a million dollars and they're quite moral. But there's a awful lot of ones in exactly the same position but they still claim their national superannuation because the incomes not in their own name. Legally they could get it and that I find obscene to be quite honest, which is why I believe in income testing. I actually believe we should be income testing but I don't think they can bring it in for the generation above us. That's where I think it is wrong, because they contributed a set amount into a superannuation fund, its like me contributing to my private scheme and then them saying no sorry you earn to much money where not gonna give you that.

Miriam distinguishes between individual and couple income testing, suggesting that income testing should only be on a individual basis so that women are not prevented from accessing their own income.

Miriam: But then the whole thing comes with what's wealthy and do you take individual or do you look at joint or In a couple's situation if the man is still working and earning \$100,000 and gets \$20,000 pension and gets taxed on an income of \$120,000 but the partner or wife or whatever is in unpaid work and she gets taxed on the \$20,000 that she gets, yes I think it should be individually.

Several women agreed with means testing but closely linked this with the need for superannuation to be set at a adequate level. Linda argued for tax incentives to be used to encourage saving rather than the stick approach of penalising people who didn't save with a low benefit.

Ann: I mean I do think it should be means tested but I do think that also the benefit should be at adequate levels. I mean my concern is not that they're means tested but that they need to be set at adequate levels, you know and particularly with superannuation. ... This whole thing about you need a gap between work, the work rate and the benefit rate in order to give people an incentive to work, well I think its crap anyway. I think most people who want to work do work and certainly in terms of superannuation its crap because lots of people don't won't to work. And I think I think that's my concern, that it should be set at a adequate level and then inflation linked and ... I don't know what the costs would be, cause I've never seen it ..

Rebecca also highlights that the superannuation level needs to be considered in relation to the cost of other services for the elderly.

Rebecca: It feels like all that's really left that's secure for people who are reaching retirement age now is basic superannuation a lot of which gets taxed back ... and it's absurdly low. Anyone I know whose trying to survive on that is

Appendix 3.11

struggling, particularly because, you know it would be different if they had housing subsidised and health subsidised but increasingly they're having to pay for hip replacements privately and having to pay all sorts of other costs, transportation costs, they can't survive on that income.

Another common concern was that means testing may result in labeling people and that realistically that would mean a substantial proportion of the elderly population would end up with a negative label. There was also a concern that this would increase the perception of the elderly as a negative burden on the rest of society.

Rebecca: In some ways I don't think that's a bad thing because on the surface it looks as though people who can afford their own comfortable retirement won't be receiving from the coffers and so people who can't afford will get more. But the reality is that the proportion who will have the money to support themselves in retirement is tiny relative to the rest of the country. I think that's a bit of a scary prospect because I don't trust the government. I don't trust what the agenda is around that, so there's I have no problem saying that people whose income is I don't know households whose income is \$100,000 or more shouldn't be receiving government superannuation. I've got no problems about it at all. But I guess if I look at it from the flip side it labels people again. Those who will need it will be labeled as having been lazy and not having saved well and should have. Again I think they're missing the point ...

A third key area of discussion was around pensions (universal retirement income) versus benefits (means tested benefit). Here some of the views against having a income tested retirement income were expressed. Miriam argues for a rights basis for retirement income and is against a system that distinguishes between the deserving and undeserving. She also sees a rights based system as being able to recognise the contribution of unpaid work.

Miriam: I really strongly believe in collective responsibility, really strongly believe in much more of a rights base rather than the code [of social responsibility] and the deserving and the undeserving. And I think the kind of philosophy that government has actually creates poverty and individuality where people just become so concerned about themselves and I think that really impacts on the kind of society you create. ... It's kind of a philosophical point of view I think, but a rights based benefit is much more preferable and leads too much more equity and it recognises the different contributions that people make.

Rebecca reflects on how a retirement pension is different from other benefits.

Rebecca: I think I'd be with a lot of people in saying it should be as of right. Because I think across the board that when people get to that age that they have a right to have, to be able to survive and I think it's a very tough age to reach because you're so vulnerable. It doesn't matter who you are if your health fails on you you're vulnerable and that's regardless of what your income's been ... so I feel quite strongly there. I don't think it should be seen as a benefit like other things because we are all going to get old. We're not all going to get sick, we're not all going to be disabled in our lifetimes but we are all going to get old and the repercussions of growing old. There are enough negatives about it in our society that I don't think the financial burden should be promoted ...

Jill was very concerned that the idea of the pension as an entitlement and a right was maintained. She highlights how it is wrong to have to feel 'lucky' to receive assistance.

Jill: It never even occurred to me to think that I could do that, you know you just don't. You just go to work and you earn money and you pay your own bills and you don't take help. And it never even occurred to me that I was actually entitled to it until someone said "you are entitled to this help, go out and get it." And I took months, it took me at least six months to actually come to terms with the fact that maybe I could do that. So it was there and I was lucky that it was there. But I don't like feeling lucky. I think it's a right and I feel lucky all the time, every time. I've been to the doctor this morning to get her to sign in the latest form and I feel lucky that

she hasn't prevaricated, never mentioned it, said oh fine, fine and sign it. And I go down and stand in the queue at income support and hand it in, and I feel lucky that that's happening. And I don't want to feel lucky, I think that's bad news for people who are sick. Why should you feel lucky? You should feel happy. I mean you should feel that it's there for you and you should be entitled to it. And I think if you lose your job and there aren't any jobs in your area you are entitled to help to keep your family with a roof over its head, you are entitled. When the first labour government brought that in way back in 1930 whenever it was you know, people didn't feel lucky they felt not even grateful, they thought "I paid my taxes damn it this is what it's for", and so if you're sick and you're unemployed and it's through no fault of your own, then damn it you know you should feel like you've got the right to be helped for as long as it takes for you to come right. The elderly should be given the right to have a retirement in their own home with the governments help if that's what's needed. Yes, I've got no objections to people, and I've been doing it myself in my own small way, of saving for your own retirement. I think that if you can you should, so that it does take the pressure off the government but you know, damn it I think it should be there anyway. I think it should be like it is now. I think it's universal, everyone gets the same if they're on government superannuation, then you get a small supplement if you're entitled to it.

Following on from Jill's reflection that people should feel entitled and not lucky to receive assistance is the view expressed by Doreen that government support should be viewed as being only for 'a time and a season' rather than a long term support.

Doreen: All along the way, I've realised how important it is that the government subsidises and supports people who can't help themselves. It's only for a time and a season, it's not like I've asked for that support all of my life, just for little spells. I see retirement as being only a time and a season. You can pop off any time can't you, at our age.

But I guess for me I don't see government welfare as being a long term thing and that's how it's worked for me and I've had help from the government through my life but it's been short term stuff, crisis stuff, you know, just to help you over a hurdle. And it was never about becoming dependent on that or having somebody else look after me. I'm a very independent person. I come from a family of independent people and so I guess that I'm not anti compulsory savings. I'm not anti paying into some sort of scheme where you pay in but I'm also not anti some of that money being used for people who have not been able to do it.

Melissa argues for a pension as of right to recognise the life work of people, particularly of women doing unpaid work.

Melissa: I would like to see it as a right, not a benefit, a right. Because I mean like my grandmother she worked until she was sixty-five and now she's getting a pension and it's her right. I feel like she should have that... She spent a big chunk of her life bringing up children on her own to because her husbands died or suffered ill health and she couldn't work and that sort of thing and why I think she deserves every cent she gets. She should be entitled to it and not have to apply or be you know fit certain criteria I believe she should get it

Several women also commented that it was wrong for women who did pick up the unpaid work to then be penalised in retirement.

Kate: I see a lot of people out there doing unpaid work and I think there's just no rewards for that at the end of the day, apart from the personal satisfaction. And so why should they be penalised at the end of the day.

Jill: I think it's harder for women. ... They do 99 percent of the childrearing 99 percent of the primary healthcare and 99 percent of time looking after homes and elderly and anybody that needs looking after it will be women who are doing it. And it's invariably not paid and therefore women are always gonna be last at the money heap when it gets to the retirement age. They're the ones who are always going to need the top up and feeling lucky. I don't want to feel lucky, I want to feel like this is my retirement and I've paid my dues, whether I've paid

Appendix 3.11

tax for 25 years or 40 years or whether I've spent that time making sure that the government didn't have to spend any extra money elsewhere. And damn it I think that's worth every cent of what they pay you for super to live on.

A number of women reflected on the importance of the old family benefit as a universal benefit recognising women caring for children and providing women with an important source of income that was their own. The link was often made between the family benefit and the pension as key sources of independent income for women regardless of the family income.

Rose: I guess I feel strongly against being making it a benefit because it's a bit like the family benefit you know like sometimes it can be the only money that women have control over. ... Also putting it into the realm of a benefit ... like encouraging people to feel like that they've got to be grateful for it and that they're only getting it because they're haven't got the assets ... sort of puts it in the heap of DPB and you know all those other people, that other in society which has to be helped because they haven't been careful or something or too lazy to go out and earn money and save. ... because the family benefit wasn't means tested women from whatever walks of life got it and so women from the wealthy families in Remuera still got it and I'm completely supportive of that because who's to say that they have access to all the wealth in the family, they may not.

Miriam: It's really interesting because my mother's just coming up to the stage where she's entitled to the pension and she's, I mean like my parents are well off but she is so excited about getting money, her own money, that doesn't have to you know that's totally hers to do with what she wants. Like I think that what the pensions done is that for many women it's created their own income, it hasn't been something they've had to ask you know it hasn't been linked to their husbands ...

Rebecca continued on this theme of valuing the unpaid work of caring for children. She raises the possibility of linking retirement savings with family benefits, suggesting that this may be a way of balancing the individual provision people in paid employment are able to make.

Rebecca: It's a tricky one because so often retirement income is totally linked to income during your working years so women are very disadvantaged ... I think my ideal would be that where there have been benefits, family benefits based on how many children you have, my ideal would be that there'd be a retirement benefit that would start to accumulate. That would somehow acknowledge women or men for that matter, the caregivers who are actually homebased who have children at home or who are working shorter hours because they're the caregivers. So it strikes me that it's not untenable that to actually do that because the government is very aware of who the children are and which house they're living in and in the same way that there has been ... an allowance that's accumulative for people who are fulltime caregivers ... because there needs to be something that balances the fact that there have been superannuation schemes that come out of your income ...

Susan St John has highlighted the different goals of retirement income policies and notes that: "The aim of retirement income policy should not be just the relief of poverty. No other OECD country takes this narrow view. The aims can be to ensure that income is sufficient to: prevent poverty - means tested benefits; enable belonging and participation - basic incomes; enable or facilitate a continuance of economic status - earnings related pensions." (St John, 1991, p. 52) The women in this study were in agreement that retirement income should be to prevent poverty and to enable belonging and participation. Although there were differing views on whether superannuation should be means tested, overall there was concern that to strong a focus on means testing could lead to stigmatizing the majority of elderly reliant on a benefit. This could point to clawing back the pension through the tax system as a means to achieve the same result, not paying a pension to people who do not need it, but without creating the stigma and insecurity of a benefit.

Debates on New Zealand Superannuation have focused heavily on questions of its future affordability. This project has looked at the issue of retirement provision from a broader perspective than just affordability. Rather than seeing the 'solution' to the cost of supporting a growing elderly population in terms of reducing the level of government support to a means tested benefit and increasing the emphasis on individual saving, this research has explored the inter-relationship between the ability of women to save and the increasing demands many women face to provide care for New Zealand's aging population. By taking a broader perspective than just affordability it is possible to identify other significant means to assist in the provision of retirement income – for example a more universal home support service as a strategy to both assist elderly people to maintain their independence and improve the ability of women to provide for their own retirement.

The reflections of the women above show an acute awareness of the increasing personal cost of unpaid work – in terms of facing an insecure and meager retirement income. Not surprisingly there were also strong views about the importance of maintaining a universal pension as a right and as to some extent recognition of unpaid work. It is important for the development of government retirement income policies that the concerns and ideas of these ordinary women are heard. For our retirement policies to work will require more than just listening to the economists, the policies must also take into account the reality of juggling paid work and unpaid caring responsibilities. If we ignore the impact of unpaid work then it is likely that government policies could disadvantage a substantial proportion of the elderly population – women who have not been able to provide for their own retirement.

Appendix 3.11

Bibliography

- Age Concern New Zealand Incorporated. (1997). *Core issues in health care services for older people*. Wellington: Age Concern New Zealand Incorporated.
- Allen, I., & Perkins, E. (1995). Chapter 11: Discussion. In I. Allen & E. Perkins (Eds.), *The future of family care for older people* (pp. 221-234). London: HMSO.
- Belgrave, M., & Brown, L. (1997). *Beyond a dollar value: the cost of informal care of older people*. Auckland: Dept of Social Policy and Social Work, Massey University, and the Disability Support Services Division of North Health.
- Davey, J. (1995). *Putting housing wealth to work. Home equity conversion in New Zealand*. Wellington: Ministry of Housing.
- Day, A. T. (1985). 'We can manage'. *Expectations about care and varieties of family support among people 75 years and over*. Melbourne: Institute of Family Studies Monograph No 5.
- Department of Statistics. (1992). *Making provision for retirement. Findings of the Survey of Retirement Provision 1992*. Wellington: Department of Statistics.
- Dickson, J., Fish, J., Marsault, A., Pool, I., & Martin, B. (1997). *New Zealand women: constraints to savings for retirement*. Hamilton: Population Studies Centre, University of Waikato.
- Finch, J. (1995). Responsibilities, obligations and commitments. In I. Allen & E. Perkins (Eds.), *The future of family care for older people* (pp. pp. 52-62). London: HMSO.
- Finch, J., & Mason, J. (1993). *Negotiating family responsibilities*. London: Tavistock/Routledge.
- Fleming, R. I. A. W. J. T., Anna Pasikale & Susan Kell Easting. (1997). *The common purse. Income sharing in New Zealand families*. Auckland: Auckland University Press.
- Ginn, J., & Arber, S. (1995). Gender differences in relationship between paid employment and informal care. *Work, Employment & Society*, 9(3), 445-472.
- St John, S. (1991). Retirement income. In G. Hawke (Ed.), *A modest safety net? The future of the welfare state*. Wellington: Institute of Policy Studies.

Women & Retirement Income A Complex Web

*A Qualitative study of retirement provision ideals
and realities with Women from West Auckland*



- ❖ *Retirement Ideals*
- ❖ *Retirement Provision Steps*
- ❖ *Expectations to Provide for Elderly Family Members & Repercussions*
- ❖ *Views on Government Responsibility for Retirement Income*

*Researched & Presented by
Women Centre West Auckland*

Here's how to order your copy

Yes I would like a copy of Women & Retirement Income: A Complex Web for \$15.00 including P&P

My Address is

*Send to Women Centre West Auckland
P.O Box 69116 Glendene*

Chapter 4: Homebuilders Action Research Project

Initial Contact and Building a Relationship

In August 1997 during a lunch with Irene de Haan and some other friends, Irene raised the possibility that I could work with Homebuilders on a project. Following this Irene invited me up for an initial meeting with Homebuilders.

This meeting was my first opportunity to gain some idea of what Homebuilders did. They provided a range of different services and programmes, each with different funding sources. My initial impressions were of the 'homeliness' of the centre, its welcoming atmosphere, and a sense of Homebuilders workers as ordinary people with a strong passion to work with families holistically in a non-threatening and empowering manner. The Homebuilders Centre was located in an old Rodney District Council house, beside the river and very close to the main shopping area. The house was very unimposing and a hive of activity with people coming and going from the opportunity shop run by Homebuilders volunteers and Homebuilders also shared the house with Senior-net.

At this first meeting an issue for Homebuilders was a lack of recognition and understanding about their work in the community, particularly the model that Homebuilders used to work with families. They saw this problem as contributing to ongoing difficulty in gaining adequate funding. One worker was also concerned about how the overall undervaluing of community work resulted in their work being underpaid. Homebuilders was aware that many people knew of only some of the programmes and services Homebuilders provided and that they had not made their overall model explicit, particularly to other agencies and funding providers. Homebuilders also thought that the lack of knowledge about their model was contributing to uncertainty in the eyes of some other professionals regarding the professionalism of Homebuilders. The Homebuilders approach of working with families on all issues rather than being specialised, and of working with families rather than exerting any professional status over them, did not seem to be well understood by all local professionals and agencies. Many other aspects of the issue were explored and there was some discussion of ways to respond to the problem. For a while it seemed that Homebuilders were not in a position to look at addressing the funding/awareness issue – I think largely because the issue overall seemed entirely unresolvable. However after talking around this for a while the group did become more positively interested in pursuing the funding/awareness issue.

A short time later, during a phone conversation, Irene stated that the group had agreed to begin working together on the issue of awareness and funding. However they had not set any starting points or decided on a process. In this discussion with Irene I raised some

ideas that had come out of my last meeting with my supervisors – updating Homebuilder workers curriculum vitae's and doing a time use survey. Irene thought that these were useful ideas. She was of the opinion that the group had already discussed the issue a lot and it would be more useful to do some action, provided they all agreed, and then use the results for reflection rather than having another meeting to again discuss the issue before doing anything. Irene was also concerned that the next meeting was not for another fortnight and she suggested just putting the ideas to the group then, asking for other ideas and then if everyone agreed being able to start. I responded by saying that the ideas I had mentioned were just two possibilities and that other group members may have other ideas and suggestions. I didn't want to be in a situation of "me doing what I want with the group" to develop. Instead I saw it as important that the whole direction and process needed to be controlled by the group.

Unfortunately I was not at the next meeting on Monday. I found out afterwards that the ideas of updating curriculum vitae's and time use studies did not go down well. One comment was that doing those activities would increase the level of angst and dissatisfaction by highlighting the current injustice. Irene also said that everyone was now on some form of salary which meant that things like driving time, that were previously not paid for, were now more adequately covered. The outcome from that Monday meeting was an early reminder of the importance of always following a collective process. There was obviously some variation in where group members were at and where they were coming from on the issue. Only through ongoing discussions of the issue could agreement on actions or steps to be taken be reached. I also began to realise that it was very important for me to spend more time at Homebuilders to gain a better understanding of where everyone was at and the issues Homebuilders was facing.

A key difficulty the collective process faced was time. The reality was that any time spent discussing the issue would have to come out of time and money allocated to other programmes. There was some discussion as to whether time on this issue could be fitted around other meetings. I sensed that because of the costs involved in looking at the issue it appeared people wanted to see how it could directly benefit them. Thus I reflected on whether it was possible for me to identify and name the potential benefits or whether this should also come out of the group reflection.

I began attending Homebuilders Scheme meetings and helping Pat set up her budget on the computer. Working with Pat to put her budgets on the computer was very helpful in gaining an understanding of the financial pressures and constraints faced by the group. Homebuilders was running seven to eight different programmes at that time and juggling the budgets for all those programmes was an important and complex task. Pat had already worked out a really good system for managing the budgets, and I helped her put this onto

a spreadsheet on the computer. Having her spreadsheet system on the computer freed up more time for doing other work.

From August through to October my main focus was building a relationship with Homebuilders through attending some of their meetings, helping with accounts, and sharing ideas about the issues they faced. The most important aspect in building this relationship was spending time with them and getting to know each other.

During the scheme meetings the issue of funding and raising awareness of the Homebuilder model and how this could be addressed continued to be explored. Strong support emerged for the idea of finding ways of telling stories – as a way of clarifying how Homebuilders worked and to assist with gaining adequate funding.

Storytelling

In November 1997 I had a discussion with the group about the storytelling idea. Irene came up with the suggestion and it had also come up at an earlier meeting. The idea was that we have the storytelling sessions with actual families. The stories were seen as a way of answering questions regarding the effectiveness of how Homebuilder's worked with families. There was a lot of support for this idea. It was left quite open in terms of them finding the families and a time that suits them and that could be in November or next year.

I was pleased with the idea of interviewing a family and homebuilders together, mainly because their reaction was so positive to that idea. Homebuilders didn't think there would be any problem in terms of people feeling pressured, rather the opposite - that people like to have an opportunity to catch up with their homebuilder. The intention was that a time would be made with both the homebuilder and myself and the family altogether and Homebuilders would think about angles to pick up on for those stories.

There were a number of positive aspects about telling the stories all together. Irene pointed out that it was closer to the actual experience of the nature of the work, the working with idea and that therefore it was a more accurate reflection of how Homebuilders works. From an ethical point of view it is easier in that there would not be two contradictory stories, the one story would bring together two perspectives and deal with them both together. This would avoid a situation of having one story from a worker's perspective and another from the family's, because if told individually they would be different stories. It meant that it should be easier to get feedback on the family's experience and the overall story would stay with the family because it was their own experience.

I thought the story idea would continue to grow, it would take time to develop and happen and that was fine. It was good that everyone seemed enthusiastic. Homebuilders also saw gathering the stories as being an action that was appropriate to their organisation. They saw it as being an alternative way of doing research and conveying their experience and that it was appropriate for the type of work they do.

By this time I was feeling quite comfortable and confident about my relationship with Homebuilders, in terms of being able to work with them and I was looking forward to continuing to build on that. We were looking at doing maybe one or two stories with each homebuilder. I was very keen not to place any pressure on them for the stories, I thought whoever was able to and really wanted to would find the time and otherwise it was fine if they chose not to.

I helped draft up a letter (Appendix 4.1) for the families about the storytelling and a consent form (Appendix 4.2), with input from Irene and Pat. The letter was also discussed at their next supervision meeting. Pat was talking about having a storytelling session with one of her families and she was keen for there to be six stories in total, two with each of the family support workers at that time.

The other discussion that occurred was around whether or not I should be present at the storytelling. The decision that I should be present was made, based on a number of reasons. One reason was that it let people know who I was and meet me. For me that was a fairly strong reason because if they had some form of relationship with me, even briefly, that was a better basis for trust in terms of telling their story (I was going to be transcribing the stories). Another aspect that Irene and Pat noted is that I would have more idea of the relationship between themselves, the homebuilder and the family and I would see the boundaries of that relationship more clearly. A third reason was to make the story telling more formal in that I would be someone to whom the story could be told. The homebuilder already knew the stories so telling only a homebuilder would not be quite the same.

The key questions Homebuilders was interested in covering in the story-telling sessions were 'in what ways has a homebuilder helped improve the situation for you and your family?' and 'what would have happened if you didn't have a homebuilder?' The story-telling sessions were also intended to highlight the nature of the relationship between a homebuilder and their family and how that relationship worked.

At the next scheme meeting we had another good discussion around the storytelling, we read out the information letter for families and everyone agreed with it. Madhuri drew it out to explore the angle we were coming at for the stories and I think everyone was quite clear on that by the end of the discussion. Pat made a time for the very first interview and I was looking forward to it.

Homebuilders also started looking at coopting me on as a member at this time, so I could formally be part of the Scheme meetings.

Due to the nature of the interviews (hearing the stories from families Homebuilders have worked with) it was not feasible to do any pilots. However considerable thought and discussion had been put into the process so far.

The first storytelling session was with Pat, one of her families and me. Following are some reflections from that time.

I had a few discussions with Pat after the first storytelling session. Pat said that she had felt very uncomfortable after the storytelling, very ill at ease because it was the first time she has ever shared a story of one of the families with someone outside of homebuilders. I could agree and understand where she was coming from. For me it was in terms of how one way all the giving was and that it was an unbalanced exchange. Pat said she could rationalise it in heaps of ways but it left her feeling uncomfortable and so I said that we should be open to thinking about the process we are using again. If we're not happy to continue in that vein, I'm not sure what process would be better for the stories but there might be ways that we could make it a little less unsettling, I'm not sure. Both Pat and I will think about it some more and see if we can think of any other ways that may work better. I don't know if other stories are as disturbing as that particular story was. Just keeping very open in terms of what people want to do, where to go with it from here. I am pleased that Pat gave me that feedback and I am looking forward to further discussions about the appropriateness of the process.

I spoke to Pat this morning, phoned her, and she has spoken to [the storyteller] and she is fine, they had a talk about the interview and how she felt afterwards. From where she is at she was fine about it, she felt that it was in the past enough for her to put out there and share and she didn't have a problem with that.

Pat also passed on to her, some of my comments afterwards and in particular the fact that I said how I wanted to honour the story, I am pleased that she passed that on. I think it does describe how I feel about it and the sense of obligation I feel under to honour, to respect it really. Pat also had her own feelings of uncertainty of having for the first time let go of the story of her work with a family. Pat is also talking of another women for an interview so I might hear back on that next week. I've put in the post a transcript up to Pat for her to look at and to pass on in person.

After I had done the transcript for the first story we discussed how to pass it back to the family. Pat decided it would be best to pass the transcript on in person and I thought this was a very good idea.

The second story-telling session was also with Pat. Again here are some of my reflections.

Just had my second Homebuilders story with Pat, it went really, really well. I just wanted to put on record some of the conversation we had afterwards, we had a short conversation in her car immediately afterwards. She had a number of comments she wanted to convey to me, one of which was she thought that I should sort of follow-up the others a bit about getting them on-board and starting the stories. I suppose that reflects that she is concerned about the reciprocity and is keen for the others to be involved in that. My comment back to her was that yes I would speak with them and I'm flexible about when it suits them and I'm happy for it to be after Christmas if that is their preference, but also that I didn't want to place any pressure on people to do the stories.

February 1998

I have just been to Homebuilders first scheme meeting this year. At the end of last year we had two story-telling sessions, both of which I transcribed last year and sent back to the homebuilder to look at and take to the story-teller. The current plan is to do another four story-telling sessions and then discuss where to go from there. At the moment there is a bit of a lull as the next sessions have not been set yet. I was also involved with helping Homebuilders prepare their health and safety policy at the end of last year.

Difficulty Finding Issue Clarity

In the New Year I continued participating in the scheme meetings and discussions about the issues Homebuilders faced. Defining the issue and finding ways of responding continued to be difficult, involving ongoing discussion and reflection.

There is a lot of analysis amongst the group, especially in terms of the context in which they're operating and the difficulties they face both at the family level and the funding level and the sort of community level. But there doesn't seem to be a single definition of a problem as such, it doesn't feel like that anyway. I mean there are difficulties around getting funding and there is all sorts of other difficulties arising from the context in which they're trying to work and I think everyone there is really well aware of those. There is a commitment to seeing the stories through but there is no shared clear picture yet of why we're doing this or what we're trying to do or

exactly what is going on. I think everyone has got different pieces of it, different pieces of a puzzle and ways of expressing it and different ways of seeing it, and I think that is one of the gifts of Homebuilders.

For me this means that my role there often feels a bit ambiguous, a bit undefined or a bit unclear, but at the same time that is okay because everyone there seems comfortable with it and I'm comfortable with it. I think the key thing is to continue finding ways of connecting with Homebuilders as a group in terms of working with them, on the issue as they define it. I am looking for ways to continue connecting with them, the stories are really one piece, one part of the process of Homebuilders trying to clarify its identity, become more visible, and claim the respect it deserves, and the resources to do the work that it can see needs doing.

The Code of Social and Family Responsibility and Homebuilder's Response

In February 1998 the National Government proposed a Code of Social and Family Responsibility (New Zealand Government, 1998) and distributed it, along with a response form, to households throughout New Zealand. The code concerned defining individual and family responsibilities in a number of issue areas identified by the government (such as looking after children, pregnancy, young offenders, sharing parenthood, work obligations and income support, managing money). For a fuller discussion of the code see Davey (2000).

Homebuilders response to the proposed code was to connect up with the Wellsford Budget Service and organise a public meeting on the code at Snells Beach. Homebuilders were very concerned about how the code could negatively affect families and particularly beneficiaries. The forum was well attended and generated a lot of public interest and discussion locally. This was an example of the type of local collective initiative Homebuilders could initiate and support. The most important key to my being able to participate in these types of responses was being physically present, so that as ideas and activities emerged I could be involved where appropriate.

Reflection on Awareness/Funding Issue

In March Homebuilders set aside time for an evaluation day. They used literature about the Homebuilders model in America, comparing it to how they were running Homebuilders here. This was a very interesting and useful exercise as it helped further identify particular features of the Homebuilders model and critically reflecting on the way they worked. In contrast to the other two projects, Homebuilders did their own literature review and I didn't need to spend time doing research and preparing a literature review for the group. I think this difference between Homebuilder's and the other projects was a reflection of the fact

that members of Homebuilders were already very familiar with the literature on the Homebuilder's model and related issues.

It feels very much like a reflection type stage at the moment and it will be interesting to see what further actions come out of it. The fact that we had this evaluation day and that they've scheduled a Social Responsibility discussion and trying to draw a picture together of who Homebuilders are, what they are, what they do, that picture is very high on the agenda at the moment, so there is a doing element. At the same time a searching for more that they can do as well, interesting.

It was around this time that I began to sense that the direction of the project with Homebuilders could change, possibly radically. I think this potential change in direction was related to Homebuilders gaining a clearer picture of how they worked in their community. Four out of the originally six planned story sessions with Homebuilders had now been completed.

Although there was some ongoing reflection on the story-telling sessions at Scheme meetings, there was no significant amount of time spent on what action to take next with the story-telling sessions. I think this may have been for a number of reasons. In part the continuing lull around the story-telling may have been due to lots of other activity around the Code of Social and Family Responsibility and in part there may have been issues over the group owning the project. I think possible difficulties in having a strong ownership of the project and direction for continuing it was related to the lack of clarity around the definition of the problem Homebuilders was seeking to address.

Following are some comments Irene made in a conversation reflecting on the multi-faceted issues Homebuilders faced and the ill-structured problems faced by families Homebuilders work with:

"Ill-structured problems are part of the nature of community work in some way. Often there is no clear parameters for the (Homebuilders) community worker – they work in response to what the family wants to change, and this can be always updatable and flexible and quite unclear, goals shift and change, and are multi-faceted. The life of any person or community is multifaceted and this is a good thing. It could be that research that deals with multi-faceted issues is on the right track, it is not isolating out one small piece from the bigger picture."

In reflecting on Irene's comments, I realised that all three group projects had sought to look at multi-faceted issues rather than narrowing their focus to one small clearly defined issue area.

Beginning of Participatory Living Standards Project

On the 10-11 of August 1988 I participated in a very intensive two-day workshop examining Homebuilders strategy and direction. This was a very fruitful workshop and there were several sessions following on from it.

During this two-day workshop, the workers on the helpdesk made a desperate plea for help because they were finding that due to changes in Work and Income New Zealand (WINZ) they were no longer able to help many families in poverty with whom Homebuilders had been working. Gary Follas, one of the Homebuilder helpdesk workers, initiated the call for a project. He had a very clear idea of what he wanted from it, and was asking for help out of frustration. Out of this plea came the idea of doing a research project on rural poverty and living standards in their area. After a discussion around the need for some research on local living standards it was decided that a useful first step would be for Irene and myself to meet with Mike O'Brien at Massey University, as this was one of his research areas, for some suggestions and background on what research existed. As well as being my supervisor, Irene and I had both worked previously with Mike O'Brien on a major research project and we valued his knowledge and input.

From this initial idea for a new project, the idea rapidly became much bigger.

Although not a conscious decision, the effect of Homebuilders shifting its attention to this new project that had arisen within the group, meant that the story-telling project was aborted for the time being. A lot more work would have been needed to further develop the story-telling project but Homebuilders was now responding with a sense of urgency around the difficulties the Help Desk was discovering. Although I could see this happening, I felt that I should continue working with Homebuilders regardless of the changes in direction they were taking. My hope was that one day the story-telling project might be picked up again, but that this would only happen when the time was right and when the group wanted to take a stronger ownership of that project. In the mean time there was a lot of work that I could be involved with on the rapidly growing Living Standards Project.

When Irene and I met with Mike O'Brien he was very interested and supportive of the project. He provided an overview of what research existed in New Zealand, noting that there was a marked gap in research on rural living standards.

Mike O'Brien was invited to the next Scheme meeting where we had a general discussion with all of Homebuilders about doing a survey on Living Standards. Out of this initial discussion a number of important decisions were made. One key decision was that Homebuilders were interested in looking at the situation of not just their clients or beneficiaries, but including the full cross-section of living standards, from wealthy to poor.

This meant the project was being defined as looking at living standards rather than just poverty. We were interested in looking at the effect of income on family wellbeing. A second key decision was to open the project group up by inviting other interested groups and individuals to work with Homebuilders on the project.

Following the Scheme meeting, Irene called a second meeting at Homebuilders for everyone who might be interested in participating in the project. In response to invitations, representatives from a number of other community groups attended, as well as interested people within the community. About fifteen people gathered to plan and work together on the project. The group consisted of some Homebuilder workers and clients, people on a range of different benefits, people on low incomes and on higher incomes, people from other community groups, such as the Wellsford Budget Service and the Kaitiaki Resource Network, and academics such as Mike O'Brien and myself.

Mike O'Brien's involvement as a well-known academic from Massey University was important for Homebuilders as they saw his involvement as giving the project some validity within the public eye. Homebuilders felt they had a strong moral standing on the issue of living standards and valid experience but they also saw involving the reputation of the university as useful for reinforcing in public that the research project was valid for the whole community. Mike O'Brien also contributed some resources from the University to the project.

This first large meeting was an energetic brainstorming session on forming the project and identifying the areas of interest. The wide range of people all brought their own knowledge and experience and all of this contributed to shaping the project. The process involved gathering together many different pieces of information. The process established was participatory rather than consultative – in that the people involved were all equal participants in discussing and developing the form of the project. It was not a case of Homebuilders seeking ideas from others and then having a final say on decisions. Rather the process was one of decisions being agreed through consensus by everyone who attended the meetings. Another important aspect of the participatory process was that the project steps had to come from the group. There was no individual dictating what steps were necessary, everyone was able to contribute to identifying the steps that should occur.

The inclusiveness of the project was to do with the people there – people involved were suggesting others that may like to be involved, thus creating a snowballing of participation. Driving the project along was evenly shared by everyone involved, although later on Irene had an important co-ordinating role.

Raising the public profile of Homebuilders was seen as a likely side effect of the Living Standards Project, however this was not a deliberate goal of Homebuilders or the project.

Values

In the living standards research project values were drawn from Homebuilders and the whole project group. The starting point was a desire to uncover detailed information to gain an accurate picture of the range of living standards in the Rodney District. For many involved in the project their strong commitment was in part a reflection of their concern regarding the difficulties faced by families in the local community. There was a strong belief that statistical information was necessary to highlight the spectrum of living standards and the impact of inadequate incomes on the well-being of families. There was also a belief that many government policies were contributing to family hardship and that government benefits were failing to meet the needs of many rural families. There was also a desire to provide the community with information and raise awareness within the community regarding the spread of living standards.

Politics

In relation to this project the research problem was defined by the project group. The study was relevant to families living in the Rodney District, to local community groups, to the local council and to a range of policy makers. The project group identified to whom the study was relevant and there was considerable interest and positive feedback from families and the community during the interviewing period. Although the project group was predominantly Pakeha the survey sample covered a range of ethnicities in the Rodney area and the information and knowledge was to be fed back to all interested groups within Rodney District. The research was accountable to the project group. The people likely to gain most from this study were the people who lived in Rodney and had an interest in the wellbeing of families in the area. As a side-effect Homebuilders benefited from a increased profile in the community. Many of the people involved in the interviewing for the project benefited from increased confidence and extending their skills. I benefited as the project was part of my continuing relationship with Homebuilders and hence was in part towards my doctorate.

Ethics

Informed consent was sought from all the families prior to being interviewed. They were given an information sheet (Appendix 4.3) explaining the project and were told they had the right to decline at any stage or to choose not to answer some questions. We guaranteed confidentiality and anonymity for all the families interviewed.

Questionnaire Development

The questionnaire evolved through a number of drafts over several months in 1999. The breadth of representation in the group, in terms of experience and differing income levels, was central to identifying the questions to ask. Ideas from past surveys were also considered. A very important repercussion of the participatory process was that all ideas for the survey were worked through and included. If someone wanted a particular question then it had to be included, nor could questions be easily edited. This was because there was no project hierarchy or leader, no one could sit in judgement on other's ideas. Although Irene, and later Hannah, took on the key co-ordinating roles, they did not have the role of project leaders.

Research Concepts

The survey sought to collect information on a wide range of topics related to family living standards. As a result we divided the survey up into the following parts:

1. Part A: Household Profile
2. Part B: Transport and Vehicle Ownership
3. Part C: Insurance
4. Part D: Housing
5. Part E: General Expenses
6. Part F: Food
7. Part G: Telephone
8. Part H: Health
9. Part I: Children
10. Part J: Household Equipment
11. Part K: Household Income and Expenses
12. Part L: Household Savings
13. Part M: General
14. Individual Adult Questions – for each adult in the household.

Because we were interested in examining family living standards, we needed to gain a clear picture of the household profile, identifying children and adults who lived in the household on a temporary and part-time basis. We also wanted to distinguish between adult household members that were effectively part of the family unit and budgets from adult boarders whose only contribution to the household was paying board and who had no role in caring for the children.

For all questions on specific expenses and incomes, we also allowed the person being interviewed to specify the timeframe of income/expenses. This was to simplify answers to questions, the amount for a known timeframe could be given, without needing to work out

another figure for a different set timeframe. The timeframe field could then be used to standardise the results.

Considerable thought was given to the wording of questions, to ensure we could differentiate cuts, for example in food, that were related to income from other lifestyle reasons. In some topics we were interested not only in financial barriers to services but also other forms of barriers that could effect living standards, for example waiting lists and distance barriers to health services.

We were seeking information not only on family's expenses, but on whether they considered they had difficulty affording certain expenses and when they did, how they resolved this issue. We also differentiated between the income and savings of individual adults in the household, from any income or savings that was owned jointly by the household. For example one adult may have had a retirement savings scheme, and both adults in the household may have owned another property from which they received rent. In the general section we were also interested in the views of families on how their living standard compared to others in the District.

The main categories we were interested in grouping the information by were family type, ethnicity, geographical area and housing type. A copy of the survey information sheet is included as Appendix 4.3 and a full copy of the final survey form is included as Appendix 4.4.

Piloting the Questionnaire

In June – July 1999 we began piloting the questionnaire. This involved trialing the questionnaire on a handful of different families. As a result a number of further changes were identified. It was also decided to seek feedback from interviewers regarding the questionnaire in the training sessions (the feedback form is included as Appendix 4.5). This would enable us to identify any final changes that would help the volunteer interviewers.

Selecting the Sample

Because we had decided to sample people in person from a cross-section of income levels we needed to draw our sample from the council rate database. Initially we got a list of all rate paying sections in hardcopy, however we quickly realised that it would be far easier logistically to select our sample by having the data electronically in a file. After extensive discussion and reflection we divided our sample up into geographical areas, choosing to start with Snells Beach, then Wellsford and finally the rural Rodney area. There was some debate over which areas to select, as we wanted to choose areas that were representative of the area. Although our sample, in terms of house numbers, was selected from the

council rate data, we used census data to identify the number of families living in each geographic area. Thus we matched the addresses into the corresponding census blocks. After deciding on the sample size and identifying all the addresses in the chosen geographic area, we divided the total addresses by the sample size to identify how many houses between each selected house ('nth' house). The addresses were then sorted, and using a small programme, we identified all the addresses for the survey. These were then printed out on the Survey Tracking Sheets for interviewers (an example blank tracking sheet is included as Appendix 4.6).

We had considerable difficulty identifying the correct formula to use for our sample size. After a number of discussions with Statistics NZ and a statistician at Massey University, we came to the conclusion that there was no simple formula available that took into account the income distribution for families in the geographic areas. The formula we eventually used was a standard formula for identifying sample size in general surveys. Using this general formula meant that we had to survey more families than would have probably been the case with a more specific formula.

Organising Funding

Funding for the project was obtained from a number of different sources and used for different purposes. Mike O'Brien applied for funding from Massey University and this was used for printing the survey forms and information sheets and for buying the address data from the Rodney Council.

Irene also made funding applications to Projecta, Caritas and the Federation of Family Budget Services – Pennywise. All of these funding sources were identified through word of mouth, and the funding organisations were all very supportive of the project. The funding was used to pay travel costs for volunteers, to pay for some of the data-entry of the survey forms and for other miscellaneous research costs (for example survey folders for interviewers).

Hannah's Role

As we were preparing to start interviewing, we were very fortunate to have Hannah Emerson join Homebuilders and the project, on a three month student placement. Hannah took on the job of setting up and running the systems used to keep track of the interviewing. She was based in the office and dealt with all the messages and organising for volunteer interviewers. It was a very difficult and big job and Hannah was able to manage it very efficiently. She took charge of a lot of the detailed work in the office to manage the project on a day to day basis.

Asking Interviewers

There was some discussion of whether to advertise for interviewers, but in the end we decided against advertising. The main reason was that it was important to gather volunteers that were known to someone in the group and that were capable and trustworthy. Given that the survey involved going into peoples' home and asking a lot of personal questions it was important that the volunteers were trustworthy. Irene spent several months leading up to and during the interviewing period, using all her local networks to find volunteers. Explaining the survey and getting the commitment of a wide range of volunteers was a very big job.

Preparing the Surveying Process

The actual surveying process and the instructions for interviewers (Appendix 4.7) were carefully considered and discussed. Safety considerations were an important concern, especially in relation to dogs. Although clear instructions regarding safety were identified for all interviewers, in practice safety was not a problem. No interviewers were threatened and on the whole interviewers were welcomed because people were aware of the survey from the publicity and were often keen to talk and tell their story.

Replacement System

Because we needed to reach our target number of interviews, we decided to use a replacement address system. Interviewers used replacement addresses when: there were no children living in the household; the respondent declined; there was a loose or dangerous dog; if when they returned for a call-back time nobody was home and the respondent had not phoned the office.

The replacement steps were:

1. Take the next highest letter box number if houses were numbered;
2. If they were not numbered go to the next house in the same direction that the interviewer was travelling and on the same side of the road;
3. If it was the end of the road, return to the immediately preceding house;
4. Continue following replacement steps until a survey is completed;
5. Update the Questionnaire Tracking Sheet with the final address surveyed.

Call-back System

One reason we had decided to do the surveying in person was to avoid biasing the survey against people that did not have a phone. But for in person interviews we still needed a method that would prevent biasing the survey against people that were out of the house during the day. After some discussion we decided on the 'call-back' system. When there

was no adult respondent at home, interviewers left an envelope with a information sheet about the survey and a call back letter. The interviewer filled in a call back date, time and interview id number on the call back letter (Appendix 4.8). This meant that if the call back time did not suit the respondent, they could call the office and either decline or arrange another time. Interviewers had to phone the office and check for messages for their interview id numbers before going back to call back appointments.

Training Interviewers

A training session for all the volunteers was organised for one evening in August 1999. The turnout for the training session was very good and there was a lot of enthusiasm for starting interviewing. The training involved explaining the project and their role, working through all the instructions and then doing a practice survey in pairs. The practice was a very useful way of familiarising the interviewers with the survey and identifying any difficulties in doing the survey. The interviewers were also all given a feedback form (Appendix 4.5) to make notes on any final suggestions for the survey (in terms of wording and layout).

Media Work

A lot of thought and time was given to contacting and building a good relationship with local papers. The papers were very supportive of the project and were very helpful in publishing a number of articles introducing and covering progress on the surveying. This media work was a very important part of preparing the community for the project. Articles in the local papers before beginning interviewing, meant that people were already forewarned that we were coming and had some knowledge about the survey. There were also several articles in the paper giving feedback on progress with the survey. This helped maintain awareness and public interest in the survey. Some of the media articles are included as Appendix 4.9.

Starting Interviewing – Discoveries

When the interviewing started in September 1999 we were relieved to discover that our basic method worked, particularly the replacement and call back steps. After a while, some of the survey tracking sheets, particularly where families had been difficult to find and the sheets had been filled in by several interviewers, became a bit difficult to read as interviewers recorded a list of households that had either been not eligible or declined. However on the whole interviewers were able to work out what houses had already been approached and where to go next to find a replacement household. There was only one major error with the system, where the interviewers got confused and visited the same household that had already declined three times. In response an apology was made in person with some flowers.

The call-back system, where households phoned the office if they had a problem with a call-back time, worked well. Many people phoned the office to say that their household was not a family with children under the age of 17. This information was very helpful for volunteer interviewers as it saved them many unnecessary call-back trips.

It rapidly became apparent that relying on volunteer interviewers meant that we couldn't control how long the surveying would take. We had to wait until volunteers were available again to continue interviewing. If a volunteer was slow at getting interviews done or had other unexpected commitments that delayed the interviewing – we could not turn them away from working on the project. We were entirely reliant on the availability of interviewers and we could not set firm time-lines on when they should have the interviews completed.

In both the interviewing and all other aspects of the project there was a 'what eventuates' nature to it. This was a result of no one being able to control exactly what happened or when. The plan was constantly being revised, everyone was clear on the overall goal of doing the surveys – the exact who and when and how had to be open to revision depending on what happened, both in individual lives and to the project. This need for ongoing responsiveness again had parallels to how Homebuilders works with families, and in that aspect the process was not unfamiliar.

However Irene has commented that the process felt too fluid and that this was a real source of worry at the time. From her position as one of the co-ordinators Irene said the project felt completely out of control and totally unmanageable at times. Part of the difficulty was that it was not possible to contain the project, it was constantly interactive with all the volunteers and the large group of people involved. Work on the project and ideas for its development were shaped by and dependent on what all the people involved could give.

The participatory process used for the project strongly reflected how Homebuilders works with their families. Homebuilder workers are very responsive to what is happening with a family. In a similar way planning and actions for the project also needed to be very responsive to changes in the situation and availability of volunteers.

Within the first day of interviewing we realised that our survey tracking sheets needed to group addresses together geographically rather than sorted alphabetically by street. It was an unfortunate oversight that we did not realise this prior to beginning interviewing, but we were able to revise the rest of the tracking sheets.

Initially the plan was for interviewers to go out in pairs, for safety reasons and for support. However this did not happen in practice, firstly because the addresses on each interviewers tracking sheet were usually too far apart for them to be working close together. Secondly,

because interviewers were often making call-back times it was difficult to co-ordinate together. Most interviewers decided for themselves that they didn't need to work in pairs.

Surveying in Snells Beach – Where are all the families?

Our first survey area was in Snells Beach and we quickly discovered the issue of 'where are all the families?' We found that Snells Beach had a substantial retired population and a number of holiday homes. As a result we found a number of whole streets with no families in them. Once this problem was identified volunteer interviewers began asking non-family households if they knew of any families in the street to try and avoid having to do callbacks for every house in a street with no families. We had known that there were many retired people and holiday homes in Snells Beach but we hadn't realised the pocketed nature of some streets having many families and other streets having no families. Fortunately when we began surveying in Wellsford finding families was a lot easier. Interviewing in Snells Beach and Wellsford was completed in March 2000.

Supporting Volunteer Interviewers

A number of volunteer interviewers quickly got jobs and thus were unable to continue interviewing. Sickness and family demands also affected the availability of interviewers. There were also some volunteers who did many interviews and stayed with the project throughout. The changing circumstances for some volunteers meant that Irene continued to look for more volunteers. Another important role that Irene played for the volunteer interviewers was to support and encourage them, particularly after difficult interviews where the families were really struggling. In these instances interviewers would leave a pamphlet with the family on help available from Homebuilders.

Benefits for Volunteers

Participating in the project led to a growth in confidence and skills for a number of volunteers. Some volunteers were able to learn things that were relevant for their own situation. Two young students gained useful work experience being paid to help with the data-entry of the survey forms.

Community Response

All the publicity around the survey and the visibility of interviewers on the street helped generate a strong interest in the survey within the community. Many people interviewed commented on being interested in the survey findings. There was also a noticeable increase in referrals to Homebuilders, as their profile was raised and many families became aware of the services they offered.

Setting up Data-entry Database

Towards the end of 1999 I set up the database ready for data-entry. We decided to enter the data using the Filemaker database programme, rather than Minitab, because the number of data fields and surveys involved would have been stretching the ability of Minitab.

Data-entry Training

In early 2000 I had a training session with one of the students doing the data-entry and systems for dealing with queries and tracking the data-entry were set-up. A few months after this the second student was set up to also help with data-entry. Data-entry began in January 2000, while the interviews were being finished, and continued through to June.

Analysis of Results

Following the data-entry I did an initial analysis of the data for collective reflection and to stimulate further areas of analysis. The initial analysis includes basic counts and percentages for most questions and all the comments and is included as Appendix 4.10. A total of 115 households were surveyed, 64 in Snells Beach and 51 in Wellsford. Likely steps early next year are calling a meeting to collectively reflect on the findings and organising feedback of the findings to the local communities through local forums and the media. There has been a lull in the project since the first round of data analysis, and this has been largely due to Homebuilders being very busy and significant energy being focused on finding a new building for Homebuilders.

Future of the Rural Section of the Survey

Our original intention was to also survey the greater rural area of Rodney, however we have identified a number of problems with that plan. At a practical level, we think that face to face interviews rurally would be very difficult for a number of reasons. Firstly the distances involved are significant and thus the cost in terms of more travel and time for volunteers is discouraging, particularly if we used the call-back method. Another difficulty is actually finding rural houses, as they are frequently not easily visible from the road. It may also be difficult to find an adult at home on a farm and finally loose dogs are more likely to be an issue on farms than in the small towns. All of the above reasons have lead us to consider other methods of surveying the greater rural area, with the most promising method being a shorter phone survey. However this would still involve a bias against families without a phone and there may also be issues in selecting a phone sample. Whether there is still sufficient impetus and energy from the project group and volunteers for this third round of

surveying remains to be seen, but given the timeframe from the beginning of the project, it is now less likely that this final round of surveying will occur.

Concluding Comments

One key difference between Homebuilder's project and the other action research projects is that Irene took the central continuity role through the whole Homebuilders project. In contrast I was the main continuity person involved through the whole course of the West Auckland Women's Centre and Autistic Association projects. This difference occurred for a number of reasons. One was that I was only able to make visits to Homebuilders, I wasn't working there daily due to the physical distance, nor did I know the local networks and community. Irene, with help from Hannah, provided the daily co-ordination of the project. In both of the other projects, key members of the groups who were most involved in the projects left and new people came on board. Thus in those projects my role as being a person involved from the beginning was more marked. With Homebuilders I had to step back from taking as active a role near the beginning of the interviewing, due to Malcolm's death, and this meant Irene had the central continuity role.

One key effect of my physical distance and not being as involved in the day to day running of the Homebuilders stories and living-standard projects, is that telling the story of the two projects is harder as I am more aware of not having a full picture of the whole story.

Feeding back drafts of this chapter provided Homebuilders with an opportunity to reflect on both the story-telling and living standards projects. One of the comments made was that they now have a much stronger and explicit awareness of the Homebuilders model, and that they now have a 'place to stand'. The view was that this change had been cumulative over time, partly through the story-telling and reflecting on American literature. Their concern over being able to make explicit and visible the Homebuilder's model and how they work is no longer as problematic, as there is now a sense of confidence in the fact that 'we know'.

I have really enjoyed working with Homebuilders, particularly their humour and warm welcomes. As with the other two groups, the living standards project is still continuing with the main priority, at the time of finishing this thesis, being feeding back the findings of the project to the community through local newspapers.



HOMEBUILDERS
WELLSFORD/WARKWORTH INC.

Family/Whanau Support Scheme

5 Baxter St. Warkworth
Ph. (09) 425-7048

Dear

Homebuilder Stories

Homebuilders is concerned about a lack of recognition and understanding about its work in the community. This problem is contributing to ongoing difficulty in gaining adequate funding.

After a lot of discussion and reflection on the many facets of this issue, we have decided that gathering together some stories of our work would be a good place to start in addressing some of the problems we face.

Thus we are inviting you to participate in an interview to share your story of working with a Homebuilder. Whether you decide to participate, or not will have no impact on your current or future relationship with Homebuilders.

The interview (approx. 1 to 1 and a half hours) would be taped, and before material from the interview is used in any way, you would have the opportunity to edit or delete any information. Great care will also be taken to preserve confidentiality and anonymity - this can be done through changing names and selected details of the story. The key questions we are interested in covering in the storytelling are 'in what ways has a homebuilder helped improve the situation for you and your family?' and 'what would have happened if you didn't have a homebuilder?'. You may leave the project at any time and participate to whatever level suits you. The tapes from all interviews will be returned to you if you wish or destroyed at the end of the story project.

How we use these stories depends in part on what emerges from the story-telling. We will ask your permission before using the stories in any form - we would also value any suggestions you may have for how the stories could be used.

To help us with this project, we are working with Carmel Cervin (see attached profile) who is a PhD student from Massey University, Albany. Her thesis is concerned with injustices in the relationship between paid and unpaid work in New Zealand and ways these should be addressed. This overlaps with the difficulties Homebuilders faces, as a community based agency with its work undervalued.

Carmel will be working with us on drawing the stories together and with your permission will participate in the interviews. She will also ask for your permission for the stories to form part of her PhD thesis. Again you will have the opportunity to edit or delete any information, and confidentiality and anonymity would be guaranteed.

Please let your homebuilder know if you would like to participate in an interview and feel free to ask any questions.

Thank you for considering this invitation.

Best wishes

Homebuilders



MASSEY
UNIVERSITY

A L B A N Y

COLLEGE OF HUMANITIES AND SOCIAL SCIENCES

DEPARTMENT OF SOCIAL POLICY & SOCIAL WORK

Homebuilder Stories Consent Form

I have read the Information Sheet and have had the details of the story project explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand I have the right to withdraw from the study at any time and to decline to answer any particular questions.

I agree to provide information to Homebuilders and Carmel Cervin on the understanding that confidentiality and anonymity will be preserved. The information will be used only for this project and publications arising from this project and for Carmel Cervin's PhD thesis. I understand that I will have the opportunity to edit or delete any information before it is used.

I *agree / do not agree* to the interview being audio taped.

I understand that I have the right to ask for the audio tape to be turned off at any time during the interview.

At the end of the project I would like the tape to be
returned to me / destroyed.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signed:

Name:

Date:



Homebuilders

Wellsford/Warkworth INC

Family/whanau Support Scheme

5 Baxter St, Warkworth
ph (09) 425-7048



School of Social Policy &
Social Work
Private Bag 102 904,
North Shore MSC,
Auckland,
New Zealand
Telephone: 64 9 443 9765
Facsimile: 64 9 443 9767

AUGUST 1999

INFORMATION SHEET

STUDY OF RURAL LIVING STANDARDS IN RODNEY

WHO IS DOING THE RESEARCH AND WHAT IS IT FOR?

A group of social services agencies in the Rodney District, coordinated by Homebuilders and the Wellsford Budget Service, is undertaking a study of living standards in the area. Massey University is assisting with the research. We plan to find out about the particular issues involved in living in a rural area and will be asking about such matters as costs of living, employment, income, costs associated with rural living such as access to work, education and health facilities.

The study will give useful information which can be used in policies for services and facilities in the area and will mean that there is better information about what is happening in the area. Your information will make an important contribution to better knowledge about this area and the demands on people living here. If you have any questions about any part of the research you should contact either Irene de Hahn 094257048, Valma Gidman 094259809 or Mike O'Brien at Massey University - 094439768.

HOW WERE WE CHOSEN AND WHAT DO WE HAVE TO DO?

We would like to ask you to participate by answering the questions in the questionnaire which our interviewer has. Your household has been selected at random from an address list of households in the area. Nobody involved in the research knows the names of anybody who has been asked to participate. You are free to decide whether you want to participate or not and you can also refuse to answer any particular questions you do not want to reply to. The interview is expected to take about 35-40 minutes.

WHAT WILL HAPPEN TO THE INFORMATION?

The information will be put together at the end of the research and written up as a report for the organisations involved. No names will be used in the final report. Copies of the report will be sent to relevant local organisations such as the Council. Other papers may also be written up for publication in journals. A summary will be available for everybody who is interviewed. A summary will also be written up for the local newspapers.

Survey Cover Sheet

Survey ID No: _____ (1) Date Completed: _____

Interviewer: _____ Data Entered: _____

If No Reply:

 Information Sheet Left

Followup Time & Date _____

Initial Questions:

1. Does this household have any children (17 years old and under) living here?

IF NO CHILDREN

Thankyou for your time but we do not need to survey this household.

2. I would like to speak to the person who takes daily responsibility for shopping and budgeting for this household.

To be Answered by Interviewer:

1. Is the home a House or
 Other (specify eg housebus, caravan, garage) (2)

2. Is the home in ... (3)

 a large town in the District 1

 a smaller town in the District 2

 a rural part of the District 3

3. Survey Completed by:

 First Household Subsequent Household

If Completed by Subsequent Household:

No. of Households Not Eligible: _____

No. of Refusals: _____

 Master List Updated

No. of Additional Individual Adult Sheets Attached: _____

Survey Checked on Return: _____

Part A: Household Profile

A1. How many families live in your household? (10)

IF MORE THAN ONE FAMILY – Do the survey for the family which is head tenant or owns this property.

A2. Do you have a one parent or a two parent family? TICK WHICH APPLIES (11)

One Parent Two Parent

IF ONE PARENT

A2.1. Does your family have a single mother or a single father? (12)

Single Mother Single Father

IF TWO PARENT

A2.2. Is your family a step or blended family? YES No (13)

A3. For each child that permanently lives in your home (include 17 years and under), please specify their age and ethnicity.

Years Old	Ethnicity
Child 1 (14)	(15)
Child 2 (16)	(17)
Child 3 (18)	(19)
Child 4 (20)	(21)
Child 5 (22)	(23)
Child 6 (24)	(25)
Child 7 (26)	(27)
Child 8 (28)	(29) (30-34 additional)

Ethnicity List

- NZ Maori 1
- NZ European or Pakeha 2
- Other European 3
- Pacific Island group (*specify*)4
- Other (*specify*)5

A4. Do you have other children (include 17 years or under) who live here on a part-time or temporary basis (for example custody arrangements, foster, overseas children)? (35)

YES NO IF NO GO TO A5.

IF YES

A4.1. How many children? (36)

A4.2. Approx. how many days per month does the child live with you? (37)

A4.3 How many months per year does the child live with you? (38)

A4.4. Does the child visit during school holidays? Yes No (39)

IF YES A4.4.1. How many weeks per year? (40)

A5. Do any children in your household have a paid job? Yes No (41) **Appendix 4.4**

IF YES

A5.1 For each child, what is their average weekly earnings, and how much of this is contributed to the family budget on average per week?

	\$AVG Weekly Earnings	\$Amount Contributed
Child 1	(42)	(43)
Child 2	(44)	(45)
Child 3	(46)	(47)
Child 4	(48)	(49)

A5.2 What difference does your child(ren) earning make to the family budget? (50)

A6. For each permanent adult resident in your home, that is the people over 17 years and normally living there, please specify their relationship to the children, gender (if not obvious), ethnicity, age group, whether they pay board, and whether they provide care within the family. (By provide care we mean taking some responsibility for the children and being viewed as part of the family.)

Relationship to the Children List	Choose the Number which applies from each list.		
		Age Groups List	Ethnicity List
Mother 1		18-19 1	NZ Maori 1
Father 2	Step-brother..... 9	20-29 2	NZ European or Pakeha 2
Grandmother 3	Step-sister..... 10	30-39 3	Other European 3
Grandfather 4	Cousin..... 11	40-49 4	Pacific Island group (<i>specify</i>) 4
Sister 5	Aunt 12	50-59 5	Other (<i>specify</i>) 5
Brother 6	Uncle..... 13	60-69 6	
Step-mother 7	Boarder 14	70 + 7	
Step-father 8	Unrelated Worker 15		

Relationship to the children	Gender(M/F) (if not obvious)	Age Group	Ethnicity	Board YES/NO	Provide Care YES/NO
Adult 1 (51)	(52)	(53)	(54)	(55)	(56)
Adult 2 (57)	(58)	(59)	(60)	(61)	(62)
Adult 3 (63)	(64)	(65)	(66)	(67)	(68)
Adult 4 (69)	(70)	(71)	(72)	(73)	(74)
Adult 5 (75)	(76)	(77)	(78)	(79)	(80)
Adult 6 (81)	(82)	(83)	(84)	(85)	(86)
Adult 7 (87)	(88)	(89)	(90)	(91)	(92)

Part B: Transport & Vehicle Ownership

B1. NOTE: In the following questions, diggers, farm bikes, tractors and heavy machinery are excluded.

Does your family own a vehicle (excluding boarders and workers)? YES NO (100)
IF NO GO TO B2.

IF YES

B1.1 How many vehicles does your family own? (101)

For each vehicle:	V1	V2	V3
B1.2 How many years old is it?	(102)	(103)	(104)
B1.3. What is the vehicles approximate \$ value?	(105)	(106)	(107)
B1.4. Is it currently registered [YES/NO]?	(108)	(109)	(110)
B1.5 Does it have a current warrant [YES/NO]?	(111)	(112)	(113)
B1.6 Is it insured [YES/NO]?	(114)	(115)	(116)
IF YES B1.6.1. How much do you pay for car insurance & how often do you pay this amount?(117)		(118)	(119)
B1.6.1. Is it 3rd party [1], or 3rd party fire and theft [2], or full insurance [3]?	(120)	(121)	(122)

B2. What is the roundtrip distance in kilometres to the following services, and the main usual means of transport that you use to travel to the following services. (INDICATE WHERE NOT APPLICABLE)

	Kilometres	Usual means of transport
Childcare	(123)	(124)
Grocery Shopping	(125)	(126)
Doctors	(127)	(128)
Primary school	(129)	(130)
Secondary school	(131)	(132)
Other education	(133)	(134)
Bank	(135)	(136)
Other regular transport needs (specify)	(137)	(138)
(139-20 additional)		

Means of Transport List

Walking	1
Own car/vehicle.....	2
Lift in friends/relative car...	3
Borrowed car.....	4
Car pooling.....	5
Motorbike.....	6
Bicycle.....	7
School bus.....	8
Bus.....	9
Taxi.....	10
Hitch-hike.....	11
Other (specify)	12
Not Applicable	13

(144-170 additional)

Part C: Insurance

C1. Which of the following items of insurance do you or your household have:

	YES	NO	Timeframe	\$ Amount
Health insurance	(171) <input type="checkbox"/>	<input type="checkbox"/>	(172)	(173)
Life insurance	(174) <input type="checkbox"/>	<input type="checkbox"/>	(175)	(176)
Earnings/income insurance	(177) <input type="checkbox"/>	<input type="checkbox"/>	(178)	(179)
House insurance	(180) <input type="checkbox"/>	<input type="checkbox"/>	(181)	(182)
Household contents/personal effects insurance (183)	<input type="checkbox"/>	<input type="checkbox"/>	(184)	(185)

IF YES TO HOUSEHOLD CONTENTS OR HOUSE INSURANCE

C1.1 Do you have coverage to fully replace...	YES	NO	Don't Know
House insurance	(186) <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Household contents/personal effects insurance	(187) <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part D: Housing

- D1. Is your home ... (190)
- Rented
 - Owned with a mortgage
 - Owned without a mortgage
- D2. Would you describe your home as ... (191)
- Perfectly maintained
 - Well maintained
 - Moderately maintained
 - Inadequately maintained
 - Not maintained
- D3. How many ... rooms does your home have (exclude kitchen)?
- Bedrooms? (192)
 - Living areas (include dining area)?(193)
 - Bathrooms?(194)
 - Study/workshop areas?(195)

D4. Do any members of your household use as their regular accommodation a ...

	YES	NO	Number of People
Sleepout	(196) <input type="checkbox"/>	<input type="checkbox"/>	(197)
Caravan	(198) <input type="checkbox"/>	<input type="checkbox"/>	(199)
Housebus	(200) <input type="checkbox"/>	<input type="checkbox"/>	(201)
Garage	(202) <input type="checkbox"/>	<input type="checkbox"/>	(203)

D5. How many times **have you** shifted in the past 10 years? (204)

IF YOU HAVE SHIFTED IN THE PAST 10 YEARS:

D5.1 Did you shift from a city within the last 10 years? YES NO (205)

IF YES

D5.1.1. Why? (206)

Part E: General Expenses

E1. Have you had to cut back on any of the following expenses in the last year?

	YES	NO
Phone/Mobile phone (<i>circle 209</i>)	<input type="checkbox"/>	<input type="checkbox"/> (210)
Electricity	<input type="checkbox"/>	<input type="checkbox"/> (211)
Insurance	<input type="checkbox"/>	<input type="checkbox"/> (212)
Transport costs	<input type="checkbox"/>	<input type="checkbox"/> (213)
Vehicle maintenance costs	<input type="checkbox"/>	<input type="checkbox"/> (214)
Clothing	<input type="checkbox"/>	<input type="checkbox"/> (215)
Health costs	<input type="checkbox"/>	<input type="checkbox"/> (216)
Recreation expenses	<input type="checkbox"/>	<input type="checkbox"/> (217)
Education costs	<input type="checkbox"/>	<input type="checkbox"/> (218)

E2. Is the majority of your households clothing purchased from... (219)

- Secondhand stores
- Large chains (eg Glassons, Farmers)
- Designers/Exclusive Stores

Part F: Food

F1. Have you had to cut back or were you concerned that you would need to cut the household food expenses in the last year? YES NO (225) IF NO GO TO PART G

IF YES TO CUTTING FOOD EXPENSES ABOVE:

F2. Why did this situation arise? (226-228)
(Try to clarify exactly why.)

F3. Did you actually cut the food bill? YES NO IF NO GO TO F3.5 (229)

IF YES

F3.1 How many times did this happen in the last six months (number)? (230)

F3.2 Which items did you cut each time (be as specific as possible)? (231-35)

F3.3 Did you or anyone else go short of food? YES NO (236)

IF YES

F3.3.1. Who went short and of what? _____ (237-242)

F3.4. Did you take any other action to resolve this? YES NO (243)

IF YES

F3.4.1 What action (eg borrowed money)? _____ (244)

(IF WINZ - ALSO NOTE IN WINZ QUESTION H3 BELOW)

IF NO TO F3. (Did not cut the food bill)

F3.5 How did you resolve this situation? (245)

F4. In the last six months did you seek a food grant from WINZ? YES NO (246)

IF YES

F4.1. How many times did you seek a food grant? (247)

F4.2. How many times did you receive a food grant in the last six months? (248)

IF DID NOT RECEIVE A FOOD GRANT

F4.2.1. What action did you take? (249)

F5. Any other comments regarding seeking any assistance from WINZ? (250)

Appendix 4.4

F6. In the last six month did you request a food parcel? YES NO (251)

IF YES

F6.1. Did you receive a food parcel? YES NO (252)

IF YES F6.1.1. How many times? (253)

F6.1.2. Was it adequate for your households needs? YES NO (254)

F7. Any other comments regarding food parcels? (255)

Part G: Telephone

G1. Do you have a telephone/mobile phone? YES NO (260)

IF YES G1.1. Do you have a tollbar? YES NO (261)

IF YES G1.1.1. Why do you have a tollbar?(262)

IF NO TELEPHONE

G1.2 Why not? (263)

G2. Do you need a telephone? YES NO (264)

IF YES G2.1. Why do you need a phone? (eg health reasons, work, family)

(265)

Part H: Health

H1. Do any household members have a disability or an ongoing health problem? YES NO (270)

IF YES

H1.1 How many household members have a disability or ongoing health problem? (271)

H1.2 Do household members have regular recurring medical costs arising from this? YES NO IF NO Go To Question H2. (272)

IF YES TO MEDICAL COSTS

H1.2.1. What costs does this create over a 3 month period?

	\$Amount	Don't Know	Not Applicable
Doctors Visits	(273)	<input type="checkbox"/>	<input type="checkbox"/> (274)
Prescription costs	(275)	<input type="checkbox"/>	<input type="checkbox"/> (276)
Transport to medical facility	(277) kms:	(278) <input type="checkbox"/>	<input type="checkbox"/> (279)
Other (specify)(280)	(281)	<input type="checkbox"/>	<input type="checkbox"/> (282)
(283)	(284)	<input type="checkbox"/>	<input type="checkbox"/> (285)

H2. In the last six months have you or your family experienced any barriers to obtaining medical care? (eg cost, waiting lists, distance) YES NO (290)

IF YES

H2.1 For each instance, what were these barriers? (291-96)

H3. In the last year have you or your family been to the dentist? YES NO (297)

IF YES

H3.1 Was this for a .. YES NO

Regular checkup (298)

Emergency (299)

Orthodontist (300)

Surgery (301)

H4. Has **everyone** who needs dental care in the last year, received it? YES NO (302)

H5. Did anyone in your household experience any barriers or problems obtaining dental care in the last year? YES NO (303)

IF YES

H5.1 What were these problems and how were they resolved? (304-308)

Part I: Children

I1. Do you have children at school? YES NO IF NO GO TO I2. (320)

IF YES

I1.1. Have you had to pay any of the following school expenses?

	YES	NO	IF YES Did you have difficulty affording this?		IF YES: How did you resolve this?
			YES	NO	
School fees	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	(321)		(322)		(323)
Subject fees	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	(324)		(325)		(326)
Stationery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	(327)		(328)		(329)
Uniforms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	(330)		(331)		(332)

I1.2 In the last year have had difficulty paying for any of the following activities in school time for your children? AND IF YES: What Happened?

	N/A	YES	NO	IF YES What Happened	Unable to Pay
Expected school trips	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>
			(333)	(334)	(335)
Optional school trips	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>
			(336)	(337)	(338)
Sports activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>
			(339)	(340)	(341)
Music lessons at school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>
			(342)	(343)	(344)

I1.3 Have your children had to forego any other educational activities at school in the last year because of cost? YES NO (345)

IF YES I1.4.1. What activities? (346)

I2. Do you use **preschool** childcare? YES NO Not Applicable (347)

IF YES

I2.1. Who provides this care? (348)

I2.2. How much do you pay for this per week? \$..... (349)

I2.3. How many hours per week? (350)

I2.4. Is this sufficient hours? YES NO (351)

IF NO I2.4.1. Why? (352)

IF NO

I2.5. Do you need preschool childcare? YES NO (353)

IF YES I2.5.1. Why are you not using childcare? (354)

I3. Do you use **afterschool** childcare? YES NO Not Applicable (355)

IF YES

I3.1. Who provides this care? (356)

I3.2. How much do you pay for this per week? \$..... (357)

I3.3. How many hours per week? (358)

I3.4. Is this sufficient hours? YES NO (359)

IF NO I3.4.1. Why? (360)

IF NO

I3.5. Do you need afterschool childcare? YES NO (361)

IF YES I3.5.1. Why are you not using afterschool childcare? (362)

I4. What activities from the following list have children in your household participated in the last month?

	YES	NO	
Movies	<input type="checkbox"/>	<input type="checkbox"/>	(363)
Played organised sport	<input type="checkbox"/>	<input type="checkbox"/>	(364)
Spectator at local sport game	<input type="checkbox"/>	<input type="checkbox"/>	(365)
Spectator at sport game in Auckland	<input type="checkbox"/>	<input type="checkbox"/>	(366)
Local shows/concerts	<input type="checkbox"/>	<input type="checkbox"/>	(367)
Shows/concerts in Auckland	<input type="checkbox"/>	<input type="checkbox"/>	(368)
Drama/dance lessons	<input type="checkbox"/>	<input type="checkbox"/>	(369)
Private Music lessons	<input type="checkbox"/>	<input type="checkbox"/>	(370)
Hired videos, playstation, computer games	<input type="checkbox"/>	<input type="checkbox"/>	(371)

I5. Do you have any other comments regarding your childrens recreational activities? (372)

Individual Adult Questions – Adult 1

Complete the Individual Adult Questions for all adults in question A6 above.
 EXCLUDE any adults who DO PAY BOARD and DO NOT PROVIDE CARE within the family.

1. Adult Number as per question A5. and relationship to children
2. Are you ... YES NO
 retired?
 a full-time caregiver?
 a full-time student?
3. Are you registered as unemployed? YES NO
 IF YES 3.1 How many weeks have you been registered unemployed?

4. Do you currently have any paid work/jobs? YES NO IF NO GO TO Q5
 IF NO 4.1 Are you currently seeking paid work? YES NO
 IF YES 4.2 How many paid jobs do you currently have?

4.3 For each job what is the ..

Actual Job	Is it Fulltime Part-time or Casual	Are you Selfemployed or an Employee
Job 1		
Job 2		
Job 3		
Job 4		
Job 5		

1. Full-time = 30 hours or more a week
 2. Part-time = regular guaranteed work each week.
 3. Casual = work which is not guaranteed regular hours on an ongoing basis.

- 4.4 Across all your jobs, what is the total actual hours you work in a typical week (this may be more than what you are paid for)?
- 4.5 Are you seeking more paid work? YES NO
- 4.6 Do any of your jobs have any benefits? YES NO
 IF YES 4.6.1. What are these benefits?
- 4.7 For each adult who travels to paid work, specify how many kms they travel per week getting to and from work (roundtrip but excluding travel at work) and the main means of transport. (See Transport List on next page.)
 Kilometres..... Main means of transport

5. Do you have any personal savings excluding savings belonging to the family? YES NO
 IF YES 5.1 From the following list indicate whether you have any of these forms of savings, and if yes the value category. (See \$Value Category List on next page.)

	YES/NO	\$ CATEGORY		YES/NO	\$ CATEGORY
Bank account			Investments		
Shares			Term Deposits		
Retirement savings			Family Trust		
Other Properties			Other (specify)		

6. Do you receive any income from the following sources? [YES/NO]?

IF YES Please estimate the net amount (less tax) received on a typical week? (For those on an erratic income ask them to estimate.)

	YES	NO	\$AMOUNT (after tax) for a typical week
Wages/salary	<input type="checkbox"/>	<input type="checkbox"/>	
Self-employed drawings	<input type="checkbox"/>	<input type="checkbox"/>	
Social Security (excluding family support and accommodation supplement)			
unemployment benefit (community wage)	<input type="checkbox"/>	<input type="checkbox"/>	
DPB	<input type="checkbox"/>	<input type="checkbox"/>	
sickness benefit	<input type="checkbox"/>	<input type="checkbox"/>	
invalids benefit	<input type="checkbox"/>	<input type="checkbox"/>	
superannuation	<input type="checkbox"/>	<input type="checkbox"/>	
disability allowance	<input type="checkbox"/>	<input type="checkbox"/>	
DPB - carers allowance	<input type="checkbox"/>	<input type="checkbox"/>	
student allowance	<input type="checkbox"/>	<input type="checkbox"/>	
training allowance	<input type="checkbox"/>	<input type="checkbox"/>	
other (specify)	<input type="checkbox"/>	<input type="checkbox"/>	
ACC	<input type="checkbox"/>	<input type="checkbox"/>	
Rent received	<input type="checkbox"/>	<input type="checkbox"/>	
Maintenance/child support	<input type="checkbox"/>	<input type="checkbox"/>	
Other (specify)	<input type="checkbox"/>	<input type="checkbox"/>	

Note: Accommodation Supplement & Family Support should be entered under household income. If impossible to separate out here, then state which household sources of income are included.

6.1 Total income received in a typical week (after tax)?

7. Are any of your sources of income erratic/not regular or reliable (eg for casual work)?

YES NO

8. What percentage of your income is usually contributed to the household/family?

9. On a scale of one to five, one being a lot more and 5 being a lot less, how does your income now compare with this time two years ago?

\$ Value Category	
0 – 199.....	1
200 – 499.....	2
500 – 999.....	3
1,000 – 1,999.....	4
2,000 – 4,999.....	5
5,000 – 9,999.....	6
10,000 – 49,999..	7
50,000+.....	8

Means of Transport List	
Walking	1
Own car/vehicle.....	2
Lift in friends/relative car...	3
Borrowed car.....	4
Car pooling.....	5
Motorbike.....	6
Bicycle.....	7
School bus.....	8
Bus.....	9
Taxi.....	10
Hitch-hike.....	11
Other (specify)	12
Not Applicable	13

Individual Adult Questions – Adult 2

Complete the Individual Adult Questions for all adults in question A6 above.

EXCLUDE any adults who DO PAY BOARD and DO NOT PROVIDE CARE within the family.

1. Adult Number as per question A5. and relationship to children

2. Are you ...
- | | | |
|------------------------|--------------------------|--------------------------|
| | YES | NO |
| retired? | <input type="checkbox"/> | <input type="checkbox"/> |
| a full-time caregiver? | <input type="checkbox"/> | <input type="checkbox"/> |
| a full-time student? | <input type="checkbox"/> | <input type="checkbox"/> |

3. Are you registered as unemployed? YES NO
 IF YES 3.1 How many weeks have you been registered unemployed?

4. Do you currently have any paid work/jobs? YES NO IF NO GO TO Q5

IF NO 4.1 Are you currently seeking paid work? YES NO

IF YES 4.2 How many paid jobs do you currently have?

4.3 For each job what is the ..

Actual Job	Is it Fulltime Part-time or Casual	Are you Selfemployed or an Employee
Job 1		
Job 2		
Job 3		
Job 4		
Job 5		

1. Full-time = 30 hours or more a week
 2. Part-time = regular guaranteed work each week.
 3. Casual = work which is not guaranteed regular hours on an ongoing basis.

4.4 Across all your jobs, what is the total actual hours you work in a typical week (this may be more than what you are paid for)?

4.5 Are you seeking more paid work? YES NO

4.6 Do any of your jobs have any benefits? YES NO

IF YES 4.6.1. What are these benefits?

4.7 For each adult who travels to paid work, specify how many kms they travel per week getting to and from work (roundtrip but excluding travel at work) and the main means of transport. (See Transport List on next page.)

Kilometres..... Main means of transport

5. Do you have any personal savings excluding savings belonging to the family? YES NO

IF YES 5.1 From the following list indicate whether you have any of these forms of savings, and if yes the value category. (See \$Value Category List on next page.)

YES/NO	\$ CATEGORY	YES/NO	\$ CATEGORY
Bank account		Investments	
Shares		Term Deposits	
Retirement savings		Family Trust	
Other Properties		Other (specify)	

6. Do you receive any income from the following sources? [YES/NO]? **Appendix 4.4**

IF YES Please estimate the net amount (less tax) received on a typical week? (For those on an erratic income ask them to estimate.)

	YES	NO	\$AMOUNT (after tax) for a typical week
Wages/salary	<input type="checkbox"/>	<input type="checkbox"/>	
Self-employed drawings	<input type="checkbox"/>	<input type="checkbox"/>	
Social Security (excluding family support and accommodation supplement)			
unemployment benefit (community wage)	<input type="checkbox"/>	<input type="checkbox"/>	
DPB	<input type="checkbox"/>	<input type="checkbox"/>	
sickness benefit	<input type="checkbox"/>	<input type="checkbox"/>	
invalids benefit	<input type="checkbox"/>	<input type="checkbox"/>	
superannuation	<input type="checkbox"/>	<input type="checkbox"/>	
disability allowance	<input type="checkbox"/>	<input type="checkbox"/>	
DPB - carers allowance	<input type="checkbox"/>	<input type="checkbox"/>	
student allowance	<input type="checkbox"/>	<input type="checkbox"/>	
training allowance	<input type="checkbox"/>	<input type="checkbox"/>	
other (specify)	<input type="checkbox"/>	<input type="checkbox"/>	
ACC	<input type="checkbox"/>	<input type="checkbox"/>	
Rent received	<input type="checkbox"/>	<input type="checkbox"/>	
Maintenance/child support	<input type="checkbox"/>	<input type="checkbox"/>	
Other (specify)	<input type="checkbox"/>	<input type="checkbox"/>	

Note: Accommodation Supplement & Family Support should be entered under household income. If impossible to separate out here, then state which household sources of income are included.

6.1 Total income received in a typical week (after tax)?

7. Are any of your sources of income erratic/not regular or reliable (eg for casual work)?

YES NO

8. What percentage of your income is usually contributed to the household/family?

9. On a scale of one to five, one being a lot more and 5 being a lot less, how does your income now compare with this time two years ago?

\$ Value Category	
0 – 199.....	1
200 – 499.....	2
500 – 999.....	3
1,000 – 1,999.....	4
2,000 – 4,999.....	5
5,000 – 9,999.....	6
10,000 – 49,999..	7
50,000+.....	8

Means of Transport List	
Walking	1
Own car/vehicle.....	2
Lift in friends/relative car...	3
Borrowed car.....	4
Car pooling.....	5
Motorbike.....	6
Bicycle.....	7
School bus.....	8
Bus.....	9
Taxi.....	10
Hitch-hike.....	11
Other (specify)	12
Not Applicable	13

Part J: Household Equipment

- J1. This section looks at a range of goods often found in New Zealand households. We are interested to know whether these items are in your household and also something about their condition.

Do you have a ...,

IF YES how many do you have in your household?
how many years old is it?
and from the following list what condition is it in?

Condition List	
As New.....	1
Good.....	2
Adequate.....	3
Marginal.....	4
Out of Order.....	5

Note: If they have more than one item eg fridge - ask for the condition of the newest and main one used.

	EXISTS YES/NO	IF YES HOW MANY	YEARS OLD	CONDITION
Fridge	(375)	(376)	(377)	(378)
Stove for cooking	(379)	(380)	(381)	(382)
Washing machine	(383)	(384)	(385)	(386)

- J2. What is your main sources of heating, how many of each source do you use, and what condition is the heating source in overall?

	EXISTS & USED YES/NO	IF YES HOW MANY	CONDITION
Fireplace	(387)	(388)	(389)
Electric Heater	(390)	(391)	(392)
Gas Heater	(393)	(394)	(395)
Other (specify)(396)	(397)	(398)	(399)

- J3 Do you have a ...,

IF YES how many, and from the following list what condition is it in?

IF NO is this because of Cost (YES/NO) and is this because of Preference (YES/NO)?

	EXISTS YES/NO	IF YES HOW MANY	CONDITION	IF NO COST YES/NO	PREFERENCE YES/NO
Clothes dryer	(400)	(401)	(402)	(403)	(404)
Computer	(405)	(406)	(407)	(408)	(409)
Dishwasher	(410)	(411)	(412)	(413)	(414)
Freezer	(415)	(416)	(417)	(418)	(419)
Iron	(420)	(421)	(422)	(423)	(424)
Microwave	(425)	(426)	(427)	(428)	(429)
Stereo	(430)	(431)	(432)	(433)	(434)
Television	(435)	(436)	(437)	(438)	(439)
Toaster	(440)	(441)	(442)	(443)	(444)
Video	(445)	(446)	(447)	(448)	(449)

Part K: Household Income and Expenses

K1. Does your household receive any of the following forms of income?

	YES	NO	\$AMOUNT	TIMEFRAME
Family support (350)	<input type="checkbox"/>	<input type="checkbox"/>	(351)	(352)
Independent Family Tax Credit(353)	<input type="checkbox"/>	<input type="checkbox"/>	(354)	(355)
Guaranteed Min. Family Income (356)	<input type="checkbox"/>	<input type="checkbox"/>	(357)	(358)
Accommodation supplement (359)	<input type="checkbox"/>	<input type="checkbox"/>	(360)	(361)
IF NO Are you eligible? YES <input type="checkbox"/> NO <input type="checkbox"/> Don't know <input type="checkbox"/> (362)				
Rent (363)	<input type="checkbox"/>	<input type="checkbox"/>	(364)	(365)
Board (366)	<input type="checkbox"/>	<input type="checkbox"/>	(367)	(366)
Other (specify) (369)	<input type="checkbox"/>	<input type="checkbox"/>	(370)	(371)

(Note: do not include income which is received by an individual)

K2. From the following list, which category was your gross (including tax) household income last tax year? (372)

- Less than 10,000
- 10,000 - 19,999
- 20,000 - 29,999
- 30,000 - 39,999
- 40,000 - 49,999
- 50,000 - 59,999
- 60,000 - 69,999
- 70,000 - 79,999
- 80,000 - 99,999
- over 100,000

K3. Do you have a weekly household budget? YES NO (373)

IF YES K3.1 Do you stick to it? YES NO (374)

K4. What is your households regular weekly estimated transport costs (Excluding Insurance, including WOF, tyres, maintenance)? \$..... (375)

K5. What amount do you pay each week in mortgage/rent for this house? \$..... (376)

K6. Are you liable for any of the following expenses and if yes what is the weekly average amount? (You can specify an amount for a certain time period if that is easier.)

	Liab	YES	NO	\$ AMOUNT	TIME PERIOD	WEEKLY
rates	(377)	<input type="checkbox"/>	<input type="checkbox"/>	(378)	(379)	<input type="checkbox"/>
upkeep	(380)	<input type="checkbox"/>	<input type="checkbox"/>	(381)	(382)	<input type="checkbox"/>
water rates	(383)	<input type="checkbox"/>	<input type="checkbox"/>	(384)	(385)	<input type="checkbox"/>
power bill	(386)	<input type="checkbox"/>	<input type="checkbox"/>	(387)	(388)	<input type="checkbox"/>
phone/mobile ph	(389)	<input type="checkbox"/>	<input type="checkbox"/>	(390)	(391)	<input type="checkbox"/>
food bill	(392)	<input type="checkbox"/>	<input type="checkbox"/>	(393)	(394)	<input type="checkbox"/>
recreation/leisure	(395)	<input type="checkbox"/>	<input type="checkbox"/>	(396)	(397)	<input type="checkbox"/>
donations	(398)	<input type="checkbox"/>	<input type="checkbox"/>	(399)	(400)	<input type="checkbox"/>
send money to other family members?	(401)	<input type="checkbox"/>	<input type="checkbox"/>	(402)	(403)	<input type="checkbox"/>
Clothing/Shoes	(404)	<input type="checkbox"/>	<input type="checkbox"/>	(405)	(406)	<input type="checkbox"/>
Hairdressers	(407)	<input type="checkbox"/>	<input type="checkbox"/>	(408)	(409)	<input type="checkbox"/>
Doctors	(410)	<input type="checkbox"/>	<input type="checkbox"/>	(409)	(410)	<input type="checkbox"/>
Presents (eg. vets bills for pet)	(413)	<input type="checkbox"/>	<input type="checkbox"/>	(414)	(415)	<input type="checkbox"/>
other (specify)	(416)	<input type="checkbox"/>	<input type="checkbox"/>	(417)	(418)	<input type="checkbox"/>
other (specify)	(419)	<input type="checkbox"/>	<input type="checkbox"/>	(420)	(421)	<input type="checkbox"/>
other (specify)	(422)	<input type="checkbox"/>	<input type="checkbox"/>	(423)	(424)	<input type="checkbox"/>

K7. Have you faced any of the following educational costs this term and if yes, what amount:

	Liab	YES	NO	\$ AMOUNT
fees or levies		<input type="checkbox"/>	<input type="checkbox"/>	(430)
school activities (camps)		<input type="checkbox"/>	<input type="checkbox"/>	(432)
sporting activities		<input type="checkbox"/>	<input type="checkbox"/>	(434)

K8. Do you have debts over 3 months old, for ...

IF YES Is it being repaid, IF YES amount for average repayment and timeframe

	YES	NO	Making repayments		\$Amount Avg repaymt	Timeframe
			YES	NO		
Car repairs	<input type="checkbox"/>	<input type="checkbox"/> (440)	<input type="checkbox"/>	<input type="checkbox"/> (441)	(442)	(443)
Court fines	<input type="checkbox"/>	<input type="checkbox"/> (444)	<input type="checkbox"/>	<input type="checkbox"/> (445)	(446)	(447)
Credit cards	<input type="checkbox"/>	<input type="checkbox"/> (448)	<input type="checkbox"/>	<input type="checkbox"/> (449)	(450)	(451)
Family repayments	<input type="checkbox"/>	<input type="checkbox"/> (452)	<input type="checkbox"/>	<input type="checkbox"/> (453)	(454)	(455)
IRD	<input type="checkbox"/>	<input type="checkbox"/> (456)	<input type="checkbox"/>	<input type="checkbox"/> (457)	(458)	(459)
Hire purchase	<input type="checkbox"/>	<input type="checkbox"/> (460)	<input type="checkbox"/>	<input type="checkbox"/> (461)	(462)	(463)
Student loans	<input type="checkbox"/>	<input type="checkbox"/> (464)	<input type="checkbox"/>	<input type="checkbox"/> (465)	(466)	(467)
WINZ	<input type="checkbox"/>	<input type="checkbox"/> (468)	<input type="checkbox"/>	<input type="checkbox"/> (469)	(470)	(471)
Other (specify)	<input type="checkbox"/>	<input type="checkbox"/> (472)	<input type="checkbox"/>	<input type="checkbox"/> (473)	(474)	(475)

K9. In the last year did you have to sell possessions to pay household bills? YES NO (476)

IF YES K9.1 Which possessions? (477)

K10. In the last year has your phone, electricity, gas or water been disconnected because of cost?

	YES	NO
Phone	<input type="checkbox"/>	<input type="checkbox"/> (478)
Electricity	<input type="checkbox"/>	<input type="checkbox"/> (479)
Gas	<input type="checkbox"/>	<input type="checkbox"/> (480)
Water	<input type="checkbox"/>	<input type="checkbox"/> (481)

K11. If you had an emergency tomorrow and needed \$500 to cover it, could you access that money? YES NO (485)

IF YES K11.1. Where would you get the money from? (what source)(486)

IF NO K11.2 If you had an emergency tomorrow and needed \$100 to cover it, could you access that money? YES NO (487)

IF YES M11.1. Where would you get the money from?
(source) (488)

Part L: Household Savings

L1. Do you have any household savings – savings which belong to the family as a whole rather than just individuals? YES NO (500)

IF YES

L1.1 From the following list indicate whether your household has any of these forms of savings, and if yes the value category.

	YES	NO	\$ VALUE CATEGORY
Bank account (501)	<input type="checkbox"/>	<input type="checkbox"/>	(502)
Shares (503)	<input type="checkbox"/>	<input type="checkbox"/>	(504)
Retirement savings (505)	<input type="checkbox"/>	<input type="checkbox"/>	(506)
Property (507)	<input type="checkbox"/>	<input type="checkbox"/>	(508)
Investments (509)	<input type="checkbox"/>	<input type="checkbox"/>	(510)
Term Deposits (511)	<input type="checkbox"/>	<input type="checkbox"/>	(512)
Family Trust (513)	<input type="checkbox"/>	<input type="checkbox"/>	(514)
Other (specify) (515)	<input type="checkbox"/>	<input type="checkbox"/>	(516)

\$ Value Category	
0 – 199.....	1
200 – 499.....	2
500 – 999.....	3
1,000 – 1,999.....	4
2,000 – 4,999.....	5
5,000 – 9,999.....	6
10,000 – 49,999..	7
50,000+.....	8

Part M: General

M1. On a scale of 1-5, with 1 being excellent and 5 financial hardship, how would you rate your family’s financial position relative to others in the District at present?

1 2 3 4 5 (520)

M2. On a scale of 1-5, with 1 being excellent and 5 financial hardship, how would you rate your family’s financial position relative to others in the District one year from now?

1 2 3 4 5 (521)

M3. On a scale of 1-5, with 1 being excellent and 5 financial hardship, how would you rate your family’s financial position relative to others in the District five years from now?

1 2 3 4 5 (522)

M4. IF YOU HAVE A TEENAGE CHILD, how do you rate their financial prospects at age 20, on a scale of 1 to 5 with 1 being excellent and 5 financial hardship?

1 2 3 4 5 (523)

M5. Can you tell us about the effect of your financial situation on your family life in the last year? (524)

Individual Adult Questions – Adult 3

Appendix 4.4

Complete the Individual Adult Questions for all adults in question A6 above.

EXCLUDE any adults who DO PAY BOARD and DO NOT PROVIDE CARE within the family.

1. Adult Number as per question A5. and relationship to children

2. Are you ...
- | | | |
|------------------------|--------------------------|--------------------------|
| | YES | NO |
| retired? | <input type="checkbox"/> | <input type="checkbox"/> |
| a full-time caregiver? | <input type="checkbox"/> | <input type="checkbox"/> |
| a full-time student? | <input type="checkbox"/> | <input type="checkbox"/> |

3. Are you registered as unemployed? YES NO
 IF YES 3.1 How many weeks have you been registered unemployed?

4. Do you currently have any paid work/jobs? YES NO IF NO GO TO Q5

IF NO 4.1 Are you currently seeking paid work? YES NO

IF YES 4.2 How many paid jobs do you currently have?

4.3 For each job what is the ..

Actual Job	Is it Fulltime Part-time or Casual	Are you Selfemployed or an Employee
Job 1		
Job 2		
Job 3		
Job 4		
Job 5		

1. Full-time = 30 hours or more a week
 2. Part-time = regular guaranteed work each week.
 3. Casual = work which is not guaranteed regular hours on an ongoing typical

4.4 Across all your jobs, what is the total actual hours you work in a typical week (this may be more than what you are paid for)?

4.5 Are you seeking more paid work? YES NO

4.6 Do any of your jobs have any benefits? YES NO

IF YES 4.6.1. What are these benefits?

4.7 For each adult who travels to paid work, specify how many kms they travel per week getting to and from work (roundtrip but excluding travel at work) and the main means of transport. (See Transport List on next page.)

Kilometres..... Main means of transport

5. Do you have any personal savings excluding savings belonging to the family? YES NO

IF YES 5.1 From the following list indicate whether you have any of these forms of savings, and if yes the value category. (See \$Value Category List on next page.)

YES/NO	\$ CATEGORY	YES/NO	\$ CATEGORY
Bank account		Investments	
Shares		Term Deposits	
Retirement savings		Family Trust	
Other Properties		Other (specify)	

Appendix 4.4

6. Do you receive any income from the following sources? [YES/NO]?

IF YES Please estimate the net amount (less tax) received on a typical week? (For those on an erratic income ask them to estimate.)

	YES	NO	\$AMOUNT (after tax) for a typical week
Wages/salary	<input type="checkbox"/>	<input type="checkbox"/>	
Self-employed drawings	<input type="checkbox"/>	<input type="checkbox"/>	
Social Security (excluding family support and accommodation supplement)			
unemployment benefit (community wage)	<input type="checkbox"/>	<input type="checkbox"/>	
DPB	<input type="checkbox"/>	<input type="checkbox"/>	
sickness benefit	<input type="checkbox"/>	<input type="checkbox"/>	
invalids benefit	<input type="checkbox"/>	<input type="checkbox"/>	
superannuation	<input type="checkbox"/>	<input type="checkbox"/>	
disability allowance	<input type="checkbox"/>	<input type="checkbox"/>	
DPB - carers allowance	<input type="checkbox"/>	<input type="checkbox"/>	
student allowance	<input type="checkbox"/>	<input type="checkbox"/>	
training allowance	<input type="checkbox"/>	<input type="checkbox"/>	
other (specify)	<input type="checkbox"/>	<input type="checkbox"/>	
ACC	<input type="checkbox"/>	<input type="checkbox"/>	
Rent received	<input type="checkbox"/>	<input type="checkbox"/>	
Maintenance/child support	<input type="checkbox"/>	<input type="checkbox"/>	
Other (specify)	<input type="checkbox"/>	<input type="checkbox"/>	

Note: Accommodation Supplement & Family Support should be entered under household income. If impossible to separate out here, then state which household sources of income are included.

6.1 Total income received in a typical week (after tax)?

7. Are any of your sources of income erratic/not regular or reliable (eg for casual work)?

YES NO

8. What percentage of your income is usually contributed to the household/family?

9. On a scale of one to five, one being a lot more and 5 being a lot less, how does your income now compare with this time two years ago?

\$ Value Category	
0 – 199.....	1
200 – 499.....	2
500 – 999.....	3
1,000 – 1,999.....	4
2,000 – 4,999.....	5
5,000 – 9,999.....	6
10,000 – 49,999..	7
50,000+.....	8

Means of Transport List	
Walking	1
Own car /vehicle.....	2
Lift in friends/relative car... 3	3
Borrowed car.....	4
Car pooling.....	5
Motorbike.....	6
Bicycle.....	7
School bus.....	8
Bus.....	9
Taxi.....	10
Hitch-hike.....	11
Other (specify)	12
Not Applicable	13

6. Do you receive any income from the following sources? [YES/NO]?

IF YES Please estimate the net amount (less tax) received on a typical week? (For those on an erratic income ask them to estimate.)

	YES	NO	\$AMOUNT (after tax) for a typical week
Wages/salary	<input type="checkbox"/>	<input type="checkbox"/>	
Self-employed drawings	<input type="checkbox"/>	<input type="checkbox"/>	
Social Security (excluding family support and accommodation supplement)			
unemployment benefit (community wage)	<input type="checkbox"/>	<input type="checkbox"/>	
DPB	<input type="checkbox"/>	<input type="checkbox"/>	
sickness benefit	<input type="checkbox"/>	<input type="checkbox"/>	
invalids benefit	<input type="checkbox"/>	<input type="checkbox"/>	
superannuation	<input type="checkbox"/>	<input type="checkbox"/>	
disability allowance	<input type="checkbox"/>	<input type="checkbox"/>	
DPB - carers allowance	<input type="checkbox"/>	<input type="checkbox"/>	
student allowance	<input type="checkbox"/>	<input type="checkbox"/>	
training allowance	<input type="checkbox"/>	<input type="checkbox"/>	
other (specify)	<input type="checkbox"/>	<input type="checkbox"/>	
ACC	<input type="checkbox"/>	<input type="checkbox"/>	
Rent received	<input type="checkbox"/>	<input type="checkbox"/>	
Maintenance/child support	<input type="checkbox"/>	<input type="checkbox"/>	
Other (specify)	<input type="checkbox"/>	<input type="checkbox"/>	

Note: Accommodation Supplement & Family Support should be entered under household income. If impossible to separate out here, then state which household sources of income are included.

6.1 Total income received in a typical week (after tax)?

7. Are any of your sources of income erratic/not regular or reliable (eg for casual work)?
YES NO

8. What percentage of your income is usually contributed to the household/family?

9. On a scale of one to five, one being a lot more and 5 being a lot less, how does your income now compare with this time two years ago?

\$ Value Category	
0 – 199.....	1
200 – 499.....	2
500 – 999.....	3
1,000 – 1,999.....	4
2,000 – 4,999.....	5
5,000 – 9,999.....	6
10,000 – 49,999..	7
50,000+.....	8

Means of Transport List	
Walking	1
Own car/vehicle.....	2
Lift in friends/relative car... ..	3
Borrowed car.....	4
Car pooling.....	5
Motorbike.....	6
Bicycle.....	7
School bus.....	8
Bus.....	9
Taxi.....	10
Hitch-hike.....	11
Other (specify)	12
Not Applicable	13

Questionnaire Tracking Sheet

SURVEY ID	ADDRESS	Final Address Surveyed ?	Message Left ?	Call Back Time & Interviewer	Date Surveyed	Interviewer
<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>			
<i>Replacement Address(s):</i>		<input type="checkbox"/>	<input type="checkbox"/>			
1.	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>			
2.	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>			
3.	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>		Survey Returned to Office? <input type="checkbox"/>	
<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>			
<i>Replacement Address(s):</i>		<input type="checkbox"/>	<input type="checkbox"/>			
1.	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>			
2.	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>			
3.	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>		Survey Returned to Office? <input type="checkbox"/>	
<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>			
<i>Replacement Address(s):</i>		<input type="checkbox"/>	<input type="checkbox"/>			
1.	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>			
2.	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>			
3.	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>		Survey Returned to Office? <input type="checkbox"/>	
<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>			
<i>Replacement Address(s):</i>		<input type="checkbox"/>	<input type="checkbox"/>			
1.	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>			
2.	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>			
3.	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>		Survey Returned to Office? <input type="checkbox"/>	
<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>			
<i>Replacement Address(s):</i>		<input type="checkbox"/>	<input type="checkbox"/>			
1.	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>			
2.	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>			
3.	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>		Survey Returned to Office? <input type="checkbox"/>	

Instructions for Interviewers

Picking Up and Returning Questionnaires

- You will be given a numbered set of questionnaires together with a *Questionnaire Tracking Sheet* which contains your list of addresses. This sheet is very important so please **do not lose it!** Please return this sheet to Homebuilders when you have completed all surveys on the sheet.
- When you have finished interviewing for the day please drop completed questionnaires into the Homebuilders centre at 5 Baxter St, Warkworth. To track our overall progress and to protect confidentiality it would be best to drop completed questionnaires back on the same day.

Safety

- Only travel in pairs or teams - keep an eye on each other as you go down a street.
- If you suspect there is a loose dog on the property, use the replacement address steps below.
- If you have any problems or queries which you cannot work out with your team co-ordinator, phone the Homebuilders mobile 025 227 4905. Irene will have this mobile on and can call you back immediately.

Confidentiality

- If you know the person at a particular address - don't interview them, instead ask to swap with another team member.
- It is very important that anything you find out while interviewing remains confidential.

Steps for when there is no adult respondent at home

- In this situation leave an envelope with a information sheet and a call back letter with a *date, time* and the *survey form id number* filled in.
- Note on your *Questionnaire Tracking Sheet* that you have left an envelope and the date and time that you are going to return.
- If this time does not suit the respondent they may phone the office and leave their survey id number and an *alternative* time.
- **Before** you return to this address check with the office to see if the respondent has left an alternative time.

When to use a replacement address:

You need to choose a replacement address in the following situations:

- a. There are **no children** in the household.
- b. The respondent in the household **refuses** to participate in the survey.
- c. There is a loose or dangerous looking **dog** about.
- d. If when you return a **second time** to a household there is **nobody home** and they have not phoned you to make an alternative time.

Replacement Address Steps

- Take the next highest letter box number if houses are numbered.
- If they are not numbered go to the next house in the same direction that you are travelling and on the same side of the road.
- If it is the end of the road, return to the immediately preceding house.
- Continue following replacement steps until you have a completed survey.
- Note on the survey tracking form the number of refusals and the number of households not eligible for a particular survey number.
- Update the *Questionnaire Tracking Sheet* with the **final address** used for the survey.

Mileage Reimbursement

- People who drive need to fill in their total mileage on the back of the Questionnaire Tracking Sheet.
- Mileage will be reimbursed at a rate of 45 cents a kilometre.

Survey Call Back Note

Dear Householder,

Your address has been selected as one of our random sample of households to be interviewed for our research on rural living standards in the North Rodney area.

We are interviewing households with children under 18 only. If this household does not have any children under 18, we would be grateful if you could phone us just to let us know that we do not need to interview you.

**Otherwise our interviewer will call in to interview you at
on**

**Our contact details are as follows.
Homebuilders Family Centre
Phone 425 7048**

When you ring you do not need to give your name, just quote the following interview number

Thank You.

Families asked for facts on hardship

By Lesley Ingham
RODNEY TIMES reporter
.....

Hundreds of north Rodney families will be questioned about their income and living expenses in an effort to find out how local households are managing.

The August survey has been instigated by Homebuilders Family Support, whose workers have noticed an increase in the number of people struggling to make ends meet.

Wellsford Budget Service and Kaitiaki Resource Network are also involved in the project, which kicks off next week with a trial survey and training for about 20 interviewers.

From next month, the volunteers will knock on doors in the Wellsford and Warkworth areas to ask families with dependent children to complete a questionnaire.

Designed with help from Massey senior lecturer Dr Mike O'Brien, it covers such topics as income, transport, housing and food costs, health care and education options.

Homebuilders manager Irene de Haan says the random survey will test the group's perception that the last six months have brought more hardship for a cross-section of local people, not just those unemployed or on benefits.

Mrs de Haan wants to find out what may have changed for families this year. "If we can find out why they are struggling, maybe we can do something."



Homebuilders manager Irene de Haan... wants to know the financial pressures on local families.

Individual survey responses will be confidential but the overall results will be made public.

Similar surveys have been carried out in cities, Mrs de Haan says, but this is the first to target families in and around rural towns.

She hopes to discover whether families in rural areas face higher living costs and whether their children are disadvantaged in any way.

Wellsford Budget Service co-ordinator Valma Gidman expects the survey to



Wellsford Budget Service co-ordinator Valma Gidman... how much do families spend on groceries?

confirm that rural living costs more.

"A lot of people come here from Auckland because the housing is cheaper, then find they are paying more in transport and toll calls," she says.

The survey will also provide a useful comparison between people who use the budget service and those who don't.

"Our clients often want to know how they compare with others - for instance, how much other families spend on groceries," Mrs Gidman says. "I can't tell them, because I don't know."

Rodney Times, 1999, July 20, p.8.

After rural answers



Up to 300 Wellsford-Warkworth area families with children are being asked whether of costs more to live in a rural area.

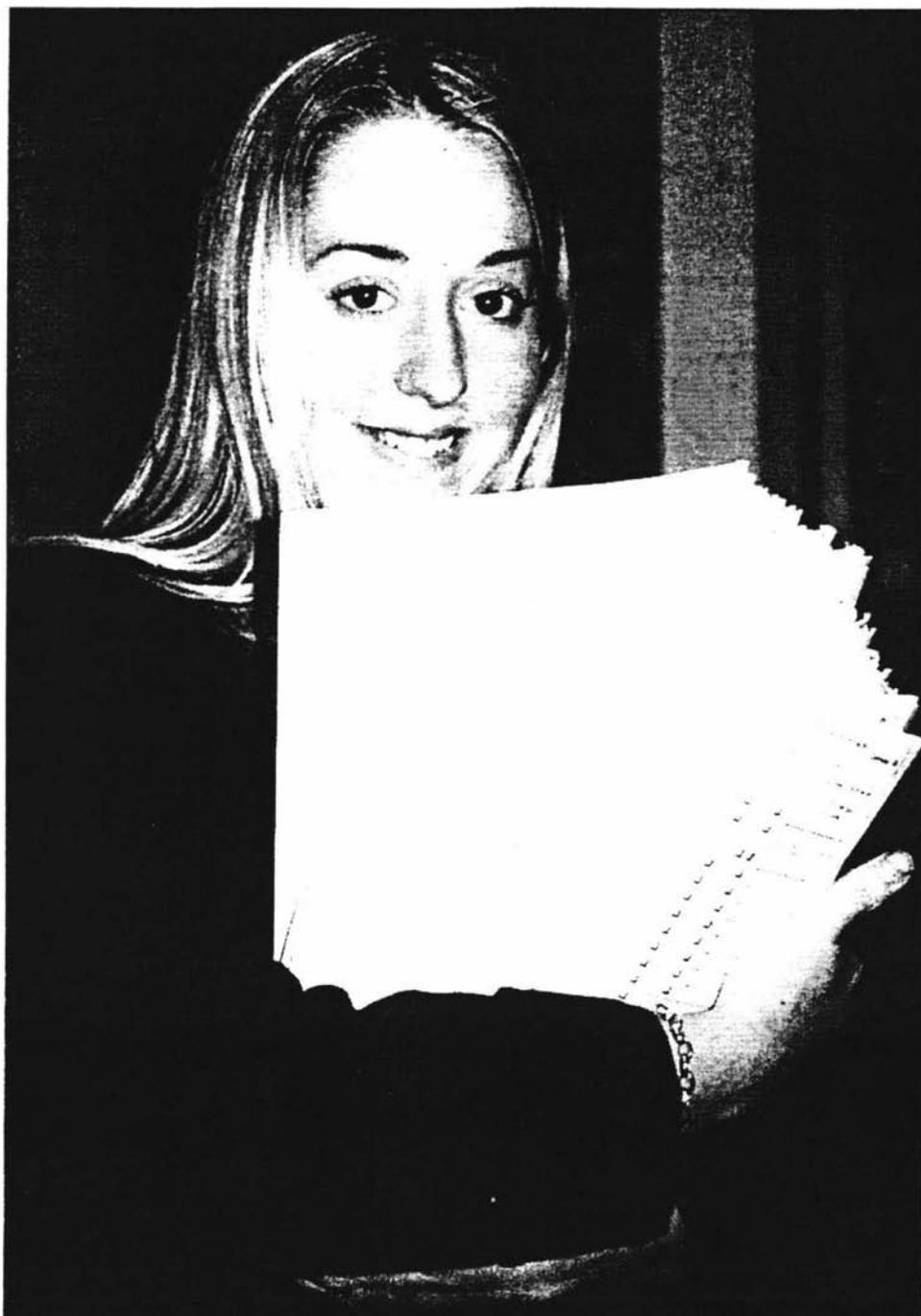
The costs of living survey, being conducted by Warkworth Homebuilders, Massey University, the Kaitiaki

Resource Network and Wellsford Budget Service, began today.

It is expected to take a month to complete.

Above, survey team volunteer John Hayday of Matakana begins doorknocking for families' answers.

Rodney Times, 1999, August 19, p. 3.



Massey University Social Policy and Social Work student Hanna Kloosterboer with a stack of completed questionnaires.

Rural quiz goes north

The Homebuilders survey on rural living costs will focus on Wellsford next week.

Students from Massey University's Albany campus will be in the area to help with the project, approaching families with questions about income and expenses, including transport, education and food.

Designed to find out whether there are higher costs attached to living in the country and rural townships, the survey is a joint effort by Homebuilders and Massey University, with help from the Wellsford Budget Service and Kaitiaki Resource Network.

Volunteers have spent about five weeks door-knocking in Snells Beach, and will cover more randomly selected streets in Warkworth and Wellsford before all the answers are analysed by computer.

Individuals' answers are kept confidential, but the aggregated responses to the questionnaire will be made public, says Homebuilders manager Irene de Haan.

Most families approached so far have been keen to take part in the survey, she says.

"People have been really helpful and even seem to have quite enjoyed it," she says. "We're really grateful for that."

Coast to Coast Courier, 1999, September 29, Issue 501, p. 5.

Homebuilders Survey Results

Number of Households surveyed: 115

Number of households in Snells Beach: 64 (56%)

Number of households in Wellsford: 51 (44%)

Part A: Household Profile

Number of families in the household: 1 – 97%, 2 – 1%, 3 – 2%.

Number of households with: one parent - 26%, two parents – 74%.

- Snells Beach: one parent – 25%, two parents 75%.
- Wellsford: one parent 27%, two parents 73%.

Of all households with one parent: single mother – 93%, single father – 7%.

- Of all Snells Beach families (n=64), single mother – 22%, single father – 3%.
- Of all Wellsford families (n=51), 27% have a single mother.

13% of all families (n=115) are step/blended, 14% of all Snells Beach families are step/blended, and 12% of all Wellsford families are step/blended.

Number of children in all families: one child – 26%, two children – 38%, three children – 23%, four children – 10%, five children – 2%, six children – 2%.

- Number of children in Snells Beach families: one child – 25%, two children 45%, three children 17%, four children - 9%, five children – 3%.
- Number of children in Wellsford families: one child – 27%, two children – 29%, three children 29%, four children – 10%, five children – 0%, six children – 4%.

Number of households that have children who live there on a part-time or temporary basis: 10% (Snells Beach – 11%, Wellsford – 8%).

Number of households with children that have a paid job: 17% (Snells Beach – 16%, Wellsford – 18%).

Comment on children with paid job:

- *not paid yet - new job*
- *Eases unplanned for expenses & not having to pay pocket money*
- *Doesn't have to give pocket money.*
- *Saves me paying for them, as they have a baby on the way.*
- *Pay for own recreation & school trips, lollies & toys*
- *Their spending money - not need to ask for money*
- *get their own extras - swings & roundabouts*
- *buy their own extra lollies bits & pieces*
- *Don't have to give her a allowance*
- *not a lot - eats it all, cover costs*
- *Uses for school expenses*
- *16 yr old pays his things - sports*
- *Child pays towards own clothing, school camps etc*
- *Teenager pays towards own clothing and magazines*
- *doesn't effect budget*
- *None (she eats it.)*
- *older son pays for own clothes - but not contribute*
- *nil*
- *no difference to the family budget*

Number of Adults in all households: one adult – 22%, two adults – 69%, three adults 7%, five adults – 2%, seven adults – 1%.

- Number of adults in all Snells Beach households: one adult – 19%, two adults – 73%, three adults 7%, five adults - 2%.
- Number of adults in all Wellsford households: one adult – 25%, two adults 63%, three adults – 8%, five adults – 2%, seven adults – 2%.

Total people in each household: two people – 7%, three people 26%, four people – 33%, five people – 20%, six people – 8%, seven people – 2%, eight people – 2%, nine people – 2%, eleven people – 1%.

Adult Profile

The 115 households included a total of 225 adults.

O these 56% were female and 44% male (Snells Beach: 54% female, 46% male, Wellsford: 57% female, 43% male).

Relationship to Children	No.	%	Snells Beach %	Wellsford %
Mother	113	50	50	51
Father	82	36	37	35
Grandmother	5	2	2	3
Grandfather	2	1	1	1
Sister	2	1	1	1
Brother	7	3	2	4
Step-father	2	1	0	2
Cousin	1	0	0	1
Aunt	1	0	1	0
Uncle	1	0	1	0
Boarder	1	0	0	1
Father & Stepfather	3	1	2	0
other	5	2	3	1
	225	100		

Age Groups	No.	%	Snells Beach %	Wellsford %
18 -- 19	8	4	4	3
20--29	41	18	15	22
30--39	88	39	45	32
40--49	69	31	29	32
50-59	10	4	3	6
70+	1	0	1	1
no response	8	4	2	5
	225			

Ethnicity	No.	%	Snells Beach %	Wellsford %
NZ Maori	31	14	7	22
NZ Pakeha	145	64	66	63
Other European	19	8	11	5
American	4	2	3	0
Australian	2	1	2	0
British	1	0	1	0
Cook Island	1	0	1	0
Cook Island/Maori	4	2	0	4
Irish/Samoan	1	0	1	0
NZ Maori/Pakeha	8	4	3	4
South African	2	1	2	0
Tongan	1	0	1	1
Philippine	1	0	1	0
Japanese	1	0	0	1
No Response	4	2	2	1
	225			

5% of adults were registered as unemployed (6% in Snells, and 5% in Wellsford).

Weeks registered unemployed:

- approx 2 yrs
- 3 months
- 13 months
- 12 months plus
- 3 months
- 4 weeks
- 6 months
- 24
- 52+
- 3 years
- over one year

Appendix 4.10

63% of respondents currently have paid work (Snells Beach: 70%, 1% no response; Wellsford: 54%, 7% no response).

Of those not in paid work 30% are seeking paid work (Snells Beach: 33%, 36% no response; Wellsford: 28%, 10% no response).

Number of Jobs for those in paid work:

How many jobs	No.	%	Snells Beach %	Wellsford %
1	124	89	83	98
2	11	8	13	0
3	3	2	2	2
4	2	1	2	0
	140			

Personal Savings (excluding savings belonging to the family)	No.	%	Snells Beach %	Wellsford %
no response	11	5	2	8
don't know	1	0	0	1
no	183	81	86	75
yes	30	13	11	16

Number of Adults with income sources that are erratic/not regular or reliable:

Erratic income	No.	%	Snells Beach %	Wellsford %
no response	21	9	7	12
no	146	65	62	69
yes	53	24	30	16
not applicable	3	1	1	2
Don't know	2	1	0	2

64% of adults contribute 100% of their income to the household/family (Snells Beach 67%, Wellsford 59%).

Income Comparison 2yrs ago	No.	%	Snells Beach %	Wellsford %
no response	12	5	3	8
1	17	8	11	4
2	31	14	11	17
2.5	4	2	2	2
3	82	36	37	36
3--4	2	1	2	0
4	34	15	16	14
5	39	17	16	19
don't know	1	0	1	0
not applicable	3	1	2	1

Part B: Transport & Vehicle Ownership

Number of households that own a vehicle: 94% (Snells Beach – 97%, Wellsford – 90%).

Number of vehicles owned by each household: one vehicle – 47%, two vehicles – 35%, three vehicles – 10%, four vehicles – 1%, five vehicles – 1%.

- Number of vehicles owned by each household in Snells Beach: one vehicle – 42%, two vehicles – 45%, three vehicles – 8%, four vehicles – 2%.
- Number of vehicles owned by each household in Wellsford: one vehicle – 53%, two vehicles – 22%, three vehicles – 14%, four vehicles – 0%, five vehicles – 2%.

Number of households with a registered vehicle: 82%, not registered – 18%.

Number of households with a vehicle with a warrant: 83%, not warranted - 18%.

Number of households with a vehicle insured: 61%, not insured – 37%.

Number of households with a vehicle with 3rd party insurance: 15%.
 Number of households with a vehicle with 3rd party, fire and theft insurances: 5%.
 Number of households with a vehicle with full insurance: 42%.

Part C: Insurance

Number of households with health insurance: 71%, no health insurance – 29%.
 ● Number of Snells Beach households with health insurance: 33%, without health insurance 67%.
 ● Number of Wellsford households with health insurance: 24%, without health insurance – 76%.

Number of households with life insurance: 43%, without – 57%.
 ● Number of Snells Beach households with life insurance: 47%.
 ● Number of Wellsford households with life insurance: 37%.

Number of households with earnings/income insurance: 17% (Snells Beach – 20%, Wellsford – 12%).

Number of households with house insurance: 56%.
 Of those who owned a house (n=66) 6% did not have house insurance.
 Of households with house insurance (n=64): 83% had coverage to fully replace, 2% did not, 6% did not know, and 9% no response.
 Of all households 57% had contents insurance, and of those with contents insurance (n=65), 83% had coverage to fully replace, 12% did not, 2% did not know, and 3% no response.

Number of Snells Beach households with contents insurance: 56%.
 Number of Wellsford households with contents insurance: 57%.

Part D: Housing

Number of households: renting – 43%, owned with a mortgage – 51%, owned without a mortgage – 6%.
 ● Snells Beach: renting – 42%, owned with a mortgage – 53%, owned without a mortgage – 5%.
 ● Wellsford: renting – 43%, owned with a mortgage – 49%, owned without a mortgage – 8%.

House condition for all households: perfectly maintained – 9%, well maintained – 44%, moderately maintained – 36%, inadequately maintained – 10%, not maintained – 1%, no response – 1%.
 ● House condition for Snells Beach households: perfectly maintained – 11%, well maintained – 52%, moderately maintained – 27%, inadequately maintained – 9%, not maintained – 0%, no response – 2%.
 ● House condition for Wellsford households: perfectly maintained – 6%, well maintained – 35%, moderately maintained – 47%, inadequately maintained – 10%, not maintained – 2%.

House condition of all rented houses (n=49): perfectly maintained – 12%, well maintained – 47%, moderately maintained – 29%, inadequately maintained – 8%, not maintained – 2%, no response – 2%.

House condition of all owned houses (n=66): perfectly maintained – 6%, well maintained – 42%, moderately maintained – 41%, inadequately maintained – 11%, not maintained – 0%.

Bedrooms by number of people in the household:

Bedrooms	People								
	Two	Three	Four	Five	Six	Seven	Eight	Nine	Eleven
One	1								
Two	3	8	9	1	1				
Three	4	16	20	11	2	1	1	2	1
Four		4	7	10	4	1	1		
Five		1	1	1	2				
Six		1							
Two & Sleepout			1						

Three households use a sleepout, each being used by one person.

Appendix 4.10

Four households use a caravan, each being used by one person (3 in Wellsford and one in Snells Beach). One household uses a housebus.

Four houses use a garage, all are in Wellsford, and one garage is used by three people (no response for the number of people using the other three garages).

Number of times each household has shifted in the past 10 years: zero shifts – 16%, one shift – 10%, two shifts – 16%, three shifts – 14%, four shifts – 10%, five shifts – 4%, six shifts – 10%, seven shifts – 2%, eight shifts – 2%, nine shifts – 1%, ten shifts – 5%, 11 to 18 shifts – 7%, 20 and over shifts – 2%, many shifts – 1%.

Of all households that had shifted within the last 10 years (n=97), 60% had shifted from the city (Snells Beach – 58%, Wellsford – 41%).

Shift city comment:

- *environment getting unsafe, horrible with kids*
- *To get away from crime and a better lifestyle for the children.*
- *to buy a business out of the rat race - better lifestyle*
- *work - new job*
- *broken marriage & cheaper land*
- *Better lifestyle - too busy in city*
- *Domestic violence*
- *better lifestyle*
- *Better lifestyle change*
- *change of occupation*
- *cost of living too high*
- *Needed accommodation that would have animals & children*
- *for the children*
- *better environment for children up here*
- *Family comes from Warkworth & want children in country*
- *life-style for the kids*
- *lifestyle - country living*
- *for daughter prefer country*
- *grew up in country, prefer country*
- *hated Auckland - too busy*
- *to expensive - partner wanted to move to farm and sick family*
- *cheaper housing*
- *made redundant*
- *found the city really scary*
- *prefer country*
- *wanted kids brought up in rural area. cheaper housing.*
- *parents wanted land*
- *work opportunities & cost of living*
- *came back home*
- *lifestyle choice, assist with employment*
- *lifestyle purposes - lower rent higher income*
- *family bereavement and work stayed on*
- *couldn't afford high cost of living in Auckland*
- *Taupo*
- *Job*
- *Better lifestyle for children*
- *business opportunities & lifestyle*
- *family & personal reasons*
- *Like the community up here.*
- *Lifestyle - Possible to make money by fixing up houses. (Housing was then cheaper, but not now.) Wanted to live by the sea.*
- *Purchasing an affordable property and lifestyle*
- *Coming back home from Australia.*
- *Wanted to get away from the rat race, too fast.*
- *Husband retired and wanted cheaper rental accommodation.*
- *For training reasons.*
- *Couldn't afford to live in the city.*
- *Changing countries, god told me to.*
- *Auckland and Wellington - Had enough of shifting, (wanted) own house.*
- *Left South Africa for political reasons.*
- *Don't like the city.*
- *Improved Lifestyle.*
- *To facilitate study (Bible College)*
- *For study*
- *to Job.*
- *relationship reasons / prefers country*
- *personal reasons - "followed a man" - very homesick, misses city*
- *city stinks*
- *change of life*

Part E: General Expenses

Number of households cut phone expenses in the last year: 47%, 1% no phone and 3% not applicable.

- Number of households cut phone expenses in Snells Beach in the last year: 45% (2% no phone and 2% not applicable).
- Number of households cut phone expenses in Wellsford in the last year: 49% (4% not applicable).

Number of households cut electricity expense in the last year: 43% (Snells Beach 41%, Wellsford 45%).

Number of households cut insurance expenses in the last year: 32%, not applicable – 9%.

- Number of households cut insurance expenses in Snells Beach in the last year: 34%, not applicable 11%.
- Number of households cut insurance expenses in Wellsford in the last year: 29%, not applicable 6%.

Number of households cut transport costs in the last year: 51% (Snells Beach – 52%, Wellsford – 51%).

Number of households cut vehicle maintenance costs in the last year: 48%, 4% not applicable. (Snells Beach 45%, Wellsford 51%)

Comment on Expenses:

- | | |
|---|--|
| <ul style="list-style-type: none"> ● <i>always been cautious with electricity and transport costs. Haven't done much recreation for a while.</i> ● <i>When first moved here had to cut phone costs. Tried to re-package insurance</i> ● <i>phone - not on 6 mth away</i> ● <i>Health costs cut for parents only</i> ● <i>cut doctors, partner made redundant</i> ● <i>no more home phone, prepay only, no electric heating</i> ● <i>can't cut transport costs</i> ● <i>car not costing yet</i> ● <i>meter minder on electricity</i> ● <i>lots of hand-me-downs - clothing</i> ● <i>clothing - secondhand & garage sales. Not cut food because of careful budgeting and spending - used to a tight budget.</i> ● <i>most clothing is made or given for free.</i> ● <i>Using free calls on mobile.</i> ● <i>Clothing mostly from hand me downs, including adults.</i> | <ul style="list-style-type: none"> ● <i>always careful about electricity, transport, health costs.</i> ● <i>Only buys essential clothing.</i> ● <i>Will go only if really necessary to Recreation.</i> ● <i>Mobile cut off.</i> ● <i>Toll calls only made in emergency.</i> ● <i>Did not pay donations in the form of school fees for the first time this year.</i> ● <i>Sews own clothing too.</i> ● <i>husband pays for wife's education costs - children's expenses still covered in household expenses.</i> ● <i>health cost -dentist</i> ● <i>-don't go to doctor</i> ● <i>-have no recreation expenses</i> ● <i>clothing is passed on</i> ● <i>obtained subsidy for childcare</i> ● <i>car pool</i> ● <i>doesn't buy clothes - mother buys for them</i> |
|---|--|

Number of households cut clothing expenses in the last year: 63% (Snells Beach 66%, Wellsford 61%).

Number of households cut health costs in the last year: 43% (Snells Beach 44%, Wellsford 41%).

Number of households cut recreation expenses in the last year: 62%, 4% not applicable (Snells Beach 64%, Wellsford 59% and 6% not applicable).

Number of households cut education costs in the last year: 30%, 8% not applicable (Snells Beach 31%, Wellsford 27%).

Clothing source for all households: secondhand – 37%, large chains – 39%, secondhand and large chains – 16%, large chains and boutique – 5%, given – 3%.

Part F: Food

Number of households concerned they would need to cut the household food expenses in the last year: 69% (Snells Beach – 73%, Wellsford – 63%).

Why concerned about cutting food bill:

- | | |
|--|--|
| <ul style="list-style-type: none"> ● <i>make money go around</i> ● <i>have to stretch money further because of food costs up here</i> ● <i>always other bills - lawn mowing, extra travel, extra training sessions for voluntary community work, dryer broke down</i> ● <i>benefit is not going as far.</i> ● <i>cost and budgeting because of sickness benefit</i> | <ul style="list-style-type: none"> ● <i>teenage appetites and concern for other accounts</i> ● <i>because doing work on house cut back other areas</i> ● <i>had to shift up here in a hurry, didn't have enough money for food - paying other set up costs</i> ● <i>insufficient income</i> ● <i>hospital costs because of daughters health</i> |
|--|--|

Appendix 4.10

- Expenses and costs have risen but income has not.
- cost of living
- unexpected bills but valid bills
- financial difficulties
- drop in income
- bills paid first from benefit, food = leftover money
- young baby, both not able to work
- lack of money
- reduced income due to reduced overtime available
- Cut her hours back for ill health but has regained them now as rent has increased over the years
- because new business costs
- not earning as much from business as anticipated, cut drawings
- partner made redundant 2x and mum now at home
- spending too much on food
- doing a training course in Auckland increased cost to family budget
- lack of money, less hours at work, childcare expenses
- work dropped off - lack of work
- can't afford to live how used to live - split with partner and so much running around & petrol cost gone up
- shifted down to one income
- had a mortgage and expensive car to run - sold car and house
- spending too much on food and prices going up
- drop in income
- not enough money, started budgeting - bills first
- doctors bills and other bills to pay
- usual situation needs care
- unexpected expenses - eg washing machine packed up, wiring needed fixing, car repairs, roof repair
- hard to run a family on one income
- unpredictable income
- extra expenses with moving into the house cost of living expenses, kids growing older, wanting more.
- food is becoming more expensive - need money put away for other things
- longterm DPB
- didn't have the money - bought specials only
- all on food - no toiletries
- gone from 2 full incomes to 1.5 incomes
- condition
- Health reasons - cost related. Sinus health costs lead to cutting back and change to diet
- not enough money, expenses gone to high for 1 wage
- lack of finance
- can't afford - paying bills first, extra expenses and partner not working
- money not stretch as far - food gone up
- financial
- Working more hours "on the run more" Uses takeaways. Properly costs more.
- Temporarily, broke because of overcommitment. Having a section and a house, also buying extra land, now sold house.
- Cost of groceries from New World to Pak n' Save
- Self employed (income related)
- Price, Bills, more goes out than comes in.
- Cost of living has increased - Husband working and getting paid less than 12 months ago.
- Family split up, led to reduced income to pay the bills.
- Mother gave up work - Daughter cancer
- Lack of money.
- On own with child- no border income (mother)
- Not enough money to pay for. One of the few ways they can cut back on spending.
- Cashflow problem because of Employment Contract Act.
- Benefits don't give you enough to survive on. Any bill eg tyres causes you to fall behind
- Now have to pay for it all.
- Trying to minimise food costs.
- Reducing 2 incomes to 1.
- Reduced income- helped make ends meet.
- Lack of funds.
- income didn't match expenses.
- biggest expense so had to look at.
- change in living circumstances, now living on DPB
- continual life on the benefit
- didn't have a job - on DPB - continual financial pressure
- clothing and school expenses
- got a telephone (via budget link), and new baby costs
- not enough money coming in
- tight government
- prices, extension to family

Number of households that did cut the food bill in the last year: 60% (Snells Beach 59%, Wellsford 61%).

how many times cut food:

	No.	% of all households
no response	5	4
zero	1	1
1	6	5
2	4	3
3	3	3
4	4	3
5	1	1
6	9	8
ongoing	24	21
fortnightly	2	2
regular	2	2
varied	1	1
10 -- 15	1	1
12	2	2
13	1	1
24	1	1

What food cut:

<ul style="list-style-type: none"> • fancy cereals, extras: soap, cleaning products - just use jif, shampoos etc. • meat, shop around more for cheaper fruit/vegies, biscuits/chippies, non-essentials • meat, vegies • lunchbox snacks, milk, fruit • wine, confectionary, sweets • canned food, fruits, cheaper meats, green vegies • meat, more pasta • baby formula, no baby food, baby wipes, household cleaners, toiletries, meat & vegies • no junk food, less meat, more pasta rice • lollies, chocolate biscuits, chips • luxury type, ie meat, sweets, bought cheaper brands • school lunch treats, did own baking, meat, eat more pasta, soups. No icecream and yoghurt and luxury food. • icecreams, biscuits, flavoured drinks, red meat • \$50 or more. No instant food, readymade packets, no biscuits or convenience/junk foods. Baby food made rather than buy cans • fast foods, milk - buy powder instead, make bread, meat, fruit • extras - anything but basics • fancy stuff - biscuits, cut amount of basics - try and balance • meat, no luxuries, cut fruit • non-necessities - chippies, liquid soap, cheaper bread, cleaning stuff • \$20 a week - not sure of exact items • food, petrol • meat & luxuries - kids lunch items, yoghurt - trimming all round • meat, sugar, shampoo, luxuries eg chips, biscuits, butter • luxury items • meat, vegetables, breakfast cereals, started 	<ul style="list-style-type: none"> • Luxury items and fast foods. • Meat and Brand items, use budget brands. • More in terms of cutting at a certain dollar figure so long as there was nappies and milk and bread. Did omit meat. • \$20 a week cut- meat cheaper, no maintenance on house for 9 years. • meat - (shifting off farm into town). Luxury items: eg. cheese. • meat/luxury food (eg. chips) • meat • meat, fruit, eggs • health products, meat, luxury items. • luxury items eg. choc biscuits • luxuries • seldom steaks and nice food, just the basics • luxury items - chocolate biscuits, icecream • meat, packet foods, basically everything • buy everything in bulk on special • children's luxury food items • luxury items, chips, chocolate biscuits • • basic food & not expensive items • vegetables (given home-grown), treat/snack foods • luxury items - meat and dairy products • growing own vegies, make biscuits instead of buying, cut luxuries • biscuits, chips, cheap meats, cleaning stuff cut back, cut fruit & vegies back • pre-prepared meat, tinned food, spreads, biscuits, snack foods • all luxuries - biscuits, fruit • more expensive meats. Change to coupon and budget brands • tea, coffee, smokes, everything on food, nappies • cleaning, meat, fresh vegies amount, getting cheaper quality
--	---

Appendix 4.10

<ul style="list-style-type: none"> • <i>making bread rather than buying</i> • <i>we just had the basics</i> • <i>Meat, bread, vegies, biscuits, shampoo, toiletries</i> • <i>Vegetable Garden, sometimes give and get given things - ie food from neighbourhood.</i> • <i>meat, ice cream, packets of biscuits, prepared meals ie pizza etc.</i> • <i>Junk food, quality of meat ie. steak to mince</i> • <i>Luxury items.</i> 	<ul style="list-style-type: none"> • <i>snacky stuff and cleaning stuff</i> • <i>Bulk buying and specials.</i> • <i>Luxury</i> • <i>Luxuries eg chocolate biscuits, chips, brand products, air fresheners.</i> • <i>Meat and freezer foods.</i> • <i>General cut - just more careful with all ex's</i> • <i>Expensive meats, fruit, puddings, school treats.</i> • <i>No treats, biscuits, meat could only be bought on special, cordials etc.</i>
---	--

Number of households where someone went short of food: 25% (Snells Beach 22%, Wellsford 29%).

Number of households that took some other action to resolve the situation: 37% (Snells Beach 33%, Wellsford 41%)

Cut food & action to resolve:

- *not buying items on payment options - farmers/Rendells*
- *didn't need to take further action other than cutting back on food bill*
- *light meals, spaghetti, eggs*
- *Tried to get help from WINZ*
- *Saving harder, only buying necessities*
- *borrow from friend, conscientious been aware of spending money*
- *went to income support and got a food voucher*
- *food parches - Salvation Army, \$20 food grant from WINZ*
- *Borrowed money from relations and made food more important than bills*
- *income support*
- *got food off her mum*
- *used food from business & borrowed money from mum*
- *Went to WINZ but only after spent all savings on mortgage for last nine months*
- *food parcels, visa card for food*
- *food grants WINZ*
- *try to cut back on other things*
- *went to WINZ for food grant & borrowed money for groceries from friend - used kids paper money*
- *sold things - car and house - doing that to have extra money at end of week*
- *borrowed from sister*
- *got a budgeter in*
- *borrowed*
- *eating with parents*
- *mum shifted in helped financially, budgeting and food parcels*
- *sold a car and also applied to budget adviser for food parcels*
- *got a part-time job*
- *onto budget*
- *stay with family - family help, generosity of others, used all food benefit from WINZ - not asked for food parcels*
- *food given to household*
- *Vegies from garden*
- *Went to WINZ, asked grandparents for help, borrow from neighbours. (food)*
- *food parcels from church, food grants from WINZ.*
Ate more bread etc than other foods at times ie toasted sandwiches for tea. Have meat 4 times a week.
- *No treats McDonald's once or twice a year.*
- *Barter for food*
- *Meals with Mum.*
- *Food parcels, WINZ food grants.*
- *Sometimes friends and family supported on own accord - visa card.*
- *just prioritised*
- *winz food grant*

- *re-educated self to get a decent job, ex-husband provided groceries.*
- *food grant from winz. family assistance.*
- *applied for help from WINZ but was refused*
- *WINZ list*
- *book up and pay later*
- *went to WINZ*
- *borrowed money, food bank*
- *food bank*
- *budgeted*

How resolved for houses that did not cut food bill:

- *asked friends for help, bake own food*
- *Homebaking, bulk buying, family helping out*
- *planned budget a bit more. Used Mastercard for shopping 2 wks*
- *mortgage not reduced as much, stay same*
- *food grants from WINZ and deferred payments on other bills*
- *cut back on other items such as clothing especially for the adults. Also healthcare/dental treatment for adults*
- *Vege Garden*
- *More effort into working - child had to be looked after.*
- *Shopping less regularly.*
- *careful budgeting*
- *was more careful with shopping, and cooked meals that went a long way and tried to make them filling.*
- *husband off work 11 months. Applied for dole but then got a job*

Number of households that have sought a food grant from WINZ in the last six months: 27% (Snells Beach 22%, Wellsford 33%).

Number of food grants sought from WINZ: one food grant – 10%, two food grants – 14%, three food grants – 3%.

- Snells Beach: one food grant – 6%, two food grants – 13%, three food grants – 3%.
- Wellsford: one food grant – 14%, two food grants – 16%, 4 food grants – 4%.

Number of households received WINZ food grant: zero – 5%, one food grant – 12%, two food grants – 7%, three food grants – 3%.

- Snells Beach: zero food grant – 5%, one food grant – 9%, two food grants – 5%, three food grants – 3%.
- Wellsford: zero food grants – 6%, one food grant – 16%, two food grants – 10%, three food grants – 2%.

Comments on WINZ:

- *don't like to ask, embarrassing to ask for food - but have done it.*
- *pretty good*
- *They make requests to go to work to ease financial situation but have been quite helpful.*
- *Not want to shop locally if getting help from WINZ.*
- *Not very understanding, supportive or helpful.*
- *receipts required but didn't have them.*
- *Feels they make you feel they control your life. It's horrible they press your buttons.*
- *really have to push (beg) for any money - limit on amount in 52 weeks.*
- *Can't really but when had too they have been helped.*
- *don't bother*
- *Doesn't try as doesn't feel they qualify*
- *Really shocked when told if partner moved out would be better off. No enterprise allowance cooperation from WINZ.*
- *good to us*
- *hopeless - in middle don't get anything. Hard to talk to - attitude of 'owe them personally'*
- *did seek food grant 12 mths back - 3x. Used up savings - WINZ helped for a while, back to work for 3 months - under investigation - letter to boss and sacked, unfortunate mess - difficult to contact by ph*

Appendix 4.10

- *When someone desperate enough to ask for food should be more lenient - told to pay other bills and ask - then refused. Lack of understanding. Hate going in there - hate asking for stuff. Refusal really bad.*
- *Getting an appointment was a nightmare, not helpful, don't say what entitled to unless find out and hound them. They never followed up on anything.*
- *WINZ sent to a church food bank - which made family 'feel low'*
- *felt the form received was not appropriate for her specific needs*
- *It would be nice to have one person instead of a different person each time*
- *ok*
- *a bit of a help with Accommodation supplement & family support*
- *asked for help for the bond*
- *Don't go in unless have to - they don't help. Humiliating dealing with them for food*
- *They need to be more consistent with what you can and can't get and have more information on what is available from WINZ*
- *Have not found them helpful - reluctant to supply needs*
- *Co-ord of timely demands can't be sought after easily, not accessible when need - stuck in Orewa 2x and can't get home*
- *too proud to go*
- *Don't give unless you ask for it specifically, they think you're trying to rip them off, attitude got worse over last 5 years. One of the staff is nice and not like that. They don't let you know what you're entitled to.*
- *It's hard to get an appointment let alone one that's suitable. Made to feel like a second rate citizen. If they give you a grant they make you feel at their mercy, like you should be grateful, they didn't have to, you would actually think it was their money.*
- *Too much pride!*
- *Grateful WINZ helped cover a bill for damage to another property caused by one child- which family is repaying \$5 a week.*
- *They don't come forward with any information you have to find out the information then go and tell them. They don't volunteer any information, "you'd think it was their own bloody money."*
- *It's humbling to do, stigma attached, makes you feel inadequate.*
- *Not eligible.*
- *Find WINZ to have been like the money was coming out of her own pocket. Only gave tiny amount. Weren't forthcoming about what was available. If you don't know the system they do not offer anything. If you tell them your situation they should tell you what you're entitled to.*
- *No accommodation allow for 19 year old, but don't look at expenses - high because of head injured child. Son in debt because of living away from home.*
- *did not get as much as asked for*
- *on the whole they're pretty good - emergency benefit provided easily during recent illness.*
- *not helpful when needed*
- *didn't find it helpful*
- *no problems*
- *had a pretty hard time trying to join WINZ - they made you feel bad, was degrading. First timers get put down.*
- *has been hard - often when they need it they don't go - embarrassing because they don't always get it. "Digging a deeper hole" because it must be paid back*
- *found it hard, don't take everything into account*
- *was not satisfactory - stand over attitude*
- *wouldn't approach WINZ*

Number of households requested food parcel: 10%, n=11 (Snells Beach 3 households, Wellsford 8 households).

Number of households received a food parcel: 7%, n=8 (Snells Beach 2 households, Wellsford 6 households). Food parcels were not adequate for 6 households.

Comment on Food Parcels:

- *always been grateful, helpful - lifesaving*
- *Don't get any choice of food available.*
- *They are a necessity nowadays*
- *Do not know where to get one from.*
- *Worth their weight in gold.*
- *find out if necessary*
- *hamperish - be nice regular. Had in past - basically good*
- *muffins were mouldy, flour had weevils*
- *its not always food that is needed - often it is incidentals such as washing powder, toilet paper etc*
- *brilliant idea - but felt there are people out there who needed it more than they did (even though they were struggling)*
- *we have helped a friend out with food*
- *I've never been in that situation*
- *put things like flour and milk powder - at time had baby on formula - not adequate or appropriate - still thankful*
- *very grateful for items received*
- *Household's church supports the family with food as needed.*
- *Great idea for people who need them.*
- *Wouldn't know where to get one.*
- *If you were in need of one - how would you go about getting one?*
- *Family helps with the food parcels.*
- *Given one 3 years ago, nice surprise!*
- *Only lasted 2.5 days as 7 in family.*
- *Never got one.*
- *Food parcels are given to help staff at Lifeway once a month. (Respondent works at Lifeway.*
- *This family does have help from a charitable organisation- without having to ask.*
- *Excellent when need them.*
- *you are only referred to get a food parcel*
- *doesn't know about these*
- *got one at Christmas - wasn't appropriate for their needs*
- *appreciate being able to get some*
- *you have to justify everything*

Part G: Telephone

Number of Households with a telephone/mobile phone: 92%, 6% do not and 2% have only a prepay. Of the seven households with no phone, 6 are in Wellsford and one in Snells Beach.

Why no phone:

- *can't afford phone*
- *messages via brother - access to ph*
- *prepaid only because of expense*
- *to reduce expenses*
- *been cut off*

Number of all households with a tollbar: 17% (Snells Beach 13%, Wellsford 22%).

Why tollbar:

- | | |
|--|---|
| <ul style="list-style-type: none"> • <i>expense</i> • <i>can't control ourselves - phoning whanau</i> • <i>expense</i> • <i>can't afford toll calls</i> • <i>can't afford tolls</i> • <i>too many toll calls to family</i> • <i>so it can't be used by others</i> • <i>friends in familiar places helps cut cost</i> • <i>Because of cost of ringing anyone out of this</i> | <ul style="list-style-type: none"> • <i>with pin number - to stop daughter pressing button 0</i> • <i>cut the cost</i> • <i>Was told it was compulsory to have a toll bar as she hadn't had a phone for a while.</i> • <i>Can't afford toll calls.</i> • <i>teenage child</i> • <i>still paying off overdue account - when it is paid tollbar withdrawn</i> |
|--|---|

Appendix 4.10

- *area (competition to Telecom welcomed)*
- *save money*
- *to keep bill down*
- *expense*

Number of households that need a telephone: 88%, 10% no response, 3% do not need a telephone.

of 9 with no phone or only

prepay

need no 3

response

no 2

yes 4

Comment on need for phone from houses with no phone:

- *health, family & voluntary work*
- *contact*
- *to contact in case of emergencies at school / kindy*
- *work / family / health*

All why need phone

<ul style="list-style-type: none"> • <i>keep in contact, family in Auckland, emergencies - if something happened, social contact</i> • <i>important</i> • <i>work, family</i> • <i>keep track of children, work</i> • <i>work, family contact, friends & doctor</i> • <i>community work, on call</i> • <i>Family being long distance away.</i> • <i>Health reasons, work, family</i> • <i>Marital problems - need assistance from welfare and legal.</i> • <i>work & family</i> • <i>contact with the outside world, work, health reasons</i> • <i>For doctors, family emergency, son who needs to go to hospital</i> • <i>kids/family</i> • <i>health, work, family</i> • <i>health reasons children</i> • <i>to keep in touch for family overseas</i> • <i>to keep in contact as only has one car</i> • <i>communication with family, work</i> • <i>for work and kids</i> • <i>health, safety, kids</i> • <i>family</i> • <i>family & small child</i> • <i>prefer to have just mobile, need for family & work</i> • <i>health</i> • <i>emergencies, to counteract possible isolation</i> • <i>safety of child - medical emergencies, family contact</i> • <i>work</i> • <i>for work</i> • <i>for son, disability for him</i> • <i>contact family</i> • <i>work for partner, baby & sanity</i> • <i>health</i> • <i>work & personal</i> • <i>health reasons & contact</i> • <i>social & work purposes</i> 	<ul style="list-style-type: none"> • <i>health and family reasons. Use familiar places scheme to contact family. No 0800 for ACC</i> • <i>work and family</i> • <i>keeping in touch -family, friends, work</i> • <i>health issues - need to phone hospital, only way stay in contact with people</i> • <i>health, family</i> • <i>health reasons</i> • <i>lifeline - important</i> • <i>urgencies - health problem, breakdown</i> • <i>business hrs, teenagers</i> • <i>3 young children, contact family</i> • <i>medical alert and family - only have a mobile phone - given to family</i> • <i>husband asthma</i> • <i>work & family</i> • <i>health, family & voluntary work</i> • <i>children - safety/health also lifeline for mum (isolation with small children)</i> • <i>family</i> • <i>For emotional well-being, not to feel isolated, work and family too.</i> • <i>Need it with children to counteract isolation. Recently had a baby. Husband rings when home late.</i> • <i>work, family</i> • <i>work, household, family.</i> • <i>Business</i> • <i>Doctors, Daughter in Dargaville, Hospital needs, Son at high school have to pay for phone calls.</i> • <i>2 children - you need a phone for health reasons.</i> • <i>Family can contact- and to get in touch with government departments. WINZ, IRD etc.</i> • <i>F2</i> • <i>Health reasons.</i> • <i>Family contact.</i> • <i>All reasons given- Security in emergency, work.</i> • <i>health reasons.</i> • <i>Work and Family.</i> • <i>Doctors, Parents. Father has had a stroke.</i>
---	---

<ul style="list-style-type: none"> • <i>medical reasons</i> • <i>for security reasons</i> • <i>family and work</i> • <i>to contact in case of emergencies at school / kindy</i> • <i>so the children can contact mum whiles she's at work</i> • <i>health and work</i> • <i>business / jobs. family contact.</i> • <i>children, emergency</i> • <i>family, work</i> • <i>health and family reasons</i> • <i>health, school</i> • <i>health, work</i> • <i>isolated, with young child - has a prepay but can't afford to use it</i> • <i>keeping in touch with friends and relatives , and using internet</i> • <i>ring people</i> • <i>work / family / health</i> • <i>doctors - children, family</i> • <i>health</i> 	<ul style="list-style-type: none"> • <i>Card, Coin phones are often out of order - what if it's an emergency.</i> • <i>Safety with no car, have children family contact in OZ.</i> • <i>Safety reasons.</i> • <i>Business.</i> • <i>Work.</i> • <i>All reasons given.</i> • <i>Work.</i> • <i>Work, Family, Social</i> • <i>Father's mobile is for work, phone is cheaper to contact Warkworth services because its more expensive to travel there to make appointments than to ring in longrun.</i> • <i>Couldn't live without, Work.</i> • <i>family</i> • <i>contact</i> • <i>work, family</i> • <i>with children + family</i> • <i>health reasons</i> • <i>family & work</i> • <i>emergency, family, contact with people</i>
---	---

Part H: Health

Number of households with a member with a disability or ongoing health problem: 59% (Snells Beach 59%, Wellsford 59%).

Number of people in each household with a health problem: one person – 38%, two people – 11%, three people – 7%, four people - 2%, five people – 1%.

Number of households with members with regular recurring medical costs arising from health problem: 48%, 11% no costs (Snells Beach 47%, Wellsford 49%).

Note: some of the no health costs are because the family member is under five and therefore healthcare is free.

Number of households that have experienced barriers to obtaining medical care in the last six months: 34% (Snells Beach 34%, Wellsford 33%).

Barriers to medical care:

- *Cost prevented seeking medical help*
- *waiting lists too long*
- *Waiting list - 2 yrs for tonsils and grommets. Mum doesn't go because of cost - also changed type of pill to lower cost one. Doctor visit \$15pw x12 in 3 mth winter period*
- *waiting list*
- *Distance, Childcare, worries if Mum in hospital, cost.*
- *cost imposed on self, doctors cost at least \$50 - put off, go for son but not for mum*
- *cost - can't afford \$1 a day for sons antihistamine*
- *financial - parents gave money, otherwise 18 month wait for tonsillectomy*
- *public waiting list for grommets - family paid for private care*
- *couldn't afford glasses*
- *cost for care at time - don't go to doctor, try pharmacy instead*
- *skin condition - classed as minor so can't get access to public services, waiting lists*
- *cost of glasses for everyone*
- *cost incurred*
- *cost - osteopath*
- *local practice is overloaded - occasionally difficult to see the doctor you want. Would benefit from a heart/lung transplant which is not done in NZ. Would have to pay for this privately in Australia*
- *2 yr waiting for tonsils/adenoids to be removed at starship or anywhere*

Appendix 4.10

- *costs and difficulty with compliance (feels she needs a hysterectomy but this has been denied)*
- *waiting list - hospital lost paper work. Distance - cost of transportation*
- *waiting for operation for nearly 2 yrs - carpal tunnel syndrome*
- *couldn't get there some days - other family response, trained and childcare - usually try*
- *cost for mum - rest go*
- *costs for physio, xrays, doctors etc. High over last while because of an injury*
- *Staggering amounts spent on re-occurring headlice problems common through schools - very frustrating. Manage from home rather than doctor visits - asthma*
- *cost - adults delaying visits to doctor or not going at all*
- *Expensive getting to treatment in Auckland and childcare problems. Needed to cancel appointments because couldn't afford transport to Auckland. Needed to take time off work.*
- *Don't go to the doctor because of cost - however feel safe (at times only) delaying or not going to doctor as Mother is a registered nurse.*
- *Wait for operation*
- *Costs, waiting lists and distance. In one instance obtained grant from Warkworth businessmen Association.)*
- *Need physiotherapy for arm. Couldn't afford this (even though with ACC it was \$8) also had to travel to Takapuna. Gave up.*
- *Costs, Distance.*
- *father: cost prevented treatment as yet. Diagnosed six months ago.*
- *couldn't get onto waiting list for treatment for continual tonsillitis*
- *been on waiting list - now treated*
- *doctors visits have been reduced - owing to costs*
- *distance - cannot drive, needs someone to take*
- *on waiting list for diagnostic tests - 3months now*
- *waiting delay because of distance for assessment for treatment of diabetes*
- *waiting lists for treatment of lump in throat. (5 months for specialist appointment) once seen, 2weeks wait till operation*
- *distance to Auckland hospital*

Number of households where someone has been to the dentist in the last year: 72%, 27% not been (Snells Beach 73%, Wellsford 71%).

Number of households where someone has been for a: regular checkup – 44% (Snells Beach 48%, Wellsford 39%), emergency – 43% (Snells Beach 47%, Wellsford – 37%), Orthodontist – 13% (Snells Beach 14%, Wellsford 12%), Surgery – 10% (Snells Beach 9%, Wellsford – 10%).

Number of households where every one who has needed dental care in the last year has received it: 49%, not received care – 49% (Snells Beach not received care – 45%, Wellsford not received care 53%).

Number of households that have experienced barriers or problems obtaining dental care in the last year: 50% (Snells Beach 52%, Wellsford 47%).

Dental Barriers:

- *cost for tooth removal has been the barrier. Not resolved.*
- *no money - trying Waipareia Trust in Henderson*
- *cost again preventing seeking help*
- *Cost of treatment, waiting for WINZ to approve.*
- *Cost of treatment*
- *Financial, no choice - had to go in the end*
- *cost - not resolved*
- *Lack of money. Was meant to go back, still has temporary filling over 2 months ago.*
- *cost - took out loan from parents*
- *financial, distance & childcare - all three problems not resolved*
- *abyss under tooth put off because of cost*
- *money - haven't gone, fillings fallen off*
- *financial - cut back elsewhere*
- *couldn't afford to go - know work needs to be done but can't afford it*
- *worry about the cost - delay going to dentist, got worse*

- *daughter sore tooth - couldn't afford to go to dentist - beared with it tooth went rotten, went to dentist to pull out*
- *money - cost prevented seeing dentist - bleeding gums, holes, almost emergency*
- *cost - mum paid the bill*
- *can't afford dentist*
- *cost*
- *cost - a problem but not a barrier - if you're in pain you have to find the money*
- *one dentist in Wellsford & 3 wk waiting list at times & expense*
- *older son has difficulty paying - 17 yrs*
- *cost*
- *lack of information about preschool services*
- *cost - delay going*
- *cost with social work*
- *Cost - unresolved - didn't go. Teeth still needing attention*
- *cost*
- *because of price if sore*
- *cost - not resolved due to lack of finances*
- *owe money and can't get back - cost - have to pay up and 2 people affected. Looking for school care - surgical need. Only go in bad pain*
- *mum not go due to cost - don't go*
- *cost - didn't go*
- *cost - both adults need more treatment - cost makes this impossible - even with the option of being able to pay it off*
- *(Too busy.) Cost is an issue.*
- *Cost.*
- *Hasn't been because of time involved, cost considerations. Wait till something goes wrong.*
- *apart from cost*
- *Expense*
- *Cost, need a partial plate F, need front two teeth done.*
- *Lack of money, had to pay it off. Also delayed getting the appointment - by a short time only.*
- *Financial (and tooth ache)*
- *Elderly should receive subsidy for dental care from WINZ.*
- *cost for adults.*
- *Had to go to WINZ to get the money, took 2 days for them to come through.*
- *Still waiting.*
- *Time, lazy, need to organize it.*
- *New to the area so dentist hasn't yet been identified.*
- *Money*
- *Cost.*
- *Cost- unresolved -not going, no regular dental care at school for kids. Stressful as have to worry about kids teeth.*
- *no spare money for treatment - eg troublesome wisdom teeth*
- *cost*
- *children received free dental care at school*
- *crooked teeth needing braces, couldn't afford it so never had it done*
- *no dentists needed*
- *cost of dentist*
- *cost - not resolved*
- *haven't tried to go because of lack of money*
- *expense*
- *mother paid for a bridge which was then lost and not replaced after one month*
- *costs*

Appendix 4.10

Part I: Children

Number of all Households with children at school: 69%, homeschool – 3% (Snells Beach 72%, Wellsford 65%, homeschool 6%).

Number of households with children at school liable for schools fees: 84% (Snells Beach 89%, Wellsford 78%).

Number of households that have difficulty affording school fees: 50% (Snells Beach 50%, Wellsford 50%).

School fees:

<i>Difficulty Affording</i>	<i>How Resolved</i>
yes	Paid in instalments
yes	Haven't been able to pay all of it.
yes	College fees still not paid, pluck it out of thin air when the money comes. Advance from WINZ, reduced income from work.
no	automatic payments a little each week, same for dentist, vet, school
yes	Still owes Leigh 20 and now at new school
yes	sold stuff
yes	paying them off
yes	family support goes to school
yes	drip feed
	don't pay
yes	did extra work
yes	just didn't pay
no	in budget
yes	can't afford
	mum pays
yes	didn't pay
yes	will pay as/when they can
yes	asked for help from other parent
yes	Didn't pay because couldn't afford it
yes	not paid - can't afford it
yes	paying drip feed \$10 a week
yes	not paid enough to pay
yes	pay 2 lots, refuse to pay for third
yes	drip fed
yes	have only paid one term
yes	Made child's father pay (He hasn't)
yes	Delayed paying
no	100 approx a yr.
yes	Grandmother paid
yes	Paid for one child, then the other.
yes	Budget
yes	Didn't pay part of power account
yes	put money aside weekly.
yes	Didn't pay
no	Budgeted for all these items over the year.
yes	Waited until the last possible moment.
yes	went into debt.
yes	donation was not paid
yes	didn't pay
yes	time payment
yes	approached WINZ for advanced loan
yes	unpaid as yet
	did not pay - donation
yes	not paid
yes	didn't pay

yes	borrowed money
yes	hard - don't pay it
yes	lucky dip

Number of all households liable for subject fees: 51% (Snells Beach 52%, Wellsford 50%).

Number of households that have difficulty affording subject fees: 29% (Snells Beach 28%, Wellsford 31%).

Subject fees:

Difficulty Affording	How Resolved
yes	sold stuff
yes	deprived ourselves of other things
yes	paying them off
yes	drip feed
yes	paid off drip feed
yes	did extra work & cut back on other bits
yes	bank card increase lots this year
yes	asked for help from other parent
yes	Spent less on food
yes	had to pay
yes	paying drip feed \$10 a week
yes	juggle budget
yes	drip fed
no	Paid for one child, then the other.
yes	pay off in instalments.
yes	\$ been gifted, otherwise went without
yes	Mum takes on extra work when she can
yes	approached WINZ for advanced loan
yes	made sacrifices
yes	work overtime, cut other things
yes	hard - don't pay it
yes	lucky dip

Number of households liable for stationery fees: 93% (Snells beach 93%, Wellsford 92%).

Number of households that have difficulty affording stationery fees: 45% (Snells Beach 50%, Wellsford 39%).

Stationery fees:

Difficulty Affording	How Resolved
yes	just had to find it
yes	Got in sales before school started.
yes	Went to cheapest place - eg warehouse - transport cost
yes	Paid some off most weeks
yes	sold stuff
yes	deprived ourselves of other things
yes	paid that first
yes	drip feed
yes	found the money
yes	extra work by partner
yes	went without groceries
no	in budget
yes	can't afford - owe
yes	budgeter organised payment

Appendix 4.10

yes	asked for help from other parent
yes	Spent less on food
no	cut back - reused from last year
yes	paying drip feed \$10 a week
yes	juggle budget
no	budgeted for
yes	used gift vouchers given to them at Christmas
yes	Made adjustments
	Paid for one child, then the other.
yes	budget
yes	put money aside weekly.
yes	Sold a few things.
yes	time payments
yes	Mum takes on extra work when she can
yes	borrowed money off ex-husband
yes	approached WINZ for advanced loan
yes	made sacrifices
	work overtime, cut other things
yes	managed to pay it - out of food money
yes	cut groceries down
yes	hard - don't pay it
yes	lucky dip

Number of households liable for uniforms: 52% (Snells Beach 63%, Wellsford 39%)

Number of households that have difficulty affording uniforms: 30% (Snells Beach 37%, Wellsford 22%).

Uniforms:

Difficulty Affording	How Resolve
yes	secondhand
yes	went to social welfare
yes	deprived ourselves of other things
yes	sales and secondhand
yes	cut back other clothing
yes	bought secondhand
	paid from trust fund for children
	no choice
no	overtime work
yes	asked for help from other parent
yes	Begged secondhand uniform at school
yes	juggle budget
yes	no choice, had to be paid
yes	drip fed for one child, welfare assistance for other
yes	Approached ex-husband to assist.
yes	282 yr
yes	secondhand
yes	gifted.
no	Budgeted for all these items over the year.
yes	Mum takes on extra work when she can
yes	paid it off in 2 lots.
yes	time payment
yes	approached WINZ for advanced loan
yes	made sacrifices
	drip fed
yes	hard
yes	savings

Number of households that have had difficulty paying for expected school trips: 44%, no 49, not applicable 5%. (Snells Beach 46%, Wellsford 42%). Number of households unable to pay for expected school trips: 6%.

How resolved paying for expected school trips:

- *not easy*
- *went without other things*
- *had to budget and juggle money*
- *Took it out of food money.*
- *son worked himself to go*
- *owe school - pay later*
- *fundraised for trip*
- *deprived ourselves of other things*
- *drip feeding & boy paying by mowing lawn*
- *got a grant from McKenzie trust - covered most of school stuff*
- *college let go and paid for it and borrowed money or don't go*
- *sometimes can't afford - pinch from other parts of budget*
- *pay delay*
- *child went - had help to pay, paying back*
- *arranged to pay in instalments*
- *school still awaiting payment*
- *doesn't go*
- *arrangements to drip feed*
- *borrowed money*
- *adjustments*
- *Budget; Parent go without something*
- *not send them*
- *Camp- put boy into another class – not go*
- *Paid and went without.*
- *Kids did everything but went into debt to do it.*
- *borrowed from ex-husband*
- *time payment*
- *paid by instalment*
- *drip fed*
- *overtime*
- *took money out of ACC payment*
- *hard*
- *paying off*

Number of households that have had difficulty paying for optional school trips: 23%, not applicable 16%, no difficulty 59% (Snells Beach 22%, Wellsford 25%). Number of households unable to pay for optional school trips: 4%.

How resolved for optional school trips:

- *went without other things*
- *he couldn't go*
- *ok if no cost*
- *college let go and paid for it and borrowed money or don't go*
- *asked for help from other parent*
- *depends on what is and if have money*
- *Budget; Parent go without something*
- *not send them*
- *ex-husband paid occasionally*
- *paid by instalment*
- *family members help out*
- *hard*
- *paying off*

Appendix 4.10

Number of households that have had difficulty paying for sports activities: 23% (Snells Beach 15%, Wellsford 33%). 2% unable to pay for sports activities.

Comment on resolving sports expenses:

- *couldn't afford*
- *borrowed off mum*
- *just have to pay out of something*
- *can't afford - pay by drip feed*
- *sometimes can't afford - pinch from other parts of budget*
- *delay costs*
- *asked for help from other parent*
- *depends on what is and if have money*
- *just made it happen*
- *Gifted*
- *someone else took him*
- *family members help out*
- *hard*
- *paying off*

Comment on resolving music expenses:

- *out of grocery money*
- *giving them up*
- *child is not having lessons unable pay*
- *Struggled to pay*
- *Put into another class. unable pay*

Number of households where children have had to forego any other educational activities at school in the last year because of cost: 16% (Snells Beach 13%, Wellsford 19%)

Activities Children have to forego in the last year because of cost:

Forego Activities	What Activities
yes	music lessons that father stopped paying for
no	always find the money
yes	Not keen to get daughter in anything as can't afford transport, fees etc.
yes	tutoring afterschool for maths
yes	Australian exams - paid for exam but not practice papers. French lessons - possibly not do \$5 a time
yes	music - no lessons
no	told mother of other child to be aware
yes	would have bought more resources if money available
yes	School trip - child did not go. Whanau activities not able to be participated in
yes	cut back on field trips
no	3 yrs ago had restricted options - missed trip
no	would like to have extra learning for one child but too costly
yes	Extra maths after school.
yes	Computer course, expected to buy a computer. Selling exercise.
yes	Took our daughter out of child-care because of cost. (Did go 2 mornings a week to local creche.)
yes	school plays + shows (as spectator)
yes	sports - netball and rugby, couldn't afford fees and uniform costs
yes	camp

Number of households that use preschool childcare: 39%, not applicable 19%, not use childcare 37% (Snells Beach use preschool 38%, Wellsford use preschool 41%).

Of those that use preschool (n=45), 22% do not have sufficient hours (Snells Beach 25%, Wellsford 19%). Of those that do not use preschool (n=43), 21% need preschool childcare (Snells Beach 19%, Wellsford 24%).

Preschool hours comment:

- *not entitled to more subsidy*
- *cost*
- *more stimulation would be good*
- *would like some time apart from the 2 yr old*
- *could do with more*
- *Likes learning*
- *Stressful coping alone with lively toddler and new baby.*
- *Would like 15 hours for 4.5 year old*
- *needs more of a break, trying hard to look for work*

Why no preschool care:

<i>Do you need preschool?</i>	<i>Why No Preschool Childcare</i>
no	choice
yes	put cost up - can't afford
yes	cost
no	won't be able to afford childcare - no family to look after, partner will have to
no	will be looking into - on maternity leave
yes	still getting there
yes	cost
yes	WINZ doesn't provide subsidy for 5 yrs old children and so must go to school or stay with mother regardless of researched evidence showing kids do better if attend school 6 yrs plus.
	Because of injuries etc.
no	Feels its her own responsibility to rear her children.
yes	Cost
yes	cannot afford it

Number of households that use afterschool childcare: 9%, 62% no, 20% not applicable, 10% no response. (Snells Beach use afterschool care 13%, Wellsford 4%). All of those using afterschool childcare have sufficient hours.

Of those not using afterschool childcare, 10% do need afterschool childcare (majority in Snells Beach).

Why no afterschool care:

<i>Do you need afterschool care?</i>	<i>Why not using afterschool care?</i>
no	because mum is always home. (is a necessary service though for working mums).
no	because mum is at home
yes	does when needed
yes	possibly soon
yes	legally need it but can't afford it
no	friends
yes	husband arranges work to cover
yes	cost
no	not needed
	I am
no	Parents home.
yes	Grandmother available.
yes	Can't afford it.
no	But needs holiday child care.

Appendix 4.10

no	Father provides care.
no	always a parent home
no	parent at home

Children Recreation Comment:

<ul style="list-style-type: none"> • Son's soccer been though school - good. Swim thing through Lotto \$20 for 10 lessons was good. A swimming pool would be good - for public. • nothing much at Snells, so have to go to Warkworth. Difficult because bus service finishing in Nov, particularly if you don't drive. • local movies would be good • use park & beach near by • would want more activities if could afford it. • Would like her to participate in activities, eg. Pippins, dancing, but can not because of cost. • If I could afford it, I would let the children do it. • Limited income restricts EVERYTHING • No cash to do stuff. • Would like to take child to swimming but can't afford • If there was more money then family outings & movies would be possible. • Limited up here in this area • limited due to funds • do stuff at home • everything you need money for. Outing is the grocery shopping. • take care of themselves, have most things they want here. • most activities using beach or local playgrounds • worry about amount of time spent on playstation, do get out, daughter finds hard to balance study & working & dancing. • no - beach, occupy selves, go fishing • no - due to age - to young • own videos, live near beach • need more things for children to do in the town • do weekend things like swimming, fishing etc • would like there to be more things for 2 yr old to do - local toy library is too expensive at present they amuse themselves, read & draw • With summer coming swimming lessons are important for younger child. We have purchased a local pool key. • we support her interest sport • Play at other children's homes or has other children to play here • go to the library, to the beach etc • Playgroup - coffee mornings through Plunket • sport at school only • does normal things when can • fishing, beach • would like to do more • do things on their own - weekends with friends. • most of the family time spent at beach. • would love to take them at least once a month to 	<ul style="list-style-type: none"> • do what they want • only because of cost - none of listed activities • The children want to go out to do things at the weekends eg. hotpools. • Would like daughter to do music • Recreational activities are all free - beach, trees, because can't afford 'paid-for' activities. • Need turf for hockey in Warkworth. • School pool not heated so additional costs for HBC pool hire / transport / car pooling etc. Swimming training at HBC. • Some facilities for children ie. sports unavailable for younger children - population too small. • Lack of playing space, skate park but not road bikes. • There is not a lot for younger children (pre-school) to do - have to travel for dance lessons. Even things like pippins take the kids when they're older than in the city. (Due to lack of interest probably) • Been to the Zoo recently with children. • "Child cancer" and "Canteen" (siblings) support finance side of activities. • Have beach playground. • Dancing only in Summer. • Given free Movie tickets. • Would like to get a decent computer as a resource for children's homework and information. • Much easier this year as 2 working last year a different story. • Would like son to play sports but the cost, including boots, transport, uniform. • Part time child care. • Feels the children are able to entertain themselves. Enjoys special outings for birthdays. Beach is near. • Limited without a vehicle. • The Family do things that are free eg. Beach, parks, walks, visit relations etc. • Not any facilities up here. Dance is in Warkworth or Orewa. Swimming is at HBC Leisure Centre. Cost plus petrol etc. plus time • Ride horses, costs a bit, where sons ability lies, will do anything to keep him away from drugs- will go into debt. By choice given where you live. • movies, spectator at sport in Auckland - with dad on weekend. • considers that they have too many computer games. • do above in holidays. has informal music lessons at home. wrong season for sport. • Church or sports. not enough places to take kids
---	--

<p><i>the movies or concert, but budget does not allow this.</i></p>	<p><i>for free</i></p> <ul style="list-style-type: none"> • <i>started karate last year in Warkworth but cost + travel too high to continue</i> • <i>would like to do more with the children but cant because of costs</i> • <i>distance is a barrier for swimming lessons</i>
--	---

Part K: Household Income and Expenses

Number of households receiving family support: 51% (Snells Beach 41%, Wellsford 65%).
 Number of households receiving independent family tax credit: 6% (Snells Beach 5%, Wellsford 8%).
 Number of families receiving Guaranteed Minimum Family Income: 4% (Snells Beach 5%, Wellsford 4%).
 Number of Households receiving accommodation supplement: 37% (Snells Beach 31%, Wellsford 43%), don't know 2%.

Of those not receiving the accommodation supplement: 7% are eligible, 29% don't know, 49% are not eligible, and 14% no response.
 Snells Beach: 7% eligible, 36% don't know. Wellsford: 7% eligible, 17% don't know, 28% no response.

Number of households receiving rent income: 3%.
 Number of households receiving board income: 9% (Snells Beach 8%, Wellsford 10%).
 Number of households receiving other income: 3%.

household income	No.	%
less than 10,000	2	2
10,000 – 19,999	36	31
20000 – 29,999	18	16
30,000 – 39,999	26	23
40,000 – 49,999	13	11
50,000 – 59,999	2	2
60,000 – 69,999	7	6
70,000 – 79,999	3	3
80,000 – 99,999	2	2
over 100,000	2	2
don't know	4	3

		%
Snells Beach		
less than 10,000		
10,000 – 19,999	18	28
20000 – 29,999	9	14
30,000 – 39,999	15	23
40,000 – 49,999	13	20
50,000 – 59,999	1	2
60,000 – 69,999	6	9
70,000 – 79,999	3	5
80,000 – 99,999	1	2
over 100,000	0	0
don't know	2	3

		%
Wellsford		
less than 10,000	2	4
10,000 – 19,999	18	35
20000 – 29,999	9	18
30,000 – 39,999	11	22
40,000 – 49,999	4	8
50,000 – 59,999	1	2
60,000 – 69,999	1	2
70,000 – 79,999	0	0

Appendix 4.10

80,000 – 99,999	1	2
over 100,000	2	4
don't know	2	4

Number of households that have a weekly household budget: 65% (Snells Beach 64%, Wellsford 67%).

Number of households that stick to their budget: 69% (Snells Beach 68%, Wellsford 71%).

Number of households that have sold possessions to pay household bills in the last year: 30% (Snells Beach 31%, Wellsford 29%).

Possessions sold:

<ul style="list-style-type: none"> • <i>not sell any but did think about it</i> • <i>books, chairs, plastic containers</i> • <i>Engagement ring & old buckle</i> • <i>garage sale</i> • <i>2 couches, 2 waterbeds, bathroom suite, baby equipment, gym equipment, car parts</i> • <i>tools, household goods</i> • <i>trailer, boat</i> • <i>baby gear</i> • <i>garage sale</i> • <i>garage sale</i> • <i>stereo - car accident, to pay repair</i> • <i>furniture made to sell</i> • <i>car & wedding rings</i> • <i>house & car</i> • <i>furniture, inflatable</i> • <i>baby clothes, equipment</i> • <i>garage sale - unwanted items</i> • <i>lounge suite 2 single beds, dining table and chairs</i> 	<ul style="list-style-type: none"> • <i>shares</i> • <i>car, breadmaker, assorted oddments</i> • <i>sold dryer to cut power bill</i> • <i>stove, 2 doors</i> • <i>home gym</i> • <i>personal</i> • <i>old beds, freezer</i> • <i>chainsaw, beds, vacuum cleaner</i> • <i>A vehicle</i> • <i>Pearls (but they wanted a \$50 evaluation)</i> • <i>Water pump, Bench press unit, (weight lifting equipment)</i> • <i>Furniture, kids toys, books, motorbike, go kart, baby gear no longer needed.</i> • <i>Car, motorbike, things he's made; steelwork, letterboxes.</i> • <i>baby gear.</i> • <i>stereo, tv, fridge</i> • <i>new tyres, household items - crockery, linen, drawers.</i> • <i>stereo</i>
--	--

Number of households that have had the phone disconnected because of cost in the last year: 8% (Snells Beach 8%, Wellsford 8%).

Number of households that have had the electricity disconnected in the last year because of cost: 6% (Snells Beach 8%, Wellsford 4%).

Zero households have had gas disconnected in the last year because of cost.

One household in Wellsford has had water disconnected in the last year because of cost.

Number of households that could access \$500 to cover an emergency tomorrow: 64%, 35% could not, and 1% maybe. (Snells Beach 67% could access \$500, and Wellsford 61%)

Of those that could not access \$500 (n=41), the number of households that could access \$100 to cover an emergency tomorrow: 49%, 46% could not and 5% no response (Wellsford 50% could not access \$100, 43% Snells Beach could not access \$100). Of all households (n=115), 17% could not access \$100 for an emergency tomorrow.

Part L: Household Savings

Number of households that have savings which belong to the family as a whole: 32% (Snells Beach 38%, Wellsford 25%).

Part M: General

present rating	No.			%
1	4			3
2	12			10
3	51			44
3 --4	1			1
4	29			25
4 -- 5	1			1
5	15			13
don't know	2			2
Snells				%
1	2			3
2	7			11
3	26			41
3 --4	1			2
4	17			27
4 -- 5	1			2
5	10			16
don't know	0			0
Wellsford				%
1	2			4
2	5			10
3	25			49
3 --4	0			0
4	12			24
4 -- 5	0			0
5	5			10
don't know	2			4
rating 1 yrs	No.	%	Snells %	Wellsford %
no response	1	1	0	2
1	6	5	6	4
2	28	24	23	25
3	46	40	36	45
4	26	23	27	18
4 -- 5	1	1	2	0
5	6	5	5	6
improving	1	1	2	0
rating 5 yrs	No.	%	Snells %	Wellsford %
no response	1	1	0	2
1	24	21	23	18
1 or 2	1	1	2	0
2	37	32	33	31
3	32	28	23	33
4	10	9	9	8
5	5	4	6	2
better	1	1	2	0
don't know	4	3	2	6

Appendix 4.10

Teenage rating	No.	%	Snells %	Wellsford %
1	3	6	3	9
2	14	27	21	35
3	12	23	31	13
4	15	29	24	35
5	7	13	17	9
if work 2, if varsity 4-5	1	2	3	0

Comments on the effect of the households financial situation on their family life in the last year (grouped by household income):

less than 10,000

- *It's always a struggle. It's better with no kids.*
- *life's interesting, frustrating, stressful, not boring*

10,000 – 19,999

- *Struggling to do activities & have normal family life & expectations.*
- *Stressful, with husband being sick and a struggle, and mum not being able to be at home when kids get in from school.*
- *Caused depression requiring medication. Do not do a lot of activities or recreation because of no money. Caused a lot of stress.*
- *Has been hard but optimistic and the family has helped and the youngest sister helped*
- *It has had its moments and makes you closer to God and to pray more, something always seems to happen when needed.*
- *Constant struggle & worry. Permanent debt situation. No partner for children.*
- *stress*
- *strict budgeter, stressful, budgeting helps*
- *pretty stressful - leads to arguments*
- *It's been painful - real bad hardship. It's been that bad I feel like killing myself - but I can't.*
- *Easy last year while living at home with Mum & dad & 3 sisters and a brother*
- *We seem to manage ok but it gets stressful paying for the phone, rates & mortgage & power. If we had no phone and no car things would be worse. We'd have to adapt to it.*
- *Stress and a feeling of deprivation is hard on the daughter (part financial - part health)*
- *Been stressful - not get to do much if don't take him anyway (son)*
- *Financial situation has probably improved since recovering debts incurred earlier.*
- *Been stressful - good at budgeting, out of blue costs caused problems, health costs threw budget out*
- *House, food, school fees horrific - wouldn't be so ill - persevering*
- *We walk lots. For my children to even have an ice-cream is a real treat. I feel my children miss out on a lot of basic life experiences because we can't afford them. Bills are always hard to pay and have to be planned and budgeted for.*
- *Stress, Sleeplessness, How to rob Peter to pay Paul.*
- *In a worse situation because of recent family split-up, but looking desperately for work and training courses.*
- *We are satisfied for what we receive but we miss having holidays and recreation because there's no money left over for extras.*
- *Every need met plus people have given money. Feel very blessed.*
- *Would like to be able to buy things for his boy without worrying, always worrying, "What if this happens and I've spent the money on this." I get paid every Tuesday and by Thursday night its all gone. "The money is catered for before I even get it."*
- *Had to start paying high bills due to coming from campus, very cheap accommodation.*
- *financial situation has not really changed family life, but other factors have brought stress (family separation)*
- *lives at "survival rates" - no way to move ahead or save.*
- *improved, as she has started working*
- *causes stress - paying bills and buying things*
- *depressing.*

- *manageable mostly. Times of memory loss can cause financial stress temporarily. ie. forgetting where money has been put, or if a bill has been payed. (as noted on interview, a car accident caused and ongoing disability to a parent),.*
- *been stressful - husband away from home more than preferred, putting extra load on wife/mother.*
- *can create arguments - hard for the kids to understand*
- *terrible*
- *Being new to the country, it was difficult to find full-time work. Six months before part-time work was found, husband now working full-time.*

20000 – 29,999

- *Hire purchase and clothing accounts have caused some hardship. Hopefully when these are out of the way we will have more spendability.*
- *Worse bills, not luxury's, not able to buy new gumboots, not able to buy pork chops instead of sausage but we have a lovely home, beautiful sea views, park & beach for children. Better life-style.*
- *Poverty is hell and you are continually hustling to make ends meet, whilst the hustle continues the kids loose out on time and aroha.*
- *lot of stress, not enough money, stress on relationship and stress on family.*
- *Very stressful. Partner ashamed of being on unemployment benefit - stigma been hell, horrible, terrible stresses on relationship. Trying to find alternatives, originally both working. No savings left, mum will have to go back to work, dad not like being housefather, no males at plunket.*
- *live close to family - next door*
- *sux - kids are expensive*
- *good for kids to see have to do something for themselves.*
- *no - can only get better*
- *Bad, can cope, a lot on plate last year, knocks confidence - court case very hard on morale. Unhealth in family - wife been sick a year, more expensive than Auckland.*
- *caused arguments with daughter, stress on things*
- *Stressful - has put a lot of stress on their relationship, went to counselling, will be hard on the kids as they get older. Counselling started free, then they started 'hassling for money' when disability allowance did not come through. Current financial situation is due to illness in past 2 or 3 yrs. It's really demoralising and depressing living on the benefit.*
- *children have been supportive and understand the need for economies, but the mother finds it hard to deny them sometimes*
- *Relative to stress level.*
- *No effect, in spite of a chosen drop in income.*
- *limits choices. learn to live within your means.*
- *we need to support one another during our struggle for survival. We have to cut right down. We help one another.*

30,000 – 39,999

- *Non-commercial rent of house owned by mom's parents has eased financial burden. Help in financial emergencies has removed worry and stress due to child's recurrent ear infections, which could have damaged child's hearing.*
- *Both parents working full time causes lots of stress due to lack of time to communicate & worry about children fending for themselves after school. Time in and out of work stressful - can't plan anything, having to work long hours for slightly more than benefit doesn't leave time and healthy feeling, all work and no play.*
- *stressful - having to cut back on things not normally have to.*
- *Have had hard times, but together have managed. Children are very understanding - have their own bank accounts*
- *It is hard to find family time which is really important to us. This is particularly so being self-employed.*
- *If had more money would have done more eg holiday and want to get dishwasher. Always other things to do if have money eg go out for dinner. Free mum up a lot more - less work around the house.*
- *Caused many arguments, general pressure on younger ones - unable to do things other kids are doing, creating general depression on adults to see light at the end of the tunnel*
- *just one income for 3 yrs*
- *Have to watch what pay but not really restricted - can't afford holidays - main thing miss out on. Weekends away buy specials to save money longterm.*
- *been the same*
- *Cut in income plus higher expenses with baby. More conservative in spending*

Appendix 4.10

- *Children not old enough yet to understand why there's no treats etc.*
- *Kids moan about having to use own money for new clothes. A few luxuries/school eg can't afford computer - on back burner. It would be nice to stockpile food a bit - can't stretch budget enough*
- *Very stressful. Medication needed to cope at times. While mothers evening part-time job brings in extra income and allows her time with pre-schoolers, it means very little time with teenage children outside of school hours.*
- *Parents dental health deteriorated, children unable to participate in afterschool activities eg music lessons, parents discouraged but still hopeful*
- *It's been very hard, it's strained the relationship between husband and wife as well as between parents and children because they haven't been able to go out and do things, even a drive in the car is a luxury to them, but they have learned to talk more about problems. Lack of money means the family is in each others space all the time - impetus to study was partly increased job prospects and partly needing own space.*
- *It has been very hard not being able to do the things that my family and I would like to do.*
- *Hard on family - missing out on outings etc. peer pressure on children having to go without. Can't afford a babysitter who will look after 5 kids for free or small amount? Will need to buy another vehicle for work soon once husband recovers from surgery.*
- *Been pretty difficult, lack of money is the main bone of contention. Not able to see how to get out of the situation.*
- *Husband is never home - hard when you have 2 pre-schoolers. Work on your marriage a lot, but it's not necessarily your financial situation that stresses your marriage. Some people have a good financial situation and still have marriage problems.*
- *comfortable living*
- *we are able to afford things that we couldn't before and we have better money management skills now. A well paid job gives the whole family a sense of security.*
- *Have changed Dramatically as she now has work again and no longer struggling. - 1 income last year was struggling*

40,000 – 49,999

- *Has got better, more comfortable financially.*
- *Become care giver, only one income. Just standing still, not going forward.*
- *It has been a struggle but realise there are people worse off. Deprives adults from spending more time with children.*
- *It has been a struggle. High increases in cost of living, I've had to work more hours and husband had to find better job with more pay to cover daily costs of living.*
- *Almost broke family up when redundant - only option father going to Australia rest staying in NZ. More government help for smaller business - business went under.*
- *assets but no money. Trying to pay for mortgage and not managing to - always watching what spending, not do without but not progressing, lots of things like but not able to make commitments*
- *Coming back from overseas to a NZ economy and wage structure which is poor compared with expatriate packages has been hard, financially and expectation wise.*
- *Devastating! (sickness in family)*
- *No Expensive holidays, and don't socialise a lot.*
- *have their ups and downs but overall they're ok. - worry a bit, but not that much.*
- *Husband health situation has affected spending ability and the confidence to manage.*
- *pretty lucky, get by, essentials are all there - no hardship.*
- *mother stressed, relationship stressed. major effect on children especially when they can't understand why there is no money*

50,000 – 59,999

- *business provides good income*

60,000 – 69,999

- *Easier as wife now works fulltime instead of part-time*
- *We've kept the family ticking over happily. No major savings yet*
- *If you've got a mortgage and sell your house and move away, then try to come back, it's too expensive to buy back in.*
- *Financial situation has improved. Husband working more, which has enabled to increase capital.*
- *Bought a business so mum now works which has improved finances but now less time with the family. 60,000 - not sure - might be higher*

70,000 – 79,999

- *Have cut back for the sake of a family recreational purchase, but the whole family now benefits from it.*
- *With fathers increase pay more family time together, less stress.*
- *Kids have everything they need. Lucky. If don't pay for activities and provide them, the asking for trouble. Teenage issue lack of activities and parents out - supervision issues, no bus to Warkworth. Drugs.*

80,000 – 99,999

- *stayed the same*
- *quite happy*

over 100,000

- *Mother stopped working due to child, cut back on clothes, average situation*
- *think twice before spending because of household alterations*

don't know

- *Definitely added stress, kids not done as much as like to in terms of recreation & sport activities.*
- *cut down on things we don't need*
- *erratic financial situation*

Household income not applicable as just arrived in the country

- *"Sick of living on the brink - just ineligible for anything" eg not eligible for community services card. Lifestyle in NZ is better*

Chapter 5: Autistic Association of New Zealand Inc., Auckland Branch Action Research Project

Initial Contact and Building a Relationship

I phoned the Autistic Association late in November 1997 after they were suggested by a previous contact. Initially I spoke with Deborah Cox, the Association worker at that time. She was very interested, and invited me along to a committee meeting to introduce myself and explain what I was looking for.

The meeting with the committee went well, they were very interested and supportive. I introduced myself, explained what I was looking for and left members with copies of my information sheet (Appendix 5.1). The initial starting point for my involvement with the association was helping in the office and attending association events. I began helping Deborah in the office one day a week – updating the membership database and some general administration. Due to the physical space constraints of the office, one very small room in the Parent and Family Resource Centre, I did not spend a lot of time in the office on an ongoing basis. Initially there were not many other staff or volunteers using the office but within a year space for association workers was a problem. I was invited to social functions, and spent time meeting and talking with other parents, gradually becoming more involved with association members and building a relationship with them. I also went along to some of the Lollipop morning tea sessions. The morning teas were a support and networking time for parents and their children were able to play in a safe play-land environment. Association social functions were a very good opportunity to learn about the struggles and problems faced by parents of young children with Autistic Spectrum Disorder (ASD) – as well as some of the joys.

At this stage I was not working on a specific project, that was still to be identified. The first stage was to learn about the association and gain some understanding of what problems parents faced. Taking time to build a relationship with association members was an important step prior to identifying a specific project. Working with the association more generally gave members an opportunity to see the skills I could offer, and gave me an opportunity to learn how they worked.

January – March 1998

By early 1998 I had a number of ideas regarding what issues the association could use as the basis of an action research project. Possibilities I could see were around funding issues (a huge ongoing concern) and concerns with Special Education 2000 (SE2000 – the government policy for children with special needs in early childhood and school in 1998).

In March 1998, after talking with Deborah, I decided that it was a good time to suggest to the committee that they could make more use of my time working with them by identifying a specific issue/project that I could work with them on. Up to this stage I had been doing general ad hoc tasks to help in the office. Given that I was hoping to work with them over a long-term time frame (two to three years), the opportunity existed to pursue a particular research project.

Following is some of my reflections from this time:

The next step I'm really looking for is to find some defined problem which I can work with them on, in terms of looking at ways of addressing a problem, being part of a process on that. So hopefully when I see Deborah this week, I'll have an opportunity to discuss that with her and get her thoughts on that and whether she thinks that will work for her particularly because she is the coordinator so the one I'll most likely work closely with. And for the association, the Auckland branch as a whole, whether that is the space that they are in yet or not or what's the story. So that is going to be an interesting meeting, I see her Wednesday this week, so I'm looking forward to that.

Project Issue Identified

A few days later I did raise the topic of identifying a project with the committee. Here is my reflections from this meeting:

Tonight was the night when I suggested to the group that they could get more use out of me if they identified a project for me to work on with them. I didn't necessarily expect that they'd choose a project tonight, but they have and it wasn't even one that I had thought of as a possibility.

I had been thinking that it would most likely be funding, as that had been obviously Deborah's number one interest. I had hesitations about the funding issue as that is already a major concern with Homebuilders. The other possibility that I was mooting was in terms of addressing some need or issue for people or parents of children with autism. The example I gave was something to do with special education, which did come up in the list of issues that people thought were very relevant and part of the list of issues they needed to address.

One parent suggested the issue of what can parents of autistic people do in terms of providing for their security once the parent dies. This overlaps in a very interesting way with retirement income in terms of the aspect of financial provision. It also overlaps with questions of collective government responsibility in terms of support,

and it also has many other angles and implications in terms of their acceptance into the workplace and guardians.

I thought this was a great idea. It also sits well alongside the retirement income issue. I don't think funding as an issue is ruled out, it may still come into the picture somewhere and I'm comfortable with that. In terms of the possibilities it opens up for looking at ways of addressing it, it can be addressed at a whole range of levels very concretely. It doesn't feel like saying oh we need to change the funding environment and it's so open ended that you just don't know where to get a handle on it. This issue we could get a handle on, so I'm really excited.

I suppose my main concern is as long as it doesn't become too self-contained, too much an isolated piece from where the association is going. But I don't think that will happen if I maintain a strong degree of involvement in terms of working with them, keeping abreast of the path planning. If I'm there participating in those aspects as well, or at least aware of what's going on, then I should be able to help keep the linkage and keep it active within the group. Yes, so it will be really interesting to see where it goes, obviously they want to see ways of addressing this issue.

The issue was defined as who will care for their children when the parents no longer can.

Our first step was to canvass members of the association to find out who was interested in being involved in exploring ways of addressing this issue and then deciding on some appropriate methods. A contact/interest sheet (Appendix 5.2) on the issue was prepared and made available at some association workshops. An item about the start of the project and inviting interested parents to phone the association was also included in the newsletter (Appendix 5.3).

There were a handful of responses, with a few people filling in the sheet. However after some time, it was decided that this was not a very effective way of identifying people interested in the issue.

Media Attention

From March 1998 media attention regarding Autism dramatically increased. The plight of people with autism and their families shifted from being completely invisible in the media to centre-stage, with front page articles and full page special features. The cause of this dramatic increase in media attention and hence public awareness, was due to the plight of two families. The first case to feature on the front page was the dire situation of the Eady family. A large picture showed Esther and Viv Eady, with their Autistic son Jonathon in

leather bonds. The heading was 'Desperation turns parents into jailers' and the article revealed how the Eady's were at their wits end with Jonathon and the total inadequacy and lack of services (Appendix 5.4).

A short time later, in mid 1998, the trial of Janine Albury-Thomson, following the tragic murder of her autistic daughter Casey, triggered an avalanche of media attention regarding autism. There was intense public debate over the actions of Janine in murdering her daughter versus the responsibility of public services to provide care for people with autism. There were many letters to the editor and many questions asked of politicians, the Health Funding Authority and other service providers (See Appendix 5.5 for a selection of some of the media articles and letters to the editor).

The public debate highlighted issues of parental versus government/collective responsibility to provide care. Casey's death also led to a debate over who was to blame – her mother or a society that did not care enough to provide desperately needed services. In sentencing Janine Albury-Thomson, the judge called for an independent inquiry into the downfall of the health services in caring for Casey.

As a result of the media attention there was a radical increase in the willingness of politicians and service providers - health, welfare and education, to address gaps in services for autism. Autism suddenly became an item on the list of areas to be urgently addressed, whereas prior to all the publicity the specific needs relating to autism were virtually invisible in the myriad of small special needs advocacy groups.

Discussion of Literature Review and Parents' Views

June 1998

While we were canvassing members regarding the issue, I did some background work preparing a literature review on the issue. For the purposes of the association I needed to present this in a summarised form at one of the committee meetings (Appendix 5.6). This generated an interesting discussion, with members expressing areas where they would like more information. The association was particularly interested in finding out about the situation of adult autistic people in New Zealand. Some members knew of a handful of adults with autism.

As a result of the discussion, I did some more investigation to see if there was any research or information on adults with Autism in New Zealand. I contacted IHC (a key provider of services to people with intellectual disabilities) who had surveyed its branches regarding service provision to people identified as having autism or who staff considered may have autistic tendencies. This survey, released in August 1998, provided some useful background information however it also had some important limitations (IHC New Zealand, 1998). The main difficulty was that the survey was filled in by IHC staff and hence it was

based on their opinions regarding the needs and adequacy of service for IHC clients. There was also a problem with incomplete forms resulting in a number of questions having a low response rate, for example questions relating to diagnosis and unmet needs.

After a number of enquires I concluded that there was very little information regarding adults with autism in New Zealand. A major issue was that most adults with ASD were undiagnosed, especially in New Zealand as it was almost impossible to get a professional to diagnose an adult. Thus even though there may be some adults with severe autism who are receiving some health services, it was unlikely that there was any collation of service information, especially if they were undiagnosed.

Needs Survey Initiated

Around June 1998 the Auckland branch initiated a needs survey. The impetus for the needs survey was several fold. The association wanted to increase its services, in response to the desperate situation of many members, and the survey was seen as a way of quantifying both the gaps and demand in a huge range of areas to funding bodies. The survey was also seen as a key tool for advocating for better health, education and welfare services. The momentum of public and government interest in autism dramatically increased during the time the survey was being developed. The effect of this increased publicity and the resulting opening of doors within government, was to reinforce the importance of the survey for the association, strengthening their commitment to it. It also became clear that there was minimal knowledge within government and other community services regarding meeting the needs of families with a family member with ASD. This again reinforced the importance of the survey in revealing, verifying and validating the needs identified by parents.

I was asked to become involved in the survey and the issue of care for ASD family members when their parents no longer could, became one area within the survey (concerns and questions relating to guardianship and the future).

The association was extremely busy in the second half of 1998. There was a very lengthy agenda at most meetings and some internal politics also needed to be addressed. As a result of being so busy, discussion of the survey was carried over at some committee meetings. It was a case of the committee being swamped with items to discuss, rather than a lack of commitment or interest in the survey.

Relevant Reports Released

In November 1998 Professor John Werry's report into the inadequate care provided to Casey Albury was released (Werry, 1998). An interdepartmental report relating to the inadequacy of services for autism was also published (Autism Services Project Team,

1998). The reports identified many gaps and problems in providing services to people with autism and highlighted the need for these to be urgently addressed.

A key feature of all reports was the fact that very little data was available on the distribution of ASD in NZ and on what services people with ASD were accessing, if any. The implication of this was that there was no readily accessible source to answer questions about the current situation for guardianship for adults and hence the association's needs survey was key to gaining some idea.

Classroom Survey

In February of 1999 I became involved with another Autistic Association survey, this one specifically on the need for an autistic classroom in Auckland. A group of parents had already done a brief one page phone survey of Auckland members and I helped with entering, analysing and writing up the findings. The survey findings were presented to a meeting with the Ministry of Education. The Ministry agreed to support the association in establishing a specific class, the association found an appropriate school and negotiations between the school, ministry and association continued through 1999. The ministry agreed to fund the set up of a classroom at Riverhill School in east Auckland. A steering group at the school was set up and preparation continued. By term one 2000 the classroom began with two students and this number gradually increased through the year. On the 1 September 2000 the classroom was officially opened. See Appendix 5.7 for a newspaper article on the opening of the classroom.

Autism Action Committee and Looking for a Building

At the end of February 1999, I also attended a meeting of the Autism Action Committee, a group that had been going for several years. The discussion focused on finding some agreement on the 'Centre of Excellence for Autism' idea which had been around for some time and was highlighted again in Prof. John Werry's report the previous year (Werry, 1998). There were still many issues to be resolved around this idea, however the association's main point was that they were now looking for a building to run their own services from.

Personal Advocacy Trust

In early 1999, I also continued finding out as much as I could about current services being provided to adults with Autism. One service that was of particular interest to the association was The Personal Advocacy Trust. The Trust's aim was to watch over the welfare and rights of its members after the death or permanent disablement of the parents. The trust was primarily established for people with intellectual disabilities, however it did have some

members with autism. An outline of the Personal Advocacy Trust was included in the association newsletter (Appendix 5.8).

Needs Survey Develops

Developing the questions for the needs survey took over a year, from mid 1998 to mid 1999. I was part of a working group formed for working on the needs survey – the group included parents and professionals. The survey grew and grew as the parents and professionals involved thought of more and more questions that interested them. We met generally each month, steadily working through the questions that should be covered and then spent a considerable amount of time working out how best to ask the questions. After each meeting the draft questions were updated and redistributed to the group for reflection before the next meeting. We met in members' homes, workplaces and cafes in town. At times work on the survey was put on hold as the availability of the working group to meet was dependent on other autistic work, paid work, and family demands.

We reported progress on developing the survey at each committee meeting. Towards the end of the survey development we began circulating a copy of the survey to all committee members for their feedback and there was also discussion of particular questions and topic areas at committee meetings. For instance there was some debate at the committee meeting about whether to include a household income question and how it should be asked.

In May 1998 a letter was sent to all branch members informing them about the survey and asking for their support (Appendix 5.9) and a number of brief articles also went into the newsletter keeping members informed about progress on the survey (an example is Appendix 5.9a).

Research Concepts

The survey covered two units of analysis – the individual with ASD and the family the individual lived with. Throughout the survey there were a number of open questions to capture comments (qualitative information) on a wide range of issues. Interviewers were also asked to write down any additional comments given, even for non comment questions, and extra comment fields were added to the database so that all qualitative comments were available for the results. A full copy of the final survey questions is included as Appendix 5.10.

We grouped the survey questions into the following sections:

- Part 1 – general demographic information;
- Part 2 – questions relating to diagnosis and follow-up;

- Part 3 – general questions on services, especially respite care, health issues, ranking sources of support and information, identifying areas of concern – both current and future;
- Part 4 – Adolescents;
- Part 5 – Adults (this section was also for adolescents not at school);
- Part 6 – Pre-school and school age children (education setting, services receiving, satisfaction with public services, home-based programmes, use of private services);
- Part 7 – Children at school (including adolescents at school) – questions relating to SE2000 and funding of education services;
- finally Part 8 – Auckland Branch (questions regarding services used, other services they would like provided and satisfaction with level of support from Auckland Branch).

Grouping the questions helped with the flow of the survey and enabled interviewers to skip sections that were not applicable, depending on the age of the person with ASD and whether they were at school.

There were questions on all major areas of services (health, education, welfare, diagnosis), and we sought information about access, quality, quantity and satisfaction. We realised there were still some additional questions that would have been useful, however the survey had sufficient depth to provide a clear picture for most issue areas. We decided that there would always be more useful questions, but the final set we used was adequate to meet the goals of the survey.

We were particularly interested in analysing the data by:

- Where the individual was on the spectrum – aspergers or autism
- Whether they were diagnosed or undiagnosed
- Age
- Education Setting
- Family Income Category
- Ethnicity
- Whether the individual was receiving private services
- Whether the school age child was funded under SE2000

After undertaking the interviews we found that only one question did not give useful information, mainly because it was redundant and hence only a few families answered it (Question 5 in Part 7). We also identified a handful of key questions that were in Part 6 (the general pre-school/school age section) but would have been better located in Part 3 (a general section for everyone) as the questions, particularly questions relating to satisfaction with public services, were also applicable for adults. These changes were identified and made for the revised version of the survey run nationally.

Piloting the Survey

June-July 1999

Deborah Cox identified a number of families that would be appropriate for piloting the survey from the association membership list. We looked for families of children of different ages and spread along the ASD spectrum. Each of the working group members phone interviewed one or two of the identified families, after checking for consent first. The instructions for the pilot interviews were an earlier version of Appendix 5.11 – Tips for Interviewers, with the same pilot consent process and information as in Appendix 5.11. The piloting helped identify a number of important changes to the survey, particularly in the phrasing of questions. These amendments were made and the full committee was given one final opportunity to make any additional changes to the survey.

By this stage we had developed a very comprehensive survey and our main concern was the length of time the survey could take. We decided not to shorten the survey but to strongly encourage interviewers to warn the families how long the survey could take, particularly if they got sidetracked on questions.

Values

The values underpinning this research project were drawn from the working group and the Auckland Branch committee.

The key values were:

- That parents were the most knowledgeable people regarding the care their child with aspergers or autism required;
- That all public services needed to recognise their responsibility, and act on it, to provide appropriate services and support for families with children with aspergers or autism.

Politics

Again drawing on Linda Smith's five central questions on power (Smith, 1986, p. 9), in this project the research problem was defined by the committee of the Autistic Association of New Zealand Inc., Auckland Branch. The study was relevant to families with children with aspergers or autism that belonged to the Auckland Branch. The Auckland branch was the group to gain new knowledge from the project, however this was also shared with the National body and the knowledge was to be further shared through lobbying activities. The research was accountable to the Auckland Branch as it was their project. The Auckland Branch gained the most from this study and I also gained from it as part of my thesis.

Because the survey was so comprehensive it covered areas that were of interest to most members of the Auckland Branch. The group of members that were least well served by

the questions included in the survey were adults with autism or aspergers, largely as a result of no adults or parents of adults being involved in designing the survey (most active members in the Auckland branch were parents of young to teenage children at this time). To fully meet the needs of adults more questions relating to issues for adults would need to have been included. It is possible that other research methods, such as in depth interviews, would be more useful for exploring the issues for adults with autism or aspergers (partly due to the fairly small number of adults in the branch membership).

I think doing the interviews by phone gave the families more power to say no or to set a time that suited them, than may have been the case with face to face interviews. On the other hand they had less power in that they didn't know who they were talking to, apart from a name.

Ethics

Informed consent was sought from all participants prior to the start of the interview. Because the interviews were by phone there was no consent form, but all the information regarding consent was in the interviewer instructions, Appendix 5.11. There was information about the survey in the newsletters and the interviewer explained the key details of the survey prior to asking for consent. The participants were told they had the right to decline at any stage or to decline to answer any questions.

We guaranteed confidentiality and anonymity for all families interviewed. Where necessary some minor details were changed in the quotes to ensure this. We respected an obligation to maintain honesty between the researchers and the families interviewed. The information gained from the interviews was used only as agreed in the original consent (thus it was not used for the purpose of updating membership databases).

Discussion of Ethical Issues

Towards the very final stages of the survey development the Autistic Association employed a new funding administrator. Because of his interest in funding and drawing on the contacts and resources of association members, he was very interested in whether the survey could be used to update the membership database, particularly with income information. This issue was discussed at a meeting between Deborah, myself and the funding administrator and at a full committee meeting. I supported the argument that the linking of survey information into the membership database was unethical as the survey information was to preserve participants anonymity and confidentiality. After some discussion the committee agreed that the survey data should remain anonymous and confidential and that the membership database should be updated separately.

It was interesting that over time, as the membership of the committee changed, the question of the use of survey data for updating and linking with membership data, did arise on further occasions. This reflected new active members in the association seeing the usefulness of the survey data for membership updates but not being aware of the assurances given to survey participants and the over-riding importance of adhering to the ethical promises of preserving anonymity and confidentiality. The question always provoked strong debate in the committee but each time the final decision was not to allow the survey to be linked back to the membership list (the membership list was used as the sample source for the survey). The re-occurrence of this debate in part involved educating new committee members about key ethical principles of research. As a result of seeing how this issue can return it has been recognised that the association needs to establish a set of protocols specifying the future use of the survey, so that future committee members are aware of the limitations in using survey data for membership update purposes.

Training and Beginning Interviewing

August - October 1999

A number of potential interviewers, all parents of children with autism or aspergers, were identified by the working group. All these people were approached and asked whether they would be happy to be volunteer interviewers and from this a list of volunteer interviewers was generated. I then contacted everyone to identify possible training times. Due to people's busy lives a number of training sessions at different times were set up. The training sessions consisted of going through the instruction sheet (Appendix 5.11) for interviewers and then getting interviewers to go through the whole survey interviewing each other. In a number of instances I had individual training sessions with interviewers. On these occasions I would still go through the survey with them, to try and ensure that all interviewers had a clear understanding of the questions. Thus the training sessions usually took over an hour. The fact that nearly all the interviewers were parents of children with autism or aspergers, meant that all the interviewers had a good understanding of the questions and issues and they could also relate to the parents they were interviewing.

Each interviewer was given the contact details of ten families from the association mailing list. The contact list was in the form of a tracking sheet (Appendix 5.12) and was our main means of tracking interviewing progress. The sets of families were grouped geographically and the interviewers were given a contact list from a different geographical area that did not include anyone they knew. The interviewers were given a timeframe of a month for their set of contacts, however a number of interviewers took longer than a month. They were also given my contact phone number to phone if they had any queries.

Discoveries when Interviewing

One of the early interviewers found that the process of going through the survey with a family that was receiving very little support made the family very upset. This interviewer contacted Deborah, the association worker to follow the family up. Other interviewers were also then advised to refer families who needed help to Deborah.

Another issue that was quickly identified was that the survey was not well designed for adult ASD respondents. The membership of the association includes a handful of adults with ASD. However the survey had been designed by parents and professionals and although there were questions relating to adults, the wording of all the questions was from the perspective of asking a parent/caregiver about their ASD family member. This meant that interviewers had the challenging task of rewording some of the survey questions and leaving out some questions that were not applicable when the person being interviewed was an adult with aspergers. Although this was a very unfortunate situation in that this problem had not really been foreseen, we did not want to completely rewrite the existing survey or do an additional survey with different questions at this stage (it had taken long enough to reach the interviewing stage). As a result interviewers were asked to do the best they could, and to use their discretion on what and how many questions to ask, having regard to how the person with ASD was coping. The interviewers were all phoned and warned of this problem.

Another issue that we had foreseen was that some families had more than one family member with ASD. In these instances interviewers were to fill in a survey form for each family member. In practice, the best means identified for this was to fill in both forms simultaneously, but to use one form as the master form for questions that were not child specific. This was the quickest way of filling in more than one form and if done very clearly was no problem for data entry.

A third very important issue was the ability of families to find time to do the survey. Because the survey took so long, the interviewing process was to ask a family if they would participate in the survey (having been fully informed about the survey and the length of time involved) and if they agreed, to set a convenient time to phone back and do the interview. Frequently families were happy to do the survey but had great difficulty finding a suitable time. Often interviewers had to phone back late at night, after all the children had gone to bed, or during school or respite care hours. It was not uncommon for some families to miss several call back times and hence interviewers had to spend considerable amounts of time calling families back to make another time. In some instances families found it impossible to find forty minutes on the phone and they sometimes requested to do the interview in smaller blocks. There was a strong sense that the difficulties involved in finding

a time did not reflect an ambivalence to doing the survey but rather the real difficulties facing these families.

Through to Christmas 1999 I spent a considerable amount of time co-ordinating all the volunteers, collecting the completed forms and surveys and setting up the database for data entry of the surveys. Many volunteers found that because of changes in their situation they were unable to complete the contact sheets, but some volunteers were able to do more than one contact sheet. I phoned interviewers every two-three weeks to check in and see how they were going. This was an opportunity to share feedback between interviewers on issues they had found and how they could be dealt with. Progress on the interviewing was reported back at each committee meeting.

Survey Feedback

The families being interviewed expressed a lot of interest in the findings of the survey and the interviewers commented on how the survey questions were raising people's awareness of the inadequacy and gaps in the services they were accessing. It became clear that the survey process was providing a real opportunity for both interviewers and interviewees to share information they had on accessing services – this information flow worked both ways, providing a benefit for both the volunteer interviewers and the interviewees. It also gave all families involved an indication that they were not unique in the problems they faced, such as difficulties with going to the doctor or hairdresser.

Searching for More Interviewers

By Christmas 1999 we were about halfway through the surveys and it became evident that we would need another round of interviews in the new year to complete the survey. After discussing progress with the committee it was decided to try and find interviewers from other sources as it was very demanding and too much to expect parents of children with ASD to be able to do all the interviewing. Posters (Appendix 5.13) asking for volunteers were put up at the Albany campus, and relevant departments at Auckland University and Auckland Institute of Technology. Unfortunately the response was small with only two people actually being able to assist with the interviews. However one of the two was a mandarin speaking student and there were still a number of mandarin speaking families that needed to be interviewed. We had already discussed and were quite concerned about the difficulties of doing the survey with people who had English as a second language over the phone. In one or two instances interviewers had instead arranged to do the interviews in person. Being able to have a mandarin speaker do the interviews with the remaining mandarin speaking families was another very fortunate solution to this problem.

Before the second and final round of interviewing began the association's membership list was updated and the updated contact details were passed on to the survey contact lists. A number of families interviewed also requested that updated contact details be passed back to the association membership list – the odd change of address or phone number. This did happen, however there was no linking of particular survey forms to the membership list.

From the time of the second round of interviewers, it was decided that all volunteers should sign a standard confidentiality form that the association had developed for all of its volunteers (Appendix 5.14). We also intended to get the new volunteers to fill in a police check form, but by the time the form was found the volunteers were already underway or finished.

It was agreed that the volunteers, especially for those who were not members of the association, should receive a certificate in recognition of their work, and a followup thank you gathering will also be organised. The gathering will be an opportunity to give the volunteer interviewers a copy of the survey findings and an update on how the survey is being used.

Survey Sample

The association membership list also included a number of families outside the Auckland region. There were various reasons why people who live elsewhere were members, such as having lived in Auckland in the past or not having an active branch where they currently lived. There was some discussion whether to interview these families or not. Because they were toll calls they had not been given out to volunteer interviewers. It was decided that although these families may have had different experiences due to their location, it would still be useful for the association to survey them, as they were association members, trying to access association services, and the difference in their location may highlight other relevant issues. I surveyed all the families that were a toll call in off-peak hours and was reimbursed by the Branch.

During the development of the survey and the actual interviewing the possibility of enlarging the number of families to be surveyed was raised. Another agency that provided services to families with autistic members was supportive of the survey and open to the idea of its clients also being surveyed. This possibility was discussed by the working group and a number of issues, relating to the need to match the other agencies families against the families already on the association's membership list, were identified. This possibility was left open, but in the end not pursued. The initial goal of the association was to survey all of its own membership before enlarging the survey to more families. It took a lot of work and time to survey the membership list and it was a relief to finally finish the surveying. I think if surveying the association's membership had not been such a large task then enlarging the

sample size could have been pursued. At the stage of finishing the interviewing the association had given a copy of the survey questions to the National Autistic Association and informed other branches that it was happy for them to use the survey questions.

Major Changes in the Auckland Branch

At the end of 1999 Deborah Cox left the Autistic Association and a number of new staff were employed. There were also some changes to the committee membership, and Angela Arnold the previous chair of the committee and a member of the working group, moved overseas. In January 2000 the association also shifted office, from one tiny room at the Parent and Family Resource Centre in Greenlane (the building at Greenlane Hospital was being demolished) to a whole building in Otahuhu. Thus the association was going through a period of considerable change and upheaval for some months. To my great relief, all of the new staff and committee members were very supportive of the survey, and were committed to continuing working on the survey. As a result there was no disruption of progress on the survey. Indeed, there was additional help available with organising interviewers and with data-entry, and there were new people willing to pick up the gaps left in the working group on the survey.

From the time work on developing the survey first began, regular, often brief updates of progress on the survey were given at each committee meeting. During 1999 the association again had periods of being extremely busy, partly as a result of all the media attention, funding applications and lobbying. At times there were 20 to 30 items to get through on the monthly committee meetings agenda. This was also the time that the committee began to look at changing the internal structures of the association, to help it cope with changes in its roles and services.

Interviewing Continues and Data Entry Begins

January - February 2000

I began to enter the surveys into the database before all the surveys were completed. The data-entry was straight-forward but fairly time consuming, especially those surveys where the interviewer had written down all the comments. I paid a friend and a volunteer from the association to help with the data-entry. They entered about twenty surveys each, twenty hours worth in total, and I continued with the rest of the data entry. A total of 180 families were surveyed and 193 people with ASD (some families had more than one member with ASD), thus there was a total of 193 survey forms entered.

Analysis and Brainstorming

April 2000

Towards the end of the survey data-entry, a new working group was formed and we began having brainstorming sessions on how the association could use information from the

survey. The small working group met a couple of times to have initial brainstorming sessions both on the analysis of the survey and on how it could be used.

Submission to Special Education 2000 (SE2000) Policy Review

June 2000

Just as the data entry was being finished, the association received very short notice of the SE2000 review. This was a major review of the government's SE2000 policy (covering education services for children with special needs) and it was open to the public to make submissions on a number of areas. The short deadline provided a very strong incentive to quickly start pulling relevant data and analysis out of the survey to be used for the branches' submission. We had a number of meetings planning the submission. The people involved in planning the submission all had a great deal of experience with SE2000 and knew a lot of its history and of the experiences of different families within the association. Based on the meetings we had about the submission and drawing on relevant survey findings, I did an initial draft for the submission at a writing retreat in Taupo, emailing versions to the association for feedback. I then worked with Priya to finalise the submission and it was sent to Wellington the following week. See Appendix 5.15 for the final version of the branch's submission. (Academic scholars may note that rigorous standards in bibliographic references were not complete in this submission, however this does not detract from the integrity of the document as a team effort and an organisational advocacy response. Because it is important to maintain all appendices in this thesis in their original form, I have not tampered with the document for my own doctoral purposes.)

Analysis of Survey for the Committee

In July 2000 an initial analysis of the rest of the survey was completed (only the education sections for school age children had been analysed for the SE2000 submission). This initial analysis of the whole survey included counts and percentages on all data and all the comments from the survey (Appendix 5.16). A number of copies were made and distributed to some committee members for them to begin to get a feel for the findings and to help identify further analysis of the data that may be useful.

Survey Results in the Newsletter

We were also very keen to start feeding back the results to all the families that had participated. We decided that the best way of doing this was to prepare an initial taster of interesting results in the newsletter and in following months doing an insert of one section at a time of the survey into the newsletter. See Appendix 5.17 for inserts placed in the monthly branch newsletter so far.

Identifying Next Survey Steps

In July 2000 there was also a meeting to discuss the next steps in using the information.

Future steps identified were:

- Planning a thank you catch-up with interviewers (this is still to occur);
- Bringing the association feedback to the attention of the committee for them to plan a process around how they are going to respond and relevant actions for the association;
- Inviting members with experience and interest with particular services to assist in preparing feedback to each service, identified agencies include the Health Funding Authority, Special Education Services (SES), Society for the Intellectually Handicapped (IHC), Crippled Children Society (CCS), and Work and Income New Zealand. More in-depth data analysis will be prepared at the time of writing a report for each service;
- Dialogue with the national association over using the data to lobby politicians and the Ministry of Health and Ministry of Education;
- Including a workshop on the survey for diagnosing professionals at the mini-conference in Auckland next year;
- Investigating the possibility of publishing some of the findings in a journal that general practitioners read;
- Possibly approaching Lifeline or Parentline regarding the need for phone support for parents outside office hours.

There was also an initial discussion around developing protocols for the ongoing use of the data by the association, the storage of survey forms and management.

National Association Begins Survey

A copy of the detailed survey findings were taken by the Auckland Branch representative, Wendy, to a National Autistic Association meeting in September and also to a meeting with the Ministry of Education and the national association. The national body was very keen on the survey and decided to run the survey nationally through all the other branches and its own national membership list. A very tight deadline was set in the hope that a considerable amount of data could be collected before Christmas 2000.

At this point I became involved in helping set up the national office to run the survey nationally. I worked with Maire, Executive Officer of the national association, to create a revised version of the survey that was appropriate for the whole country. The changes made included some of the lessons learnt from the Auckland branch survey, some additional adult and adolescent questions, and revising Part 8 to include questions about both national and branch services. The Auckland branch interviewer instructions and the system for tracking progress on interviewing (through the use of the contact sheets) was used as the model for the national survey. This saved national having to 're-invent the

wheel' regarding how to manage the interviewing. I sent down a full set of instructions as well as the notes I had made on the process (basically the same as sections of this chapter) that I thought could be useful for the national office. I then set up a database for the data entry of the national survey, again duplicating and revising the Auckland branch database, and also sent this down to the national office with instructions for data entry. The tracking of the interviewing and data entry was then run by the national office.

In early November 2000 the national association e-mailed me the file of the data entered to that date and I did a first draft of the results. This was specifically for a meeting of the national association with the Ministry of Education. An afternoon was spent discussing the survey findings to that date and this was an important step in working with the Ministry to improve education services for people with aspergers and autism.

The national office is continuing both the interviewing and data entry ready for further analysis of the interviews when all the data entry is complete. I will continue assisting with the national survey next year.

New Committee

As in previous years, another new committee for the branch was elected in October 2000. Some of the previous committee members have continued on the committee and they explained the history and purpose of the survey to new committee members.

Ongoing Use of Survey

The Auckland branch is now in a position to continue using the survey for the next steps already identified and for any other submission or lobbying possibilities that arise.

Concluding Comments

Working with the Autistic Association has been a very enjoyable and rewarding experience. One of the key lessons I learnt from the survey process with the association was recognising and allowing for each step in the process to take a considerable amount of time. Some steps did happen quickly, for instance the SE2000 submission, but most steps in the process had to be juggled with all the other association activities and personal commitments of each branch member. Allowing time for the process has meant that the survey and lobbying activities that have evolved were an achievement beyond anyone's expectations – and there is still more to do.



MASSEY
UNIVERSITY

A L B A N Y

Carmel Cervin
89 John St
Ponsonby
Ph 376 3662

FACULTY OF SOCIAL SCIENCES
DEPARTMENT OF SOCIAL POLICY & SOCIAL WORK

Background Information Sheet

Personal Background

- My name is Carmel Cervin and I am starting a PhD at Massey University, Albany campus.
- My area of interest is injustices in the relationship between paid and unpaid work in New Zealand and ways these should be addressed.
- Marilyn Waring and Mike O'Brien are my supervisors. Marilyn Waring may be contacted on ph 443 9665 and Mike O'Brien on ph 443 9768.
- My undergraduate degree was a BA/BCom at Auckland University, in NZ history and computers.
- Over last summer I worked on a research project, co-ordinated by Mike O'Brien, looking at Social Service needs and responses in Auckland.
- I have been a member of the consultative group of Catholic Family and Community Services for the past couple of years.
- I am a young Pakeha women, the oldest of a family of six.
- A strong part of my upbringing has been to question and challenge injustice, whether through the Springbok protests, anti-nuclear campaigns, or questioning church structures and injustices. Thus this motivation for social justice shapes my interests and questioning.
- I am rooted in a belief in community, both as a source of identity and as the means of challenging injustice. Community is a key source of empowerment for both question and action.

Study Background

- I am interested in working with a handful of community groups on a specific injustice of concern to them in the area of paid and unpaid work. Thus I am working the West Auckland Women's Centre on the issue of retirement income for women. I am also working with the Homebuilders Family-Whanau Support Scheme Wellsford/Warkworth and possibly one more group. My role is on the terms decided by each group and I am aware that the specific issue a group is interested in may change or develop over time.
- We are using the action research method which involves an ongoing process of collective planning, acting and reflecting on a specific issue. This method is a key way of orienting the relevance and use of this study towards social change.



Autistic Association of New Zealand Inc.

Including Asperger Syndrome and Related Disorders

Auckland Branch,
P.O. Box 9407 Newmarket,
Auckland, NZ.

Phone 0-9-631-5644
Fax 0-9-631-0126

Who will care for your autistic child after you?

At the last branch meeting the issue of how autistic people will be provided for when their parents/caregivers have died was raised. A number of parents felt that this was a real concern and were interested in finding ways of addressing this problem.

The purpose of this form is to let the branch know who is concerned about this issue and who would be interested in ways of addressing this problem. We would be grateful if you could take a minute to answer these two questions.

Many thanks

Deborah Cox
Auckland Coordinator

-
1. I am concerned about the issue of how autistic people will be provided for after their parents/caregivers die. Yes
No
 2. I would be interested in ways of addressing this problem. Yes
No

Name: _____ Phone Number: _____
Address: _____

<p>COGS I would like to say a big thank you to COGS. They supply us with wages for the Auckland Co-ord and</p>	<p>without their financial support we would simply cease to exist. At the accountability meeting I saw a bunch of very committed</p>	<p>people who really care about organisations like ours. Thanks COGS for your ongoing support. We appreciate it.</p>
---	--	--

Who will care for your autistic child/adult after you?

At a recent branch meeting the issue of how autistic people will be provided for when their parents/caregivers have died was raised. A number of parents felt that this was a real concern and our Branch has decided to carry out some comprehensive research into this area.

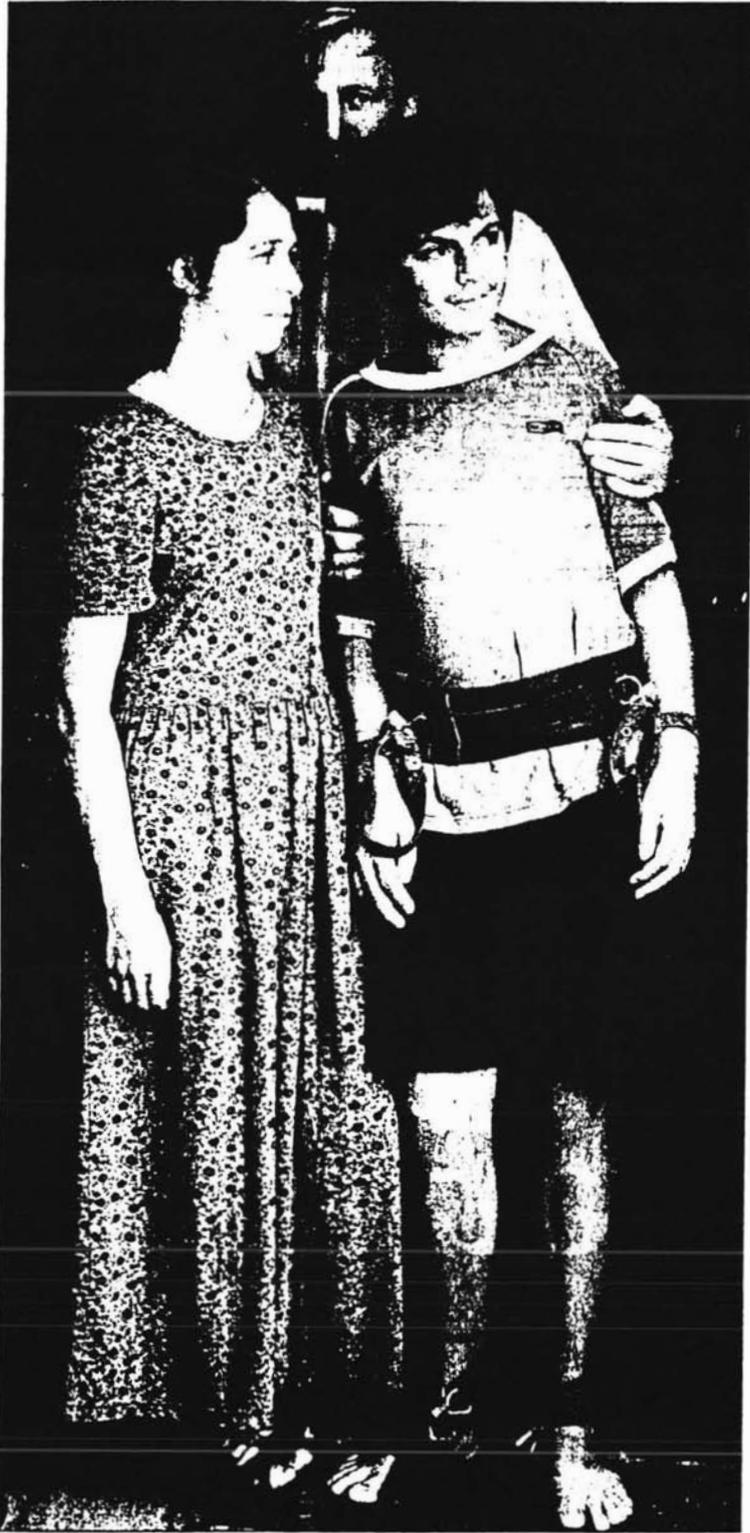
This issue may raise the questions for your autistic child/adult around:

- housing
- income support
- guardianship
- employment
- leisure
- respite care and quality of care available



Another question is whether you would be happy for another family member, for instance siblings, to take over full caring responsibilities. Although this issue may still seem a way off, it may be useful to give some thought to the steps you would/will take to prepare your daughter/son to live with someone else some day. Is the transition of passing care responsibilities onto someone else (who?) a process you would like some control over?

The Branch would like its research on addressing these questions to be guided by your views and concerns, hence we would be very grateful if you could give Deborah Cox a call at the office 631 5644 if you are able to contribute. ***It is an important issue for us all!***



DESPERATE MEASURES: Esther and Viv Eady bind their autistic son Jonathan because of his violent behaviour.

HERALD PICTURE / YANSE MARTIN

A Northland family at their wits' end have been forced into tying up their disturbed son. ADELIA FERGUSON reports why.

Desperation turns parents into jailers

Jonathan Eady spends hours of each day bound and tied to save his family from his destructive violence.

His parents, Viv and Esther Eady, say they have resorted to the harsh measures because they cannot get specialised help for their 14-year-old autistic son.

They bind his hands with leather thongs, clipped to a leather strap around his waist.

His feet are bound with leather straps and he is tied to a wooden bench in the living room of their home at Ruatangata, north of Whangarei.

In the past week he has still smashed five holes in the walls of the house.

Last month he slammed a door on his mother's hand, cutting off the top of her finger.

Mr and Mrs Eady say they and their four other children are at their wits' end.

Having to keep Jonathan a prisoner is the heartbreaking last straw.

"Somehow we've managed until now, but Jonathan's now stronger than I am, and he knows it," Mrs Eady said.

"I can't manage him any more, and he can just about overpower my husband too."

The strain faced by the Eady family is one that up to 17,000 families round the country who have autistic children could one day confront.

Worst off are those in rural areas, away from the supervised residential care facilities that are based mainly in larger cities and towns.

City facilities are stretched too, with fewer than the recommended health-care workers available.

Doctors say Jonathan's plight is an indication of the state of New Zealand's health services which fail to meet the needs of many chronic cases.

With the family unable to cope, Jonathan is today being sent to a clinic in Palmerston North for six weeks.

His paediatrician, Dr Roger Tuck, said the clinic was not really suitable but it was the only place that could take Jonathan.

At seven he was diagnosed as having autism, a condition which affects communication and can cause severe obsessive or violent behaviour.

Jonathan has long been violent, but his condition worsened late last year.

Dr Tuck said Northland had no facilities to deal with people like Jonathan.

"What the Eadys need is a place nearby with specialised care where they can take him when they need a break and where experts can train his behaviour to allow him to live in the community," he said.

A specialist in childhood development, Dr Rosemary Marks of the Starship children's hospital in Auckland, said Jonathan's situation could have been avoided had he got the treatment he needed when he was younger.

"It is a tragic condemnation on the rest of us."

Jonathan's plight was by no means unique, and was a symptom of an under-funded mental health service, she said.

The Community Child, Adolescent and Family Service has just 56 full-time workers for the one million people of Auckland.

Last year the Mental Health Commission recommended that there should be 55 workers for every 100,000 people in a region, said Dr Marks.

"By my calculation we've got a tenth of the service we need."

A Health Funding Authority representative, Sandie Waddell, said the Eady case was a crisis.

She was alerted to it by the child's doctor last week and immediately searched for residential care.

Sandie Waddell said a full needs assessment would be done and services designed around that.

• Help begging for autistic children — A14.

LETTERS TO THE EDITOR

Govt, not mother, should be in dock

I too am a mother of a special needs child, who recently turned 17. I have never thought about killing my son but have often wished him dead. I wished he did die in his first year of life, if only to save him from the hurt and humiliation we have faced since, about which I could write volumes.

People often express their admiration for the great job I have done with him and that they couldn't possibly have coped. Yeah, well I had to cope because he is my flesh and blood; and so would they, too. No one could imagine the sleepless nights, the sick days, the soiled pants, the tantrums, and so on and on.

No average person could handle one night of it let alone 17 years — and that is just about my son's life. No one could imagine what I had to sacrifice in order to put my son's needs first, only to realise that my role is not appreciated by the Government.

No judge or jury in their right minds could honestly convict a woman without understanding the circumstances leading up to the recent tragic event, not days before but years ago. No mother on this Earth could ever imagine doing what she did to her child without being forced to make a change because there is no help for them.

If anyone should be on trial, it should be the Government. Because of its so-called policies implemented 20 years ago and the radical changes they have made in the areas of health, education and welfare, this woman and her late daughter were doomed to be victims of our soulless society.

My wairua and aroha go with Janine Albury-Thomson. Although I cannot support her in person, I am here, carrying on the struggle with the hope for good times to come.

Tauke Clark.
Whangarei.



• Janine Albury-Thomson ... • ... and critic Calder

perhaps the following will suffice:

The phrase represents a contraction of "let that be as it may be." As in Latin, reiteration of the verb "to be" is unnecessary, hence the omission of the final verb. The awkwardness of the initial verb phrase, "be that" arises from the progressive loss of the subjunctive tenses in English.

Vestiges of the subjunctive still survive in English, but only just. "God save the Queen" provides another example, preserved by its ceremonial application. More commonly, the subjunctive survives in conditional constructions, but here erosion is clearly evident. The young generally resort to the past tense, saying "if I was ..." rather than using the subjunctive, "if I were ..."

If only grammar were seen to be more relevant than circumstances in busi-

We need a tation of what t indication of it sex scenes and not likely to camouflage.

Then those enjoy the film; home and not

Cheap to seen not

I view with scramble these munications co lucky we are notes. It has

 **THOUGHT FOR THE WEEKEND**

Sorry, but we just didn't notice

We are very sorry, Casey, for what happened to you. You see, you were born into the wrong country controlled by a heartless Government. It is true that you were born into "God's own," but at the wrong time and with the wrong disability.

Today's society only likes winners and has no time for losers like you. It is governed by self-admiring, self-important lawyers and accountants headed by the star of the show, erstwhile Health Minister Jenny Shipley. It was unfortunate for you that these characters' total managerial skills seem to consist of ganging up on the weak and the disadvantaged.

Now, if you had come from high society, with a swanky private school education, and had a genial, extro-

vert, fun personality, a gold-plated private health insurance, credit cards and cellphones, and had you been hip, mobile and competitive, free from any embarrassing ailment, we would have respected you.

As it happens, we simply did not notice you because the sea of noise in the selfish world we live in drowned your cry for help.

In hindsight, we have a lot of compassion and sympathy for you but it won't last long. For good measure, and in the interest of foresight, we have punished only your mum for her part in your misfortune — in the hope that this will exonerate the rest of us from your tragedy.

Peter Koloszar.
Titirangi.

Weekend Herald, August 8-9, 1998, p. A21

Weekend Review

Stress that drives a mother to kill



How much torment can a severely autistic person, like Casey Albury (left) cause? Carroll du Chateau on the outer limits of endurance.

By 8.30 on the evening of July 15, 1988 Janine Albury-Thomson felt reasonably in control.

Her two preschoolers, Hannah, aged 2½, and Shannon, 12 months, were asleep. Even Casey, her 17-year-old autistic daughter, at home from the Holopua Home in Taradale where she boarded during school terms, was "in bed" — albeit still chanting and rocking in her room.

Janine stayed up to do some baking — Casey had an insatiable appetite — and went to bed around 11.

At last everyone, including her carpenter husband Bruce, was asleep.

It had been a tough couple of weeks. Janine herself was suffering the after-effects of a miscarriage.

Casey had got her period which she had been unable to manage, leaving sanitary pads lying around — even eating some, meaning she could not go to Woburn House, the IHC home supposed to provide respite care for two nights a week.

Then, when Janine eventually did take Casey to Woburn House she had been evicted. IHC said Casey had been wrecking her room, shredding her curtains and displaying inappropriate sexual behaviour.

She had probably grabbed young men by their genitals and exposed herself to them. One youth had started trying to get into Casey's room and other males at the house were showing sexual interest.

Dawn Fleming, of Woburn House, said she could no longer guarantee Casey's safety, that she would have to go home.

Altogether Janine tried eight agencies, including her doctor, MP, the Children and Young Persons Service and IHC, for help.

She told people she felt like killing Casey. Yet she could not do so overnight as

Key points

□ Casey's behaviour deteriorated — sheets were shredded and mattresses ruined by being urinated on.

□ Casey was sleeping just three hours a night until about 11 pm.

□ The terrible bang of Casey ramming her bed against the wall, shouting: "The sun is rising. The sun is rising."

□ The end — it took five long minutes before Casey stopped struggling and gasping.

the holidays her mother noticed Casey's behaviour had deteriorated. By the second week she had shredded dozens of changes of clothes, several sheets and ruined mattresses by continually urinating on them.

She was more aggressive and violent. Because she constantly stripped, wet her bed and poured her hot water bottle over the mattress, she was always cold.

Also, because of the added expense, the family was now in financial trouble.

For the first time Janine had to ask for a food grant. "I was very angry about that."

Most stressful of all, because Casey was sleeping just three hours a night, Janine was existing on an average of two hours' sleep.

bed against the wall and began a loud chant: "The sun is rising. The sun is rising."

Janine sat up and shouted: "Shut up, please, Casey," waking Bruce, who was cross at being disturbed.

Although Bruce went back to sleep, Casey did not stop her noise.

"I remember lying in bed thinking, Casey is getting worse instead of better."

By 2.15 Janine was near breaking point. She went into Casey's room, told her to get dressed. "Casey, you're going to heaven. You're going to be with God."

Although she initially hid under her blankets, Casey finally met her mother's eye, dressed and ran out to the old Corina Mk II coupe.

Over the next hour and a half, Janine Albury-Thomson drove round Feilding in a frenzied yet curiously calm state.

First she drove to the Aorangi bridge and tried to get Casey to jump.

Next she went home, picked up an orange towelling cord from behind the bedroom door ("I wanted something reasonably thick and soft"), all the while willing Bruce to wake and stop her.

Then she made another bargain with herself: "If the car doesn't start I'll call the whole thing off."

But the Corina did start. A sign, Janine drove to South St, stopped the car and turned to her daughter sitting on the bench seat beside her.

"My lovely Casey, you're misplaced in this world and I really want you to be much happier than you are here."

And she leaned over and slipped the cord round her neck and pulled tight. At 17, Casey was a big girl. Her smaller mother had to summon all her strength.

"I said, please God, let it be quick for Casey's sake. But it wasn't quick. Oh



VICTIM OF DESPAIR: Janine Albury-Thomson was convicted of the manslaughter of her daughter Casey Albury.

PICTURE: EVENING STANDARD

Albury stopped struggling and gasping.

"I lay her head in my lap, stroked her cheek and told her I loved her. That I

way out were numerous:

□ Unrealistic hopes for her daughter's improvement.

their parents is far higher than that suffered by those of either intellectually impaired or physically disabled children."

Even the latter can be difficult enough. Erin Redgrove, a mother whose intellectually and physically handicapped daughter, Lydia, died six years ago after 13 years with the abilities of a four-month-old baby, says: "I had all the help in the world and a lovely, happy, placid child, yet I was on the verge of breaking down at times."

"There were moments wondering if I could go on — maybe for the rest of my life. Because these kids don't grow up and go away."

Then there was sleep deprivation, especially when Lydia was sick. "That near full-on care. There were times when I took two hours to feed her — every day, every meal for months on end."

"If I hadn't had my parents to relieve me I don't know what I'd have done. How could I have hung it together?"

Underpinning the sheer exhaustion of Erin Redgrove's situation was constant anxiety.

"Anyone with a handicapped child is constantly dealing with grief [because their child is missing out on so much], guilt [for not being able to make things better] and fear caused by the enormous vulnerability — of what's going to happen to your child if you predecease her."

Although she never actually felt like killing her daughter, Erin Redgrove can well understand how Albury-Thomson was driven to do it.

"If there's no one you can hook into emotionally you feel so alone ..."

"Questions need to be asked about what there were no services available. Why the woman was so over-loaded."

Erin Redgrove is also sceptical about Woburn House's ability to manage Casey's several life years.

Autistic kids 'falling through health gap'

By CATHERINE MASTERS

Officials concede children with autism are falling through gaps in the health system.

The *New Zealand Herald* yesterday highlighted the case of a Northland couple who tied up their violent autistic adolescent son because they could no longer control his aggression and there were no specialist facilities for him.

The Autistic Association says dozens of families are in a similar plight and that many more will not know what to do when their usually placid and withdrawn children reach adolescence.

Adolescence is often "crunch time" for people with autism, says Maree Whitworth, association executive officer.

She said the case of 14-year-old Jonathan Eady, who spends hours each day bound and tied, was distressing but not unusual.

"The situation that has arisen with this particular family should not have happened in New Zealand in 1998. It is imperative that families receive ongoing support in order to maintain a semblance of family life.

"More and more of these cases are going to come

to light if something isn't done. Autism is a lot more common than a lot of other disabilities and there are no specific services."

The Health Funding Authority's director of disability support services, Carol Searle, said there must be gaps in the system for the Northland couple to have reached a point where they took such drastic action.

More support workers and residential placements were needed, she said, but often families managed to care for their loved ones until a crisis point was reached.

Within half an hour of the authority hearing of the boy's plight, respite care was being arranged.

Carol Searle said it was difficult to work out how many services would be needed and when because it was difficult to predict a crisis.

A Christchurch mother, Cheryl Munro, yesterday told the *New Zealand Herald* that a lack of specialist knowledge in the medical profession was a big problem.

She said her profoundly deaf son James, now 26, had been misdiagnosed and had spent the past five years in a psychiatric institution until a visiting specialist said he had aspergers syndrome, a high functioning form of autism.

NZ Herald, Tuesday, March 17, 1998, p. A3

Diagnosis of autism 'inadequate'

Professor slams 'political correctness'

By EUGENE BINGHAM

WELLINGTON — A politically correct practice of avoiding "labelling" people has seen autistic children miss out on being properly diagnosed, says a leading child psychiatrist.

Professor John Werry was appointed to investigate the care given to Casey Albury, the autistic 17-year-old strangled by her desperate mother last year.

The Government released his report yesterday.

Professor Werry says frontline professionals need more training to be able to recognise autism in children.

"However, lack of recognition is not just a defect in training but in some instances, particularly in the non-medical professions such as education, social work and psychology, it is due to mis-education.

"These professions and sectors generally hold views about 'labelling' which are anti-intellectual, anti-scientific and anti-medical and, in the end, anti-parent and anti-

child. It is driven in the main by politically correct ideology rather than knowledge."

Professor Werry's report on Casey Albury, which the Government released along with an inter-departmental report on autism services, found that the teenager did not get the specialist care she needed.

One of Professor Werry's criticisms was that Casey was not properly diagnosed until she was 7.

"The diagnosis of autism in Casey was unacceptably delayed,



Casey Albury

though I do not wish to suggest in any way that this is professional negligence.

"More needs to be done, to educate all frontline persons about autism, its detection and the need for referral to properly designated specialists in autism."

Professor Werry, an emeritus professor at the University of Auckland, said one of the big failings of the system was that no agency was

declared primarily responsible for dealing with autism.

"It has to be said most emphatically that though Casey and her family did receive a great deal of support over the years ... they lacked proper awareness and focus on autism."

The Director-General of Health, Dr Karen Poutasi, said she accepted that better coordination of services was required and that the Ministry of Health would take the lead.

The Minister of Health, Bill English, said the reports made it clear action was needed.

"The inter-departmental report lays out a detailed timetable for action to improve services, which I have endorsed."

The vice-president of the Autistic Association, Chris McGuire, said parents wanted a case-manager style of care for children. "At the moment parents have to go on their own odyssey to access services.

"They have to wheedle them out because they are spread over three sectors."

Professor Werry said the death of Casey should be a shakeup for the country. "It is unfortunate that it took the death of one autistic person to alert Government and the people of New Zealand to what parents and professionals have been saying for years about the lack of adequate services for persons with autism and their families."

NZ Herald, Thursday, November 19, 1998, p. A3

Autism remand shows gaps says minister

Desperate mum fears autism help too late

By **ANDREW YOUNG**
health reporter

The Government has ordered a review of autism services, but a desperate Northland mother fears changes may come too slowly for her ailing son, Jonathan.

Esther Eady, who earlier this year resorted to binding her violent son's hands and feet, said Jonathan was removed from the family home five months ago and was suffering as a result.

The Minister of Health, Bill English, yesterday announced the review, instructing health officials to identify gaps in services and recommend improvements for the up to 17,000 estimated autistics in the country.

Mrs Eady said the work was long overdue, as each day her son's condition worsened through the lack of home-based specialist services. Since social welfare staff put him into residential care, he had lost weight, suffered ill health and had felt abandoned.

She said a huge difficulty was that her husband, Viv, believed Jonathan was better off in an Auckland facility as he was so destructive at the family's Northland home and too far

from the needed support.

The Government yesterday also commissioned an independent review of the treatment of autistic teenager Casey Albury, who was killed by her mother, Janine Albury-Thomson, in July last year.

Albury-Thomson strangled her daughter after trying to persuade the teenager to jump off a bridge. A jury found Albury-Thomson guilty of manslaughter, not murder, after accepting she was provoked through her daughter's disturbing behaviour.

After the trial, Mr English said it was important authorities reviewed Casey's treatment and care and learned from it.

An Auckland child and adolescent psychiatrist, Professor John Werry, will review the 17-year-old's case history and the services provided to her and her family, assess the availability and standard of those services and recommend improvements.

Mr English said the reviewers were due to report by mid-October.

The coordinator of the Auckland Autistic Association, Deborah Cox, said the Government action was a relief, given years of unsuccessful pleas for help.

She said many families were on knife-edge,

WELLINGTON — The Government conceded again yesterday that there were gaps in services for people with autism after revelations that an autistic man had been remanded in prison.

The Labour MP Ruth Dyson highlighted the case of a 27-year-old Christchurch man, James Packer, who was remanded to Addington Prison and then transferred to Sunnyside Psychiatric Hospital for assessment but still has nowhere to go.

"The Government must fully address this issue. If James Packer had appropriate treatment and care, he would not end up in prison," Ruth Dyson said.

The Minister of Health, Bill English, acknowledged in March that there were gaps in services for autistic people after reports that the parents of a Northland boy, Jonathan Eady, bound his hands and feet with leather straps because they could not get specialised help to deal with his violent outbursts.

Since then, a Palmerston North woman, Janine Albury-Thomson, has been found guilty of the man-

slaughter of her autistic daughter, Casey, after trying unsuccessfully to get respite care.

The Associate Minister of Health, Roger Sowry, replying to questioning in Parliament on behalf of Mr English, said the Health Funding Authority was aware that some people had trouble getting access to residential and other services for family members with autism.

"A general assessment of disability support and mental health services is currently under way by the authority that would include any gaps in services for people with autism," he said.

"As a result of that assessment, I expect to see new service development and improved service coordination for people with autism by the authority and other agencies."

Ruth Dyson said James Packer's parents had made repeated submissions to Mr English, as she had.

Mr Sowry said in Parliament that he did not want to discuss individual cases, and Ruth Dyson should take up the matter with Mr English.

— NZPA

Mother heads for breakdown instead of break

By **CATHERINE MASTERS**

Bea Rowe fears she is heading for her second breakdown in two years.

The Waiheke Islander has a 17-year-old autistic and suicidal son who refuses to get out of bed or leave his room and is losing weight because of anorexia.

After struggling to care for him for years — three times she has walked into his room just in time to

stop him from killing himself — Mrs Rowe has finally been allocated 12 days of respite care, so she can have a break.

Despite the good news, she has hit a major obstacle. No facilities are available for her son, and she can find nowhere to place him. So she is struggling on, but fears she will break down as she did 18 months ago.

"I get the impression everyone thinks I'm just a neurotic mother and

it's all right, she'll keep coping you know; it's not like he's going to fall off the face of the earth," which they're quite right, he's not.

"But that's not the point. My resources in my own body have reached zero. And I have major surgery myself coming up in seven weeks. I'm getting desperate about what I can do, who's going to listen, where are we going to go now. We've tried everywhere.

"You know that ad on the TV with the battery. That's what we are, we're those people and we just have to keep going and going and going and then they wonder why mothers turn around and kill their kids."

She does not believe she would ever go as far as Janine Albury-Thomson, the Palmerston North woman convicted of manslaughter for strangling her teenage autistic daughter, Casey.

But Maree Whitworth, executive officer of the Autistic Association, said it was only a matter of time before another parent killed.

Mrs Rowe was one of 30 desperate families she knew of in the same boat around the country, she said.

The Government had said it would as a priority look at respite care issues, but that did not help families who were not coping right now, she said.

A Health Funding Authority spokesman acknowledged last week that services were needed in respite care areas.

The authority also acknowledged that respite care was one of the 11 ways to provide support to families so they could continue being at home and was targeting resources at areas.

● **Autism** — early screen helps, A12.

Autism Literature Review Summary

This summary outlines some of the main areas of literature which relate to caring for Autistic adults and my reflections on some possible implications of this.

A first major area of literature focuses on carers. Its worth noting that carers of people diagnosed as having a mental illness are neglected in the main 'carer' literature and the psychiatric literature tends to marginalise the position of carers in favour of the 'patient'. The main aspects covered in carer literature are:

- categories of carers
- burden and satisfactions of caring - long history of studies documenting stress on family caring for mentally ill.
- coping studies - assumes families should learn to 'cope better'
- limitations of services to support carers
- relationship between carers and professionals
- cost of caring studies

A second major area of literature is community care. There is a recognition that family/women are the basis of community care and it is important to clearly locate where and who is providing care. Of the pro community care literature the goal is to maintain family support for the person needing care. This leads to a tension for service providers - "how far should services be concerned with the well-being of carers as opposed to encouraging the continuance of caregiving? In certain situations the two aims go together, but in many they do not ..."

A third major area of literature is around the responsibility for caring, drawing on feminist critiques and questioning the assumption of family responsibility. There is literature examining why women care and critiques of existing arrangements, the negotiation of responsibility within families, choice, and alternatives to women caring. This leads into the major question of public versus private responsibility for caring - state role and family role.

A fourth area of literature is reflections on the current political context of care provision. Here it is recognised that community care has been a means of cost cutting for the state and that the family has become de facto caregivers. Case management is also seen to be strongly shaped by the need to ration scarce resources. There is recognition that social services are increasingly being limited to statutory duties. A UK study on housing providers and care provision found that whoever was left 'holding the baby', whether that be a housing provider or a relative, was also most likely to be the de facto caregiver.

A fifth and very small area of literature is around peoples future intentions for caring provision. The key point here is that there is a lack of future planning and a lack of realistic options for future planning. The 'Letting Go' study in UK provides the most interesting and indepth perspective of some of the key issues in preparing for mentally disabled adults to leave home.

In reflecting back on our starting question of who will care for your autistic child after you, there are a range of paths we could take. One option may be to focus in on addressing specific areas of provision, such as guardianship, housing, income support, respite care, employment, leisure. Another option may be to find ways of addressing the broader question of state vs. family responsibility.....

Some Key Quotes:

A UK study examining housing management and care provision found that “During our research social services made it clear they had money only to cover statutory duties, in the main child protection. In such a situation it looks likely that housing managers will inevitably have to provide care and support unless they are prepared to see tenants go without the care they need Community care has been described as ‘everybody’s distant relation and nobody’s baby’. Our research indicates that whatever the outcome of the current uncertainty regarding the balance between housing and care, at the end of the day housing managers will still be left holding the baby ...” (Gregory, Sally and Sue Brownill, *The Housing/Care Divide*, p. 66).

“Services assist the carer to do certain tasks, or relieve the carer from doing them. Implicit in this is an assumption that the carer is already defined as such and that the responsibility for the dependant lies with them. The danger of such an approach is that while it recognises the importance of the carer and places him or her at the centre of things, it can at the same time lock the carer more firmly into a relationship of responsibility that many have been concerned to question (Finch, 1984; Dalley, 1988).” (Twigg et al 1990, p. 13)

DO
ld
n-
on
ur-
re
ys
to
u-
re
on
a
r-
y
er
ld
fr
at
w
is
ill
st
to
ed
ic
es
PA



STREAMLINED: Autistic pupil Elliot Duff, 6, works with teacher aid Rebecca Croft at Riverhills Primary.

HERALD PICTURE / PETER MEECHAM

of its time.



Autistic pupils dive into the mainstream

Reid sits hunched over a table in the middle of the classroom and puts his felt tip pens in order.

The five-year-old plucks them one after another from a blue plastic container and lines them along the table. There is no particular colour order — but the line must be straight and when the container is empty, he fills it and begins again. And again.

But his world is interrupted by his teacher aid, who turns his head to face hers and tells him that it is time for maths.

The Phoenix Centre at Riverhills Primary School in Pakuranga is New Zealand's first class for autistic children to be integrated into a mainstream school.

The class started in January but officially opened this week. It is the result of three parents' desire for an autistic class within a mainstream school.

The parents, aided by Specialist Education Services and the Education Ministry, found that Riverhills School had a spare classroom and its principal, Christine Mason, was willing to take the children.

They would normally have attended a special education school, or an extension unit at a primary school.

Apart from a safety fence, the room appears the same as every other classroom. But its interior has been purpose-built for autistic

children. Inside are individual work cubicles so pupils are not disrupted by others. "quiet rooms" for time alone and carpet to minimise loud noises which the children cannot tolerate.

From the combined funding of nine children, the class receives a full-time and part-time teacher, as well as teacher aids and speech and occupational therapists.

Several mainstream classes are held in the Phoenix Centre to include the autistic children, with a buddy system between mainstream and autistic children. There is now a waiting list and parents in other cities are looking to set up similar classes.

— Stacey Bodger

THE PERSONAL ADVOCACY TRUST



The Personal Advocacy Trust Incorporated was established in the late 1960s primarily as a means of providing future friendship and personal advocacy when parents are no longer alive. Many parents feel deeply concerned about who will be there in the future, to continue to take a personal interest in the welfare of their autistic son or daughter, and to watch over his or her rights. Siblings may not be available or may have their own responsibilities. The idea of setting up a scheme to provide for such needs arose from the concern of many parents and other interested persons. Since that time, the trust has slowly but steadily increased its membership to the point where in 1993 there were approximately 750 people enrolled in the scheme.

Parents may enrol a son or daughter at any age for future services. Whilst the parents remain fit and active the Trust maintains a low profile, visiting the family perhaps once or twice a year and gradually building up a familiarity with the family and the autistic person, together with an understanding of the needs of that person and the hopes and expectations of the parents for his or her future.

When the parents are no longer available to continue to watch over the interests of their enrolled son or daughter, the Trust selects and appoints a personal advocate to take a special and individual interest in the welfare of the member. The personal advocate will visit regularly and keep an eye on the member's general health and well-being, checking that satisfactory arrangements are continuing in regard to education, work, accommodation and leisure activities. A check is also made that adequate pocket money is being received and that the member's financial interests are being protected. Where necessary, an advocate will spend additional time helping with any difficulties or misunderstandings which may occur in much the same way as a parent would.

To summarise, the Trust will:

- Watch over the quality of service its member is receiving wherever he or she is living.
- Assist the member where things are not going well or where his/her rights are not being upheld.
- Keep regular contact throughout the lifetime of the member in a stable and caring relationship.

Funding the Trust

In setting up the Trust it was recognised that in order to be able to speak out on behalf of its members without fear or favour, then the Trust must not be dependent on any outside source for the funds to meet the cost of its service. This financial independence could only be assured if costs were met by the members themselves or their families, hence an enrolment fee is the funding basis of the Trust. The Trust receives no government funding.

The Enrolment Fee

The enrolment fee may be arranged in one of several ways. A parent/guardian or the person wishing to arrange enrolment may:

- Make provision within their will for the enrolment fee to be paid from their estate.
- Make cash payment of the enrolment fee at the time of enrolment or during the lifetime of the parent/guardian. Payment by instalments may be negotiated.
- Take out an insurance policy on the life of the parent/guardian.

The enrolment fee depends on the age of the parents at the point of enrolment. If the parent midpoint age (calculated by adding current ages of parents and halving) is 50 years or below the fee at 1 August 1997 was \$3937.50. For payment from an estate and/or full support at enrolment the fee at 1 August 1997 was \$12375.00.

For more information regarding the Trust, contact:

The Personal Advocacy Trust Inc., PO Box 6575, Wellington. Ph (04) 385 9175.



Autistic Association of New Zealand Inc.

Including Asperger Syndrome and Related Disorders

Auckland Branch,
P.O. Box 9407 Newmarket,
Auckland, NZ.

Phone 0-9-631-5644
Fax 0-9-631-0126

7 May 1998

Dear Members

re: Client Survey

The Auckland Branch is constantly working towards obtaining better services and support for families living with Autism & Aspergers. We are doing a lot of work, both with parents and professionals, in the hope that we will make radical changes to the services (or lack thereof).

In order to achieve this we need your help. We are conducting a comprehensive survey of our clients to establish what specific services are lacking. I am sure that you can think of some!!

Sometime in the future you will be contacted by one of your Committee members and asked a few questions surrounding these issues. Our hope is to get some concrete data.

If you, for some reason, do not want to take part in this survey please contact our office and let us know. As you can imagine this is going to be a very time consuming task. Be patient with us, we will be in touch.

Thank you for your support.

Yours sincerely

A handwritten signature in black ink that reads "DEBORAH" in a cursive, slightly stylized font.

DEBORAH COX
Auckland Co-ordinator

Survey finally up and running.....

The Autistic Association of NZ Inc., Auckland Branch is conducting a major survey of all its members and other families in the community.

The purpose of the survey is to gain a clear picture of the current level of service provision to families with an ASD member and to highlight gaps and problem areas. The Association will use this survey to advocate for improved services for people with ASD.

The survey is being conducted by phone and will take approximately 20 minutes to complete. Your answers will be kept confidential and your anonymity preserved. You have the right to withdraw from the survey at any time and to decline to answer any particular questions.

Please take the time to contribute. We thank you in anticipation of your assistance.

Autistic Assn of N.Z. Inc Auckland Branch July Newsletter, 1999

Auckland Autistic Association Survey

Survey ID No:

Date Completed:

Interviewer:

Note: If more than one family member, use a separate questionnaire for each.

Part 1

1. Is your ASD family member male or female? Male Female

2. How many years old is your ASD family member? Years

3. Is your ASD family member a ...

NZ European or Pakeha	<input type="checkbox"/>
NZ Maori	<input type="checkbox"/>
Other European	<input type="checkbox"/>
Pacific Island group (specify)	<input type="checkbox"/>
Other (specify)	<input type="checkbox"/>

4. Does your ASD family member still live at home?

Yes No Not Applicable

IF NO

4b. Who is their main provider of accommodation?

Spectrum Care

IHC

Private Trust

Other (Specify)

4c. Where do they live?

Flatting

With other family (specify)

Other (specify)

5. What suburb/area do you (or they) live in?

6. How many children live in your home?

7. How many adults live in your home?

7b. Are you a two parent or single parent family? Two Parent Single Parent

7c. Who (mother, father, other adult – specify) is most responsible for daily care provision for your ASD family member? (NOTE IF SHARED EVENLY)

.....

Appendix 5.10

8. In your opinion where does your child/teenager/adult sit within the ASD spectrum?

Aspergers

Autism

Don't Know

Other

Comment

.....

9. Is your ASD family member verbal or non-verbal?

Verbal

Nonverbal

10. Do they have no functional communication, some functional communication or full functional communication?

No functional communication

Some functional communication

Full functional communication

Part 2 – Diagnosis and follow-up

1. Has your ASD family member been diagnosed with ASD? YES NO

If NO

1.1 Has another diagnosis been reached? YES NO

IF NO THEN SKIP QUESTIONS 4 – 9

IF YES 1.1.2. What diagnosis?

.....

If YES

1.2. Was your first diagnosis for ASD? YES NO

If NO 1.2.1 How many diagnosis were you given before ASD was confirmed?

1.3 At what age was your child officially diagnosed with ASD?

Under 2	<input type="checkbox"/>	4 years	<input type="checkbox"/>	11-15 years	<input type="checkbox"/>
2 years	<input type="checkbox"/>	5-7 years	<input type="checkbox"/>	Over 15 years	<input type="checkbox"/>
3 years	<input type="checkbox"/>	8-10 years	<input type="checkbox"/>	still undiagnosed	<input type="checkbox"/>

2. Did you have any indication that your child may have ASD prior to diagnosis? Eg from family, friends, playcentre

Yes No

IF YES

2b. From whom?

Family

Friends

Playcentre

Other (specify)

Appendix 5.10

3. Did you see any other professionals while you were looking for a formal diagnosis?

Yes No

4. Who gave your child the 'formal' diagnosis? Was it a .. and were they from ..

	Public Sector	Private Sector	SES	CCS
Psychiatrist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatrician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General Practitioner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (give details)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

.....

5. When you had your official diagnostic interview, did you find the diagnosing professionals ...

Extremely supportive

Moderately Supportive

Barely Supportive

Not Supportive

6. Were you offered a second opinion? Yes No

IF YES

6b. Was it from a ... and were they from the ...

	Public Sector	Private Sector	SES	CCS
Psychiatrist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatrician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (give details)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

.....

7. Did you seek a second opinion? Yes No

IF YES

7b. Was it from a ... and were they from the ...

	Public Sector	Private Sector	SES	CCS
Psychiatrist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatrician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (give details)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
.....				

8. Immediately following your diagnosis were you referred to...

	YES	NO
SES	<input type="checkbox"/>	<input type="checkbox"/>
Referral to Child Health Dev. Team (O.T.s)	<input type="checkbox"/>	<input type="checkbox"/>
Referral to Child Mental Health Team	<input type="checkbox"/>	<input type="checkbox"/>
Marinoto	<input type="checkbox"/>	<input type="checkbox"/>
Campbell Lodge	<input type="checkbox"/>	<input type="checkbox"/>
IHC	<input type="checkbox"/>	<input type="checkbox"/>
CCS	<input type="checkbox"/>	<input type="checkbox"/>
Autistic Assoc	<input type="checkbox"/>	<input type="checkbox"/>
IF YES Were you referred to Auckland	<input type="checkbox"/>	<input type="checkbox"/>
National	<input type="checkbox"/>	<input type="checkbox"/>
Other (Specify)	<input type="checkbox"/>	<input type="checkbox"/>

9. At the same time were you advised of ..

	YES	NO
Carer Support Days	<input type="checkbox"/>	<input type="checkbox"/>
Handicap Child Allowance	<input type="checkbox"/>	<input type="checkbox"/>

Appendix 5.10

10. From the following list, what sources lead you to available services for ASD?

	YES	NO	Which service
Phone Book	<input type="checkbox"/>	<input type="checkbox"/>
Citizens Advice Bureau	<input type="checkbox"/>	<input type="checkbox"/>
Doctor/Paed	<input type="checkbox"/>	<input type="checkbox"/>
School	<input type="checkbox"/>	<input type="checkbox"/>
Media	<input type="checkbox"/>	<input type="checkbox"/>
Word of Mouth	<input type="checkbox"/>	<input type="checkbox"/>
Spectrum Care	<input type="checkbox"/>	<input type="checkbox"/>
SES	<input type="checkbox"/>	<input type="checkbox"/>
CCS	<input type="checkbox"/>	<input type="checkbox"/>
IHC	<input type="checkbox"/>	<input type="checkbox"/>
Autistic Association	<input type="checkbox"/>	<input type="checkbox"/>
IF YES Auckland	<input type="checkbox"/>	<input type="checkbox"/>
National	<input type="checkbox"/>	<input type="checkbox"/>
Other (Specify)	<input type="checkbox"/>	<input type="checkbox"/>
.....			

Part 3 – General

1. Is there anyone working with your child who specialises in Autism?

Yes

No

IF YES

.1 Who (role and name)?

2. Do you need any of the following forms of respite care?

Yes

No

Crisis respite care

Regular/ongoing respite care

Occasional non-crisis respite care

IF YES TO ANY OF ABOVE

2.1 Can you access this respite care?

Yes

No

Crisis respite care

Regular/ongoing respite care

Occasional non-crisis respite care

2.2 Are you satisfied with the quality of any respite care you receive?

Yes

No

Crisis respite care

Regular/ongoing respite care

Occasional non-crisis respite care

2.3 Are you satisfied with the quantity of respite care you receive?

Yes

No

Crisis respite care

Regular/ongoing respite care

Occasional non-crisis respite care

Appendix 5.10

3. Have you received any carer support days this year? YES NO

If YES 3.1 How many days have you received this year?

1-14 over 28

28 Not Applicable

4. Have you received any paid hours of home support? Yes No

If YES

4a. How many hours per week?

4b. Who do you receive home support paid by?

SES IHC

CCS Other (specify)

1. From the following list, does your ASD child/teenager/adult have any other issues? (tick as many as are appropriate)

Major health problems Eating

Minor health problems Sleeping

Medication Mobility

Epilepsy Other (specify)

Toileting

5b. Have you accessed support for any of these from a ...?

Problem (Specify)

Paediatrician

GP

Starship

Autistic Association

IF YES Auckland

National

Other

2. How does your child/teenager/adult cope with attending the following people?

	Fine	Difficult	Extremely Difficult
GP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hairdresser	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dentist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialist (specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

.....

3. We are interested in identifying who in your life are your main sources of support to enable you to cope with your ASD family member. Using a scale of 1-extremely supportive, 2-very supportive, 3-moderately supportive, 4 barely supportive, 5-not supportive, and 6-not applicable rank the following sources of support.

	Rank
IHC	<input type="checkbox"/>
CCS	<input type="checkbox"/>
Health (Specify)	<input type="checkbox"/>
SES	<input type="checkbox"/>
Family	<input type="checkbox"/>
Friends	<input type="checkbox"/>
School	<input type="checkbox"/>
Church	<input type="checkbox"/>
Other parents with ASD children	<input type="checkbox"/>
Autistic Assoc	<input type="checkbox"/>
IF YES	<input type="checkbox"/>
Auckland	<input type="checkbox"/>
National	<input type="checkbox"/>
Other (specify)	<input type="checkbox"/>

Appendix 5.10

4. From the following list what sources do you think have provided the basis of your knowledge of ASD, using a scale of 1 very important through to 5 unimportant and not used.

	Rank
Health Professionals	<input type="checkbox"/>
SES	<input type="checkbox"/>
Books	<input type="checkbox"/>
Internet	<input type="checkbox"/>
Workshops	<input type="checkbox"/>
Conferences	<input type="checkbox"/>
Other parents	<input type="checkbox"/>
Autistic Assoc	<input type="checkbox"/>
IF YES Auckland	<input type="checkbox"/>
National	<input type="checkbox"/>
Other (specify)	<input type="checkbox"/>

5. Which category does your household fit into?(It would be helpful for us to have some indication of your ability to purchase private services, that is why we ask this question.)

Below \$30,000	<input type="checkbox"/>
\$30,000 – \$45,000	<input type="checkbox"/>
\$45,000 – \$60,000	<input type="checkbox"/>
Over \$60000	<input type="checkbox"/>

6. Would the provision of the following support services be at all relevant to your families needs?

	Currently	In the past	In the future
Sibling Support Groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social Skills Groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Grief Counselling on diagnosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. From the following list, what are your most pressing concerns now and in the future? (tick as many as appropriate)

	Now	Future		
Schooling	<input type="checkbox"/>	<input type="checkbox"/>		
Housing	<input type="checkbox"/>	<input type="checkbox"/>		
Respite Care	<input type="checkbox"/>	<input type="checkbox"/>		
Employment	<input type="checkbox"/>	<input type="checkbox"/>		
Live in care	<input type="checkbox"/>	<input type="checkbox"/>		
Pressure on siblings	<input type="checkbox"/>	<input type="checkbox"/>		
Lack of counsellors for teenagers	<input type="checkbox"/>	<input type="checkbox"/>		
Lack of support services	<input type="checkbox"/>	<input type="checkbox"/>		
Financial issues	<input type="checkbox"/>	<input type="checkbox"/>		
Caring for ASD member after death	<input type="checkbox"/>	<input type="checkbox"/>		
Friends/social skills	<input type="checkbox"/>	<input type="checkbox"/>		
Guardianship	<input type="checkbox"/>	<input type="checkbox"/>		
Abuse	<input type="checkbox"/>	<input type="checkbox"/>	By them <input type="checkbox"/>	By Others <input type="checkbox"/>
Bullying	<input type="checkbox"/>	<input type="checkbox"/>	By them <input type="checkbox"/>	By Others <input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>		

8. Does your child/adolescent/adult require assistance with ...?

	Assist	Non-assist	Not Applicable
Daily Living Skills			
Dressing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeding self	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cooking for self	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hygiene	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transport			
Catching a bus	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Can they drive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Managing their own finances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix 5.10

9. Have you received any support to assist your child/teenager/adult with ...?

	Yes	No	N/A	If yes from whom
Daily living skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Teenager: Sexuality issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Academic Support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Self-esteem/ counselling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anger Management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (Specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

13b. If support was available, would you want to utilise it?

	Yes	No	N/A
Daily living skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Teenager: Sexuality issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Academic Support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Self-esteem/ counselling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anger Management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (Specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. Is your child/teenager/adult aware of their diagnosis?

Yes No Not applicable

IF YES

14b. Is it difficult for your child/teenager/adult to currently accept their diagnosis?

Yes No Not Applicable

Part 4 – Adolescents

1. Is your adolescent still at school?

Yes

No

If No please complete the adult section as well as the adolescent section.

2. On a scale of 1 to 10, 1 being totally independent, 5 as requiring regular supervision and 10 being totally dependent, where would you rate your adolescent?

.....

Part 5 – Adults

1. What does your adult do?

	Yes	No	
Student	<input type="checkbox"/>	<input type="checkbox"/>	
Unemployed	<input type="checkbox"/>	<input type="checkbox"/>	
Sheltered Workshops	<input type="checkbox"/>	<input type="checkbox"/>	
Part-time work (specify)	<input type="checkbox"/>	<input type="checkbox"/>
Full-time work (specify)	<input type="checkbox"/>	<input type="checkbox"/>
Other (specify)	<input type="checkbox"/>	<input type="checkbox"/>

2. Does your adult attend other programmes or activities? (eg. Computer groups)

YES No

If YES 2a. Specify

.....

Appendix 5.10

3. Does your adult receive income from any of the following sources, and which is their main source of income?	YES	NO	MAIN SOURCE
Parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sickness benefit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community Wage (Unemployment benefit)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Part-time work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Full-time work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Student allowance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Domestic Purposes Benefit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Disability Benefit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (Specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. On a scale of 1 to 10, 1 being totally independent, 5 as requiring regular supervision and 10 being totally dependent, where would you rate your adult?

Part 6 – If your child is a pre-schooler or school age

1. Is your child's educational setting a ...	
Mainstream school	<input type="checkbox"/>
Satellite Class (mainstream)	<input type="checkbox"/>
Special school	<input type="checkbox"/>
Mainstream early childhood centre	<input type="checkbox"/>
Specialist early childhood	<input type="checkbox"/>
Correspondence	<input type="checkbox"/>
Home school	<input type="checkbox"/>
Other (specify)	<input type="checkbox"/>

2. Do you currently receive support from ...

	SES	CCS	Public School	IHC	Other (specify)
Yes	<input type="checkbox"/>				
No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

IF NO GO TO QUESTION 4

IF SES, IHC OR CCS

2b. For ... is the Auckland area ...

	SES	CCS	IHC
North	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
South	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Central	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
West	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
North Shore	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Do your public services currently provide a

	YES	NO
Early Intervention Teacher	<input type="checkbox"/>	<input type="checkbox"/>
Speech Language Therapist	<input type="checkbox"/>	<input type="checkbox"/>
Psychologist	<input type="checkbox"/>	<input type="checkbox"/>
Educational Support Worker	<input type="checkbox"/>	<input type="checkbox"/>
OT	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapy	<input type="checkbox"/>	<input type="checkbox"/>
Teacher Aid	<input type="checkbox"/>	<input type="checkbox"/>
Dietician	<input type="checkbox"/>	<input type="checkbox"/>
Other (Specify)	<input type="checkbox"/>	<input type="checkbox"/>

Appendix 5.10

3b. When was the last time your child had input from a public ... How many weeks?

	N/a	1-2 wks	2-4 wks	4-8 wks	over 8 wks	Don't Know	On Waitin List
Early Intervention Teacher	<input type="checkbox"/>						
Speech Language Therapist	<input type="checkbox"/>						
Psychologist	<input type="checkbox"/>						
Educational Support Worker	<input type="checkbox"/>						
OT	<input type="checkbox"/>						
Physiotherapy	<input type="checkbox"/>						
Teacher Aid	<input type="checkbox"/>						
Dietician	<input type="checkbox"/>						
Other (Specify)	<input type="checkbox"/>						

.....

4. Would you say you are happy with the level of support you currently receive from your public services?

Yes No Comment/ IF NO why?

.....

4b. Would you say you were happy with the level of support you received from your public services in the past?

Yes No Comment/ IF NO why?

.....

5. Do you currently run a home-based programme for your child?

Preschool age School age

Yes

No

IF YES

5b. What is the main basis for your programme?

Self-constructed, self-made

Other (specify)

6a Do you pay for any non-public services/people?

Yes No

IF YES

6b. How do you find these services/people? (tick as many as is appropriate)

Advertise privately

Via SES

Via IHC

Student Job Search

Uni. of Auckland Psych dept

Autistic Assoc

IF YES Auckland

National

Other (specify)

Appendix 5.10

6c. Why do you use private people?

Education Providers unable to provide enough hours

Cannot access sufficient public services

Quality of private therapists higher

Other (specify)

.....

6d. How long did it take for you to establish your non-public support?

6e. Did you encounter any barriers in establishing this support? Yes No

IF YES

6f. What were these barriers?

.....

7. How did you choose your early childhood centre/school?

With input From

Decided on your own

Other (specify).....

8. Is your early childhood centre/school receptive to outside private support?

Yes No

8b. Do they receive outside support from a private therapist? Yes No

IF YES How regularly?

	One off support	Weekly	Mthly	Termly	Yrly	As Needed
Private therapist	<input type="checkbox"/>					

9. Has your ASD child in their education settings been ... If YES, how many times?

	Yes	No	Number of times
Suspended	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Asked to take your child home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Encouraged to change school/ early childhood centre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part 7 – If your child is at school (includes adolescents at school)

7. Is your child currently funded under SE2000?

YES No

If YES 1a. Is it ...

ORS

Behavioural

Communication (SL)

Funded but don't know what scheme

IF YES

1b. How many hours of direct teacher aid / preschool / Communication Support worker or one on one support does your child get per week?

	SES	CCS	Other Provider (Specify)	Don't Know
less than 5	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5-9 hours	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10-14 hours	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15+ hours	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Don't Know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix 5.10

2. How many times did you apply for SE2000 before it was given, or before you gave up?

1	<input type="checkbox"/>	4	<input type="checkbox"/>
2	<input type="checkbox"/>	5+	<input type="checkbox"/>
3	<input type="checkbox"/>	don't know	<input type="checkbox"/>

2b. Did you give up? YES NO

3. How many times did your school apply for SE2000 before it was given, or before they gave up?

1	<input type="checkbox"/>	4	<input type="checkbox"/>
2	<input type="checkbox"/>	5+	<input type="checkbox"/>
3	<input type="checkbox"/>	don't know	<input type="checkbox"/>

3b. Did your school give up? YES NO

4. Does your child receive extra support at school which is not funded under SE2000?

Yes	<input type="checkbox"/>	If YES 4a. How many hours
No	<input type="checkbox"/>	As required <input type="checkbox"/>
Don't Know	<input type="checkbox"/>	

4b. If yes, who funds it?

You fund it	<input type="checkbox"/>
School funds it	<input type="checkbox"/>
Someone else funds it (specify)	<input type="checkbox"/>
Don't know who funds it	<input type="checkbox"/>

5. Does your child receive extra support through the school (school funded) from a

	Daily	Weekly	Monthly	Termly	Yrly	As Req.	Don't Know
SLT	<input type="checkbox"/>						
OT	<input type="checkbox"/>						
Physio	<input type="checkbox"/>						
Psychologist	<input type="checkbox"/>						
Other	<input type="checkbox"/>						

(specify)

6. Do you think that specialist workshops concerning ASD for teachers would be beneficial for your child's school experiences?

Yes No Don't know

6b. Do you think your school would be receptive to attending these?

Yes No Don't know

Part 8 – Auckland Autistic Association

1. Are you a member of the Auckland Autistic Association? YES <input type="checkbox"/> NO <input type="checkbox"/>		
2. Do you ever attend Auckland Autistic Association events? (tick as many as is appropriate)		
	Currently	In Past
North Shore Support Group	<input type="checkbox"/>	<input type="checkbox"/>
Playgroup	<input type="checkbox"/>	<input type="checkbox"/>
Pakuranga Group	<input type="checkbox"/>	<input type="checkbox"/>
Mt Eden Coffee morning	<input type="checkbox"/>	<input type="checkbox"/>
Evening workshops	<input type="checkbox"/>	<input type="checkbox"/>
Picnics	<input type="checkbox"/>	<input type="checkbox"/>
Adult Social Functions	<input type="checkbox"/>	<input type="checkbox"/>
Weekend Workshops	<input type="checkbox"/>	<input type="checkbox"/>
2b. What would make these events more accessible to you?		
Change of venue	<input type="checkbox"/>	
Change of time	<input type="checkbox"/>	
Not interested	<input type="checkbox"/>	
Other (specify)	<input type="checkbox"/>

3. Do you read your newsletter?		
Yes	<input type="checkbox"/>	No <input type="checkbox"/>

4. Do you read your flyers?		
Yes	<input type="checkbox"/>	No <input type="checkbox"/>

5. Would you use a holiday programme if it was run by the Auckland Branch?		
Yes	<input type="checkbox"/>	No <input type="checkbox"/> Not Applicable <input type="checkbox"/>

6. Can you detail any extra support that you would like from the Auckland Autistic Association?

.....
.....
.....
.....
.....

7. Do you know any other families living with ASD who are not on the Auckland mailing list?

Yes No

7b. If yes, do you know why?

8. Do you find the level of support you receive from the Auckland branch ...?

Highly satisfactory
Satisfactory
Unsatisfactory

8b. Any Comments:

.....
.....
.....
.....

Appendix 5.10

9. Do you see the Auckland branch of the association as a service provider?

Yes No Don't Know

10. The Auckland Branch employs a programme developer, would you like to be using this service?

Yes No Don't Know Not Applicable

IF YES,
10b. How would you use this programme developer (eg. Programmes for playschools, social skills, language skills etc)

.....

11. Are you a member of the National Branch in Christchurch?

Yes No

Tips for Interviewers

Phone Introduction

- Because this survey is conducted over the phone it is very important that you pass on the following key points to the person you wish to interview.
 - Use your own words to make these points, but be sure not to miss any of the points.
1. Autistic Association of NZ Inc, Auckland Branch Survey - Title
 2. The Autistic Association of NZ Inc, Auckland Branch is conducting a major survey of all its members.
 3. The purpose of the survey is to gain a clear picture of the current level of service provision to families with an ASD member and to highlight gaps and problem areas. The Association will use this survey to advocate for improved services for people with ASD.
 4. The survey is being conducted by phone and will take approximately 30 to 40 minutes to complete.
 5. Your answers will be kept confidential and your anonymity preserved.
 6. You have the right to withdraw from the survey at any time and to decline to answer any particular questions.

Interview Timing

- Because of the length of time the survey takes, you should check with the person you wish to interview, when it would be okay to actually do the interview.
- If possible do the interview when you first call, but if this is not convenient, ask to make a time that would suit them.
- **Write the call back time on the Interview Tracking Sheet.**
- If you are unavailable at the times the person wishes to be interviewed phone Carmel on 376 3662 and she will try to fill the gap.

Confidentiality

- If you know the person or anyone in the family at a particular phone number – don't interview them. Instead ask to swap with another team member.
- It is very important that anything you find out while interviewing remains confidential.

Doing the Survey

- As you go through the questions try to avoid getting too involved in discussing them and only make comments if the interviewee needs clarification of the meaning of the question.
- If the interviewee is looking for a discussion on a issue, suggest that you could come back and discuss it after the survey is completed.
- The reason for trying to avoid discussions during the survey, is that your comments could influence the response of the interviewee.

Refusals

- If the person declines to participate in the survey, then just thank them for their time and mark them off as a refusal on the interview tracking sheet.

Returning Questionnaires

- When you have completed your interview tracking sheet, please return all the surveys and the tracking sheet to Carmel in the envelope provided. You can return them either post or drop them off.
- Carmel will phone once a week to check how things are going and get a feel for overall progress.
- If for any reason you are unable to continue doing the interviews, please let Carmel know as soon as possible, so that the interviews can be handed on to someone else.

Problems or Queries

- If you have any problems or queries, please **phone Carmel on 376 3662.**

Questionnaire Tracking Sheet

SURVEY ID No.	Name	Phone Number	Message Left ?	Call Back Date & Time	Refused	Date Surveyed
<input type="checkbox"/> 1	<i>title</i> <i>first names</i> <i>surname</i>	<input type="text" value="hm phone"/> <i>suburb</i>	<input type="checkbox"/>	_____	<input type="checkbox"/>	
<input type="checkbox"/> 1	<i>title</i> <i>first names</i> <i>surname</i>	<input type="text" value="hm phone"/> <i>suburb</i>	<input type="checkbox"/>	_____	<input type="checkbox"/>	
<input type="checkbox"/> 1	<i>title</i> <i>first names</i> <i>surname</i>	<input type="text" value="hm phone"/> <i>suburb</i>	<input type="checkbox"/>	_____	<input type="checkbox"/>	
<input type="checkbox"/> 1	<i>title</i> <i>first names</i> <i>surname</i>	<input type="text" value="hm phone"/> <i>suburb</i>	<input type="checkbox"/>	_____	<input type="checkbox"/>	
<input type="checkbox"/> 1	<i>title</i> <i>first names</i> <i>surname</i>	<input type="text" value="hm phone"/> <i>suburb</i>	<input type="checkbox"/>	_____	<input type="checkbox"/>	
<input type="checkbox"/> 1	<i>title</i> <i>first names</i> <i>surname</i>	<input type="text" value="hm phone"/> <i>suburb</i>	<input type="checkbox"/>	_____	<input type="checkbox"/>	
<input type="checkbox"/> 1	<i>title</i> <i>first names</i> <i>surname</i>	<input type="text" value="hm phone"/> <i>suburb</i>	<input type="checkbox"/>	_____	<input type="checkbox"/>	
<input type="checkbox"/> 1	<i>title</i> <i>first names</i> <i>surname</i>	<input type="text" value="hm phone"/> <i>suburb</i>	<input type="checkbox"/>	_____	<input type="checkbox"/>	
<input type="checkbox"/> 1	<i>title</i> <i>first names</i> <i>surname</i>	<input type="text" value="hm phone"/> <i>suburb</i>	<input type="checkbox"/>	_____	<input type="checkbox"/>	
<input type="checkbox"/> 1	<i>title</i> <i>first names</i> <i>surname</i>	<input type="text" value="hm phone"/> <i>suburb</i>	<input type="checkbox"/>	_____	<input type="checkbox"/>	
<input type="checkbox"/> 1	<i>title</i> <i>first names</i> <i>surname</i>	<input type="text" value="hm phone"/> <i>suburb</i>	<input type="checkbox"/>	_____	<input type="checkbox"/>	

VOLUNTEERS WANTED

Autistic Association of NZ Inc.

**Are looking for volunteers with a clear speaking voice
and access to a telephone to help us collect
information about families affected by
autism/Aspergers**



**Full training
will be given**

**If you think that you can help, please contact Priya or
Christina on 276-1396 by 18th February 2000**

Volunteer
Autistic Association
Phone: 09-276-1396



Autistic Association of N.Z. Inc.

Including Asperger Syndrome and Related Disorders

Auckland Branch
PO Box 22275 Otahuhu,
Auckland, N.Z.

Phone: 09 276 1396
Fax: 09 276 8790
e-mail: autism_auck@xtra.co.nz

I, _____, hold the position of
_____ at the Autistic Association of NZ Inc.
(Auckland Branch).

I understand that in this position I may have access to confidential information.

I understand that any information I learn about a client is confidential and that information about a client or any member of a client's family cannot be disclosed to anyone.

I agree that I will not:

Reveal to anyone the name or identity of a client.

Repeat to anyone statements or communications made by or about the client

Reveal to anyone (including my spouse) any information that I learn about the client as a result of discussions with others providing care to the client.

Write or publish articles, papers, stories, or other written material which will contain the names of any client, or information from which the names or identities of any client can be discerned. If a paper is written about my work here, I agree that I will submit it to the Management Committee for approval.

I have read this statement. I understand my obligation to maintain client confidentiality and I agree to follow that obligation.

Signed: _____

Witnessed: _____

Date: _____



Autistic Association of N.Z. Inc.

Including Asperger Syndrome and Related Disorders

Auckland Branch
PO Box 22275 Otahuhu,
Auckland, N.Z.

Phone: 09 276 1396
Fax: 09 276 8790
e-mail: autism_auck@xtra.co.nz

Submission to the Review of Special Education 2000

A. Summary of Recommendations

Following are the recommendations of the Autistic Association of New Zealand Inc. (AANZ Inc.), Auckland Branch. These recommendations are based on a comprehensive survey of Auckland Branch members.

The AANZ Inc., Auckland Branch undertook an in-depth survey of all their members to identify issues in service provision affecting families with an Autistic Spectrum Disorder (ASD) family member. 180 families were surveyed, collecting information on 193 people with ASD (13 families had 2 family member with ASD). There were 16 refusals. The survey covered issues such as diagnosis, respite care, sources of support and information, and schooling issues and experiences. Parents and professionals developed the survey over a 12-month period and parents and volunteers undertook the interviewing by phone. The survey was completed in May 2000. Many questions and issues raised by parents in the survey are directly relevant to the SE2000 review.

Out of 193 people with ASD, 138 were under the age of 21 and still in a school education setting. All of the following survey data is for this group of 138 children/adolescents with ASD who are still in an education setting (this does not include young adults in tertiary education).

See Appendix I for the demographic profile of the 138 school students in the survey.

<i>Key Recommendations</i>	<i>Secondary Recommendations</i>
1. Shift from crisis-based intervention to needs based intervention – following are our recommendations to facilitate this.	
2. Establish Special Needs Advocates (essential for all three terms of reference).	2.1 Establish channels of referral to access Special Needs Advocates, especially for those with a late diagnosis. 2.2 Awareness for all of policies in existence to promote holistic and integrated service provision (especially between public and private services).
<i>First Term of Reference</i>	
3. Ministry of Education must collate data on the number of children with special needs and use this information in the allocation of funds, including the Special Education Grant (SEG).	3.4 Establish a different form of Transitional Resource Scheme.
3.1 Establish an ongoing audit process to assess the effectiveness of funding allocation, expenditure and gaps in services.	3.5 Establish monitoring of existing support to children to determine effectiveness.
3.2 Improve frequency of service input of professional therapists to children to ensure they are not receiving only a token service.	3.6 Implement an education awareness programme for verifiers, principles and SES staff re ASD.
3.3 Not cut funding for children with ASD when improvements are noticed.	

<p><i>Second Term of Reference</i></p> <p>4. Ensure Government maintains overall responsibility for the full range of education options, including satellite classes and special units.</p>	<p>4.1 Address service provision for mainstream students with special needs aged 18-21 years.</p>
<p><i>Third Term of Reference</i></p> <p>5. Change the basis of allocating SEG to be on the needs of identified children, rather than based on school decile rating and roll.</p> <p>5.1 Ensure Accountability in how Schools use SEG. Assist accountability through clear definitions on the use of SEG and policies/procedures for schools to follow.</p> <p>5.2 Establish procedures for schools to enable transparency in the use of SEG.</p>	
<p>6. Teacher Aide training, pay and status urgently needs to be addressed.</p>	<p>6.1 Establish Training for Teachers on how to utilise Teacher Aides in the classroom.</p>
<p>7. Policy makers, assessors, fund-holders and service providers need awareness of the potential of children with ASD, their specific needs and how to meet them. They also need to be aware of the continual personal burden on families, both financially and emotionally. Finally they need to be aware that there is hope for children with ASD and their families.</p>	

B. Recommendations

1. Shift from Crisis Based Intervention to Needs Based Intervention

The inadequate funding of SE 2000 is driving a crisis-based model of allocation of funds rather than a needs based model. Many parents have found that services and support only materialise when there is a crisis. Our survey of families with ASD members found that 8% of school students with ASD surveyed have been suspended at least once. The parents of 27% of children surveyed have been asked to take their children home from school at least once, and that 23% of parents have been encouraged to change schools for their child. Obviously many schools are struggling to cope with children with ASD. Special needs services must be adequately resourced to ensure services are provided on the basis of need rather than waiting for a preventable crisis.

2. Establish Special Needs Advocates

There is a dire need for Special Needs Advocates to assist parents in the process of obtaining support for their children. Many parents talked about being forced into the role of being a 'stropky parent' or a 'paranoid parent'. It is very difficult for parents to feel they are being taken seriously when they are being forced into this role. There is also concern over the level of services children without a 'stropky parent' are receiving. Parents face many difficulties in finding out how the system works and how to access resources. Special Needs Advocates could play a valuable role by assisting parents through the system.

Special Needs Advocates could also have an important role:

1. Assisting parents in maintaining ongoing appropriate services.

- Many parents are very concerned at the drop in funding and resources for their children at the start of each year. As students progress through their schooling, special needs assistance is steadily cut, yet children with ASD are not 'cured' as they go through school. Their needs may change but by definition of having ASD they still have special needs. Of students surveyed in a mainstream school and receiving SE2000 funding (n=32): 28% are 5-6 yrs, 34% are 7-8 yrs, 19% are 9-10 yrs, 13% are 11-12 yrs, 3% are 13-15 yrs and 3% are 16 to 21 yrs.
 - A number of parents have identified that when their child's behaviour improved, this was seen as a reason to cut their support rather than being seen as a sign that the support was working.
2. Assisting parents of children with a late diagnosis to access services. "Howlin (1998) reports the average age of formal diagnosis for children with autism is 5.5 years, for Asperger Syndrome 11.3 years." Given the marked decrease of services as children age, children receiving a late diagnosis have a greater risk of falling through the cracks and missing out on necessary support.
 3. Assisting parents in co-ordinating a holistic and integrated service, especially between public and private services.
 4. Informing parents about the educational options available and the process to access these.
 5. Practical support in accessing services, i.e. guidance in completing ORS application forms

2.1 Establish Referral Channels for Special Needs Advocates

Clear referral channels need to be established to enable parents to access special needs advocates. Diagnosis professionals and schools should refer on to special needs advocates. The AANZ Inc., Auckland Branch has also frequently assisted parents and is another resource that parents can be referred to.

2.2 Awareness for all of policies in existence to promote holistic and integrated service provision.

Everyone should be aware of policies and procedures that exist, such as IEPs, to promote a holistic and integrated service package. A number of parents have experienced difficulties between the provision of public and private sectors. There have been a number of instances where parents who wish to provide additional private support for their children have been told that if they use private services they will no longer be entitled to public services. Some parents have also felt that they must keep their private assistance secret due to disapproving attitudes by public special needs staff. There are already policies and procedures that exist to assist with the relationship between different service providers, and it is essential that everyone is aware of these so that children can receive an integrated service.

"SES were anti [family using private services] and also unhappy to provide services to our son as quote 'we had our own [private] services'."

"SES said if we go private they won't help any more."

First Term of Reference

3. Collection & Collation of Data for Realistic Funding Allocation

The AANZ Inc., Auckland Branch has identified the funding cap for special needs as a major barrier to students receiving appropriate support.

Section nine of the Education Act states that children with special needs have the same rights to a quality education as those without special needs. For this right to be realised, appropriate support must be resourced and accessible.

The Ministry of Education needs to collate data on how many children in school have special needs in order to set a more realistic funding cap. The current cap of 1% is grossly inadequate. Children with ASD alone could fill a sizeable proportion of the funding cap. "Autism can range from mild to extremely severe

and although estimates vary, studies indicate that the incidence of autism is found in almost one child out of every hundred.” p11

Diagnosis of ASD should be sufficient identification that the child does have educational needs. See Appendix II for an analysis of the special needs of children with ASD. It is inconceivable that children diagnosed with ASD and not receiving the very high needs level of support, could be experiencing the same level of quality education as children without ASD.

- Only 62% of students with ASD surveyed were receiving SE2000 funding, 34% were not, and 4% don't know.
- Only 39% of students with Aspergers were receiving SE2000 funding, 59% were not, and 2% don't know. 86% of students with Autism were receiving SE2000 funding, 8% were not, and 6% don't know.
- Only half of the students on the border of Aspergers and Autism were receiving SE2000 funding.
- Of students in a mainstream school (n=77), 42% are receiving SE2000 funding, 57% are not, and 1% don't know.

3.1 Establish An Ongoing Audit to Assess Effectiveness of Funding Allocation and Gaps in Services

For the government to meet its obligations under section nine of the Education Act it is essential that there is an ongoing audit process to assess the effectiveness of funding allocation and identify any gaps in services. Findings from our survey illustrate gaps in service and issues in both effectiveness and implementation of SE2000 policies. This survey is a one-off. For the government to know whether it is meeting its obligations an ongoing audit process is essential.

Some of the issues we have identified are:

- A lack of standardisation in who receives support. Children with ASD who display more obvious signs of a special need, such as severe behavioural difficulties, are more likely to receive support than children who are passive and have ASD.
- As mentioned above, there is a sharp drop off in support as children age, yet there is no evidence that need drops with age. ASD is a pervasive developmental disorder and is, therefore, life long.
- The actual process of applying for funding is very difficult, with parents frequently having to reapply, and obtaining support is heavily dependent on a parent's ability to formulate a convincing written argument. Therefore, parents of limited educational background, or for whom English is a second language, frequently miss out on services for their children. It is unacceptable that services are based on parental ability and not individual need.
- Parents are using private services because of a high degree of dissatisfaction with the quality and quantity of public services.
- Some parents found that the limited support available forced them to choose between addressing either the social or academic needs of their child.

Reasons why Parents are Using Private Services – Dissatisfaction with Public Service

- Parents of 41% of all students are paying for private services. Of students with Aspergers, 34% are paying for private services, and 49% of students with Autism are paying for services.
- Of parents paying for private services (n=57), 93% said that one reason for using private services was because they could not access sufficient public services.
- 18% of parents using private services also said they were using private services because the quality of public service was poor, or poorer than private services.
- 68% of parents paying for private services also gave other reasons, such as not wanting to wait for public services, and finding it easier to organise their own services than trying to obtain them through the public system.

Parents are indicating strong dissatisfaction with public services. The main concerns are over accessing sufficient services (particularly in terms of frequency of professional input), the quality of public services (particularly the lack of training for teacher aides), and the waiting time for services to be set up. This dissatisfaction indicates that, in the view of many parents, SE2000 is not delivering the goal of equal educational opportunities for children with special needs.

Barriers to Private Services

The main barrier for private services is cost. Of households with an income below \$30,000 26% are paying for private services, 33% for households between \$30,000 - \$45,000, 33% again for households between \$45,000 - \$60,000, and 58% for households over \$60,000. A number of parents paying for private services commented on the fate of parents and children who were missing out in the public system and did not have the personal income to provide privately.

3.2 Improve Frequency of Service/Input of Professional Therapists

Another key concern for many parents was the infrequency of service input from professional therapists, particularly speech language therapists, occupational therapists and psychologists.

Of children receiving input from a psychologist (n=51), 16% had last seen a psychologist in 1-2 weeks, 12% in 2-4 weeks, 23% in 4-8 weeks, 45% in over 8 weeks, 12% don't know when last seen, and 4% seen as required.

Of children receiving input from a speech language therapist (n=67), 24% were within the last seen 1-2 weeks, 15% in 2-4 weeks, 15% in 4-8 weeks, 27% in over 8 weeks, 16% don't know when last seen, and 3% are on a waiting list.

Of children receiving input from occupational therapists (n=14), 24% were last seen 1-2 weeks ago, 12% 2-4 weeks ago, 15% 4-8 weeks ago, and 29% were last seen over 8 weeks ago.

3.3 Do Not Cut Funding for Children with ASD when Improvements Noticed

A number of parents have identified that when their child's behaviour improved and/or progress was noted, support was cut. An assumption appears to be made that support is no longer required. Given that ASD is a pervasive developmental disorder, this is unlikely to be correct. Appropriate forms of support for children with ASD should continue through to the end of their schooling.

3.4 Establish a Different Form of Transitional Resource Scheme

Transitional funding is currently only for 5-7 year old children on the basis that it is unknown whether they will need ongoing funding through school. For children with ASD a different and more useful version of transitional funding would be funding for support not only for the transition to primary school, but also for the transition from primary to intermediate school and the transition from intermediate to secondary school.

For many students with ASD the difficulties they face often become more apparent during secondary school. This is because there is a different set of expectations at secondary school that highlight social and behavioural difficulties faced by students with ASD. Discrepancies are far more marked between children with ASD and their peers in their later school years.

"A recent study has suggested that...children may have considerable academic achievement in primary school but a deterioration in grades during high school (Goldstein, Minshew and Siegal 1994). Research has shown that this is due to the changing nature of abilities required by the curriculum. In primary school the tasks involve rote mechanical procedures, long-term memory and fairly simple linguistic instructions. At high school, the child is expected to acquire skills in

Appendix 5.15

comprehension, conceptualisation, analysis, teamwork and problem solving. These areas can be relatively less well developed for the teenager with Asperger's Syndrome" p122

3.5 Establish Monitoring of Existing Services to Determine Effectiveness

The services children are receiving should be monitored to ensure they are working appropriately. A monitoring process would enable any problems to be identified and then steps can be taken to address these.

3.6 Implement Education Programme for Verifiers, Principals and SES Staff re ASD

A number of families have been advised not to apply for ORS by school staff, such as principals, and by SES staff. They were told that their child would not be eligible and/or not severe enough to warrant help. This raises two issues – firstly the need for standardisation of eligibility, and secondly the need for education so educational professionals are fully aware of the learning specifics associated with an ASD diagnosis (see Appendix II for an analysis of the special needs of children with ASD). Parents of children with an ASD diagnosis are being misinformed when they are told not to apply because the criteria for an ASD diagnosis matches the high needs criteria for ORS. Verifiers, school principals and SES staff need an education programme to raise their awareness of the special needs of ASD and to assist with greater standardisation in children with ASD accessing special needs support.

Second Term of Reference

4. Ensure Government Maintains Responsibility for Full Range of Educational Options

The government appears to be shifting control of satellite classes and special units to individual schools and in the process abdicating responsibility. This indicates a significant gap in government responsibility for ensuring that appropriate resources and options are available in all geographic regions and for all needs. Leaving responsibility at a micro level prevents government from ensuring that no area (of need or region) is overlooked. Schools are not in a position to individually respond to needs that require national planning and implementation. It is neither feasible nor realistic to expect schools to deliver all special need services required without national guidance from government. Government must maintain overall responsibility to ensure parents can access the full range of educational options.

Satellite classes and special units can have an important role in the education of children with ASD. They can adopt learning strategies helpful to specific students, can provide a "safe haven" beneficial when introducing integration to a mainstream setting. They can also provide an optimum learning environment that may be particularly relevant to children with ASD due to sensory sensitivity so characteristic of these disorders. It is vital that these educational options continue, and are available to all.

4.1 Address Service Provision for Mainstream Students with Special Needs Aged 18-21 years.

There needs to be consideration given to service provision for ASD students who are under 21 years and have completed mainstream education. Currently these students have few supported, appropriate educational options available to them and this is a significant concern for some families.

Third Term of Reference

5. Change Allocation of Special Education Grant (SEG) to be based on needs of identified children.

The allocation of SEG should be based on the identified specific learning needs of children and not based solely on decile rating and school numbers. The SEG must be separated from grants to cover additional funding in relation to school decile ratings. Currently SEG funding is allocated on the assumption that lower decile schools will have greater needs to cater for. In practice this method of allocation provides no assurances that needs are met, regardless of decile rating. Additional monies to assist schools with lower decile ratings must come out of a separate designated budget.

The level of the SEG is currently inadequate to meet moderate needs. As well as the basis of allocation being changed, the amount allocated should also be reviewed in light of data collated on special needs from the audit process recommended above.

5.1 Ensure Accountability in how Schools Use SEG

There needs to be a clear definition of what needs are to be covered by SEG, and clear policies for schools to follow. Schools need to have a process for accountability and transparency to ensure that funding is used in the manner intended. The policy should also allow options for parent participation.

Many parents are unsure of exactly who is receiving what support in the classroom. Some parents have difficulty determining what they are entitled to, information is not being passed on to parents, and there is a lack of welcomed parental input. Many schools seem to be unsure of how to operate SEG, their own allocation of it and the rights of special need students.

5.2 Establish Procedures for Transparency in How Schools Use SEG

A number of parents in the survey did not know whether they were receiving any funding, whether the school or SES was the fundholder, what scheme they were receiving funding from, what actual services/input their child was receiving or how frequently their child was receiving input.

"Not sure of SES support, lots of professionals involved at school, but not sure whether SES or school funded. The whole of the SE2000 concept is confusing. I am confused about whether there is a relationship between SES and the school. I made some enquires about structure/processes from school but had no real clear answers."

Comments were frequently made about not understanding how the system really works. Some parents are not informed of the basis for decisions re who is entitled to funding for SEG, nor are they informed regarding what assistance is being provided. They are not informed as to what assistance they are receiving. This highlights the urgent need for the establishment of special needs advocates.

Parents have a right to be informed of all aspects of service provision and availability so that they can be central in procuring the most appropriate education for their child. All procedures must be child focused and parent friendly so parents are not obliged to battle for the basic rights of their children.

6. Address Teacher Aide Training, Pay and Status

A common belief amongst parents is that teacher aides are babysitting their children. *"SES aides are babysitters, not trained, wasting everyone's time."* Parents are very critical of the mostly non-existent training teacher aides receive prior to working with their children. Parents are also sceptical about how useful this untrained support will be in the long-term. Without standardised training there is no standardised measure. At present the quality of service is largely dependent on the personal qualities of each individual teacher aide. It is unacceptable for the government to provide only a token education delivered by untrained teacher aides for children with ASD. The majority of children with ASD can learn and desperately need a quality education. This must be delivered by informed, knowledgeable staff.

Increasing the quality of teacher aide support also requires a substantial increase in the pay and status of teacher aides.

A major gap in service for a number of children is that no replacement teacher aide is provided when their regular teacher aide is sick or goes on holiday. For some children this means they cannot attend school during these times.

6.1 Establish Training for Teachers on How to Utilise Teacher Aides

It cannot be assumed that all problems will be solved by the presence of a teacher aide, especially when we consider that many teacher aides are untrained. We also cannot assume that all classroom teachers will be equipped with knowledge of how to best utilise teacher aides. The AANZ Inc., Auckland Branch believes many teachers may benefit from some training on how to utilise and work with teacher aides in the classroom environment.

7. Awareness of Potential of Children with ASD, their needs and how to met them, the personal burden on their families, and the hopes of families and children with ASD.

For parents with ASD children, possibilities for the future are highly dependent on the support and assistance their child receives throughout the school years. Of deep concern to many parents is the social and behavioural development of their child with ASD. The extent to which their child can become more independent in their adult years is very dependent on the degree of trained professional assistance received at school.

Parents are already under huge pressure to cope with the continuous needs of their child with ASD. The last thing they need is to be forced to battle for adequate support within the school environment. Parents who have deliberately opted out of the battle for public services and have the income to pay for private services are very aware that they have increased their own personal burden, and let the government off the hook. Many commented that providing the assistance they were accessing privately should be a responsibility of government – however they could not afford to wait for public services to get their act together.

Parents of children with ASD are acutely aware that their children can learn and grow towards becoming successful contributing adults in our society. However this is highly dependent on receiving support geared towards their specific, individual needs and processing methods. Without this support there is a real risk children with ASD will be dependent long-term on both their parents and the public welfare system. Parents of children with ASD cannot manage on their own – their children need an education equal to those without special needs.

References

Attwood, Tony (1999) "Asperger's Syndrome: A Guide for Parents and Professionals" (6th Impression) Jessica Kingsley Publishers Ltd

Howlin, P. (1998) Children with Autism and Asperger Syndrome, A Guide for Practitioners and Carers. Chichester: John Wiley and Sons.

Jordan, Rita & Powell, Stuart (1995) "Understanding and Teaching Children with Autism" John Wiley & Sons

Waterhouse, Stella (2000) "A Positive Approach to Autism" Published Jessica Kingsley Publishers Ltd. Copy write Stella Waterhouse

Appendix I: Demographic Profile

- 80% Males, 20% Females
- 44% with Aspergers, 47% with Autism, 4% with Aspergers/Autism border, 1% with Other, 4% Don't Know.
- 72% NZ European – Pakeha, 1% Maori, 4% Maori/NZ European - Pakeha, 4% Chinese, 4% European, 3% Indian, 12% Other.
- Of students receiving SE2000 funding (n=86): 77% are on ORS, 5% are Behavioural, 6% are Transitional, 1% are Communication Initiative, and 12% Don't Know.
- Of Students with Aspergers receiving SE2000 funding (n=24): 71% are ORS, 17% are Behavioural, 4% are Communication Initiative, 4% are Transitional and 4% Don't Know.
- Of students with Autism receiving SE2000 funding (n=55): 80% are ORS, 5% are Transitional and 15% Don't Know.

Appendix II: ASD and ORS Criteria

ASD is a Pervasive Developmental Disorder. It is life long. We can therefore surmise that a person is likely to have ongoing needs. The capped figure of 1% of total school age population to receive ORS funding is grossly under estimated. 1% of the population suffer from autism (Waterhouse 2000) and as we will show here, by definition of that diagnosis, all these children meet the criteria for high needs. However reality and capped funding results in many of these children not having their educational needs met and not receiving what they are entitled to.

Criteria for High Needs:

"Students with very high needs are expected to have ongoing needs throughout their school years because they require one or more of the following:

- Total adaptation of all curriculum content (when compared with students of similar age who do not have special education needs)
- Special assistance to engage in all face-to-face communications
- * Specialist one-to-one intervention at least weekly or specialist monitoring at least once a month, together with daily special education support provided by others.

This support must be to assist with any or all of:

- Personal care
- Mobility, positioning, transfers
- Needs arising from severe disorder of both language use and social communication."

How ASD Matches the Criteria for High Needs:

Research has shown that people with ASD have a predominantly visual style of thinking (Hurlburt, Happ & Frith 1994). There are definite advantages to this, but there are also drawbacks, especially if information is presented verbally. This requires many processing stages for the visual thinker. They must translate the verbal information into visual information, then process and respond, then convert the visual response into a verbal response and then execute their response verbally. All these stages require time, and each stage involved in any process increases the likelihood of mistakes being made to the end product. In a fast moving education setting, where teachers may be asking pupils questions, the time required for a visual thinker to respond is often not accommodated by the teacher who believes that the student is either unable to answer or has 'chosen' not to. **These children will require total adaptation of the curriculum to accommodate their processing methods.**

An interesting characteristic of Asperger Syndrome is that people "may not conform to the traditional sequence of stages in acquiring scholastic abilities and may take some time to learn basic skills or acquire

precocious or original abilities using an unconventional strategy." (Attwood 1999) These children appear to have different modes of thinking and problem solving and this will require adaptation of the curriculum.

With children with autism or Asperger Syndrome, "the prime fact to remember is the maxim that **a child should not be expected to learn more than one new thing at a time and that levels of difficulty within a problem should not be increased within more than one dimension at a time.**" (Jordan & Powell, 1995). This also demonstrates a clear need for total adaptation of a curriculum for children with ASD. Adaptation of curriculum is mostly across, not necessarily down and can sometimes be up.

Rimland (1990) found that **40% of children with autism suffered from sensory sensitivity**. Studies have shown that this figure is also accurate for Asperger Syndrome (Garnett & Attwood, '95; Rimland, '90). Sensory sensitivity has many implications. "When I was a child, loud sounds like the school bell hurt my ears like a dentist drill hitting a nerve. Children with autism need to be protected from sounds that hurt their ears. The sounds that will cause the most problems are school bells, P.A systems, buzzers...and the sound of chairs scraping on the floor...Some autistic people are bothered by visual distractions and fluorescent lights. They can see the flicker of the 60-cycle electricity" (Grandin '98). These children need special consideration in the classroom setting. Not only will they require adaptation of the curriculum, they **may also require modification of the environment**.

In terms of communication ability, the diagnostic criteria coincide with the criteria for very high needs.

"Qualitative impairment in social interaction, as manifested by at least two of the following:

1. Marked impairments in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction
2. Failure to develop peer relationships appropriate to developmental age
3. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. By a lack of showing, bringing, or pointing out objects of interest to other people)
4. Lack of social or emotional reciprocity"

DSM IV Diagnostic Criteria for Autistic Disorder 299.00 and Aspergers Disorder 299.80

These criteria clearly outline difficulties that each and every person has in the area of face-to-face communication, in order to be diagnosed as having autism or Asperger Syndrome. "Communication is at the core of the autistic difficulty with learning and it must therefore be at the heart of any effective educational approach" (Jordan & Powell 1995).

Autistic Association Survey Results

193 People with ASD surveyed

180 Families surveyed (13 families had 2 family members with ASD)

16 Refusals

Parents and professionals developed the survey over a 12-month period and parents and volunteers undertook the interviewing by phone.

The survey was completed in May 2000.

PART 1

ASD Spectrum:

- 44% Aspergers, 4% Aspergers Autism border, 48% Autism, 3% Don't know, and 2% other.

Gender:

- 80% Male, 20% Female

Age Groups:

Age Group	Number	%
Under 5	28	15
5-6 years	43	22
7-8 years	30	16
9-10 years	23	12
11-12 years	19	10
13-15 years	12	6
16-19 years	19	10
20-25 years	10	5
26-29 years	2	1
30-39 years	3	2
40-45 years	4	2
	193	100

****Geographic Area:**

Still live at home:

- 93% of respondents with ASD still live at home

Accommodation Provider for those not living at home:

Spectrum Care	4
Private Trust	1
Accommodation for Mental Health, Nth Shore	1
Creative Enterprises	1
Private Tenancy	1
Foster Parents	1
With Brother	1

How Many Children Live at Home for those living at home(n=174):

Children at Home	Count	%
0	2	1
1	35	20
2	92	51
3	42	23
4	6	3
5	1	1
6	1	1

Appendix 5.16

Number of Adults Living in Home:

- 1 Adult 13%, 2 Adults 76%, 3 Adults 6%, 4 Adults 3%, 5 Adults 1%, 6 Adults 1%

Number of Parents at home:

- One Parent 13%, Two Parent 82%, Not applicable 1%, No response 4%.

Person most Responsible for Care:

- Mother 71%, Shared by Parents 14%, Father 4%, Self 3%, Parents and Grandparents 2%, Accommodation caregiver 2%, Parents and Self 1%, Other 5%, No response 2%.

Verbal/Nonverbal:

- 77% Verbal, 21% Nonverbal, 2% Between verbal and nonverbal.

Communication Level:

- No Communication 6%, Some Communication 52%, Full Communication 41%, Don't Know 1%, No response 1%.

PART 2: Diagnosis and Follow-up

Diagnosed with ASD:

- 91% Diagnosed, 9% Not Diagnosed

Of the 17 Undiagnosed 7 had another diagnosis.

Number Diagnosed with ASD on First Diagnosis:

- Of those diagnosed with ASD (n=176), 61% were diagnosed with ASD on their first diagnosis and 36% were not.

Number of Diagnosis before ASD Diagnosed:

- Of those not diagnosed with ASD on their first diagnosis (n=63), 38% had one other diagnosis before ASD, 27% two other diagnoses, 14% 3 other diagnoses, 3% 4 other diagnoses, 2% 5 other diagnoses, and 2% 6 other diagnoses.

Age Diagnosed:

- Of those diagnosed with ASD (n=176), 5% were diagnosed under 2, 15% at 2 years, 24% at 3 years, 10% at 4 years, 22% at 5-7 years, 9% at 8-10 years, 6% at 11-15 years and 9% over 15 years.

Diagnosis Comment:

- *Diagnosis a relief*
- *Very vague with diagnosis*
- *2 paed both hesitant to confirm - oct last yr, june reassess. Mum jumped up and down from 2.5 to 4 yrs, things not the same, no help or clues*
- *SES thought something else. Sought second opinion for SES, for SES so didn't have to wait. SES said not to join - would treat Asperger differently - why sought second opinion - for support*
- *Team reluctant to give her a diagnosis - Kathy from assoc came & wanted diagnosis - took 6 months*
- *SLT knew that was some disorder - didn't say anything. Tried to get diagnosis at school age, Starship, didn't agree to go to health camp, wouldn't help after that*
- *Professionals here did not recognise - highly functional*
- *Diagnosis at insistence of mum, IHC wrong. No hope or support - no better off after diagnosis, knew what coping with, name helped. Felt got right diagnosis.*
- *No referrals at all, left to mum because knew was a EIT, mum had to do all herself*
- *No one would diagnose, hidden in intellectual handicap*
- *Kindy noted may be autistic at 3 and a half. Daughter is now uni student - psychologist - understand and confirm*
- *Professionals didn't want to be one that pursued and nailed, can't be bothered doing scales and real reluctance to tell parents. Don't like glamorising autism, diagnosing professional makes out as wonderful - think something wrong with you, lot of hard work, not address difficult staff, not want to frighten other parents but need realism. NZ lip service - ejected from offices, given only a few minutes, couldn't say what to do with parents, can't be right, just paid \$120 for 4.5 minutes - devastating news and ejected.*

Indication of ASD Prior to Diagnosis:

- 75% had an indication of ASD prior to diagnosis, 24% had no indication, and 1% no response.

Source of Indication of ASD:

- 48% had an indication of ASD from family, 13% from friends, 11% from playcentre/kindy, 2% from a doctor, and 5% from Special Education Service.

Number seeing other professionals while looking for a diagnosis:

- 74% saw other professionals while looking for a diagnosis, 23% did not, 1% don't know and 3% no response.

Comment re seeing other professionals – of note is the number of professionals parents are having to see in order to reach diagnosis and the perseverance required to keep looking for a diagnosis:

- South Auckland Development Team
- Campbell Lodge first, Tony Attwood confirmed
- Ref by GP to Dr Warwick
- In Starship for a yr a lot
- Paed, GP, SES
- Saw all professionals. Went to roughly six diagnosing professionals to try and get diagnosis. Starship supportive up to a point - then door closed. 3 or 4 diagnosis was from Tony Attwood
- Lesley centre
- Ear specialist
- Paed said may or may not be ASD
- Glenburn Behaviour Mod Programme, Allergist privately - trying to get diagnosis. Numerous Parenting courses
- Have seen 3 Paed
- Plunket & GP
- Everyone, since 1.5
- Paed really & son ADHD
- Autism Association, GP
- Andrian Trenholm, Children's Health
- Rosie Marks, SES, Mark Gudex
- Hearing Specialists
- Many doctors - said Autism
- Starship Rosie Marks
- SLT, OT, Psychologist, Psychiatrist, saw everything.
- Originally Christchurch lady said nobody could diagnose adult - only person Tony Attwood, on waiting list. Then told not coming- another call re another person for diagnosis.
- Tony Attwood
- Campbell Lodge Clinical Psych. Ed Psych through Speld
- Specialist - under IHC when found out brain damaged
- Child Development Unit - Team
- Team supportive - CCAF - needs assessor Com Child & Adolescent - not sure from where
- SLT - Paed - GP
- First diagnosis SES team, second Warwick Smith
- Another paed
- Plunket - hearing tests - SLT
- School counsellor, private psychologists late 1970s early 80s
- Hearing specialists
- 4 paediatricians
- Through SES saw SLT and psychologist, took through diagnosing stages
- SLT
- Used Marinoto clinic who said that child did not have ASD. With referral's, was originally referred to Bernadette Salmon, then Greenlane Clinic
- Professor Werry
- Rosemary Marks
- Hearing tests and ENT

Appendix 5.16

- GP and ENT specialists
- GP, Paediatrician and Marinoto Clinic
- Psychiatric unit at Auckland University and Campbell Lodge CMHT
- diagnosis supposed to be public but ended up being billed
- Psychiatrist, Paed, SLT
- SES involved from Kindy - not say what was
- Child Psychologist
- Superclinic, SES, Presbyterian Support, Paed
- GP specialised in Attention Deficit & Vital Services Education backup
- Marinoto Clinic
- Warwick smith
- SES - doesn't need another label. Campbell Lodge, tested for fragile x, once Rosemary (very supportive) left - no support. Tried to get diagnosis through public but wouldn't give - waiting list, not zoned for Auckland Hospital. Relief to have diagnosis - didn't feel happy with previous diagnosis
- Rosie Marks
- GP, Paed, Plunket Nurse. first diagnosis by Tony White at Mangere under Prof Werry, before closed
- Hearing tested, paediatrician
- SLT
- Tony Attwood
- GP, SES - left to mum
- GP & head injury, Epilepsy, full track, SPELD, fobbed off. Diagnosed at Henderson House
- Paed, Auckland Hosp, IHC,
- SES, Auckland Hosp
- Also saw ** private - big hangup about saying 'may' have Autistic Tendencies with Developmental delay. No referral process with Asperger boy - no needs requiring assistance considered.
- GP several times, Child Development Unit, SLT, OT, Rosemary Marks

Public/Private sector of formal diagnosis professionals:

36% of respondents received a formal diagnosis from the private sector.

49% received a formal diagnosis from the public sector.

2% received a formal diagnosis from the public and private sector.

2% received a formal diagnosis from SES

8% no response

- triple a team, overseas, Auckland uni, CCS, SES & public
- includes those not receive a diagnosis

Supportiveness of Diagnosing Professionals:

- 42% found their diagnosing professionals extremely supportive, 33% moderately supportive, 2% moderately to barely supportive, 9% barely supportive, 6% not supportive, 1% supportive because paying for support, and 7% no response.

Number Offered a Second Opinion:

- 70% were not offered a second opinion, 19% were offered a second opinion, 3% said they did not need a second opinion, 1% don't know, and 8% no response (the no response group includes people who have not been diagnosed and people who were diagnosed overseas).
- Out of a total of 36 respondents offered a second opinion, 17% were offered a psychologist, 17% a psychiatrist, 25% a paediatrician, and 11% Other.
- Of the same 36 respondents offered a second opinion, 25% were offered a second opinion from the private sector, 31% were offered from the public sector, 6% from SES, and 3% from SES and the public sector.

Number Seeking a Second Opinion:

- 28% of respondents did seek a second opinion, 61% did not, 2% are currently seeking a second opinion, 1% don't know, and 8% did not answer.
- Out of a total of 55 respondents who have sought a second opinion, 31% saw a paediatrician, 11% saw a psychiatrist, 27% saw a psychologist, 7% saw Tony Attwood, and 11% saw a other.
- Tony Attwood, Rosie mark, psychologist overseas

- Out of the same 55 respondents, 47% sought a second opinion from the private sector, 31% sought a second opinion publicly, 2% saw public and private, 4% sought a second opinion from SES, and 2% from the Wilson Centre.

Referral to Other Services Following Diagnosis

Referral to SES following diagnosis:

- Immediately following diagnosis 25% were referred to SES, 32% were already there, 18% said SES was not applicable, 2% said SES did not help, 1% self referred.

Referral to Child Health Development Team following diagnosis:

- Immediately following diagnosis 25% were referred to Child Health Development Team, 9% were already there, 3% don't know, 2% not applicable, and 1% CHDT gave diagnosis.

Referral to Child Mental Health Team following diagnosis:

- Immediately following diagnosis 5% were referred to CMHT, 3% were already there, 3% don't know, 2% not applicable, 61% were not referred and 27% no response.

Referral to Marinoto following diagnosis:

- Immediately following diagnosis 8% were referred to Marinoto, 2% were already there, 1% don't know, 1% were diagnosed at Marinoto, 2% not applicable, 63% were not referred to Marinoto, and 25% no response.

Referral to Campbell Lodge following Diagnosis:

- Immediately following diagnosis 5% were referred to Campbell Lodge, 2% were already there, 1% were diagnosed there, 1% not applicable, 66% were not referred and 26% no response.

Referral to IHC following diagnosis:

- Immediately following diagnosis 15% were referred to IHC, 4% were already there, 2% not applicable, 1% were referred but nothing happened, 1% were made aware of IHC, 61% were not referred to IHC, and 18% no response.

Referral to CCS following diagnosis:

- Immediately following diagnosis 8% were referred to CCS, 4% were already there, 1% don't know, 1% not applicable, 62% were not referred to CCS, and 24% no response.

Referral to the Autistic Association Auckland Branch following diagnosis:

- Immediately following diagnosis 49% were referred to the Auckland branch, 4% already knew about the branch, 1% don't know, 23% were not referred to the Auckland branch, and 23% no response.

Referral to the National Autistic Association of New Zealand following diagnosis:

- Immediately following diagnosis 9% were referred to National, 2% already knew, 1% don't know, 39% were not referred to National, and 50% no response. (No response includes those that are not members of National)

Referral to other services following diagnosis:

- A number of families mentioned other services which they have been referred to. Two families had been referred to Nascent, 3 families specifically mentioned a referral to Spectrum Care, two families have been referred to people at Auckland University, two families said that Tony Attwood had been mentioned, two families said they were referred to counselling and two families commented that they had to do all the referrals themselves.

Other referrals mentioned were:

- *tough love*
- *Autistic Assoc South Africa & School for Autistic Learners in South Africa*
- *internet sites*
- *Speech Sch Riverhill*
- *Psychologist through the school special needs*
- *private OT*
- *CYPS*

Appendix 5.16

- *later Hearing Assistant*
- *Ed (speech/OT) private*
- *Income Support*
- *another parent*
- *hearing assessed*
- *Developmental Paed*
- *SES*
- *Dietician*
- *social worker Wilson Home*
- *Carrington took charge - no referral*
- *Early Intervention Team at Mangere Hospital*
- *Greg Smith at Middlemore*
- *network of other parents*

Number Advised of Carer Support Days:

- At the time of diagnosis 26% of respondents were advised of Carer Support Days, 8% already knew, 53% were not advised, 4% said not applicable, 7% did not respond, and 1% were advised later.

Number Advised of Handicap Child Allowance:

- At the time of diagnosis 35% were advised of Handicap Child Allowance, 44% were not advised, 9% already knew, 4% said not applicable, 1% were advised later and 1% other.

Sources used to find out about Available Services:

Phone book	19%
Citizens Advice Bureau	4%
Doctor	46%
School	14% (8% said school was not applicable)
Media	7%
Word of mouth	48%
Spectrum Care	7%
SES	44%
CCS	16%
IHC	17%
Autistic Association Auckland branch	69%
National Autistic Association	17%
Other source	44%

- 12% of respondents used the phone book to find the Autistic Association. The phone book was also used to find a needs assessor, OT, SLT, music therapy, SES, Youth Law Project, WINZ, and paediatricians.
- 3 respondents used the Citizens Advice Bureau to find the Autistic Association and one respondent used it to find a kindy.
- 2 respondents used a article in the newspaper to find out about and contact the Autistic Association.
- Spectrum Care was used by a handful of respondents to find out about/access the Autistic Association, behavioural programs, toileting programs, and a social worker.
- 2 respondents found out about swimming classes from CCS. Respondents also found out about the following from CCS: the Hallberg Trust, information on preschool, SES, IHC, SLT, OT, Physio, toy library, social worker, helped organise respite care, and their handbook lead to the Autistic Association.
- 6 respondents found out about Tony Attwood from the National Autistic Association, 2 videos, 7 books, 2 newsletters and one found out about workshops from the National Autistic Association.
- 133 Respondents found out about services from the Autistic Association, Auckland branch. Of these 16 respondents specifically mentioned support groups, 9 found out about the Handicapped Child Allowance, 8 specified carer support days, and 5 CCS.
- 33 respondents found out about services from IHC. Of these 7 mentioned IHC's own services and 3 specified the Handicapped Child Allowance. Of those that did not find IHC a source for services 4 mentioned IHC could not help.
- 84 respondents found out about services from SES. Of these 4 specifically mentioned finding out about the Autistic Association from SES, 4 specified the Handicapped Child Allowance, 3 specified IHC, and 2 specified carer support days. 2 respondents also commented that they found SES did not inform them of available services.

- 93 respondents found word of mouth a source of services. Of these 14 specifically mentioned finding out about the Autistic Association through word of mouth, 8 specified Handicapped Child Allowance, 7 specified CCS, 6 specified carer support days, and 7 specified respite care. 15 respondents commented that their main source of word of mouth was from other parents. Many other services were also identified through word of mouth.
- 27 respondents found out about services from school. Of these 4 specified finding out about SES from school, 3 specified teacher aides, and 2 specified respite care. 100 respondents said that school was not a source to find out about services. Of these 5 commented that they had more information than the school and three commented that their schools' were dreadful.
- A doctor was a source for services for 89 respondents. Of these 19 specified finding out about the Autistic Association from a doctor, 7 specified SES, 5 specified Handicapped Child Allowance, 4 specified respite care, 7 specified paediatricians, 3 specified Spectrum Care, 2 specified IHC and 3 specified a referral to Starship. Parents were also informed of a range of other services from doctors.
- Out of the 84 respondents who used other sources to find out about services 2 used Barnados, 9 used kindy/childcare centres, 3 used friends, 6 used the internet, 3 used Marinoto, 8 used needs assessor/nascent, 3 used other parents, 2 used a pamphlet seen at a doctors surgery/Starship, 2 used Plunket, 6 used psychologists, 7 used SLTs, and 5 self-referred to other services.

Parents also mentioned the following sources to find out about services:

- Auckland Uni Noticeboard - Autistic Assoc
- Another Support group (their guest speaker). East Auckland SNSG
- caregivers
- Carer support assessment Dr referral to IHC. Kindy lead to SES. IHC Area manager Denise Wilcox most helpful. Letters to MPs. Parent to Parent through respite carer.
- Child health development team
- coffee groups
- Degree at Massey
- Glen Stenhouse
- Hohepa
- Little Treasures magazine - Autistic Assoc contacts.
- Mangere Hospital team
- UK, NSW, USA via internet
- visit MP for Christchurch
- Waitemata health care
- Wilson Home
- noticeboard at Community Child Adolescent & family
- OT
- paediatrician
- Parent Down Syndrome
- Schizophrenia Fellowship referred to mental Health Autistic Assoc Christchurch - ref to Auckland.
- Waitemata Health - lead to Spectrum Care

Following is the services that other sources lead to:

Source	Service
yes - can't remember	needs assessor
School	
Waitemata Health - lead to Spectrum Care	SES, IHC
Plunket nurse started service trial off	lead to preschool - OT & SLT
needs assessor	lead to Spectrum care or IHC
Glen Stenhouse	Autistic Assoc Auckland.
Newsletter - lead to Arohuni (IHC).	
Asked MP for help.	
Used Parent to Parent	
yes	Prof Werry. Handicap - carer support
yes	other parents
Daycare	Autism assoc
psychologist	referred to psychiatrist
Kindy	SES

Appendix 5.16

	Only just found out branch in Waikato from Auckland newsletter. Psychologist hinted why were they there - just accept him.
local kindy had special unit	SES, early intervention
Child health development team	OT
	Internet as a source, also school, into suggestions, things to try
kindy	IHC, Campbell Lodge
	Rely on self - not rely on others, don't go to organisations for help
parents	coffee groups, carer support, HCA nappy service
Parent Down Syndrome	Respite Care, initially HFA said not eligible - Nascent organised, HCA
Wilson Home	Marinoto
SLT, Nascent	meet in Howick
self referral	IHC, Autistic Assoc
kindy	SES
SLT, Jill Bulian	Autistic Association
yes	I initiated all contact with any services . I did this prior to contacting CAB and then later the local Autistic Assoc. No referral was given on services from diagnosis or when contacted a NZ GP - appalling.
yes	internet for information
Psychologists, Mangere Central Unit	info on Aspergers
other parents	respite care, SLT, OT, Disability Allow from friend. Waitemata Health Karen McConachy - assessed for respite care
needs assessor	parent to parent, not much around
Mangere Hospital team	found out everything, OT, SLT preschool, Spectrum care, heaps of help, support and ideas
needs assessor	asked for respite care, interested in respite care - can't get information on that
SLT - pamphlet & business cards	remembered Autistic Assoc
Private Montessori preschool	6 hr TA - at school no set TA
needs assessor	holiday programme
	nothing really firm - not knowing who was talking to - bit of a blur
	see Angela Arnold for extra help
Waitemata health care	carer support days. Respite care person - IHC and CCS
yes	tutor
yes	Angela Arnold at university. Referral for HCA & respite care. Said what was available
Plunket identified slow talking,	contacted SLT through another parent, referred to SES, referred to paediatrician
yes	asking questions, SLT
yea	own reading and researching on the internet
coffee groups	parents very informative
OT & SLT	put in contact with other parents whose children have language disorders
needs assessor and self (organised OT by self)	CHA, Spectrum Care (no help) organised OT by self
yes	internet info
Nascent	IHC. Self - initiated to find out information and research. Internet - logging onto conferences, international research
playcentre	had a social worker - wanted diagnosis - ref to Marinoto
Internet	overseas contacts. Pathfinder bookshop good.
visit MP for Christchurch	happy to push in Parliament if needed
Marinoto	Autistic Assoc
internet and library	general information, contact professional in states
paediatrician	Marinoto main service - hard to remember what referred to

self referral	SLT start, Autistic Assoc. Stumbled on things - no handbook spelling out what entitled. Nascent - found out late.
childcare centre	called in SES for TA, mum not understand, referred to public health doctor for hearing tested & eventually diagnosis, CS used 7-8 yrs. Grandmother was TA - did lots of investigating - public system relied on her - went to bottom of list because grandma there helping.
Self referral	investigated all services before came to NZ, Autistic Assoc, Somerville. North Health - carer support but didn't use it much
Hohepa	respite later on, into ** for 3 days, supposed to have been 3 weeks but could only cope for 3 days
yes	through neighbours referred to another family with a child commencing a home programme
Barnados	Family member of Barnados woman has ASD - large knowledge
Barnados worker	shared knowledge
self-referral	Brain injury assoc supported him. Family counsellor through Health service hopeless
yes	Went to US - Seattle University, overseas services
friend	Campbell Lodge & Health Development - lead to SES. SLT lead to OT
caregivers	HCA, carer days - 28 days last year
Degree at Massey	Special needs papers list all services available - big eye opener

PART 3: General

Percentage of people with ASD with specialist in ASD working with them:

- 33% of respondents have someone working with their child who specialises in ASD, 64% do not, 1% don't know, and 3% did not respond.

Who Specialises (need to refine groups and check totals):

Through school:

- Arohuni special school some staff
- Autism class at Arohanui Special School
- only caregivers untrained Mt Richmond school
- satellite unit at MT Richmond school, teacher trained in Australia
- at school Psychologist every 15 days, Karen from Spectrum
- only at school now
- Phoenix Center Pakuranga - teacher experienced, TA beginning
- school only 1 teacher
- School psychologist has done lots of learning
- Special Satellite class for autism
- Special school set up for parents
- Special unit at school, in Hong Kong learnt from Autistic society
- Sunnybrae & Aranui special schools - assume teachers and professionals involved have Autism training
- TA has Aspergers himself, 2.5 hrs wk, pay privately
- TA worked with Aspergers before & SES psychologist
- teacher
- Teacher - Robyn Heatherington
- Teachers at Arohanui

Precision Teaching – 4 respondents:

- group of Precision Teachers
- Autism Action Precision Teaching Ctr
- Precision Teaching run out of Wilson Home

Appendix 5.16

- Superclinic at Campbell Lodge, specialised team
- Mum - 2

Professionals:

- lost ** since 4 years old. Asked for referral, 5 minute appointment in August, can't recommend
- Michael Horton, music therapist who specialises in autism
- only Sue Robertson & Colin involved with him
- Paed but not working with
- Paediatrician - Warwick Smith
- Parents & ESW team from SES
- Pro Ed social skills
- psychiatrist
- Consultant from Card, Australian
- David Lyons, clinical psychologist with SES (only saw once), and SES regional manager worked with for a year. Jenny Spring was excellent.
- Dr Rosemary Mark
- Rosemary Marks
- Glen Stenhouse
- Gretchen
- Warwick Smith, Tony Attwood
- with Prof at Waikato Uni through friends in the States - as a favour, ph him with problems
- Ann Christie
- Angela Arnold – 5 respondents
- past Angela Arnold
- Clinical Psychologist critiqued programme

Therapists – 7 respondents:

- Home Therapists - 1 from Lovass, another attending Precision learning in Perth
- Lianne Smith, therapist done precision teaching, worked in England. home programme 2.5 hrs a week, 5 days a week
- GP or Therapist who heard of Aspergers
- Behaviour therapist
- therapist - Leslie Hanson
- therapists
- therapists @ Wilson Home Sch, Michael Horton, music therapist

Students – 2 respondents:

- Masters Student
- women doing cast study uni

Respite care workers:

- IHC & Spectrum - helpers trained
- Spectrum Care worker - training in Autism in house, & Special Needs School trained.
- Spectrum Psychologist, Marinoto - Psychotherapist, Arohanui special school
- Use Spectrum care. Medicated son to ease behaviour, IHC promised more time - not received. Quality is sometimes a problem

Psychologists – 3 respondents:

- Psychologist
- psychologist with SES
- Psychologist. Vanessa Geel EM SES

SLTs – 7 respondents:

- SES, SLT, Psychologists, Needs Assessors
- SLT & Psychologist at school
- SLT from England quite specialist

- SLT last year worked with autism. Private therapist training at uni had worked with other children with autism, and Angela Arnold
- SLT or TA
- speech therapist
- experience SLT from Proed

Percentage needing crisis respite care:

- 21% need crisis respite care, 5% said not applicable, 1% don't know, and 59% do not need crisis respite care.

Percentage accessing crisis respite care:

- Of the 41 respondents who need crisis respite care 73% cannot access it, 15% can, 5% don't know.
- Of the 6 who can access crisis respite care 3 are satisfied with the quality and 2 are satisfied with the quantity.

Percentage needing regular/ongoing respite care:

- 54% need regular/ongoing respite care, 1% don't know, 4% not applicable, 33% do not need regular/ongoing respite care.

Percentage accessing regular/ongoing respite care:

- Of the 104 respondents who need regular/ongoing respite care 53% can access this care, 40% cannot, 1% other and 6% no response.
- Of the 55 who can access regular ongoing respite care, 84% are satisfied with the quality and 11% are not satisfied.
- Out of 55, 62% are satisfied with the quantity and 33% are not.

Percentage needing occasional non-crisis respite care:

- 51% need occasional non-crisis respite care, 23% do not, 1% don't know, and 4% not applicable.

Percentage accessing occasional non-crisis respite care:

- Of the 98 respondents who need occasional non-crisis respite care 48% can access this, 47% cannot, and 5% no response.
- Of the 47 accessing occasional/non-crisis respite care, 72% are satisfied with the quality (one noting that it is her mother) and 1% are not.
- Of the same 47, 55% are satisfied with the quantity and 32% are not.

Many comments were made regarding respite care, particularly the difficulty of finding someone to provide approved carer support days.

- Care required is at home or *carer taking child out for the day. Respite care is too far from home, too distant, too frightening for boy. Receive no help.*
- *Need respite earlier but not accessible*
- *I don't have any idea - re accessing respite care*
- *Spectrum care is provider. Room for improvement in quantity, need to book a long way ahead.*
- *Don't know how to access crisis respite care, holidays really hard re quantity of care*
- *Still waiting for respite care*
- *Respite care always said to be available but difficult to access*
- *Unable to obtain respite care*
- *Don't know where to obtain respite care from*
- *Can't find suitable person. Plenty of days but no person*
- *Can access crisis respite care but needs ongoing respite care*
- *Different caregivers couldn't cope and not suitable (has other diagnosis). Regular respite has been struggle - people came and went. Abused by caregiver. Quantity insufficient because needed more - wore everyone out.*
- *TA not taught anything, babysitting, OT & SLT not there*
- *Not had a day off since 2. Read about Asperger 1 year ago. Services not help at all - try to take off you - Starship. 28 days but no caregiver.*
- *Found difficult to find qualified carers - trust friends more*
- *Crisis respite care from parents, regular respite care from IHC home help*

Appendix 5.16

- *Learn to live with quantity*
- *Won't leave mum, very hard. Have to get through.*
- *Family provide care - want money for them*
- *Trying to get regular ongoing respite care*
- *24 hours at Spectrum, see alternate days, there for 2 years*
- *Spectrum Care*
- *Foster parent works at school, loves working with Autistic children, IHC asked to them to foster. In past lived on own in 1 bedroom flat - IHC 6 hr a wk, 28 days respite, left work to look after him.*
- *Not now son in 13. Did have when younger for a little while. Only got 2 days when applied for 28, gave up after that. Carer had 13 children at a time. Now sometimes leave with grandparents. Counting days til 17 years.*
- *Was looking after grandmother for 11 years - thought grandma was source of sons problem. Had respite from grandma. Son unlikely to leave home - can't up stranded in any way. Need someone to housekeep and look after him - when do go away gets into great difficulties.*
- *But do not know where occasional respite care is available - never used any.*
- *Not tried respite care. would use if son would go.*
- *Don't need respite now as in full time care. Use to at home through IHC. Short stay Mangere. first IHC home Monday to Friday. Permanently once husband died.*
- *Need respite care but wouldn't use unless if someone knew*
- *Sister is respite care, never enough*
- *Don't know how*
- *Son very attached to mum - unsure if use. 2 friends - 28 days not much*
- *Greatest need is for crisis respite care. looking into using grandmother for non-crisis respite care. Not followed up and setup yet, paperwork only*
- *Manage between family*
- *But respite care is always in own home, would like to take him somewhere instead.*
- *Grilling for extra days - very unhelpful, run out of days, desperately need more times. Mother-in-law takes her - services relying on her*
- *Desperate for respite care*
- *Older children provide respite care - unpaid*
- *Would like money for own respite staff - hire own nanny, go to care put in place by parents*
- *Gets some funded and uses family*
- *Therapists not qualified. Respite care provided by family only for crisis. Use respite care for therapy, chosen people, like more.*
- *No family in Auckland. High functioning. Not sure who to trust.*
- *Not easily access respite care - not used*
- *Access respite care privately - just been increased*
- *Very hard to find someone for respite care*
- *Respite care by 2 aunties*
- *Could not access in the past. Now through Spectrum. In Past really bad problems over 10 years - not totally comfortable with level of care, not what like but is necessary.*
- *Mum not fit enough to do activities and supervision lacking. Respite care not had staffing and activities needed. Not found quality wanted - trying Ashley college. 4 year term not work with 21 days. Would love to have 28 days - been cut.*
- *In past needed respite care - family support, brother or sister, would have been appropriate. Someone he knew - so not living with strangers in institution type setting, wanted family type situation, working had for progress.*
- *Don't trust people in institutions - lack understanding, not professional. Don't use because of quality. 28 days is good.*
- *Respite care not issue yet because have good family support - grandparents provide care. But as they get older and son grows bigger may become a problem. Pays for occasional respite care from niece - mother works full time to can afford to pay. Because organised by mum good quality - never used a stranger. If not working fulltime family wouldn't be able to afford to pay for respite care - 28 days on own would not be enough, especially when have to use school holidays. As son gets older becoming more of a strain.*
- *Keep lid on hours by not suppling good quality. Having to use family members or people know, limited - can't find anyone else.*
- *No behaviour related problems, not expecting a dramatic change, looking to set up a trust fund.*
- *Not sure if respite carer can manage alone, has to be somebody at home and carer asks for help. Carer is not a professional person, does not know how to manage/deal with child. Mother would*

like more time on own. Daughter cannot understand English so it is very difficult to find a good carer. Given 21 days the first year but didn't spend 1 day because couldn't find the right person. Next year spent only 13 days, this year only 10 days so far - not sure if can transfer days across years. Cannot use only English speaking carers.

- Not have people can trust with son, lots of bad experiences. Doing everything ourselves and need a break
- Using Carer Support Days, organising own carers, in home.
- Use carer support days, organise my own, in home.
- Liz Jewel - Wison home, use home therapists
- Use family members for respite care - excellent
- Family members excellent
- More if possible
- Brother provides respite care. Not enough, 28 days first year, 6 days second year - having to justify, go cap in hand, not worth it.
- TA from Kindy provides respite care
- Got through worst - needed earlier on. Respite care through IHC - use motherinlaw
- IHC and Spectrum sent out poor workers, inappropriate, not paying for calibre, lot of desperate people. Use respite to pay workers over holidays - not enough. Not interested in resistant workers.
- Would like respite care
- Daughter passed 16 - no respite care
- Still trying to get respite care - would like together in holidays
- Quality of respite care excellent
- Tried to get into Bridgeman House

Percentage receiving Carer Support Days:

- 50% of respondents received Carer Support Days, 35% did not, 2% had not applied, 1% don't know, 6% not applicable, and 7% no response.

Number of Carer Support Days Received:

- Of the 96 respondents who are receiving Carer Support Days, 14% have received 1 to 14 days, 40% 15 to 28 days, 29% 28 days, and 18% over 28 days.

Percentage receiving Home Support:

- 18% of respondents received Home Support, 69% did not, 6% not applicable, and 7% no response.

Hours of Home Support (n=35)

Hours	No Respondents	%
2	1	3
3	4	11
4	7	20
5	4	11
6	6	17
7	1	3
8	4	11
9.5	1	3
12	1	3
17	1	3
28	1	3
Appropriated but no one to do	1	3
Occasional	1	3

Home Support Paid By:

- Of those receiving home support IHC pays for 63% of respondents, Focus 2000 pays for 6%, Spectrum Care pays for 9% and the HFA, Nascent, North Health, SES & IHC, and voluntary organisation all pay for 3% each.

Appendix 5.16

Percentage of people with ASD with other health issues:

- Medication is a issue for 26% of respondents.
- Epilepsy is a issue for 12%, and in the past 1%.
- Toileting is an issue for 38% for respondents and in the past 2%.
- Eating is an issue for 47% of respondents, fussy eating 1% and eating in the past 1%.
- Sleeping is an issue for 34% of respondents, 2% sometimes, and 1% in the past.
- Mobility is an issue for 14% of respondents, and 1% in the past.
- 16% of respondents have a major health problem.
- 25% of respondents have a minor health problem.
- 39% of respondents have other issues. Out of these 76 respondents, 10 have asthma, 11 have behavioural issues, 6 have social issues, 4 have ear infections, 3 have grommets, 3 have teeth issues, 3 have ADHD, 2 cannot communicate pain, 2 have anger issues, 3 have depression issues, 2 have skin problems, and 2 have bowel problems.

Other health issues specified were:

- learning *problems*
- *migraines*
- *low muscle tone, epilepsy, toileting and sleeping all issue in the past*
- *Developmental delay. Poorly controlled epilepsy, speech still developing*
- *hits walls & furniture, over 70 kg - too big*
- *Asthma - can't take preventative*
- *issues around menstrual care*
- *Schizophrenia, Asthma*
- *Special diet*
- *hygiene, clumsy*
- *Behaviour, danger to himself and others extreme*
- *Absence spells*
- *brain damage*
- *diabetic, short sighted, multiple allergies, ENT, phobias*
- *Severe anxiety, shadows of obsessive Compulsive Disorder, on anti depressant - not subsidised*
- *very hyperactive, use to self injure and abuse, really bad, why now in care*
- *runner*
- *deafness, eyesight*
- *eye patch*
- *Collarbone - limited vision*
- *puberty, initial insomnia - not a big problem*
- *assoc disorders - genetically*
- *Squint, should wear glasses. Various wounds.*
- *safety*

Sources of support accessed for above health issues:

- 26% of respondents have accessed support from a paediatrician.
- 28% have accessed support from a GP.
- 18% have accessed support from Starship.
- 11% have accessed support from the Auckland Branch of the Autistic Association.
- 2% have accessed support from the National Autistic Association.

Cope GP:

Fine	58%
Fine to difficult	4%
Difficult	26%
Extremely difficult	9%

1% don't know, 1% not have one, 1% varies, and 2% no response.

Cope Hairdresser:

Fine	42%
Fine to difficult	1%
Difficult	19%
Extremely difficult	27%
Not been	2%
Mum cuts	4%
Family cuts	1%
No response	3%

Cope Dentist:

Fine	34%
Fine to difficult	1%
Difficult	18%
Extremely difficult	33%
Not been	7%
Don't go there	1%
No response	5%
Not applicable	3%

Cope Specialist:

Fine	37%
Difficult	17%
Extremely difficult	9%
Not applicable	3%
No response	34%

Cope Other:

Fine	4%
Fine to difficult	1%
Difficult	6%
Extremely difficult	7%
Not applicable	1%
No response	82%

Following are some comments regarding how their family member with ASD copes attending the dentist, GP, hairdresser and other specialists.

Dentist:

- off the scale for dentist
- dentist impossible - have to knock out
- Dentist - knocked out at Starship
- General Anaesthetic for dentist
- mum has to make dentist appointment (for an adult with Aspergers)
- not tried dentist
- needs general anaesthetic at the dentist
- cost problem and getting her there problem. General anaesthetic for dentist
- Under school dentist - need someone
- dentist have to knock out
- need general for fillings
- General anaesthetic for teeth
- lot of work into coping with dentist

Hairdresser:

- sister cuts hair
- don't go to hairdresser
- Hairdresser impossible.
- don't even try hairdresser
- never taken to hairdresser. Freaks at white uniforms.
- Never been to hairdresser, need team of 4 to cut hair. Avoid specialists.
- Can't sit in waiting room. Hairdresser was extremely difficult in past

Appendix 5.16

- *can't go to hairdresser, do themselves, has to be held down*
- *not taken to hairdresser for 3 years, do herself. not attempt dentist*
- *mum cuts hair*
- *hairdresser comes to home. Not go to dentist.*
- *Haircuts impossible.*

Past:

- *He has found these visits difficult in the past, now 23.*
- *Ears are painful. GP extremely difficult in past.*
- *GP extremely difficult in past*
- *all extremely difficult in past*

Other:

- *cranial osteopath has really helped*
- *wouldn't go to specialist*
- *well behaved with strangers*
- *any physical contact or demand made are resisted*
- *any touching of head extremely difficult*
- *Nails cut - huge problem. Hairdresser & GP used to be extremely difficult, now improving. Doesn't like being touched around ears and face*
- *sometimes ok sometimes not*
- *becomes anxious and fearful when visiting specialists*
- *not keen, have to bribe*
- *fine except for ears*
- *got used to them*
- *Lots of work to make work. Parades, supermarket, shopping - learnt strategies*
- *Never let instruments in mouth*
- *Not go to hairdresser. Gets general care form psychologist - very bad, not notice squint, GPs hate psych patients, very uncomfortable (Adult with ASD)*
- *language is a problem*
- *fine as long as dad is there*
- *therapy - difficult*

Ranking of sources of support to enable to cope with ASD family member (1 = extremely supportive, 2 = very supportive, 3 = moderately supportive, 4 = barely supportive, 5 = not supportive, 6 = not applicable):

- **IHC:** 1 – 3%, 2 – 9%, 3 – 7%, 4 – 2%, 5 – 7%, not applicable 66%, past 1 – 1%, blank – 6%.
- **CCS:** 1 – 3%, 2 – 8%, 3 – 4%, 4 – 3%, 5 – 5%, not applicable 69%, blank 7%.
- **All Health Services:** 1 – 12%, 2 – 17%, 3 – 22%, 4 – 10%, 5 – 7%, not applicable 42%, other 1%, blank 9%.
- **SES:** 1 – 13%, 2 – 12%, 3 – 17%, 4 – 8%, 5 – 14%, not applicable 25%, blank 6%.
- **Family:** 1 – 34%, 2 – 17%, 3 – 17%, 4 – 8%, 5 – 9%, not applicable 7%, blank 6%.
- **Friends:** 1 – 17%, 2 – 22%, 3 – 24%, 4 – 8%, 5 – 10%, not applicable 8%, blank 7%.
- **School:** 1 – 18%, 2 – 31%, 3 – 15%, 4 – 2%, 5 – 7%, not applicable 15%, blank 9%.
- **Church:** 1 – 4%, 2 – 6%, 3 – 6%, 4 – 2%, 5 – 4%, not applicable 74%, blank 5%.
- **Other parents with children with ASD:** 1 – 20%, 2 – 22%, 3 – 9%, 4 – 4%, 5 – 2%, not applicable 37% (of which 6% don't know any other parents), blank 5%.
- **Autistic Assoc Auckland Branch:** 1 – 22%, 2 – 24%, 3 – 21%, 4 – 8%, 5 – 1%, not applicable 10%, blank 12%.
- **National Autistic Association:** 1 – 4%, 2 – 4%, 3 – 7%, 4 – 4%, 5 – 1%, not applicable 30%, blank 50%.

Ranking of Sources of knowledge (1 very important through to 5 unimportant), for families (n=180).

- Health Professionals: 1 – 12%, 2 – 18%, 2 to 3 – 2%, 3 – 23%, 4 – 14%, 5 – 23%, not use 3%, na 1%, no – 2%, blank 2%.
- SES: 1 – 11%, 2 – 13%, 3 – 18%, 4 – 13%, 5 – 25%, not use 11%, na – 4%, blank 6%.
- Books: 1 – 59%, 2 – 18%, 2 to 3 – 1%, 3 – 13%, 4 – 2%, 5 – 2%, not use – 2%, blank 2%.
- Internet: 1 – 26%, 2 – 14%, 2 to 3 – 1%, 3 – 10%, 3 to 4 – 1%, 4 – 3%, 5 – 18%, not use 20%, na 7%.
- Workshops: 1 – 25%, 2 – 16%, 3 – 9%, 4 – 4%, 5 – 14%, not use – 18%, na – 11%.
- Conferences: 1 – 22%, 2 – 11%, 3 – 3%, 4 – 2%, 5 – 18%, not use – 26%, na 14%, 1 Hong Kong – 1, 2 Canada – 1, blank – 2%.
- Other Parents: 1 – 27%, 2 – 17%, 3 – 23%, 2 to 3 – 1%, 4 – 5%, 5 – 11%, not use 7%, not know any 2%, na 4%, blank 4%.
- Autistic Assoc Auckland Branch: 1 – 34%, 1 in past – 1%, 2 – 28%, 2 to 3 – 1%, 3 – 20%, 4 – 5%, 5 – 1%, 4 to 5 – 1%, not use – 1%, na 1%, blank – 7%.
- National Autistic Assoc: 1 – 8%, 2 – 9%, 3 – 10%, 3 to 4 – 1%, 4 – 3%, 5 – 3%, not use – 13%, na 4%, blank – 49%.
- 4% ranked the Autistic Assoc but did not specify whether this was Auckland or National.

Household Income (n=180)

Below \$30,000	22%
\$30,000 - \$45,000	23%
\$45,000 - \$60,000	20%
Over \$60,000	26%
Declined	3%
Don't Know	2%
Not applicable	1%
No Response	3%

Sibling Support Groups relevant to families needs (n=180):

Currently Yes	28%
Currently NA	8%
Past Yes	26%
Past NA	1%
Future Yes	45%
Future NA	1%

Social Skills groups relevant (n=193):

Currently Yes	53%
Currently NA	3%
Past	26%
Future	56%

Grief Counselling relevant (n=180):

Current	15%
Current NA	2%
Past	56%
Past NA	1%
Future	11%
Future don't know	1%

Appendix 5.16

Most Pressing Concerns for all respondents (n=193)

	Now %	Future %		
Schooling	61	72		
Housing	18	51		
Respite Care	39	50		
Employment	12	77		
Live in care	8	33		
Pressure on siblings	53	52		
Lack of counsellors for teenagers	21	59		
Lack of support services	62	66		
Financial issues	45	63		
Caring for ASD member after death	32	71		
Friends/social skills	72	79		
Guardianship	29	56		
Abuse	50	64	By them 25%	By Others 70%
Bullying	55	66	By them 21%	By Others 69%

Comments re most pressing concerns now and in the future:

Adolescents & Adults:

- If gets right help know ok in future. Guardianship - none arranged now.
- Live in care - hopefully under housing
- Unpredictable as in mental health - blessing in disguise - big concern is not organised or recognised for young adult with Aspergers - needs different from mental health - not ideal. Lack of activity, stimulation, education, exercise. Power of attorney given to organisation to look after - control amounts he has to be responsible with.
- Respite care for older children bit gap
- Would like homes for respite care especially for Autism. Can't afford services. Where to live is biggest concern - may not go back to mother.
- Concerned about suicide - when becomes depressed will kill themselves, not just attempt to. Concerned about day to day care when parents no there - medication, expectation of what he can do, not clean clothes. Grandparents have said they will not have him.
- Concerned tertiary education. Privacy Act is problem re managing money
- Restcare has now taken over and is the solution - lots of concerns in IHC.
- Not just son's employment prospects but mum's as well, are limited, in case needed by son in future.
- May have to get a granny flat. University concern money - student loan. Needs financial help. No join clubs and things. Still rocks and things, wonder if some medication can help - harms employment
- Financial issues in past
- Found Hoparta - for when not living at home - need supervised housing. Is worried about care after death especially with health problems for mum. Did have guardianship in place - don't know who else could take responsibility - trying to find a place.
- Will not be able to work or earn money. Worried about abuse because cannot explain.
- Financial issues definitely a problem in the past. Friends in past - especially making and keeping. Embarrassed re daily living skills needing assistance.

Comments re Support:

- Systems of support are very fragmented.
- Totally ignorant of support services. Concerned about abuse & bullying in the past by others
- If have money lots of issues not come up - pay for own services. Supervised access been issue in past re abuse.
- Lack of support services was issue for mum. More of information role at this stage
- Lack of support services especially since not ORS funded - left out in cold. High needs at home, moderate needs at school
- Feels as though parents are left to their own devices, and that parents are left to arrange everything, especially worried about being out of SES system the years are creeping by too much for family to cope
- Can access counsellors but have to pay and cannot afford to. Worried that you can never be guaranteed support

- *Need more followup with services*
- *Lack of support services not fair. Always paying out.*
- *Major lack of support services.*
- *Lots of grief having sibling treated so badly and suffering due to lack of services. Mum wants guardianship but not permitted. Husband wants to have in care - caused major problems, gave HFA an outer - now involved in legal system, due to lack of services. HFA not fund care he needs - not approach from a futuristic point of view - minimum for specific stage, instead of contribute to quality life later on, means have to spend heaps more later on.*
- *Lack of support services was a issue in the past but family has now adjusted their life to support themselves. Vulnerable to abuse because not speaking.*
- *If can't buy services for yourself - wonder how much there really is available, user pays environment means some parents not coping because cannot get support they need.*
- *Financial cost of son damaging house is very taxing, eg breaking all the windows. Concerned by lack of support services in the past but now wiped it all and doing all in family. CYPs took son away and had to fight to get him back, was placed in a unsafe home. Not worth using support services, lack a lot of knowledge. Abuse was issue in SYPS care because they didn't know how to care for him. Education - signing a really big concern. Hopes somebody will be there to care for son when parents no longer can.*
- *Schooling in past & now is huge concern - is TA at school & completing education. Sometimes mother would like a break from husband - quite demanding, would like to spend time with kids on own. If something happened to mother - father would lose the kids. Everything revolves around mother - go to custard if anything happens to mum. Really struggled financially - went to apply for disability allowance - both are tactile defensive, but WINZ reluctant to assist, nothing for mother re clothing, support not there financially. Unfortunate with head injury can't access full support system because if ACC found out dual diagnosis they would chuck him off.*
- *Not interested in what system provide, only shortterm solutions at school. Never support in system to level required. Can't get out of crisis mode, not getting anywhere, stuck in gloom. Hope a trust is set up for care after parents. Don't like IHC & Spectrum - police checking not enough, concerns about safety*
- *Concerned respite care going to change and have less choice. Constantly repairing video and computer - weekly, really poor. Paying petrol for workers and bonus them, gets really expensive.*
- *Lack of support for fresh diagnosis - once know what is there ok. Pressure on siblings is big issue. 8 year old is very aggressive.*

Comments re Siblings:

- *Maybe (if my job is not done properly). re son abusing - More a misunderstanding through communication*
- *Pressure on siblings issue in past also.*
- *Spectrum care have been good re: sibling issues.*
- *Last thing want is for older son to be responsible when parents are not around - setting up a trust.*
- *Sibling pressure been huge issue in past. Daughter happy to be guardian after she is 21.*

Comments re Schooling:

- *Schooling difficult & ongoing concern*
- *Schooling has been nightmare in past - out of second school and home schooling*
- *Pre-school facilities, too late for him, for younger no expertise out there to help, need facilities for pre school therapy really important*
- *Need for diagnosis/assessment for siblings*
- *Current level of TA support may diminish over years - cut back this year - if become a trend - concern*
- *Schooling issue past. Pressure on siblings issue past. Guardianship is sorted.*
- *Worried about high school.*

Comments re Abuse:

- *Abuse also issue in past*
- *Bullying always a issue in past*
- *Bullying in past, financial issues in past, friends' social skills in past. future education biggest worry*
- *Concerned about abuse in respite care*
- *Abuse was a concern in past until could talk*

Appendix 5.16

- Not left alone at school

Assistance with Daily Living Skills

<i>Dressing:</i>		<i>Received Support re Sexuality Issues</i>	
Assist	53%	Yes	5%
Non-assist	40%	No	28%
Not Applicable	4%	Not Applicable	62%
<i>Feeding Self</i>		<i>Would like to use support re Sexuality Issues if available:</i>	
Assist	30%	Yes	34%
Non-assist	62%	No	5%
Assist Occasionally	2%	Not Applicable	33%
Not Applicable	3%	Later	1%
<i>Cooking for Self</i>		Don't Know	1%
Assist	26%	No response	27%
Non-assist	14%	<i>Received Academic Support</i>	
Not Applicable	56%	Yes	54%
<i>Hygiene</i>		No	32%
Assist	65%	Not Applicable	11%
Non-assist	27%	<i>Would like to use Academic Support if available:</i>	
Not Applicable	3%	Yes	57%
Assist Sometimes	1%	No	5%
<i>Catching a bus</i>		Not Applicable	11%
Assist	17%	In the past	2%
Non-assist	9%	Ok at present	1%
Not applicable	64%	Don't know	1%
••		No response	24% (note: includes those who have support)
<i>Driving</i>		<i>Received Self-esteem/Counselling Support</i>	
Assist	4%	Yes	9%
Non-assist	4%	No	46%
Not applicable	85%	Not Applicable	41%
<i>Managing their own finances</i>		<i>Would like to use Self-esteem/Counselling Support if available:</i>	
Assist	17%	Yes	52%
Non-assist	7%	No	9%
Impossible	1%	Not Applicable	15%
Not Applicable	70%	In past	1%
<i>Received Living Skills Support</i>		No response	23%
Yes	29%	<i>Received Other Support</i>	
No	57%	Yes	7%
Not Applicable	11%	No	8%
No response	3%	Not Applicable	2%
<i>Would like to use Living Skills Support if available:</i>		No response	83%
Yes	54%	<i>Would like to use Other support if available:</i>	
No	14%	Yes	11%
Not Applicable	9%		
Managing at present	1%		
Depends how done	1%		
No response	22%		
<i>Received Anger Management Support</i>			
Yes	19%		
No	52%		
Not Applicable	26%		

<i>Would like to use Anger Management Support if available:</i>		
Yes	61%	
No	10%	
Not Applicable	11%	
No response	18%	

Comments re Living Skills:

- *If more support available, sufficient at present*
- *School provision sufficient*
- *Depend on quality, who offering*
- *Took him to ProEd because SES did not do their job for assessment. Paid teacher aid to do course, Banatine & purchased books for use at school*
- *Future for sexuality issues*
- *More 1 on 1 hands on support in home*
- *Doing everything privately because system not*
- *Self esteem & anger management useful in future*
- *Desperately need support services - try to trade off with own work hours*
- *He does need self-esteem and anger management help but mum not sure where to access it - would like to. Generally wants support around issues of anger, self-esteem. Outburst at comparison with siblings. Teachers lumping him with other kids - comparing him to his school peers.*
- *Daily living skills & sexuality issues in future maybe*
- *Needs living skills help - independent person telling him and financial help*
- *Would like more academic support*
- *Anger management is problem. Self-esteem is real issue - may be part of knowing.*
- *Needs refresher courses to improve OT work. If specialised academic support available would benefit more*
- *Lacking academic support - rest is sufficient*
- *Can't walk somewhere on his own*
- *Need good programs, flexible on how they work, small group or 1 on 1, out in real world*
- *Lots of problems getting homework done - needs mother to do it with him, grandmother is getting to old - need for resources to help with after school study.*
- *Academic support is good but not even 10 % of what could access overseas with money*
- *Anger management depend on quality of service*

Aware of Diagnosis:

Yes	38%
No	50%
Not Applicable	6%
Sort of	1%
Don't know	4%

Difficulty to accept diagnosis for 74 who are aware:

Yes	39%
No	39%
Not applicable	8%
Don't know	5%
No response	8%

Appendix 5.16

PART 4: Adolescents

There are 31 adolescents in the survey (teenage years) and of these 84% are still at school.

Rating of Independence of Adolescents

<i>Rating</i>	<i>Number</i>	<i>%</i>
No Response	1	3
1	1	3
2	1	3
3	4	13
4	1	3
4 to 5	2	6
5	9	29
6 to 7	1	3
7	3	10
7 to 8	1	3
8	2	6
8 to 9	1	3
9	1	3
10	3	10
	31	

PART 5: Adults

- 6 Adults (teenagers or older who are not at school) are students, 3 are unemployed, 2 are in sheltered workshops, 10 are in part-time work, 5 are in full-time work three are other.
- 8 adults attend other programs or activities.

Adult Income Sources (24 Adult Responses)

Parents	3
Sickness benefit	2
Invalids benefit	4
Unemployment benefit	0
Part-time work	7
Full-time work	5
Student allow	3
Domestic Purposes Benefit	0
Disability Allowance	4
Government Benefit	4
Other	3

Main Income Source for 24 Adults who specified their income source(s).

ACC	1
Disability benefit	3
Invalids benefit	5
Sickness benefit	2
WINZ	1
Parents	1
Full-time work	5
Part-time work	1
Not specify main source	5
	24

*Adult Dependency Responses
(includes 6 older teenagers)*

1	2
1 to 2	1
2	1
3	2
3 to 4	1
4	1
5	9
7	1
7 to 8	1
8	2
8 to 9	1
10	1
	23

Note: 1 = totally independent, 5 = requiring regular supervision, 10= being totally dependent.

PART 6: Pre-schooler or School Age

138 respondents were under the age of 21 and still in a school education setting.

- Only 62% of students with ASD surveyed were receiving SE2000 funding, 34% were not, and 4% don't know.
- Only 39% of students with Aspergers were receiving SE2000 funding, 59% were not, and 2% don't know. 86% of students with Autism were receiving SE2000 funding, 8% were not, and 6% don't know.
- Only half of the students on the border of Aspergers and Autism were receiving SE2000 funding.
- Of students in a mainstream school (n=77), 42% are receiving SE2000 funding, 57% are not, and 1% don't know.
- Of students surveyed in a mainstream school and receiving SE2000 funding (n=32): 28% are 5-6 yrs, 34% are 7-8 yrs, 19% are 9-10 yrs, 13% are 11-12 yrs, 3% are 13-15 yrs and 3% are 16 to 21 yrs.

Reasons why Parents are Using Private Services – Dissatisfaction with Public Service

- Parents of 41% of all students are paying for private services. Of students with Aspergers, 34% are paying for private services, and 49% of students with Autism are paying for services.
- Of parents paying for private services (n=57), 93% said that one reason for using private services was because they could not access sufficient public services.
- 18% of parents using private services also said they were using private services because the quality of public service was poor, or poorer than private services.
- 68% of parents paying for private services also gave other reasons, such as not wanting to wait for public services, and finding it easier to organise their own services than trying to obtain them through the public system.

The main barrier for private services is cost. Of households with an income below \$30,000 26% are paying for private services, 33% for households between \$30,000 - \$45,000, 33% again for households between \$45,000 - \$60,000, and 58% for households over \$60,000. A number of parents paying for private services commented on the fate of parents and children who were missing out in the public system and did not have the personal income to provide privately.

- Of students receiving SE2000 funding (n=86): 77% are on ORS, 5% are Behavioural, 6% are Transitional, 1% are Communication Initiative, and 12% Don't Know.
- Of Students with Aspergers receiving SE2000 funding (n=24): 71% are ORS, 17% are Behavioural, 4% are Communication Initiative, 4% are Transitional and 4% Don't Know.

Appendix 5.16

- Of students with Autism receiving SE2000 funding (n=55): 80% are ORS, 5% are Transitional and 15% Don't Know.
- Of children receiving input from a psychologist (n=51), 16% had last seen a psychologist in 1-2 weeks, 12% in 2-4 weeks, 23% in 4-8 weeks, 45% in over 8 weeks, 12% don't know when last seen, and 4% seen as required.
- Of children receiving input from a speech language therapist (n=67), 24% were within the last seen 1-2 weeks, 15% in 2-4 weeks, 15% in 4-8 weeks, 27% in over 8 weeks, 16% don't know when last seen, and 3% are on a waiting list.
- Of children receiving input from occupational therapists (n=14), 24% were last seen 1-2 weeks ago, 12% 2-4 weeks ago, 15% 4-8 weeks ago, and 29% were last seen over 8 weeks ago.
- 8% of school students with ASD surveyed have been suspended at least once. The parents of 27% of children surveyed have been asked to take their children home from school at least once, and that 23% of parents have been encouraged to change schools for their child

PART 8: Autistic Association Auckland Branch

99% of families are members of the Auckland Branch and 1% are not members (the survey was based on the membership list).

Participation in Branch Activities (n=180 families)

Participate in	Currently	Current %	Past	Past %
North Shore Group	11	6	18	10
Playgroup	11	6	25	14
Pakuranga Group	13	7	22	12
Mt Eden Coffee Morning	1	1	10	6
Evening Workshops	23	13	43	24
Picnics	8	4	35	19
Adult Social functions	12	7	26	14
Weekend Workshops	18	10	57	32
Lollipops	7	4		

7 (4%) of families commented no to all events, 2 families commented not applicable to all events and 5 families commented that they had just joined.

Other comments re branch events were:

- *None of these - but if we were aware years ago we would have*
- *Lollipops Sunday morning*
- *Phoenix centre group*
- *Committee meetings*
- *Music therapy, sibling workshops*
- *General interest meeting after a conference*
- *Used to visit a lot. To upset to attend events*
- *No - not appropriate for Asperger adult*
- *Mt Eden coffee morning - not been happening when went to go despite fact being promoted*
- *Go to support group regularly, inappropriate to go to picnics for teenagers*
- *No - only Tony Attwood seminar in Auckland*
- *No - only because of where live, geographic thing, telephone only*
- *Don't see how they help my son - I'm not the problem*
- *Been to support group at Greenlane McDonalds in the past. Not sure still something*
- *Conferences - not sure if Auckland or National*
- *Only 1 art class*
- *Seldom go because to tired*
- *Visuals group Pakuranga*
- *At moment have a small group in South Auckland we ring on the phone when I need support*

- *Western Springs picnic not so good - to public and needs to be separate from carparks.*
- *Not done anything in long time, did when kids younger, mine bogging, neat to see other kids & people surviving. Not good doing with kids together - brings about stress, need to be doubly on the ball.*
- *Trying to contact Pakuranga group - hard to contact*

Making events more accessible:

- *A change of venue would make branch events more accessible for 17% of families. Four families specified a preference for events on the North Shore, one for city or North Shore, three for central Auckland, 1 for South Auckland, 2 for south south (Papakura) Auckland, and one for West Auckland.*
- *A change of time would make branch events more accessible for 12% of families. Five families specified a preference for evenings over day times.*
- *7% of families are not interested in branch events currently.*
- *16 families commented on the childcare as a issue for attending branch events.*
- *Nine families commented on a lack of time to attend events.*
- *Ten families commented on how branch events clash with paid work.*
- *Nine families commented on the distance to branch events as an issue.*
- *Three families commented on needing more notice of branch events.*

Other comments re accessibility of branch events:

- *Don't feel they fit in*
- *Difficulty in attending because work and needs someone to look after children*
- *Less cost*
- *They are too far away*
- *Too expensive - national conference*
- *Problem with communication is big barrier to contact with Assoc. Wife has worse communication but would like to have more contact. Husband is very busy.*
- *Interested in daytime coffee group for children about 8 - Blockhouse Bay, New Lynn, Avondale area*
- *Evening coffee group*
- *Evening groups instead of day, more advanced notice*
- *Always in city, puts off sometimes, good if not in same place all time, move around*
- *Range of topics for Asperger adults*
- *Fenced for a picnic!*
- *Weekend times preferable, can't make midweek workshops*
- *Distant, to far away. Organised adults social events on North Shore*
- *Respite care - can't get away*
- *Not noticed anything for parents of adults Aspergers*
- *Often when mixed with Autism - difference great, discouraged from attending because differences so great*
- *Lack of transport - don't drive a car*
- *Had to give up on coffee morning because during day and now at work, happy to travel*
- *Somewhere more locally would be good - very difficult. Met some parents in Papakura but petered out*
- *To many other commitments*
- *Support groups mostly for younger children. Group for parents of adult Aspergers on North Shore not transpired so far*
- *Keen to join mothers group, morning tea, can't join because working - after hours or weekend preferable*
- *More things out south. Being notified in time in the newsletters, missed out on mini-conference as notice too late,*
- *Cost - free events and question standard of presenters eg home based programs*
- *Some things get really booked out*
- *Working last year - office always during day*
- *Would like to make more of effort - work most days so evenings would be helpful*
- *Weekends preferable or after work. Auckland central initially to meet more people, things for whole of family*
- *New information*
- *Talks good - eg Harold Stone, Warwick Smith*

Appendix 5.16

- *Well advertised*

- 99% of families read their newsletter.
- 98% of families read their flyers.

Would use holiday programme run by the Auckland Branch:

- Yes – 44%, yes if age appropriate – 2%, yes need transport – 1%, yes on other condition – 5%, yes & have used – 3%, if suitable – 1%, in future 1%, depend – 3%, maybe – 3%, don't know – 3%, no – 17%, na – 14%, blank – 5%.

There was a very wide range of suggestions on additional support that families would like from the Autistic Association Auckland Branch. Following is a summary of some of the ideas:

Siblings:

- *Attend holiday programme if siblings could attend.*
- *Sibling workshops for all ages*
- *Siblings group - not beneficial, need to be more spec Asperger/Autism and age groups - different power struggles & issues.*
- *Regular sibling workshops - ongoing basis, every 3 months.*
- *More support for siblings, workshop backed up, advanced sibling workshop, move on to next stage.*

Auckland Branch:

- *More availability without mobile calls*
- *Higher more aggressive profile.*
- *Money – funding*
- *Lobbying for North Shore Centre*
- *Office open in school holidays.*
- *Change policy of not recommendations. Would like to see them make recommendations on therapies, programs, medical intervention*
- *Childcare arrangements for events.*
- *A wider network of health providers (inc dentists, physios etc) having a closer relationship with AA Assoc ie professional who 'know' who they're treating ie extra patience, tolerance and so on. All parties need to feel comfortable.*
- *Library, chase up people who don't return books on time*
- *Concerned that all information passed on to parents and let parents sift.*
- *Flyers are to short notice. Workshops for GPs and other professionals*
- *More about treatments - less support groups, more action for child.*
- *Fairly well set up. Comes down to accessibility - luck to get support when needed, funding/timing issue when get busy - potentially problem*
- *Need to ask people what they want, need to include greater variety of parents - very narrow. New ideas to the table in NZ, not encouraging at all in accepting ideas. Need more followup ph calls to meetings, more encouragement for participation, get parents by inviting, giving parents a voice. Need to separate Aspergers and Autism - different group and different issues, to focused on Aspergers.*
- *Increased accessibility - somewhere to go and chat if have a problem, need to talk to someone*
- *Good having visit at home after diagnosis. Good if someone had followed up.*
- *One organisation in charge of co-ordination.*
- *Not want Assoc to be service providing - not skills to do properly.*
- *Like to see another office on North shore - 2 bases, could have drop in for teenagers, more accessible for them or move to central Auckland.*
- *Access to networks out in community eg good counsellors - need someone really qualified for professional counselling on tough calls.*
- *Wish that assoc had more power - group of parents struggling with the system. Want government to empower parents more - don't know how could become more powerful body. Children not getting sufficient by any means - very impoverished group of parents. Elderly get*

ten times services son receives - son virtually a prisoner. Very disempowered group of people

- *Aspergers vs Autism - now feel like second class citizen rather than supported by other mothers. Put off and don't know anybody there any more, lost touch of good friends. Parents of younger children don't want to hear from older parents still facing problems*
- *Venues further away, can't get south, prefer more North west. Group up in Wellsford/Warkworth area desperate for contact. Northwest lots of families not able to access support - 25 families not in Auckland way on outskirts. Husband would like to be involved in committee - couldn't be because can't be involved in all of meetings - not been asked again - thinking about sub-branch in North west, in touch with 25 families. Needs to be more working in with rural communities, physical distance is a issue.*
- *Parents need to get together more than kids - leave kids with someone, throw on a heap of IHC helpers, need to see kids when first diagnosed though. Choose venues really well. Holiday programs if staffed appropriately, usually understaffed.
Apart from doing job of SES and health supposed to do - information pack got to include contacts and user friendly, families need networking to especially at beginning. Really push supports and things to keep going, get funding for counselling especially, sure lots of families breakdown, need comes in waves, need to network to good people, need real oil.*
- *Assoc had role difficulty in past - looking for therapies but not able to align themselves - situation been improved with disclaimer in newsletter - really good.*

Services:

- *Grief counselling*
- *Advocacy.*
- *Holiday programs.*
- *Workshops for caregivers, schools*
- *Needed more personal support*
- *More counselling for self.*
- *Activity groups for the ASD children.*
- *Holiday programme run consistently with structure.*
- *Would like somebody who can phone from time to time - at the moment use Marinoto and SES, would like to phone another parent - a parent to parent line or coffee group*
- *Visiting home, to assist family.*
- *Depends on resourcing, support to keep in contact with families every 3-4 months, keep in touch, someone is there, support groups too difficult to attend, case work to call up or ear of someone who understands would be wonderful particularly if funded.*
- *Bring Kath Owen back, found her brilliant, go round & meet face to face & talk about just to - excellent, has all the answers,*
- *Would like support group in West Auckland area*
- *In an ideal world home visits for help or tips.*
- *More social functions for age groups and similar functioning.*
- *Good to have a network of children with similar ages & functions with a view to phone.*
- *More follow-up from co-ordinator*
- *More social skills workshops*
- *More workshops on Asperger information and on skills training*
- *Workshops - follow through. Attended workshop for parents of recently diagnosed children with ASD and would have loved a followup workshop with same parents to share, swap successes, ideas etc. even 1 yr later.*
- *Booklet of all the things - where could go for SES, Marinoto, Wilson Home, where could be assessed.*
- *Having stuff sent out to schools eg SES puppet show.*
- *Consumer rep to check in with families (10 minutes) to see what they need, identify problems, liaison for family, information source. No one offered up information freely*
- *Something for/with fathers - not sure how go down. Like to have guest speakers for group meeting - 20 mins, 20 mins questions and then chat - for specific things. eg violence, moral issues, verbal abuse - encourage to participate or do own thing.*
- *Couples counselling.*
- *Workshops like on sexuality*
- *Anger management especially for Aspergers.*

Appendix 5.16

- *Day with sports equipment at Pakuranga really good Asp & Autistic together and siblings*
- *Tony Attwood presentation would be good.*
- *More information on different options for programs, more in newsletter about what people using at the moment, more about special units satellite classes set up - pick up networking when SES not doing. List of programs that are there and taken for granted things.*
- *Need contact list for families in area*
- *Comparatively new member - would like older member as buddy system. Overwhelmed - can't get out and ask for help*
- *Art classes on North Shore, holiday things on North Shore*
- *Would like to be able to just phone up. Lucky to have a supportive family*
- *See somebody from AA in person*
- *Helping with finding employment*
- *Parent support available outside office hours. Perhaps a phone list.*
- *Regular professionals and speakers coming in*
Keen on sibling groups not like those in town
More notice and south based for social gatherings
A support group for step-fathers
A little meeting for step-fathers to air their concerns
Parent doing Lovass - to stand up and explain.
- *More information on presenters, especially for parents further down the track.*
- *Grief counsellor initially or later.*
- *Package and books to read and access clued up parents. Need followup visits to go through pack - overwhelmed at first. Staff need to be more trained in therapy approaches - not found anybody can tell more than what already know.*
- *Want more input from adult Aspergers - ver interested.*
- *Coffee mornings in the evenings*
- *Interested in drama classes. Now being more selective - cost issue*
- *Really enjoy family days at lollipops, brilliant, prepared to pay. Children happy and parents start to network.*
- *Need workshops that are next stage up - not same information over and over again eg Tony Attwood. Need to keep with age group of kids, what to do with adolescents.*
- *Establish respite place that is more appropriate for kids - run by people know what they are doing with experience*
- *More holiday programs, run all holidays and more than just once a blue moon, ideal would be everyday of holidays.*
- *More help to set up effective programs involving caregivers.*
- *As a father support groups need to be more than just meeting other mothers - would be good to meet whole families - including fathers.*
- *TA workshops*
- *Love anecdotes for things that have worked for other people eg gluten diet, scrap off paint on pencil & now write. Tips of the week.*
- *Not a lot of activities for sons age group. nothing for 6-8 years children and parents of similar age group more relevant*

Adults & Adolescents:

- *Social skills for adolescents getting employment*
- *Something out that included children around 13 age.*
- *More adults with ASD*
- *Sexuality issues concerned about.*
Help in finding sheltered flat/living environment, setting up
Help with work, social skills - roleplay type things
- *Would like more respite care. Help him become independent, manage time and finances.*
Assist with finding regular supervision for ASD family member.
- *Run classes on daily living skills, self-esteem counselling, education for ASD member on the disorder*
- *Outside support for living, flatting situation. (Because his child is an adult and he is getting on he wanted the child to be picked up so he didn't have to do anything).*
- *Internet support group for the children with Aspergers*

- *Groups with similar age group adolescents would be helpful, contact with parents of older children would be helpful.*
- *Want more mix of members in Asperger group, more females, bigger interest in group, more adults involved.*
- *Information on benefits when turn 16 - guardianship and financial side, information re benefits & spectrum care & parents rights to have a say*
- *Very aware of puberty changes - more support for parents regarding teenage years issues & girls. Talk with adults - female Aspergers - learn how they have coped.*
- *More social things - to meet other parents same age group. More for teenage, middle age. Rest seems to be for small children & young adults.*
- *Push political for specialised services separate from psychiatric - inappropriate. Focus for adults is somewhere to live, something to do, someone to look after them, someone to turn to and general advocate to overcome privacy act. Son would go to Aspergers drop in - attaches himself to people, substitute family, better than miming psychiatric.*

Resources:

- *Info on education games eg CD's books, feedback from others. Website, feedback from other parents on things.*
- *More detailed information on a wider variety of treatments/programs.*
- *More 'what's happening' info.*
- *More workshops.*
- *More networking of parents*
- *Workshops - social skills/siblings etc on shore or Whangaparoa.*
- *More videos on anger management, more practical books*
- *Library more accessible.*
- *More information, list of services which exist for autistic children, list of teaching programs, information on behaviour management programs, buddy system with older children/families who have been there.*
- *A list of respite care workers (a day/month or 1 afternoon per week)*
- *Respite care information where to take child for weekends that son could get used*
- *Professional trained care could leave children with and know safe or list of registered carers, referral list.*

Professionals:

- *Phycologist for parents to access for written confirmation of diagnosis and skill levels.*
- *Pool of accessible therapists, more help with treatment options*
- *A 'bank' of therapists*
- *Would like association to enable professionals to be available regularly eg Tony Attwood, so can assist and go to and ask questions.*
- *Get to GPs & Paed - earlier diagnosis, get them information packs.*

Schools:

- *School awareness pack. School visits by AAA rep. Greater/any relationship between AAA & schools*
- *Training workshops for teacher aides/teachers.*
- *When have parent teacher meetings would like AAA person present. Need someone teaching background, itinerant teacher to go round schools and help support teachers and TAs - need to be qualified teacher firs.*

Other:

- *Weekend outing with son to allow family to have peace as soon as possible. (ie need respite care)*
- *Having trouble accessing respite care*
- *If it is possible I would like to ask association to do the interpretation when we need it, eg. with school, paediatrician*
- *Anything to do with walks, exercise, team activities. Not fit into CCS programs, anything at all of cultural experiences, drama, dance, sport, singing*
- *Like to find families closer to home, Howick/Papakura*

Appendix 5.16

- *People who recently discovered with older son - information and how to go about helping in some way.*
- *Very difficult for parents to network when things get difficult.*
- *Parents of children now teenagers are pioneers, bored being one to do it, first wave, breaking ice in community, lots now in Intermediate school, unheard of 5 years ago.*
- *Like monthly newsletters, but because of poor English not understand all of it. Likes to have information, library, toy library.*
- *Crisis respite care.*

Families not on the Auckland mailing list:

- 17% of families know another family with a family member with ASD who are not on the Auckland branch mailing list.
- Four families know another family they thought was in denial.
- Three families know another family that has just recently been diagnosed.
- Two families know another family that is not diagnosed, and two identified another family that is not ready.
- Two families identified another family that is not on the mailing list because they are disillusioned with the Auckland branch.

Other comments re why families are not on the Auckland mailing list:

- *Has another child with another syndrome which takes up more of their time, their ASD child is very mild.*
- *Not ready to fully accept or ASD diagnosis tentative.*
- *On Christchurch mailing list*
- *Haven't been told where to obtain help from*
- *Probably a member of another branch*
- *Frustration with their own situation, struggling to cope*
- *Not people who acknowledge*
- *Distant from Auckland or in denial*
- *To much infighting, politics. Previous newsletter not enough info*
- *Has support, just been diagnosed in crisis situation, taking their time to come to terms with it*
- *Recent diagnosis - working on them*
- *In denial*
- *Chinese boy in class parents not a member - don't speak English*
- *Just diagnosed - in touch with national but not Auckland yet*
- *Acceptance - lot of families children with high IQ Aspergers - gifted rather than connect to Autism, cultural - where disability frowned upon, families not acknowledge.*
- *Religious experience - don't need support.*
- *Overwhelmed by experience, depression & burnout - don't need to hear more stories from mums.*
- *Not quite accepted diagnosis*
- *Recently diagnosed*
- *Lots once kids get older don't bother*

Ranking of support received from the Auckland branch:

- 36% of families ranked the level of support they receive from the Auckland branch as highly satisfactory, 45% satisfactory, 8% unsatisfactory, 2% not applicable, and 9% no response.

Following are many of the comments made by families regarding the level of support they have received from the Auckland branch.

Positive Comments:

- *They do a good job. Some areas could be better*
- *Doing the best it can with limited resources*
- *Congratulate us on putting together this survey - quantification is very important*
- *From newsletters and flyers think they are doing a good job*
- *What support we do get has been ok, ie newsletters/flyers*
- *I am always happy to receive my newsletter and I'm finding the get togethers good times as well*

- *Good bunch of dedicated people, really coming together*
- *Do their best*
- *Terrific*
- *I can't speak more highly of them*
- *Very good. More focused dealing with younger age groups.*
- *One ladies gave a talk at Torbay - benefit heaps.*
- *Auckland branch appears to be doing a great job. Well done.*
- *New staff really good repour with people*
- *Auckland branch do a great job, without Auckland branch would be floundering, wouldn't be able to have school on, should be government funded*
- *Good with newsletters*
- *Few times I have phoned usually phoned back and issues resolved that day*
- *With financial means - highly satisfactory.*
- *When rang very helpful.*
- *Free to ring up and check/ask things, receptive*
- *Do a really good job.*
Interesting info in newsletter
- *Whenever ph person on other end of ph extremely supportive - try to find real help.*
- *Really doing a good job, incredibly impressed. A lot to do with parent uptake of what's on offer.*
- *Always there and always return my calls*
- *They are there, can ring, like newsletters.*
at this point fine, really getting it together. Newsletter unrecognisable, used to be unhelpful, now really open, look forward to it and used to shelve it.

There if need it:

- *There if need it*
- *Can't provide us with much, nice to know there, no hands on stuff*
- *For what I've had, not requested that much, than when needed*
- *Supports there if I access it.*

Negative Comments:

- *Lots of listening but expectation of actual practical help not met.*
- *Eg in mailer recently telephone support is mentioned but difficult to access, support person not there, and promised support visit has not eventuated or contact initiated.*
- *Sometimes found it difficult to contact someone initially (about 5 yrs)*
- *I have had calls unreturned, this is off putting*
- *Satisfactory to unsatisfactory - don't get any support, no one contacts me, not know anyone new there*
- *Not at a personal level*
- *Times rung not there, left message and get back a week later - more annoyed them, more they got on your case.*
- *Initiated contact each time. took weeks to get anybody there - very frustrating to wait so long, deb away. Support group at Maretai - rang number but was family that needed help themselves. Other people - haven't been able to meet, got scared - not prepared to face problem, didn't want to pressure. Given Asperger chat room on internet - never anyone in it - typical all waiting.*
- *Just don't find informative enough, more aware what's going on in world. Awareness week - then heard nothing about it, very frustrating. See as service provider if everyone who worked there got paid. Criticisms result of shoestring budget, lack of resources*
- *Haven't tapped into it for a while. Wasn't impressed when she first joined and knew nothing much about her son's condition. She was very distressed upon diagnosis and the parent support worker who was assigned to her scared her very much. Wasn't explained that ASD is very wide spectrum ranging from mild to extreme. The support worker focused on the more severe forms (which her son didn't have) telling her her son wouldn't be able to do this and this etc. She found it very distressing.*
- *Group 14 families at private school - no one even asked to comment, no one interested to look, none in newsletter. Ignorant and shocking. Should be facilitating what going on in community - don't have to agree, give knowledge*

Appendix 5.16

- *Not being there when phoned - very frustrating in the early days*
- *Only trouble is not getting through to anyone*
- *Not needs based on needs of individual.*
- *I am still getting so many counselling calls from other parents to my home who are all saying they cannot get the information or help they need from the Autistic Assn. Since the last co-ordinator has now been replaced by 3 people, I find that staggering.*

Not Need or Accessed:

- *Haven't taken advantage of assoc*
- *Haven't used it much. Only in last year looked at ASD.*
- *No contact up to now*
- *Because not really needed to access, especially with changes.*
- *Don't request support*
- *Haven't asked for it*
- *Na - no need*
- *Not really tried to access*
- *Don't have much contact*
- *Not much contact yet*
- *Not yet - maybe not ready, don't know how bad son is yet*
- *Not had a lot of support - only a little involvement.*
- *Don't want any support from assoc. Advertising and organising workshops is good - wish there was more of them when son younger.*

Mixed response:

- *Satisfactory currently. Unsatisfactory in past. Don't care who is in charge, want help for their babies. Reneged on membership because of infighting.*
- *Was highly satisfactory until got to pre-teens - lots for parents young children, not so much helpful now older - preteen / young teen age good if had family activities, gap in middle - understand a awkward age. Picnics*
- *Now, has changed - improved*
- *Need to return calls. Love newsletters*
- *Minimal, grossly inadequate. Not blaming. Only just heard 6 months go, doctor last year triggered diagnosis - son had mention of diagnosis in notes from years ago but professionals not told mother.*
- *Good at times and varied not so good at other times. Room for improvement, best assoc can do with lack of resources and people hours that they have.*
- *I feel as though lots of other people are heaps worse off, so I don't get access first*
- *Newsletter only*
- *Only support is newsletter*

Suggestions:

- *Not providing information without recommendations for anyone therapy. Need positive information, not negative. Needed positive recommendations. Money from HFA should have been spent elsewhere than on booklets. Not much has changed in 30 years. Money for grants, fundraising, should be spent on services for ASD*
- *Would like more info on medical treatment*
- *Not applicable currently, not much for young adults who can't drive. When diagnosed, too late, not such in high need for mother*
- *Don't receive a lot, get newsletters, let parents decide whether to take further, shouldn't block info from flowing, let parents use common source, don't vet info*
- *Given the financial constraints the Auckland branch work under the support level is adequate but more support would be preferred.*
- *5-day a week cover in office would be helpful. 2-3 day wait for response is difficult.*
- *Would like more on the North Shore towards Hibiscus Coast, holiday activities and workshops.*
- *Information - good if could go further re help*
- *Not involved enough with members because don't have the money. Not enough lobbying to government re the role of Autistic Assoc - should be much greater - co-ordinator of services for families.*

- *Need to cater for country more - southwards or central*
- *I think an area that could be improved is facilitating families to meet apart from coffee mornings, currently slipping through the cracks. Have met families in the past but not since then. In the past all the assistance accessed is found out from other parents. Problem is don't met other parents in the normal course of events - real need for facilitating parents meeting.*
- *Would like overseas experts - if we had the money. Education of what they are capable of.*

Auckland Branch as a Service Provider:

- 58% of families see the Auckland branch as a service provider, 30% do not, 7% don't know, 3% no response

Below are some comments made by families re Auckland Branch being a service provider:

- *See more as a support than service provider*
- *Generally services very good. See as service provider to minor extent - more of a advisory role, information*
- *Need services where people go - there isn't anywhere else, stands to reason*
- *Currently not have trained people & resources to back up, still pseudo professionals, best left to truly qualified. Don't think you have to look for people with huge credentials in ASD - good behavioural program can use in any situation. Go back to mission statement for branch - is it still appropriate? Need proper management systems - more structure within organisation to free other people up and make smother - attract people and money. Still lurching from crisis to crisis.*
- *More of a support group in what used.*
- *Don't think the assoc has to have the people to provide services - but could facilitate - as long as can get service don't care who is paying them, would like to call the assoc to get services. National is hung up with being a service provider - would be better for parents that assoc work to utilise existing services and build them up and improve and input in quality - rather than duplicate and reinvent the wheel - leave control with parents, otherwise denied access, eg IHC.*
- *Is for peoples who needs are greater - but not so much for us, not what asked of them*
- *Assoc is place for seeking information to go and seek out services.*
- *If it tries to be and not effective will be very quickly grouped in with other bad agencies, need to be careful, still must be family support. Crux is lack of money - if makes same mistakes. Hate to see it trying to fundhold - no matter who fundholds not enough money, demoralising, SES workers defeated by situation.*

Use of Programme Developer Service:

- 64% of families would like to be using the programme developer service, 12% do not wish to use it, 12% said not applicable, 7% don't know, 3% gave no response, 1% said in the future possible and 1% said they would have used it in the past.
- Of the 115 families who would like to be using the programme developer service, 41 would like to use it for social skills, 14 specified language or communication skills, 9 specified all examples, 5 specified behaviour management, 2 specified anger management, 2 said in the past, and 5 noted cost as a issue.
- Other comments were:
 - *Behavioural problems, holiday programme, music therapy*
 - *Can't cope with eating issue, especially for ADHD*
 - *Communication book system - streamline to indicate choice and preference, more revision on signing*
 - *Depends on form it takes - if in area could tap into*
 - *Depends on whether have to pay - if expensive might not afford*
 - *Education programme & anger management programme*
 - *For social skills training for Asperger adults*
 - *If accessible out where live*
 - *If not to high in cost*
 - *In future*
 - *In past, lack of social skills, lost work because couldn't talk to employer*

Appendix 5.16

- *No program for all people looking after daughter - mum, school, respite*
- *Programme for daily living skills*
- *Programs for schools - social skills, playground skills*
- *School, social skills, language skills*
- *Set things up at home, schedules*
- *Social skills - materials for inhome programme*
- *Social skills - small groups who could be shown social etiquette, sharing, reasons for niceties/politeness, emotional understanding, role playing*
- *Social skills, stress management*
- *Social skills & toileting*
- *Tertiary education concerns*
- *Use if programs for older persons were accessible/available.*
- *Very much wants self-esteem and anger management programs*
- *When goes to school*
- *Would like a steer in the right direction to find the best for her son*
- *Would love to see programs to develop social & language skills. Not just one offs but regular on-going programs. Also more educational workshops for parents & care givers.*

Membership of the National Autistic Association:

- 43% of families are members of the National Autistic Association, 53% are not, 3% don't know, and 1% did not give a response.

Auckland Branch Survey Results

Firstly, a huge thank-you to everyone who participated in the survey. The response was fantastic - 180 families were interviewed with only 16 refusals. As a result of your generous participation in the intense and often lengthy interviews, the Association now has a considerable amount of information on members' needs and experiences. All the information is anonymous and confidential - no survey forms can be linked back to the family interviewed.

The survey has already been used to support the Association's submission to the SE2000 review. Over the coming months the survey findings will also be a valuable tool in advocating for better services from all other providers and improving the Association's service.

Following is a taster of findings from the survey. The rest of the survey findings will be covered in installments in future newsletters.

If you would like to be involved in any of the working groups using the survey, contact the office on 276-1396.

Survey Taster

193 People with ASD surveyed

180 Families surveyed (13 families had 2 family members with ASD)

Findings relating to family member with ASD

- Where on ASD Spectrum (in opinion of person interviewed): 44% Aspergers, 4% Aspergers Autism border, 48% Autism, 3% Don't know, and 2% other.
- Gender: 80% Male, 20% Female

Age Group	Number	%
Under 5	28	15
5-6 years	43	22

7-8 years	30	16
9-10 years	23	12
11-12 years	19	10
13-15 years	12	6
16-19 years	19	10
20-25 years	10	5
26-29 years	2	1
30-39 years	3	2
40-45 years	4	2
	193	100



- Verbal/Nonverbal: 77% Verbal, 21% Nonverbal, 2% Between verbal and nonverbal.
- Communication Level: No Communication 6%, Some Communication 52%, Full Communication 41%, Don't Know 1%, No response 1%.

• Diagnosed with ASD: 91% Diagnosed, 9% Not Diagnosed. Of the 17 Undiagnosed 7 had another diagnosis.

- Number of Diagnoses before ASD Diagnosed: Of those not diagnosed with ASD on their first diagnosis (n=63), 38% had one other diagnosis before ASD, 27% two other diagnoses, 14% 3 other diagnoses, 3% 4 other diagnoses, 2% 5 other diagnoses, and 2% 6 other diagnoses.

Age Diagnosed:

- Of those diagnosed with ASD (n=176), 5% were diagnosed under 2, 15% at 2 years, 24% at 3 years, 10% at 4 years, 22% at 5-7 years, 9% at 8-10 years, 6% at 11-15 years and 9% over 15 years.

Indication of ASD Prior to Diagnosis:

- 75% had an indication of ASD prior to diagnosis, 24% had no indication, and 1% no response.

Public/Private sector of formal diagnosis professionals:

- 36% of respondents received a

formal diagnosis from the private sector.

- 49% received a formal diagnosis from the public sector.
- 2% received a formal diagnosis from the public and private sector.
- 2% received a formal diagnosis from SES
- 8% no response

Supportiveness of Diagnosing Professionals:

- 42% found their diagnosing professionals extremely supportive, 33% moderately supportive, 2% moderately to barely supportive, 9% barely supportive, 6% not supportive, 1% supportive because paying for support, and 7% no response.

Sources used to find out about Available Services:

Phone book	19%
Citizens Advice Bureau	4%
Doctor	46%
School	14% (8% said school was not applicable)
Media	7%
Word of mouth	48%
Spectrum Care	7%
SES	44%
CCS	16%
IHC	17%
Autistic Association Auckland branch	69%
National Autistic Association	17%
Other source	44%

Continued next month





Autistic Association of NZ Inc Auckland Branch Newsletter

Autistic Assn of NZ
Inc. (Auckland Branch)

Volume 1, Issue 7

December 2000

Branch Survey Results Update

Hi everyone. Here is the second instalment of findings from the Auckland Branch Survey.

For those that have the heard about it - 193 People with ASD surveyed, 180 Families surveyed (13 families had 2 family members with ASD). The Association now has a considerable amount of information on members needs and experiences. All the information is anonymous and confidential - no survey forms can be linked back to the family interviewed. Over the coming months the survey findings will also be a valuable tool in advocating for better services from all other providers and improving the

Association's service. The national office has picked up the survey and it is now being run nationally through all the branches. Some preliminary results from the combined Auckland and National data are being dis-



cussed with the Ministry of Education in November.

If you would like to be involved in any of the working groups using the survey contact the office.

Survey Findings Instalment Two

Still live at home:

93% of respondents with ASD still live at home

Accommodation Provider for those not living at home:

Spectrum Care	4
Private Trust	1
Accommodation for Mental Health, Nth Shore	1
Creative Enterprises	1
Private Tenancy	1
Foster Parents	1
With Brother	1

Number of Parents at home:

One Parent 13%, Two Par-

(Continued on page 3)

Australian Conference 2001

The next Biannual Australian National Autism Conference is to be held in Glenelg, Adelaide and will run from the 27th to the 29th September 2001.

Speakers include:

Dr Paul Shattock, Dr June Groden, Professor Patricia

Howlin, Dr Tony Attwood, Dr Laurie Bartak, Professor Bruce Tonge and



Wendy Lawson

To find out more you can contact:

Conference Secretariat, Plevin and Associates, PO Box 54, Burnside, South Australia 50666

Or by email:

plavin@camtech.net.au

Diary Dates

December:

Second Thursday, 10.00am-12.00.

McDonalds Greenlane Parent Support Group. Contact: Martine Ph: 634 4118 or Davina Ph: 521 9997.

16th December, 12.00-2.00pm

Pakuranga Parent Support Group. To be held at 32 Albion Road this month. Contact: Janet Ph: 626 5084.

19th December, 1.00 - 3.00pm

Chinese Support Group. This group will be meeting at the Pakuranga Community Centre. Contact the office 276 1396 for more information.

8th December, 9.30am.

Home Programme Support Group. For details contact Andrea Ph: 416 1987 or Megan Ph: 529 9298.

...Survey Update cont.

(Continued from page 1)

ent 82%, Not applicable 1%, No response 4%.

Person most Responsible for Care: Mother 71%, Shared by Parents 14%, Father 4%, Self 3%, Parents and Grandparents 2%, Accommodation caregiver 2%, Parents and Self 1%, Other 5%, No response 2%.

Following Diagnosis:

Number Offered a Second Opinion: 70% were not offered a second opinion, 19% were offered a second opinion, 3% said they did not need a second opinion, 1% don't know, and 8% no response (the no response group includes people who have not been diagnosed and people who were diagnosed overseas).

Out of a total of 36 respondents offered a second opinion, 17% were offered a psychologist, 17% a psychiatrist, 25% a paediatrician, and 11% Other.

Of the same 36 respondents offered a second opinion, 25% were offered a second opinion from the private sector, 31% were offered from the public sector, 6% from SES, and 3% from SES and the public sector.

Number Seeking a Second Opinion:

28% of respondents did seek a second opinion, 61% did not, 2% are currently seeking a second opinion, 1% don't know, and 8% did not answer.

Out of a total of 55 respondents who have sought a second opinion, 31% saw a paediatrician, 11% saw a psychiatrist, 27% saw a psychologist, 7% saw Tony Attwood, and 11% saw a other. Tony Attwood, Rosie Marks, psychologist overseas

Out of the same 55 respondents, 47% sought a second opinion from the private sector, 31% sought a second opinion publicly, 2% saw public and private, 4% sought a second opinion from SES, and 2% from the Wilson Centre.

Referral to SES following diagnosis: Immediately following diagnosis 25%

were referred to SES, 32% were already there, 18% said SES was not applicable, 2% said SES did not help, 1% self referred.

Referral to Child Health Development Team following diagnosis:

Immediately following diagnosis 25% were referred to Child Health Development Team, 9% were already there, 3% don't know, 2% not applicable, and 1% CHDT gave diagnosis.



Referral to Child Mental Health Team following diagnosis:

Immediately following diagnosis 5% were referred to CMHT, 3% were already there, 3% don't know, 2% not applicable, 61% were not referred and 27% no response.

Referral to Marinoto following diagnosis:

Immediately following diagnosis 8% were referred to Marinoto, 2% were already there, 1% don't know, 1% were diagnosed at Marinoto, 2% not applicable, 63% were not referred to Marinoto, and 25% no response.

Referral to Campbell Lodge following Diagnosis:

Immediately following diagnosis 5% were referred to Campbell Lodge, 2% were already there, 1% were diagnosed there, 1% not applicable, 66% were not referred and 26% no response.

Referral to IHC following diagnosis:

Immediately following diagnosis 15% were referred to IHC, 4% were already there, 2% not applicable, 1% were referred but nothing happened, 1% were made aware of IHC, 61% were not referred to IHC, and 18% no response.

Referral to CCS following diagnosis:

Immediately following diagnosis 8% were referred to CCS, 4% were already there, 1% don't know, 1% not applicable, 62% were not referred to

CCS, and 24% no response.

Referral to the Autistic Association Auckland Branch following diagnosis: Immediately following diagnosis 49% were referred to the Auckland branch, 4% already knew about the branch, 1% don't know, 23% were not referred to the Auckland branch, and 23% no response.

Referral to the National Autistic Association of New Zealand following diagnosis:

Immediately following diagnosis 9% were referred to National, 2% already knew, 1% don't know, 39% were not referred to National, and 50% no response. (No response includes those that are not members of National)

Referral to other services following diagnosis:

A number of families mentioned other services which they have been referred to. Two families had been referred to Nascent, 3 families specifically mentioned a referral to Spectrum Care, two families have been referred to people at Auckland University, two families said that Tony Attwood had been mentioned, two families said they were referred to counselling and two families commented that they had to do all the referrals themselves.

Number Advised of Carer Support Days:

At the time of diagnosis 26% of respondents were advised of Carer Support Days, 8% already knew, 53% were not advised, 4% said not applicable, 7% did not respond, and 1% were advised later.

Number Advised of Handicap Child Allowance:

At the time of diagnosis 35% were advised of Handicap Child Allowance, 44% were not advised, 9% already knew, 4% said not applicable, 1% were advised later and 1% other.

Written by Carmel Cervin

Chapter 6: Conclusion

Action Research and Retaining My Own Analysis

Shifting from my initial questions to problems defined by the groups reflects a key aspect of action research – returning power to the community rather than academic/professionals controlling the research and political agenda. All three projects were owned, controlled and run by the groups – my role was as a student working with them on each project.

However being involved in three projects gave me a unique opportunity to reflect on the commonalities and differences between the three group projects – in terms of process, context and themes. The power to make this comparison has to some extent undermined my non-elitist role with the groups as the ability to make comparisons gives me a more 'expert' knowledge of the action research process and context. This has become evident towards the final stages of the projects and as I have given and discussed drafts of my thesis chapters with each group. At the beginning I do not think either the groups or myself foresaw the aspect of comparing the projects and particularly the power this would give me. It was only over time that my focus and interest shifted from the issue of each project to the comparisons between the projects. Thus it was part way through the projects that I began to emphasise to the groups, that I was becoming very interested not only in the issue chosen by each group but also in the process of each group's project. Formal consent in regard to writing about each group and their project's process could only be sought in the final stages as the groups had to see what they were consenting to. If I was starting again, I would emphasise the importance of studying the process from the beginning, however the formal consent process would still have to occur towards the end of the projects for the groups to know what they were consenting to.

Choosing to make my own comparison across the three projects involved stepping onto a tight rope. I was very conscious of the contradiction of supporting the groups taking ownership and control of their projects and yet at the same time retaining the power to study and compare the groups' processes and projects. My ability to proclaim the praises and virtues of action research as an empowering tool for community groups, comes in part from my retaining the power to study them doing action research. I have discussed further how the power dynamic between myself and the groups changed over time in my methodology chapter. It is also useful to reflect on power in the context of a relationship – as power with, power over, power to, or power for - rather than power as a good or bad thing in itself. In the case of my power to compare the group projects, I think this was predominantly an example of power to do something rather than power over the groups.

What to Conclude?

There are many themes arising from each project and the action research process that could be further explored in this conclusion. Making sense of the findings of each research project and the steps taken to act on this to solve specific problems has already, and is continuing, to occur in and by each group and some of this is included within each project chapter and its appendices. Within the methodology chapter I have explored a number of the process commonalities and differences between the projects. As mentioned above, this leaves my comparison of the context and overall themes between the projects. Working with all three groups enabled me to develop my own perspective on the context that shaped their projects. This perspective is not the perspective or frame the groups have been using, instead it is based on my own reflections comparing the three projects.

Two Key Themes: Funding and Responsibility

Firstly, throughout the time I was working with all three groups funding was an ongoing concern, particularly for the Autistic Association and Homebuilders. In recent years the issue of funding for community groups has been very topical and there have been a range of articles addressing different angles (Adams, 1998), (Cull, 1993), (Florence, 1996), (New Zealand Council of Christian Social Services, 1998), (New Zealand Federation of Voluntary Welfare Organisations, 1992), (Nowland-Foreman, 1995), (Saville-Smith & Bray, 1994). Of key concern has been the actual funding processes used by government and quasi-government bodies, the changing nature of the relationship between community groups and funding bodies and the impact of the funding environment on community groups existence, autonomy, structure and mission.

Secondly, over time the issue of responsibility became another strong commonality across the three projects. All three projects involved questioning who should be responsible for providing specific social services to meet identified needs.

For the WAWC the issue area started off as retirement income for women - with the injustice being the direction of government policy for retirement being increasingly disadvantageous for women. This issue broadened as we realised that retirement income was too narrow a focus - and limiting the debate to income was itself part of the disadvantaging for women. The stories of different woman's life experience and expectations of retirement pointed to a much broader range of issues more accurately captured under the heading of 'retirement provision'. Within this were major areas of debate such as housing, income and most importantly care provision. Care provision was particularly central as when care is being provided by the family (i.e. in most cases by women) for elderly and children this in turn affects the ability of women to make their own

financial provision and the experience and location of care they will receive themselves in retirement.

The issue of care provision involves a tension between government/state and family/women responsibility. The degree to which this responsibility is split between or shared by government/state and family/women has the most fundamental impact on shaping a person's actual retirement. Thus if government provided an extensive home support system for the elderly (taking an active responsibility in maintaining the elderly in their own homes), then it would be reasonable for the elderly to expect a retirement of independence and to be able to plan for this. However if responsibility is left to the family then the elderly's expectations of retirement are fundamentally shaped by the resources and financial situation and relationships of their family and are highly subject to change. Thus there may be very limited choices in reality for how their retirement will be experienced. When government acknowledges a responsibility, for instance to provide comprehensive home care services, a funding dimension should follow.

The WAWC explored the difficulties many women face in preparing for their own retirement, recognising the impact one set of responsibilities can have on another set of responsibilities/expectations. They sought to use the research in their advocacy role to influence government policy and broaden public debate on retirement income so as to generate a more realistic and informed debate regarding the ability of individual women to save for retirement and the role of government superannuation policy/provision. The WAWC was aiming to influence government policy regarding the boundaries for individual and collective responsibility for retirement provision.

Homebuilders' second research project explored the range of living standards in Rodney and the difficulties of inadequate income for family life. They were concerned that a lack of recognition by Work and Income New Zealand of very real income needs for some families resulted in families being declined desperately needed assistance. The Homebuilders survey sought to provide valid objective data on family living standards in Rodney, in order to influence and educate the community regarding the situation of low income families in Rodney. Homebuilders was also seeking to advocate for adequate government support for families with a poor living standard – showing the need and repercussions of not providing assistance.

Through their survey, the Autistic Association sought to quantify and make visible gaps in services, to government and service providers at all levels, so that their needs may be recognised and to pressure government into taking responsibility for meeting those needs.

As I reflected on these two commonalities of funding and responsibility, I began to see how closely they were interrelated, and how, along with the distribution of power, they were

shaping the context of all three groups and the action research projects. This led me to reflect on the funding environment as an inadequate forum for negotiating responsibility for specific social services.

The Funding Environment as an Inadequate Forum for Negotiating Responsibility

The funding (or lack thereof) for non-government social service providers has become increasingly topical in recent years. This is largely due to ongoing changes by government in its funding policies and processes, including a tightening of the boundaries for government provided/funded services, resulting in significant pressure and difficulty for social service providers. Although there has been some discussion of where responsibility for providing social services should lie, this has not been a major theme in the funding debate in New Zealand. However I think it is useful to look at the funding environment as a forum of negotiation of responsibility for social service provision.

By social services I am referring to the continuum of paid/formal social services through to unpaid/informal social services. Within the category of paid social services I am excluding services paid for totally by the person/family receiving the service (however this is another dimension of responsibility – where the individual/family has full responsibility for the service and is buying it privately). Government and other funding bodies largely determine which social services receive payment. These paid social services have been recognised as requiring some form of collective provision. The service is funded by someone other than the person receiving the service indicating that the funder has accepted some shared responsibility for ensuring this service is provided. The degree to which the responsibility for a social service is shared/owned by government varies, with certain legislated responsibilities, such as through the Department of Child, Youth and Family Services (DCYFS), representing total responsibility being assumed by government.

At the other end of the social services continuum is unpaid/informal social services. These are social services that have limited or no collective provision, resulting in the actual provision of a service being left to an individual/family. The individual/family is entirely responsible for meeting the need and usually they have no choice but to respond as best they can (for example having to provide continuous care for an autistic family member). The need is generally unrecognised by government and other funding bodies or sometimes funders have explicitly rejected any responsibility for meeting the need (often as a result of disputes between funders over who holds the relevant funding bucket). Because service provision is left to the immediate family, the need can easily remain invisible and individualised. An individual/family may be compelled to make considerable personal sacrifices depending on the severity of the need facing them.

Along the social services continuum there is a wide range of services that lie somewhere between fully funded services and completely unpaid social services. Community groups may provide paid, part-paid (which may be under-paid) or unpaid social services. For these services the responsibility to fund and provide them has become shared between government, social service providers and the families in need. How and who determines how responsibility is shared, depends on the location of power.

Social service actors can be divided into three main groupings: funders, social service providers and those in need of social services. Funders of social services include government policy makers, who determine priorities and processes for funding social services, government funding bodies (eg. the Community Funding Agency and the Health Funding Authority) and other non-government social service funders (eg. ASB Trust). Social service providers can be divided into four main groups: government providers (eg Children, Young Persons and their Families Service), large national non-government providers (usually partly government funded eg. IHC, Barnados), small local community agencies (part-paid and/or voluntary eg. Homebuilders), and finally families (usually unpaid and without a choice in providing care). Finally there are the individuals, families and communities actually needing social services.

The funding environment is where the distribution of responsibility for a specific social service is actually negotiated. Unfortunately throughout the 1990s the term "negotiation" was a misnomer because the power relationship between funders and social service providers has been unequal. Funders have had the ability to unilaterally decide (and change) the process, terms, timeframes, and service boundaries for obtaining funding. Social service providers have then had the unenviable task of responding to new (and changing) requirements of various funding bodies in the hope that their funding application will be accepted. Large, institutional providers have had the best ability to negotiate with funding bodies to have necessary services recognised and funded. Families and individuals in need of a particular service have usually had no direct access to negotiations with a funding body. Instead community groups that have been helping meet a particularly need or who became aware of that need, have picked up an advocacy role for groups of families.

There are many possible definitions and forms of community groups. One key point that Gordon notes is that: "The language of community is not restricted geographically, nor does it refer to a national homogeneity. Instead community signifies political struggle for resources, material and symbolic, rather than static, bounded relations of clearly defined insiders and outsiders." (Gordon, 1993, p. 435). Eade and Williams have also identified a number of benefits of organisations that represent poor people and I think these can be equally applicable to community groups. Community groups can:

- offer mutual support and solidarity;
- enhance self-esteem and collective confidence;
- improve people's ability to combat injustice, through collective action;
- promote discussion and analysis of common concerns;
- increase citizen's participation in the wider political process;
- lobby on issues of direct interest;
- demand access to government and other powerful officials;
- negotiate with official bodies, and with aid agencies. (Eade & Williams, 1995, p. 335)

Community Groups as 'Piggy in the Middle' of Responsibility Debates

Many community groups were in a difficult situation; they found themselves caught between declining government funding and increasing family need. As they tried to share the burden of responsibility families were struggling with, by working with families and providing more services, some community groups recognised that they had insufficient resources to meet the needs. Accepting the needs of a family and attempting to help by providing both services and advocacy, while attempting to secure funding from a declining pool, virtually guaranteed increased responsibility for services by community groups. Community groups that moved beyond purely providing a service and took on a role of advocating for greater government responsibility, and hence funding, to meet the needs of families they work with, end up playing 'piggy in the middle' of responsibility debates.

Community groups were in the untenable situation of trying to negotiate/lobby funders to take greater responsibility for specific social services while the funders set all the rules of this 'negotiation'. The situation for community groups was further complicated by having to lobby a number of service providers and funders, each with different boundaries of responsibility. In some instances this could contribute to a debate of where did responsibility lie – with educational services such as Special Education Services, health services – either locally or with the Health Funding Authority, with welfare services, such as the Community Funding Agency, or at some other level of government. In reality, for families with a family member with autism, it was the family that had to bear total responsibility for their own survival and caring for their ASD family member.

Finding adequate funding for both just continuing the existence and survival of the Autistic Association and then obtaining funding for the vast amount of desperately needed services identified by the association has been the main focus of the association throughout the time I have been working with them. Other than day to day support for parents, chasing funding has been the association's main activity – this has involved everything from trying to negotiate with government funding bodies to running sausage sizzles.

The ongoing issues Homebuilders had with its identity and people understanding the nature of their work compounded their funding difficulties – they had to continually assert their professionalism to funding bodies and educate funders about the Homebuilder's model. As an agency working at the coalface, the staff of Homebuilders were also very aware of the needs and issues of people struggling in their community. However they realised that the work done by Homebuilders on its own could not sufficiently address broader structural issues and that it was necessary to take a more pro-active advocacy and educational role in the community rather than just trying to respond to needs at an individual level. The living standards survey undertaken by Homebuilders was initiated partly to provide more quantitative evidence of the financial struggles faced by families in Rodney, and partly to make more visible the needs within the community which funders should be aware of and sensitive towards.

For some community groups, such as the Autistic Association and Homebuilders, there is also an inherent tension in combining the roles of both service provider and advocate for more/better services for families in need. For the Autistic Association, one unresolved difficulty is the recognition that increasingly trying to become a provider of services to families – as a result of responding to the needs of families and the poor response of all other service providers to provide assistance – calls into question the original role of the association as a support and advocacy group for parents. In trying to respond to the needs of families the association is looking to take on some of the responsibility for meeting those needs, even though this would require a significant increase in skill and resources, simply because the responses of all other agencies have been so inadequate. The appropriateness of increasingly becoming a service provider is questioned by the association itself, but that direction is still being followed as no other agency is adequately picking up responsibility for providing the services needed.

Impact of Public Responsibility Debates

Public debate on government versus family/individual responsibility provided a background context and had a fundamental role in shaping negotiation possibilities with funding bodies. The public debate also influenced the direction the groups chose for the projects.

All three research projects developed with a backdrop of media attention and significant public debate around responsibility in each project area. For Homebuilders and the WAWC the ongoing public debates were predominantly of a negative nature. The public debate around retirement income centred on the idea that government would not be able to continue providing a universal pension at the current level relative to living standards and therefore people should expect less from government and needed to provide for their own retirement. The debate was very focused on demographics and economics and this was

contributing to a perspective that it was bad for people to rely on government and that individual responsibility was essential. The one-sidedness of the debate was seen as negative from the WAWC perspective as it was overlooking the realities and implications for many women who would not be able to save for their retirement.

Homebuilders participated in the public debate generated by the National Government's Code of Social and Family Responsibility and this code was a significant part of the context in which the living standards survey was set. The Code clearly portrayed the power of the government to try and define both the terms of debate around individual/family/government responsibility and shape public attitudes.

The absence of an adequate, properly designed, public, pilot study carried out before the bulk of questionnaires were sent, has meant that the subject coverage in the questionnaire has almost certainly emphasised the interest and concerns of government. Given public response since the release of the proposed Code, it is clear that the questions used do not reflect the range of public opinion on the subject of social and family responsibilities. (Survey Appraisals and Public Questions Committee, 1998, p. 3-4)

The Code was heavily critiqued by a number of community and academic groups and created a climate of concern about how the government's agenda could negatively affect families and particularly beneficiaries.

This dual focus on social issues for the population at large, and financial issues for government, has two important aspects. One is that the questionnaire contains little to indicate how all members of the New Zealand public might reasonably meet the costs of the proposed Code The other is that the extent of government responsibilities outlined in the documentation are essentially limited to the financial, as distinct from the social or infrastructural, and there are strong constraints placed on any further government expenditure. (Survey Appraisals and Public Questions Committee, 1998, p. 10)

The publicity for autism was also negative as the news was predominantly of tragedies rather than positive actions. The public trial of Janine Albury-Thomson generated a heated public debate regarding whether Janine or the government should have been held responsible for the tragedy. It led to explicit questioning of the status quo of leaving families to struggle on their own. The tragedy highlighted the inadequacies of a welfare state built on the fundamental assumption that family/women will provide fundamental services and that the welfare state will only provide what cannot be provided elsewhere. "When it is said that women cannot 'cope' [with demands of unpaid work] or are in some way inadequate because they are not successfully fulfilling the role expected, the standard derives from an

expectation upon which the welfare state is founded." (Sassoon, 1992, p. 172) The public outcry in the media reflected a strong questioning of the expectations being placed on parents of children with ASD and a realisation that the status quo of expecting families to cope was unjust and this led to an opening of doors by government and funding agencies.

The media attention on the above issues combined with an acute awareness of families struggling to cope and the difficulties community groups faced in negotiating responsibility through funding application forms, contributed to the impetus for the groups to take some form of action and thus the research projects were one aspect of the groups' respective responses.

The Power to Define Legitimate Need and Responsibility

I have deliberately been using the words 'responsibility' and 'need' broadly partly because both terms are constantly being contested. In all three projects the exact definition of 'need' was being socially constructed. The groups were seeking to have the general needs that they identified recognised, however they were also very aware that the precise nature of a need could vary between families and individuals.

The location of power is key to what definitions of need and responsibility become recognised and accepted. As Clarke and Langan note:

... need as a contested concept leads us to issues of power. Central to this argument is that the power to define 'need' and the processes, practices and relationships associated with needs has been and continues to be central to the organization and provision of social welfare. Forms of economic, social, political and organizational power are involved – in different ways and at different levels – in constructing definitions of legitimate need. (Clarke & Langan, 1998, p. 270)

When those in positions of power recognise and accept some responsibility for particular needs, the needs become viewed as legitimate and this can lead to access to services. "Some of this contestation is about social and political recognition – to be defined as an individual or groups who/which has needs is to be admitted to a place within the 'welfare community'. Having (legitimate) needs means social inclusion rather than exclusion." (Clarke & Langan, 1998, p. 271) In the case of families with members with ASD accessing services can truly mean the difference between social inclusion or exclusion – families without support were frequently very isolated and simply could not participate in normal social life, for example going to church or social events.

The status quo is for government or service providers to define and recognise needs – at a collective level through funding contracts and at an individual level through needs assessments. People can only access services by proving they fall into recognised categories of need. The processing of what meets the criteria in practice occurs primarily at an individual level through individual need assessments.

The processing of people is conducted through the categories of need. It is also the process in which 'lay' perceptions of need (the perceptions of the would-be service user) meet 'professional' constructions of need – sometimes matching, sometimes conflicting, but always a process that requires negotiation of some kind. (Clarke & Langan, 1998, p. 266)

Within New Zealand both the definition of need and the proposed solutions are defined primarily by medical, welfare or educational professionals. In the United Kingdom the 1989 Caring for People White Paper UK "... concluded that the responsibility for assessing need should lie with social services authorities, who should also have the responsibility for designing and purchasing care packages."(Barnes, 1998, p. 95) Within New Zealand it is primarily professionals who have the power to define needs and proposed solutions, rather than the families and individuals with the need. Individual needs assessments provide at best very limited opportunities for influencing professional constructions of need and eligibility.

A related issue is that there has been a tendency for the criteria for eligibility in needs assessments to shift depending on the degree of resource rationing by service providers. As resources for social services become stretched there has also been an increasing emphasis on risk rather than need being the basis of eligibility, and this has been particularly evident in difficulties accessing mental health services. The increasing emphasis on risk rather than need may be affecting the ability of adolescents and adults with ASD to access mental health services.

The increased emphasis on risk, in a rationed service environment, rather than need can also have a particularly negative impact for carers.

Decisions about the priority to be given to offering a service must take into consideration the impact on the carer of continuing to provide care. However, since eligibility for services is increasingly being determined by reference to risk, the availability of an informal carer is likely to mean an assessment that the level of risk is lower than would be the case if no carer were available. (Barnes, 1998, p. 111)

The situation of service providers emphasising risk rather than need in a rationed environment can effect women caring for their elderly parents. A women's role as a carer

reduces the risk for the elderly person and in a rationed environment the carer may therefore have more difficulty in accessing services.

A number of studies have also pointed to the conflict of interest that can occur between recognising the needs of carers and the people they are caring for, and also service providers. Twigg et al 1990, comment on problems in evaluating services for carers:

The aims of policy, and thus of interventions, are vague and contradictory. How far should services be concerned with the well-being of carers as opposed to encouraging the continuance of caregiving? In certain situations, the two aims go together, but in many they do not. [Twigg] has also outlined some of the problems posed to agencies in their conceptualisation of their relations with informal carers, and, in particular, in the tensions between regarding carers as resources, as co-workers and as co-clients (Twigg, 1989). (Twigg, Atkin, & Perring, 1990, p. 10)

The power of service providers to decide who qualifies can disadvantage carers. This is particularly likely in a rationed environment where there may be a conflict of interest between a service provider, trying to minimise demand on their stretched services by relying on the resource of informal carers, and a carer who may no longer want the responsibility of being the daily caregiver.

The power that individual needs assessments can give to service providers over those being assessed, can be very problematic for both carers and people with needs. As a result of the fundamental power imbalance involved in the recognition of needs, the argument in favour of seeking rights rather than recognition of needs has been strengthened.

Oliver argued against the fundamental notion that 'need' should have a central place in determining welfare policy and provision. He identified an 'unfortunate retreat from active to passive citizenship and from rights-based to needs-based welfare provision' (Oliver, 1996, p. 68) at an early stage in the implementation of legislation to introduce a range of welfare provisions at the end of the Second World War. No professionalized service based on the assessment of need rather than on citizenship rights to welfare can redress the imbalance of power between disabled people and service providers, nor ensure that the receipt of support is not dependent on budgetary constraints. (Barnes, 1998, p. 121)

However the trend within government in New Zealand in recent years, particularly under the National Government, was a shift away from the "notion of rights and entitlements (particularly welfare rights) and onto the notion of responsibilities and obligations" (Boston, 2000, p. 178). Sitting alongside this shift away from rights was "a shift in emphasis away from the responsibilities of the state (or the idea of 'collective' responsibility) to a greater

focus on the responsibility of individuals and families to provide for their own needs.”(Boston, 2000, p. 178). Thus New Zealand has been moving steadily away from rights based public services and collective responsibility and towards an emphasis on individual/family responsibility.

The three groups I worked with tended to focus on needs rather than rights. This reflected their experience of need and their perception of the current policy environment as being more needs rather than legal rights orientated. This is not to say that they did not believe, for instance, that children with autism had a legal right to an education – many parents did believe this and were closely following legal action taken by another group of parents with children with special needs. However to enable real education to happen the Auckland Branch parents were focusing on identifying the immediate specific needs that had to be met for learning to be a reality for their children, for instance in terms of teacher aide training and suitable classrooms, rather than legal action.

Like need, responsibility is similarly contested and influenced by those with power. In recent years responsibility has predominantly been used in the context of advocating for increased individual responsibility – a key theme of the ‘New Right’. The government’s proposed Code of Social and Family Responsibility in 1998 led to heated debate regarding family responsibilities and the power of the state to enforce its definition of family responsibilities, particularly on beneficiaries through the use of sanctions. As with needs, it is government and social service providers that hold the power to define responsibilities, rather than families or community groups. The Autistic Association could lobby for greater government responsibility for meeting needs, but they had no power to force government into taking responsibility. Their most effective tool for getting the government’s attention was the media highlighting the plight of some families. For parents of children with autism, it is likely that they will always have overall responsibility, the debate is over the extent to which the responsibility, and related funding, of meeting needs/delivering services can be shared in a more balanced and just way.

The shift in emphasis away from responsibilities of the state has weakened the ability of families and individuals to rely on government actually delivering on its responsibility to provide certain services. For instance, the vigorous promoting of private retirement schemes and private health insurance in recent years, coincided with increasing public scepticism and concern that public services are/will be sufficient and accessible. The shift to State Owned Enterprises and the selling and separating off of what were previously government services has also weakened the claim of citizens to receiving services as of right. Many social and health services are increasingly being provided on a provider-consumer basis.

Questioning the Distribution of Power and Responsibility

A case can be made that those with the most power have the least responsibility and those with the least power have the most responsibility. Those with power can choose not to take responsibility, but those without power cannot pass responsibility onto someone else. My view is that the distribution of responsibility for social services should be broader than just need or risk based eligibility for services. The distribution of responsibility for social services should reflect human rights – families, and unrelated members of the public like Malcolm Beggs, should not be left with responsibilities that result in their human rights being infringed.

The collective provision of social services to meet needs and share responsibility is one means of enabling social justice. What society regards as 'just' has always been and will continue to be a shifting horizon over time. Marilyn Waring states that there are three distinct theories of government accountability: "government agency, government complicity by failure to act, and government responsibility for the unequal application of the law." (Waring, 1996, p. 119) Government can be critiqued and called to account on its responsibility to uphold all human rights, particularly in terms of its accountability by failing to act.

Importance of Reversing Power Relationships

I believe that one of the keys to creating real change and addressing the needs faced by those suffering injustices is the reversing of power relationships. As Eade notes: "People's capacity to create appropriate structures through which to participate effectively in the decisions that affect their lives is crucial to the development of civil society, and must underpin the search for social justice." (Eade & Williams, 1995, p. 331) Participating effectively is not possible through individual needs assessments or through funding applications. Participating effectively needs to go far deeper than making the odd submission on a review. On the day to day provision of social services it should involve professionals, be they academic researchers or medical, welfare, or educational professionals, handing power over to the groups they are supposed to be serving. My basis for this claim is the recognition that both the power to define a need and ideas for solutions can and should come collectively from the people affected. It is less likely that a 'professionals' interpretation will adequately address the real/right problems. As the example of action research shows, the people affected are the 'experts' and the role of a group's collective reflection and analysis is critical to identifying problems and solutions. Funding bodies can retain the power to distribute their funds but the definition of needs and ideas for how they should be addressed should come collectively from the people affected.

Such broad-brush statements about power reversals are probably more common in the context of projects from developing countries than from projects with community groups in New Zealand. However many of the same lessons from action/participatory research projects in developing countries apply in New Zealand, even though the language may be different. A number of development project studies have pointed to the mistakes created by distant 'experts' having the power to analyse and make decisions for communities. "Distance blacks, blurs and distorts vision, and distance is institutionalized. Most of those who were wrong were physically, organizationally, socially and cognitively distant from the people and conditions they were analysing, planning and prescribing for, and making predictions about." (Chambers, 1997, p. 31) This statement can apply not only to aid providers and poor rural communities but also to government funding agencies in New Zealand and families with a family member with autism.

Chambers highlights the limitations of normal professionalism in understanding the complexity of people's lives:

Normal professionalism – the ideas, values, methods and behaviour accepted and dominant in professions or disciplines – is a means to status, power and wealth. Commonly, its elements derive from, and fit, things more than people. Universals are valued, based on measurement in controlled conditions. Specializations and reductionism separate parts from wholes. Complex realities are simplified and ordered in single scales such as poverty lines, and measures of production and employment. In the social sciences and policy, economics dominates, and gives primacy to mathematical analysis; what has been measured and counted becomes the reality. All this makes it hard for normal professionals to understand and serve the local, complex, diverse, dynamic and unpredictable realities of the conditions, farming systems and livelihood strategies of poor people. Normal professionalism creates and sustains its own reality. (Chambers, 1997, p. 33)

The normal reflex of professionals faced with complexity – of people, environments, farming systems and so on – has been to extract, process and analyse data and use them to decide what to do to those people, environments and farming systems. The processing and analysis of data are private activities under the control of professionals: power, in the name of planning and science – the project plan, the district plan, the farm plan, even the national plan – is retained in their hands and expressed in prescriptions for others. (Chambers, 1997, p. 54)

In contrast and in varying ways, all three community groups had a 'working with' approach to the families and women they helped (recognising the expertise within the families) rather than as professionals with power over the families and individuals. It is this shift from being 'normal professionals' as identified by Chambers above, to being a resource working with

community groups (just as the groups worked with their families) that could be invaluable to addressing specific injustices.

This shifting of power to community groups has more in common with community development than community care. The community development model reflects a greater power reversal, however many professionals seem to still have a preference for listening to individual consumers (who individually may be easier to ignore) rather than community groups, that often include consumers, with collective interests.

Community care is based on an assumption that individual unorganised carers (that is, families) will be the major source of care provision outside institutional settings. This differs from community development, which sees active organization on the part of groups of people living within a locality as a source of involvement in determining the nature of problems and needs which are collectively experienced, and the action required to address them. Community development explicitly takes community to be the object of policy, and community groups as subjects in determining the nature of local action. ... collective action on the part of organised groups of disabled people, carers and others is starting to impact on community care policy and practice. However, there remains a substantial reluctance among professional social care providers to accept as legitimate the involvement of 'community groups' with collective interests, as opposed to input from a series of disconnected individuals whose voices may be listened to as individual consumers of services. (Barnes, 1998, p. 87)

All three projects involved the groups claiming their own power to do social research from their own perspective. The first step in reversing the power relations was for the groups to do their own analysis, drawing on their own theoretical perspectives, of the problems as they defined them. In order to run their own projects, group members recognised and began to have their own expertise in the issue areas validated. The focus was not on emphasising detailed statistical analysis, but rather on revealing complexities, making comparisons and presenting findings in an accessible way. The projects gave the groups the opportunity to make their own plans regarding how the findings should be used and to propose their own solutions for aspects of the issues involved.

However I think the choice of the survey method by Homebuilders and the Autistic Association, was due to their desire to influence those with power – politicians, policy makers and funding bodies. The survey method was chosen because the groups believed creating quantitative data would be more persuasive and carry more weight than qualitative information, particularly stories. If the groups had not needed to confine their method to what was 'professionally' most acceptable, then I think that the use of a range of other methods may have been more likely. The power imbalance between the community groups and the professionals they sought to lobby was real and this did affect the validity of the

research projects in the eyes of some 'professionals'. For example in one meeting with a government agency on the findings of the Autistic Association Needs Survey a professional commented that all the quotes in the findings report should be in the back as an appendix. Again this reflected the 'normal professional' preference for quantitative mathematical analysis over the complexity of qualitative material.

Another very significant difference between the model of 'normal professionals' and action research by community groups is the very long-term and open-ended nature of community group action research projects. As Eade and Williams notes "Social organisation and capacity-building are long-term processes, without predictable or easily quantifiable outcomes." (Eade & Williams, 1995, p. 343) Action research projects have a very evolving nature, continually being shaped by their context and the changing mix of people involved. I think Chambers comment regarding the evolving direction of participatory projects is particularly apt. "An overarching problem is that participatory development cannot be planned in this way: its course is not foreseeable; it is a sea voyage, not a Swiss train journey." (Chambers, 1997, p. 43) A sailing sea voyage (relying on the wind) is a good analogy of action research as in all three projects we were not entirely sure where we would end up or when we would get there or what it would look like when we did. When the direction of a project is so open and responsive to how things are unfolding, trusting the process of action research is essential. An action research project may involve many plans but its course can not be pre-determined as research controlled by 'normal professionals' usually is.

The open-ended nature of action research projects also means that they are unlikely to be perfect. Their imperfections in part reflect the projects being shaped by 'the way things worked out', with no one individual in control, and the possibility that the group may not stick to the process or perhaps take longer to 'get around' to some steps than might be desirable in a more perfect world. However the process in action research often becomes as important as the data and findings. The attention given to the process reflects the collective commitment of a group, their internal relationships and their relationships to other local networks and communities that may participate or become involved in the project in different ways. The variety and importance of a community groups external relationships and commitments can provide a strong incentive to run the projects with integrity and inclusively.

Action research is one means for community groups to regain power in negotiating responsibility and defining problems and solutions. With action research and participatory methods "it is the reality of local people that comes to count." (Chambers, 1997, p. 156) Through collective participation, knowledge creation and reflection action research can be empowering both collectively and for individuals in community groups.

When action research is used as a tool to empower people to participate effectively in decisions that affect their lives, it also has the potential to enhance democracy. Action research has been closely related to 'education for liberation' (linking the acquisition of knowledge and skills to social needs and mobilisation). Eade and Williams have identified a number of indicators of change that can come out of social education programmes. These outcomes are also applicable to action research projects and reflect the potential for action research to enhance democracy. The outcomes may include:

- increased collective and individual confidence among the participants in assessing and finding solutions to social and political problems facing them;
- increased participation in the processes of decision-making among the women and men who were previously excluded from these;
- women and men's increased ability to understand and address the connections between their day-to-day living conditions, and the socio-political and economic context within which they live;
- women and men's greater ability to organise to press the State or other agencies for better living conditions or civil rights;
- the collective acquisition of specific skills – whether in the spheres of organisation, literacy, agricultural development, or primary health care – in conjunction with increased political awareness and skills in social analysis. (Eade & Williams, 1995, p. 363)

Power Reversals and Democracy

One consequence of increasing the power of community groups in the provision of social services (defining needs and solutions), but not necessarily leaving them responsible for more social services, would be increased democracy. "Democracy, as the word itself indicates, is the power of the people, that is to say, the link established between a social reality, the people, and a political reality, power." (Touraine, 1998, p. 87) Current trends of drawing heavily on professional experts (for example the increasing reliance by government agencies on consultants for advice) is effectively reducing democracy.

Modern societies are therefore giving rise to an increasing number of problems which require solutions that are outside the competence of the citizen. Only experts are in a position to propose the solutions. The fact that society is becoming more technological has considerably narrowed the range of decisions that can be taken by the man or woman in the street. (Villoro, 1998, p. 98)

The explicit reversing of power relationships, between the 'professionals' in government social service and funding agencies and the community groups that are lobbying them, and

recognising the expertise of community groups, would provide an opportunity to develop the radical democracy envisaged by Villoro. "Radical democracy is that which returns to the people their capacity to participate actively in decision-making on all collective matters affecting their lives, with the result that the people only obeys its own soul." (Villoro, 1998, p. 99)

Action research is an appropriate tool that can be used by community groups to reverse power relationships and enhance democracy. Through using action research the significance of tragedies, voices, statistics, achievements and collective action and reflection can all be recognised and drawn together to create a more just society.

Postscript (February 2002):

The West Auckland Women's Centre, following the receipt of funding, has now published their report on the findings of their women and retirement income project. The published document is very accessible and reader friendly. The formal launch of the report is being prepared along with a distribution plan.

A first instalment of the Homebuilders Living Standards Survey findings has been published in a local paper. We are now working on future instalments and other ways of feeding back the main survey findings into the local community.

The National Autistic Association has had ongoing meetings with the Ministry of Education and Health to present the findings of the national survey. In total 932 families have been surveyed nationally, representing 979 individuals with ASD. The data entry and analysis is complete and a comprehensive report of the findings has been published by the national office. The survey is an invaluable tool for the Associations ongoing consultations with various government agencies. At the Auckland branch's last mini-conference, a summary pamphlet of the Auckland survey results was distributed (this occurred prior to the full national results being completed).

Bibliography

- Abel, E. K. (1987). *Love is not enough: family care of the frail elderly*. Washington: American Public Health Association.
- Adams, K. (1998). *NZCCSS evaluation survey of funding agencies*. Wellington: New Zealand Council of Christian Social Services.
- After rural answers. (1999, August 19). *Rodney Times*, p. 3.
- Age Concern New Zealand. (1997). *Core issues in health care services for older people*. Wellington: Age Concern New Zealand.
- Allen, I., & Perkins, E. (1995). Chapter 11: discussion. In I. Allen & E. Perkins (Eds.), *The future of family care for older people* (pp. 221-234). London: HMSO.
- Armstrong, N. (1992). Handling the hydra: feminist analyses of the State. In R. du Plessis (Ed.), *Feminist voices* (pp. 224-238). Auckland: Oxford University Press.
- Ashton, T., & St John, S. (1988). *Superannuation in New Zealand. Averting the crisis*. Wellington: Victoria University Press for the Institute of Policy Studies.
- Atweh, B., Kemmis, S., & Weeks, P. (Eds.). (1998). *Action research in practice. Partnerships for social justice in education*. London: Routledge.
- Auckland Branch Survey Results. (2000, November). *Autistic Association of NZ Inc, Auckland Branch Newsletter, 1, 2*.
- Autism remand shows gaps says minister. (1998, July 23). *NZ Herald*, p. A5.
- Autism Services Project Team. (1998, October). *Autism services in New Zealand*. Wellington: Ministry of Health.
- Babbie, E. (1998). *The practice of social research*. (8th ed.). Belmont, CA: Wadsworth Publishing Company.
- Baldwin, S. (1995). Love and money: the financial consequences of caring for an older relative. In I. Allen & E. Perkins (Eds.), *The future of family care for older people*. London: HMSO.

- Ballard, K. (Ed.). (1994). *Disability, family, whanau and society*. Palmerston North: The Dunmore Press.
- Ballard, K., Bray, A., Watson, M., Burrows, L., & MacArthur, J. (1992). *The Otago Family Network. A joint project of the Donald Beasley Institute and the University of Otago*. Dunedin: The Otago Family Network.
- Baretta-Herman, A. (1994). Revisioning the community as provider: restructuring New Zealand's social services. *International Social Work*, 37, 7-21.
- Barnes, M. (1998). Whose needs, whose resources? Accessing social care. In M. Langan (Ed.), *Welfare: needs rights and risks* (pp. 81-126). London: Routledge.
- Belgrave, M., & Brown, L. (1997). *Beyond a dollar value: the cost of informal care of older people*. Auckland: Dept of Social Policy and Social Work, Massey University, and the Disability Support Services Division of North Health.
- Belgrave, M., Brown, L., & Northern Region Case Management Study. (1997). *Informal care and the Northern Region Case Management Study*. Auckland: Massey University Department of Social Policy and Social Work.
- Bingham, E. (1998, November 19). Diagnosis of autism 'inadequate'. *NZ Herald*, p. A3.
- Blakeley, R. (1997). *New policy for old problems*. Paper presented to the AIC Public Policy Conference, Wellington.
- Bodger, S. (2000, September 9-10). Autistic pupils dive into the mainstream. *Weekend Herald*, p. A15.
- Bogard, M. (1995). *The legal rights of people with intellectual disabilities*. Wellington: Legal Resources Trust.
- Bonita, R., Broad, J., Thomson, S., Baskett, J., & Richmond, D. (1989). *Long term care in Auckland: a study of elderly people in public and private institutions*. Auckland: University of Auckland and North Shore Hospital.
- Borowski, A., Encel, S., & Ozanne, E. (Eds.). (1997). *Ageing and social policy in Australia*. Cambridge: Cambridge University Press.

- Boston, J. (2000). Morals, codes and the State: reflections on 'another New Zealand experiment'. In G. Sullivan (Ed.), *Another New Zealand experiment: a code of social and family responsibility* (pp. 168-181). Wellington: Institute of Policy Studies.
- Brown, L. D., & Tandon, R. (1983). Ideology and political economy in inquiry: action research and participatory research. *The Journal of Applied Behavioral Science*, 19, 277-294.
- Bywater, M. (1989). *Income security for older women*. Wellington: Ministry of Women's Affairs.
- Campbell, C., Ny, A. M., & Thorns, D. C. (1987). *Housing provision for the elderly: a focus on four locations*. Wellington: The National Housing Commission.
- Carr, W., & Kemmis, S. (1986). *Becoming critical. Education, knowledge and action research*. London: The Falmer Press.
- Cervin, C. (2000, December). Branch Survey Results Update. *Autistic Association of NZ Inc, Auckland Branch Newsletter*, 1, 1, 3.
- Cervin, M. (1982). *A Study of a Mediator's Role*. Unpublished Research Paper for the Degree of Master of Public Policy, Victoria University, Wellington.
- Chambers, R. (1997). *Whose reality counts? Putting the first last*. London: Intermediate Technology Publications.
- Chetwynd, M., Ritchie, J., Reith, L., & Howard, M. (1996). *The cost of care. The impact of charging policy on the lives of disabled people*. Bristol: The Policy Press.
- Clark, T. (1998, July 25-26). Govt, not mother, should be in dock (Letter to the editor). *Weekend Herald*, p. A21.
- Clarke, J., & Langan, M. (1998). Review. In M. Langan (Ed.), *Welfare: needs rights and risks* (pp. 259-272). London: Routledge.
- Cody, J. (1990). Devolution, disengagement and control in the statutory social services. In P. McKinlay (Ed.), *Redistribution of power? Devolution in New Zealand* (pp. 159-190). Wellington: Victoria University Press for the Institute of Policy Studies Victoria University of Wellington.
- Collier, J. F. (1992). Negotiating values: 'you can't have it both ways'. In P. L. Johnson (Ed.), *Balancing acts. Women and the process of social change* (pp. 163- 177). Boulder, Colorado: Westview Press.

- Cull, M. (1993). *The effects of funding requirements on the management of voluntary organisations*. Palmerston North: Department of Management Systems, Massey University.
- Dalley, G. (1988). *Ideologies of caring. Rethinking community and collectivism*. Hampshire: The MacMillan Press.
- Davey, J. (1995). *Putting housing wealth to work. Home equity conversion in New Zealand*. Wellington: Ministry of Housing.
- Davey, J. A. (2000). *Another New Zealand experiment: a code of social and family responsibility*. Wellington, New Zealand: Institute of Policy Studies.
- Davis, R. (1997). *Social Capital: A Critique*. Wellington: Joint Methodist-Presbyterian Public Questions Committee.
- Day, A. T. (1985). 'We can manage'. *Expectations about care and varieties of family support among people 75 years and over*. Melbourne: Institute of Family Studies Monograph No 5.
- de Haan, I. (1998). *Prevention or cure*. Unpublished Dissertation, Massey University, Albany Campus, Auckland.
- Delphy, C. (1984). *Close to home. A materialist analysis of women's oppression*. Amherst: The University of Massachusetts Press.
- Denzin, N. K. (1989). *The research act: a theoretical introduction to sociological methods*. (3rd ed.). Englewood Cliffs, New Jersey: Prentice-Hall.
- Denzin, N. K., & Lincoln, Y. S. (1994). *Handbook of qualitative research*. Thousand Oaks: Sage Publications.
- Department of Statistics. (1992a). *Making provision for retirement. Findings of the survey of retirement provision 1992*. Wellington: Department of Statistics.
- Department of Statistics. (1992b). *A survey of retirement provision*. Wellington: The Research Unit of the Social Policy Agency, Department of Social Welfare.
- Derrick, E. (1993). *Community development and social change. Learning from experience*. Auckland: Auckland District Council of Social Services.
- DeVault, M. L. (1996). Talking back to sociology: Distinctive contributions of feminist methodology. *Annual Review of Sociology*, 22, 29-50.

- Department of Statistics. (1992a). *Making provision for retirement. Findings of the survey of retirement provision 1992*. Wellington: Department of Statistics.
- Department of Statistics. (1992b). *A survey of retirement provision*. Wellington: The Research Unit of the Social Policy Agency, Department of Social Welfare.
- Derrick, E. (1993). *Community development and social change. Learning from experience*. Auckland: Auckland District Council of Social Services.
- DeVault, M. L. (1996). Talking back to sociology: Distinctive contributions of feminist methodology. *Annual Review of Sociology*, 22, 29-50.
- Dickson, J., Fish, J., Marsault, A., Pool, I., & Martin, B. (1997). *New Zealand women: constraints to savings for retirement*. Hamilton: Population Studies Centre, University of Waikato.
- Driver, S., & Robinson, D. (1986). *Voluntary social services: a review of funding*. Wellington: New Zealand Planning Council.
- du Chateau, C. (1998, July 18-19). Stress that drives a mother to kill. *Weekend Herald*, p. A15.
- Duelli Klein, R. (1983). How to do what we want to do: thoughts about feminist methodology. In R. Duelli Klein & G. Bowles (Eds.), *Theories of women's studies* (pp. 88-104). London: Routledge & Kegan Paul.
- Duelli Klein, R., & Bowles, G. (Eds.). (1983). *Theories of women's studies*. London: Routledge & Kegan Paul.
- Eade, D., & Williams, S. (1995). *The Oxfam handbook of development and relief*. (Vol. 1). Dublin: Oxfam.
- Eichler, M. (1997). Feminist methodology. *Current Sociology*, 45(2), 9-36.
- Elden, M., & Chishom, R. P. (1993). Emerging varieties of action research. *Human Relations*, 46, 121-142.
- Else, A. (1996). *False economy. New Zealanders face the conflict between paid and unpaid work*. Auckland: Tandem Press.
- Else, A., & St John, S. (1998). *A super future? The price of growing older in New Zealand*. Auckland: Tandem Press.

- Ferguson, A. (1998, March 16). Desperation turns parents into jailers. *The New Zealand Herald*, p. A1.
- Finch, J. (1995). Responsibilities, obligations and commitments. In I. Allen & E. Perkins (Eds.), *The future of family care for older people* (pp. pp. 52-62). London: HMSO.
- Finch, J., & Mason, J. (1993). *Negotiating family responsibilities*. London: Tavistock/Routledge.
- Fink, A. (1995). *How to ask survey questions*. Thousand Oaks, California: Sage Publications.
- Fleming, R., in association with, Julia Taiapa, Pasikale, A., & Easting, S. K. (1997). *The common purse. Income sharing in New Zealand families*. Auckland: Auckland University Press.
- Florence, J. (1996). *Culture of partnership to culture of contract*. Unpublished Masters in Social Work Thesis, Massey University, Albany.
- Fowler, F. J. (1995). *Improving survey questions: design and evaluation*. (Vol. 38). Thousand Oaks, California: Sage Publications.
- Gallagher, S. K. (1994). *Older people giving care. Helping family and community*. Westport: Auburn House.
- Ginn, J., & Arber, S. (1995). Gender differences in relationship between paid employment and informal care. *Work, Employment & Society*, 9, 445-472.
- Goodin, R. E. (1998). Social welfare as a collective social responsibility. In R. G. Frey (Ed.), *Social welfare and individual responsibility* (pp. 97-195). Cambridge, United Kingdom: Cambridge University Press.
- Gordon, D. A. (1993). Worlds of consequences: feminist ethnography as social action. *Critique of Anthropology*, 13, 429-443.
- Gregory, S., & Brownill, S. (1995). *The housing/care divide. Community care and the management of single person housing in Oxford*. Oxford: School of Planning, Oxford Brookes University.
- Gross, E. (1992). What is feminist theory? In H. Crowley & S. Himmelweit (Eds.), *Knowing women. Feminism and knowledge* (pp. 355-369). Cambridge: Polity Press in association with The Open University.

- Heimer, C. A., & Staffen, L. R. (1998). *For the sake of the children. The social organization of responsibility in the hospital and the home*. Chicago & London: The University of Chicago Press.
- Heycox, K. (1997). Older women: Issues of gender. In A. Borowski, S. Encel, & E. Ozanne (Eds.), *Ageing and Social Policy in Australia* (pp. 94-118). Cambridge: Cambridge University Press.
- Howe, A. (1996). Changing the balance of care: Australia and New Zealand. In OECD (Ed.), *Ageing in OECD countries. A critical policy challenge* (Vol. Social Policy Studies No. 20, pp. 219-238). Paris: OECD.
- Hyman, P. (1994). *Women and economics. A New Zealand feminist perspective*. Wellington: Bridget Williams Books.
- IHC New Zealand. (1998, August). *Autism review. A review of current service users registered with IHC*. Wellington: IHC New Zealand.
- IHC New Zealand. (1999, January). Autism survey. *Community Moves*, 36, 28.
- Ingham, L. (1999, July 20,). Families asked for facts on hardship. *Rodney Times*, p. 8.
- Johnson, P. L. (Ed.). (1992). *Balancing acts. Women and the process of social change*. Boulder, Colorado: Westview Press, Inc.
- Kemmis, S., & Wilkinson, M. (1998). Participatory action research and the study of practice. In B. Atweh, S. Kemmis, & P. Weeks (Eds.), *Action research in practice. Partnerships for social justice in education* (pp. 21-36). London: Routledge.
- Kent, D. (1998). *The joy of lobbying. Campaigning to influence government decisions and public attitudes*. Wellington: Gateway Lobbyskills.
- Koloszar, P. (1998, August 8-9). Sorry, but we just didn't notice (Letter to the editor). *Weekend Herald*, p. A21.
- Koopman-Boyden, P. G. (Ed.). (1993). *New Zealand/s ageing society. The implications*. Wellington: Daphne Brasell Associates Press.
- Krishnan, V. (1995). Modest but adequate: An appraisal of changing household income circumstances in New Zealand. *Social Policy Journal of New Zealand*(4), 76-97.
- Krishnan, V. (1997). Divergent paths: changes in public and private income provision amongst older households. *Social Policy Journal of New Zealand*(9), 151 - 163.
- Laczko, F., & Victor, C. R. (Eds.). (1992). *Social policy and elderly people*. Aldershot: Avebury.
- Laing, W. (1993). *Financing long-term care. The crucial debate*. London: Age Concern England.

- Ingham, L. (1999, July 20,). Families asked for facts on hardship. *Rodney Times*, p. 8.
- Johnson, P. L. (Ed.). (1992). *Balancing acts. Women and the process of social change*.
Boulder, Colorado: Westview Press, Inc.
- Kemmis, S., & Wilkinson, M. (1998). Participatory action research and the study of practice. In
B. Atweh, S. Kemmis, & P. Weeks (Eds.), *Action research in practice. Partnerships for
social justice in education* (pp. 21-36). London: Routledge.
- Kent, D. (1998). *The joy of lobbying. Campaigning to influence government decisions and public
attitudes*. Wellington: Gateway Lobbyskills.
- Koloszar, P. (1998, August 8-9). Sorry, but we just didn't notice (Letter to the editor). *Weekend
Herald*, p. A21.
- Koopman-Boyden, P. G. (Ed.). (1993). *New Zealand/s ageing society. The implications*.
Wellington: Daphne Brasell Associates Press.
- Krishnan, V. (1995). Modest but adequate: An appraisal of changing household income
circumstances in New Zealand. *Social Policy Journal of New Zealand*(4), 76-97.
- Krishnan, V. (1997). Divergent paths: changes in public and private income provision amongst
older households. *Social Policy Journal of New Zealand*(9), 151 - 163.
- Laczko, F., & Victor, C. R. (Eds.). (1992). *Social policy and elderly people*. Aldershot: Avebury.
- Laing, W. (1993). *Financing long-term care. The crucial debate*. London: Age Concern England.
- Langan, M. (1998a). The contested concept of need. In M. Langan (Ed.), *Welfare: needs rights
and risks* (pp. 3 - 34). London: Routledge.
- Langan, M. (1998b). Rationing health care. In M. Langan (Ed.), *Welfare: needs rights and risks*
(pp. 35-80). London: Routledge.
- Lather, P. (1986). Research as praxis. *Harvard Educational Review*, 56, 437-457.
- Lewis, H. (1991). *Home health care in the United States and Canada. Lessons for New
Zealand: report on a Winstone Churchill Fellowship*. Wellington: Winstone Churchill
Memorial Trust Board.
- Lewis, J. (1996). What does contracting do to voluntary agencies? In D. Billis & M. Harris (Eds.),
Voluntary agencies: challenges of organisation & management (pp. 98-112).
Hampshire: Macmillian Press.

- List, P., Hubbard, A., & Dolan, G. (1991). *Budgeting for cuts: A study of poverty in Palmerston North after the April 1st benefit cuts*. Palmerston North: Methodist Social Service Centre, Palmerston North.
- Maguire, P. (1993). Challenges, contradictions, and celebrations: Attempting participatory research as a doctoral student. In P. Park, M. Brydon-Miller, B. Hall, & T. Jackson (Eds.), *Voices of change. Participatory research in the United States and Canada* (pp. 157-176). Westport, Connecticut: Bergin & Garvey.
- Malcolm, M., Rivers, M., & Smyth, K. (1993). Emerging trends for the voluntary sector: New Zealand and beyond. In G. R. Hawke & D. Robinson (Eds.), *Performance without profit: the voluntary welfare sector in New Zealand* (pp. 125-140). Wellington: Institute of Policy Studies, Victoria University of Wellington.
- Mallory, B. L. (1986). Interactions between community agencies and families over the life cycle. In R. R. Fewell & P. F. Vadasy (Eds.), *Families of handicapped children. Needs and supports across the life span* (pp. 317-356). Austin, Texas: Pro-ed.
- Massey University Human Ethics Committee. (1999). *Code of ethical conduct for research and teaching involving human subjects*. (Revised ed.). Palmerston North: Massey University.
- Masters, C. (1998, March 17). Autistic kids 'falling through health gap'. *NZ Herald*, p. A3.
- Masters, C. (2000, September 4). Mother heads for breakdown instead of break. *NZ Herald*, p. A3.
- Maynard, M. (1994). Methods, practice and epistemology: the debate about feminism and research. In M. Maynard & J. Purvis (Eds.), *Researching women's lives from a feminist perspective* (pp. 10-26). London: Taylor & Francis.
- Maynard, M., & Purvis, J. (1994). Doing feminist research. In M. Maynard & J. Purvis (Eds.), *Researching women's lives from a feminist perspective* (pp. 1-9). London: Taylor & Francis.
- McDonald, P. (1997). Older people and their families: issues for policy. In A. Borowski, S. Encel, & E. Ozanne (Eds.), *Ageing and social policy in Australia* (pp. 194-210). Cambridge: Cambridge University Press.

- McNiff, J. (1988). *Action research: principles and practice*. London: Macmillan Education.
- McPherson, J. (1994). *Making changes. Action research for developing Maori-language policies in mainstream schools*. Wellington: New Zealand Council for Educational Research.
- McTaggart, R. (1991). *Action research. A short modern history*. Geelong: Deakin University.
- McTaggart, R. (1996). Issues for participatory action researchers. In O. Zuber-Skerritt (Ed.), *New directions in action research* (pp. 243-255). London: The Falmer Press.
- Middleton, S., Ashworth, K., & Walker, R. *Family Fortunes. Pressures on parents and children in the 1990s*. London: CPAG Ltd.
- Mies, M. (1983). Towards a methodology for feminist research. In G. Bowles & R. Duelli Klein (Eds.), *Theories of women's studies* (pp. 117-139). London: Routledge.
- Mies, M. (1993). Towards a methodology for feminist research. In M. Hammersley (Ed.), *Social research. Philosophy, politics and practice* (pp. 64-83). London: Sage Publications in association with The Open University.
- Miller, J. A. (1991). *Community-based long-term care*. Newbury Park, California: Sage Publications.
- Milne, S. (1998). *Shifting ground: the position of women parenting alone in Auckland and their access to housing in a restructured environment*. Unpublished PhD Thesis in Philosophy, Massey University, Albany, Auckland.
- Ministry of Women's Affairs. (1999). *Panui: Ko Nga Kuia. Older women. An occasional publication of the Ministry of Women's Affairs*. Wellington: Ministry of Women's Affairs.
- Ministry of Women's Affairs. (1990). *Valuing women's unpaid work*. Wellington: Ministry of Women's Affairs.
- Ministry of Women's Affairs. (1996a). *The full picture. Guidelines for gender analysis*. Wellington: Ministry of Women's Affairs.
- Ministry of Women's Affairs. (1996b, June). *Retirement Income and Women Conference, June 1996: proceedings*, Wellington.

- Moore, A., & Tennant, M. (1997). *Who is responsible for the provision of support services for people with disabilities? A discussion paper commissioned by the National Health Committee*. Wellington: National Health Committee.
- Morgan, G. (1997, 5 August 1997). Let's send a clear message to politicians on super. *NZ Herald*, p. A11.
- Munford, R. (1992). Caregiving. In C. Briar, R. Munford, & M. Nash (Eds.), *Superwomen where are you? Social policy and women's experience*. (pp. 82-103). Palmerston North: Dunmore Press.
- Naples, N. A. (1991). Contradictions in the gender subtext of the war on poverty: the community work and resistance of women from low income communities. *Social Problems*, 38, 316-332.
- New Zealand Council of Christian Social Services. (1998). *Towards a real partnership. A NZCCSS review of the relationship between voluntary social services and NZ Community Funding Agency*. Wellington: New Zealand Council of Christian Social Services.
- New Zealand Council of Christian Social Services. (1999). *Criteria for judging government funding arrangements for the community sector*. Wellington: New Zealand Council of Christian Social Services.
- New Zealand Council of Trade Unions. (1989). *When I'm 64. Income security for the elderly*. Wellington: New Zealand Council of Trade Unions.
- New Zealand Council of Trade Unions. (1997). *Say no to compulsory superannuation*. Wellington: New Zealand Council of Trade Unions.
- New Zealand Federation of Voluntary Welfare Organisations. (1992). NZFVWO members' survey 1990/91. *Dialogue*, 71(September), 5-8.
- New Zealand Government. (1998). *Towards a code of social & family responsibility*. Wellington: Corporate Communications Unit, Department of Social Welfare.
- Nolan, M., Grant, G., & Keady, J. (1996). *Understanding family care. A multidimensional model of caring and coping*. Buckingham: Open University Press.

- Nowland-Foreman, G. (1995). *Neither mendicants nor deal-makers. Contracting, government funding and voluntary organisations*. Wellington: New Zealand Council of Christian Social Services.
- NZ Federation of University Women. (1997). *Report of 'The Super Seminar' on the Compulsory Retirement Savings Scheme for the public referendum in September 1997*. Auckland: NZ Federation of University Women.
- O'Brien, M., & Briar, C. (Eds.). (1997). *Beyond poverty. Citizenship, welfare and well-being in the 21st century. Conference proceedings, Massey University, Albany, March 1997*. Auckland: Peoples Centre.
- O'Brien, M., Chile, L., Haan, I. D., & Cervin, C. (1997). *Social services in Auckland: needs and responses. A report for the Catholic Caring Foundation*. Auckland: Dept of Social Policy and Social Work, Massey University, Albany Campus.
- Oakley, A. (1981). Interviewing women: a contradiction in terms. In H. Roberts (Ed.), *Doing feminist research* (pp. 30-61). London: Routledge.
- OECD. (1996). *Ageing in OECD Countries. A Critical Policy Challenge* (Social Policy Studies No. 20). Paris: OECD.
- Office of the Minister of Women's Affairs. (1997a). *Retirement savings scheme paper*. Wellington: Office of the Minister of Women's Affairs.
- Office of the Minister of Women's Affairs. (1997b). *Women and retirement income: current issues*. Wellington: Office of the Minister of Women's Affairs.
- Oja, S. N., & Smulyan, L. (1989). *Collaborative action research: a developmental approach*. London: The Falmer Press.
- Opie, A., in association with, Fulcher, L., Hawke, G., & Allen, N. (1992). *There's nobody there. Community care of confused older people*. Auckland: Oxford University Press.
- Palmer, G. (1994, 17-18 May). *Cohousing*. Paper presented at the Housing Research Conference, Wellington.
- Park, J. (1992). Research partnerships: A discussion paper based on case studies from 'The Place of Alcohol in the Lives of New Zealand Women' project. *Women's Studies International Forum*, 15, 581-591.

- Park, P. (1993). What is participatory research? A theoretical and methodological perspective. ✓
In P. Park, M. Brydon-Miller, B. Hall, & T. Jackson (Eds.), *Voices of change. Participatory research in the United States and Canada* (pp. 1-20). Westport, Connecticut: Bergin & Garvey.
- Pasikale, A., & George, T. (1995). *For the family first. A study of income allocation within Pacific Islands families in New Zealand*. Wellington: Destini Incorporated.
- Patton, M. Q. (1990). *Qualitative evaluation & research methods*. (2nd ed.). Newbury Park, California: Sage Publications.
- Perring, C., Twigg, J., & Atkin, K. (1992). *Families caring for people diagnosed as mentally ill: the literature re-examined*. London: Social Policy Research Unit.
- Prebble, M. (1991). Critical new elements in government thinking. In G. R. Hawke (Ed.), *A modest safety net?* (pp. 1-6). Wellington: Institute of Policy Studies.
- Prime Ministerial Task Force on Positive Ageing. (1997). *Facing the future: A strategic plan*. Wellington: Dept. of the Prime Minister and Cabinet.
- Reason, P. (1994). Three approaches to participative inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 324-339). Thousand Oaks, California: Sage Publications.
- Reay, D. (1996). Insider perspectives or stealing the words out of women's mouths. Interpretation in the research process. *Feminist Review*, 53(Summer), 57-73.
- Reinharz, S. (1992). *Feminist methods in social research*. New York: Oxford University Press.
- Richards-Ward, L. A. (1996). *From the ward to the home: caring for a family member diagnosed with schizophrenia in New Zealand*. Unpublished Doctor of Philosophy in Social Policy and Social Work, Massey University, Palmerston North.
- Richardson, A., & Ritchie, J. (1989). *Letting go. Dilemmas for parents whose son or daughter has a mental handicap*. Buckingham: Open University Press.
- Richmond, D., Baskett, J., Bonita, R., & Melding, P. (1995). *Care for older people in New Zealand. A report to The National Advisory Committee on core health and disability support services*. Wellington: Core Services Committee, Ministry of Health.

- Richmond, D., Northey, R., & Moor, J. (1997). *Home is where the heart is: The Northern Case Management Study*. Auckland: North Health & Waitemata Health.
- Robson, C. (1993). *Real world research: a resource for social scientists and practitioner-researchers*. Oxford, UK: Blackwell.
- Rochford, M. W. (1987). *A survey of living standards of beneficiaries* (Research Report Series No. 8). Wellington: Research Section, Department of Social Welfare.
- Rural quiz goes north. (1999, 29 September). *Coast to Coast Courier*, p. 5.
- Sarantakos, S. (1993). *Social research*. Melbourne: Macmillan Education Australia Pty.
- Sassoon, A. (1992). Women's new social role: contradictions of the welfare state. In A. Sassoon (Ed.), *Women and the State* (pp. 158-188). London: Routledge.
- Saville-Smith, K., & Bray, M. (1994). *Voluntary welfare: a preliminary analysis of government funding to the non-profit welfare sector*. Wellington: New Zealand Institute for Social Research & Development.
- Sawer, M. (1996). Gender, Metaphor and the State. *Feminist Review*, 52, 118-134.
- Scott, R. (1997). *An assessment of community care service provision for older people residing in Feilding*. Unpublished Master of Philosophy in Social Work, Massey University, Palmerston North.
- Seymour, J. (1992). No time to call my own: women's time as a household resource. *Women's Studies International Forum*, 15, 187-192.
- Sheila, S. (1998). Universality or selectivity in income support to the aged? A comparative assessment of the issues. *Journal of Social Policy*, 27, 231-230.
- Shiple, J. (1997a). Superannuation and compulsion. Address to National Council of Women Northern Regional Seminar 10 May 1997 . Auckland.
- Shiple, J., Hon. (1997b). There's nothing super about compulsion. Address to Auckland Executive Club 14 July 1997. Auckland.
- Small, S. A. (1995). Action-oriented research: models and methods. *Journal of Marriage and the Family*, 57, 941-955.
- Smith, L. T. (1986). 'Te Rapuranga I Te Ao Marama - The Search for the World of Light', a discussion paper reflecting Maori perspectives on research in New Zealand.

- Smith, S. E., & Willms, D. G. with Johnson, N. A. (Eds.). (1997). *Nurtured by knowledge: learning to do participatory action-research*. New York: Apex Press.
- St John, S. (1991a, 2 March). *Income support for an ageing society*. Paper presented at the Conference on Superannuation, Wellington.
- St John, S. (1991b). Retirement income. In G. Hawke (Ed.), *A modest safety net? The future of the welfare state* (pp. 50-63). Wellington: Institute of Policy Studies.
- St John, S. (1992). *Women and superannuation. A comparative analysis: NZ, the USA, Australia and the UK*. Wellington: Ministry of Women's Affairs.
- St John, S. (1996). Keynote speech. In Ministry of Women's Affairs (Ed.), *Retirement Income and Women Conference, June 1996: proceedings*. Wellington: Ministry of Women's Affairs.
- Stanley, L., & Wise, S. (1983). 'Back into the personal' or: our attempt to construct 'feminist research'. In G. Bowles & R. Duelli Klein (Eds.), *Theories of women's studies* (pp. 192-209). London: Routledge & Kegan Paul.
- Statistics New Zealand. (1994a). *New Zealand now – families*. Wellington: Statistics New Zealand.
- Statistics New Zealand. (1994b). *New Zealand now – Maori*. Wellington: Statistics New Zealand.
- Statistics New Zealand. (1995). *New Zealand now – children*. Wellington: Statistics New Zealand.
- Statistics New Zealand. (1998a). *Ageing & retirement in New Zealand*. Wellington: Statistics New Zealand.
- Statistics New Zealand. (1998b). *New Zealand now. 65 plus*. (1998 ed.). Wellington: Statistics New Zealand.
- Stephens, R. (1996). Social services. In B. Silberstone, A. Bollard, & R. Lattimore (Eds.), *A study of economic reform: the case of New Zealand*. (pp. 451-495) Amsterdam: Elsevier Science.
- Stokes, E. (1985). *Maori research and development*. Wellington: A discussion paper prepared for the Social Sciences Committee of the National Research Advisory Council.

- Stringer, E. T. (1996). *Action research. A handbook for practitioners*. Thousand Oaks, California: Sage Publications.
- Survey Appraisals and Public Questions Committee. (1998). *Appraisal of "Towards a Code of Social and Family Responsibility: Public Discussion Document, February 1998"*. Wellington: New Zealand Statistical Association.
- Survey finally up and running. (1999). *Autistic Assn of NZ Inc Auckland Branch July Newsletter*, 8.
- The Joint Methodist Presbyterian Public Questions Committee, & The New Zealand Council of Christian Social Services. (1998). *Myths about poverty in Aotearoa New Zealand*. Wellington.
- The New Zealand Council of Christian Social Services. (1992). *Windows on poverty*. Wellington.
- The Personal Advocacy Trust. (1999). *Autistic Assn of NZ Inc Auckland Branch July Newsletter*, 21-22.
- The West Auckland Women's Centre. (1994). *Feeling stretched: women and families in transition*. Auckland: The West Auckland Women's Centre.
- Touraine, A. (1998). Democracy: its necessary conditions, its enemies and its opportunities. In The Inter-Parliamentary Union (Ed.), *Democracy: its principles and achievement* (pp. 87-94). Geneva: The Inter-Parliamentary Union.
- Twigg, J. (1996). Issues in informal care. In OECD (Ed.), *Ageing in OECD countries. A critical policy challenge* (Vol. Social Policy Studies No. 20, pp. 81-92). Paris: OECD.
- Twigg, J., & Atkin, K. (1995). Carers and services. *Journal of Social Policy*, 24, 5-30.
- Twigg, J., Atkin, K., & Perring, C. (1990). *Carers and services: a review of research*. London: HMSO.
- Ungerson, C. (1987). *Policy is personal. Sex, gender and informal care*. London: Tavistock Publications.
- Villoro, L. (1998). Which democracy? In The Inter-Parliamentary Union (Ed.), *Democracy: its principles and achievement* (pp. 95-103). Geneva: The Inter-Parliamentary Union.
- Waring, M. (1988). *Counting for nothing. What men value and what women are worth*. Wellington: Allen & Unwin New Zealand.

- Waring, M. (1996). *Three masquerades. Essays on equality, work and hu(man) rights*. Auckland: Auckland University Press with Bridget Williams Books.
- Warren, H. (1996). *The hard end of community care*. Auckland: Dept. of Sociology, University of Auckland.
- Werry, J. (1998). *Extracts from the report to the Director-General of Health under 247 of the Health & Disability Services Act 1993 on Casey Albury*. Wellington.
- West, P. (1984). The family, the welfare state and community care: political rhetoric and public attitudes. *Journal of Social Policy*, 13, 417-446.
- Whakatupu, T. O. (1993). *Maori women and private provision for retirement*. Wellington: Ministry of Women's Affairs.
- Who will care for your autistic child/adult after you? (1998). *Auckland Autistic & Asperger Association June/July Newsletter 1998*, 4.
- Whyte, W. F. (1991). *Participatory action research*. Newbury Park, California: Sage Publications.
- Wiener, J. M., Illston, L. H., & Hanley, R. J. (1994). *Sharing the burden. Strategies for public and private long-term care insurance*. Washington: The Brookings Institution.
- Wilson, A. G., Houghton, R. M., & Piper, R. K. (1995). *Budgeting assistance and low-income families. A survey of patterns of income and expenditure of New Zealand Federation of Family Budgeting Service clients*. Wellington: Social Policy Agency.
- Worrall, J. M. (1996). *Because we're family. A study of kinship care of children in New Zealand: A thesis submitted in partial fulfilment of the requirements for the degree of Master of Social Work*. Unpublished Thesis, Massey University, Albany, Auckland.
- Worrell, J., & Etaugh, C. (1994). Transforming theory and research with women: themes and variations. *Psychology of Women Quarterly*, 18, 443-450.
- Young, A. (1998, August 28). Desperate mum fears autism help too late. *NZ Herald*, p. A3.