An analysis of the skills and knowledge base for Needs Assessment and Service Coordination

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Social Work, Massey University, Palmerston North, New Zealand

Susan Foster

2002

Abstract

This research analysed the skills and knowledge base of the Needs Assessor and Service Coordinator (NASC), a new role created by the Health and Disability Act (1993). The purpose of this role as stated in the Act was to try to ensure that the services offered to the disability community were not only sensitive to their needs, but also appropriate and of acceptable quality (Ministry of Health, 1993). In the seven years that this role has been in existence, much work has been done by both the Regional Health Authorities (RHAs) and its successor the Health Funding Authority (HFA) in defining acceptable standards for service delivery, (Ministry of Health, 1994) however little research has been carried out to determine what the skill base should consist of to meet those standards. Each region delivers this service differently, and there appears to be enough anecdotal evidence to suggest that there is a wide variation in the standard of service delivered to consumers. The issue of training has largely been met by internal means, rather than through a national qualification.

Two focus group meetings were conducted with NASC workers and in-depth interviews were held with six consumers in the 16 to 64 age group. One group of workers provided a service to older people, (over 65 years) and the other group provided a service primarily to the adult population, but did include two assessors who worked with older people (16 to 64, and 65+). The questions asked in the workers' groups were to determine what skills they identified as being important to their role, whether their prior training was sufficient for the role, and what training they considered they needed for the role. From the consumers' interviews I asked for their perceptions as to the necessary skills for providing a needs assessment and for coordinating services, and compared the differences between the groups. The data was analysed under five headings, allowing for elucidation of the key findings. These headings were: assessment skills, service coordination skills, concepts of need, user participation, and professional knowledge base. The data showed that assessments by health professionals, (who make up the majority of those employed as NASCs), are client-centred and inclusive, and indicated that the concept of partnership building was understood. However, the data also showed that the more sophisticated skills

of conflict management, negotiation with providers and coaching were emerging as the role continued to evolve and develop. It also showed that knowledge based around disability issues was emerging across disciplines. The final discussion considered the role of training in light of these findings.

Acknowledgements

First and foremost I would like to thank my partner, Helen Frances. It is never easy providing the space and support that is needed to get one through such a venture as this, especially as this has been essentially a year of widowhood for you. I am grateful not only for your unfailing support but also for seeing me through the times of confusion and doubt. Your clarity and wisdom in your critique of my initial efforts were invaluable, as has been your continued willingness to talk things through when I became muddled. Thank you.

A great vote of thanks goes to the staff and management of the NASC services of both the Waitemata District Health Board and of Disability Support Link, Waikato. Your cheerful energy and enthusiasm that you showed in the focus groups was heartening, and your commitment to research in this area was clear. Given the busy schedule that you as health professionals experience in the day to day work I was grateful for the time you gave, and it was your voices that gave this research its meaning. Thank you, too, to the group of consumers I talked with. Without you this research would have no meaning, and I am grateful for the time you spent with me.

Thank you too, to my supervisors, Neil Lunt and Professor Robyn Munford. Your support has been generous, and my work has benefited hugely from your guidance and suggestions. It really has been you two who have taught me how to write at this level, and indeed, the meetings, Neil, kept me on track when I was losing the way, and similarly, your emails of reassurance and critical comments, Robyn, kept my belief in my ability alive.

Finally, I would like to give special thanks to my friend and boss, Liz Beddoe. You have been unstintingly generous in giving me the time to complete this research, especially at a time when my full attention was really needed for the job in front of us. Never once did you complain, and just when I was despairing of finding any literature for a particular area, you were always able to come up with just the book I needed, and often a highly relevant article would be placed in my pigeonhole. I am indeed fortunate to have a friend who has been as supportive as you.

Table of Contents

Chapter 1 - Introduction

The research question

The purpose of this thesis is twofold: one, to determine the skills and knowledge base required for the functions of needs assessment and of service coordination. I will do this by comparing the skill base that exists in two teams of Needs Assessors and Service Coordinators (NASC), one team from Waitemata Health who work with older people (over 65 years), and another who works primarily with the adult population based at the Disability Support Link in the Waikato. Consumer views from those in the 16-65 age group will also be sought to establish their needs in relation to the skills being offered, and to find out whether access to assessments under this legislation meets their needs. Secondly, I wish to examine whether the role of the NASC worker in practice is consistent with the aims of the Health and Disability Act that created it. The role itself has been in existence for over seven years and in that time the teams have faced considerable changes, not only in their processes relating to the collection of information, but also in the scope of the role. Throughout this period, there has been an assumption that existing professionals, for example, district nurses, physiotherapists, and social workers are in the best position to carry out this role. This has led me to question what is the best mix of skills for the job and what new skills they might need to develop to engage in robust assessments that best reflect the spirit of the policy. The implementation of the Health and Disability Act 1993 occurred following considerable consultation with the disability community. Therefore, I have included some discussion with a consumer group, in order to enquire whether gaining access to assessments under this legislation has met their needs, and whether the skills currently utilized by the NASC workers meet their expectations.

The context of the research

Constructing a research project involves making assumptions about the world, how it works, and how we can collect evidence on it. A fundamental aspect of research design and implementation is the identification of the researcher's philosophical roots. The beliefs, values and worldview of the researcher have the potential to impact greatly upon

each level of the study. Therefore it is important to have an understanding of where the research is based. The research topic was formulated as a result of three separate events.

Firstly, during my years as a social worker at Auckland Hospital I witnessed the restructuring of the community health social workers as a result of a change in policy implemented in the Health and Disability Act, 1993. This change saw the majority of team members formed into the newly established Needs Assessment and Service Coordination team, while a few retained the role of social worker. For many of their colleagues, myself included, this resulted in a great deal of confusion as we came to understand the difference in the two roles. This confusion has taken many years to dissipate.

The second event was my decision to undertake further study. During my years of work (and study) my focus has been in the area of health and disability. However, as my work has largely taken place in hospitals, I have to admit that I have largely been captured by the medical model. As a result of my studies I began to understand other models through which the disabled person's experience could be framed.

The third event was my attendance at a Case Management conference in Melbourne in February 1999. At this conference I began to weave together my own recent learning and the desire to provide the Needs Assessment and Coordination Service with a training package that was relevant to those workers who had been employed in this role both within the health services and in the community. My question was that if the NASC workers were not to be social workers, then what was the skill base required for this role? Specific training in this area does not exist. As a social work educator I saw the education institutions having a role to play in providing the environment where NASC workers could develop their skill base by creating a training package that reflected the needs of their new role. The first part of this is to consult the NASC community (both professionals and users) and to examine what they consider to be the existing skill-base.

Method

The theoretical framework for the research is qualitative methodology, specifically the use of focus groups. This was facilitated by the use of method triangulation (Denzin, 1989), namely, follow-up individual interviews and a consumer focus group. The inclusion of the views of consumers is vital when considering research in this area, as research in areas that affect disabled people often only serves to further disempower them if their views are not taken into consideration of the whole (Oliver, 1996). This was complemented by an evaluation of the literature pertinent to the concepts of power and empowerment, professionalism, and models of disability within which professionals operate.

There were two focus group meetings with NASC workers and six interviews with consumers. The NASC workers were chosen from two discrete areas, one that worked in the older person's population (over 65) and a group that worked primarily with the adult population (16-65). Both groups were selected by calling for volunteers. The older person's group was attached to a District Health Board, which holds the contract to provide the NASC service to this age group, and the other was attached to a community group. The groups provided their service in different cities. The data collected was then organised into themes and analysed against relevant literature and against the intention of the Health and Disability Act 1993. This information allowed me to make recommendations for future training in this area.

Format of thesis

The structure and format of this thesis has been designed to provide a sequential explanation of the information contained within it. It begins in Chapter Two by examining the historical and political development of the health and disability sector and shows how the Health and Disability Act 1993 emerged and how the Needs Assessment and Service Coordination role came into existence. Chapter Three discusses the theoretical perspectives relevant to the disability arena, and which informed the direction of the policy. These perspectives look at the major themes of power and empowerment, models of disability, and the concepts of illness and impairment. Chapter Four examines the development of professionalism and how this has impacted on disabled people. Chapter

Five discusses the research framework, including the methodological process, and provides a detailed description of the setting up and conduct of the focus groups.

Once the literature and the legislation have been detailed, an analysis of the data is explored in Chapters Six and Seven. Chapter Eight includes a discussion of the findings and links them to the literature as well as identifying recommendations for future training purposes. Finally Chapter Nine concludes the research by summarizing the outcomes of the research.

Chapter 2 - The historical and political context

Historically, health care and education have been commonly regarded as the cornerstones of the welfare state. Universal state provision of health care featured as one of the key elements of the 1938 Social Security Act in New Zealand. Public provision of health care has, however, been subject to close scrutiny in the last two decades both in New Zealand and in most Western industrialised countries, resulting in fundamental questioning of the pattern of public provision (Cheyne et al.,1997).

A brief overview of the state's involvement in health care indicates that reform and struggle over the allocation of responsibility for health care is a constant theme in health policy in New Zealand. Up until the mid-1870's, central government played very little part in the provision of health care, with the provision of facilities for the mentally ill being its main concern. However, with a growing population that state of affairs did not last long and in 1885 the Hospitals and Charitable Institutions Act was passed, which provided for the establishment of 12 locally elected hospital boards. By this time there was a growing understanding of the relationship between sanitation and health. This resulted in the Public Health Act of 1900 in which, for the first time, a government department was created to be responsible for health services. However, it was not until a new Public Health Act was passed in 1920 that an integrated health system emerged (Cheyne, O'Brien & Belgrave, 1997).

The experience of the depression in the late 1920s brought a growing commitment by the Labour Party to the policy of universal access to medical care. This was finally realised in the 1938 Social Security Act, which provided for a state-funded and state-run health-care system. The aim of this was to ensure equal access to health care regardless of ability to pay. This would be guaranteed by the state itself becoming the dominant funder of health services.

The policy of universal access remained as a core value of our health system over the next 30 years, even though it became increasingly difficult for successive governments to meet

the cost of health care. By the 1970s efforts were being made to review health expenditure and the structure of services. In 1974, during the term of office of the third Labour government, a major discussion paper, *A Health Service for New Zealand,* was released which recommended that 14 regional health authorities be established which would provide primary and secondary health-care services. This policy was not adopted because of the change of government in 1975, but in 1983 the Area Health Boards Act was passed, permitting the formation of Area Health Boards.

The purpose of the area health boards was to rationalise the delivery of primary and secondary health care in a geographical region. Rationalisation was achieved through organizational changes in which primary and secondary health care were brought under the jurisdiction of the one governing body (the Area Health Board). Before this, primary health was delivered by the Department of Health and secondary health was delivered by the then hospital boards, and the two functioned largely independently. The new boards were also required to establish service development groups to assess the needs for provision of services in particular areas (for example, women's health services, child and family health, and services for older people).

It was, however, the 1984 Labour Government that orchestrated a significant shift in the way health care services were delivered in this country and the years 1986–1990, in particular, represented a watershed in health policy. While there were always difficulties expressed about the rising costs of health care, for the first time arguments were put forward as to the limits of public responsibility over the provision of health care. There was a significant shift to the idea of private provision. This shift occurred because of major deficiencies that were perceived in government intervention into the provision of health care. First, the level of government expenditure on health had increased without proportionate improvements in health status. Second, under the current system individuals were perceived as having insufficient incentive to adjust their lifestyles to reduce the risk of certain forms of ill health and accidents. Third, with the state not only funding health care but also providing it, there was not the scope for efficiency in service provision that

government believed was possible when services were devolved to providers who competed for delivery of services (Cheyne, O'Brien & Belgrave, 1997).

The Policy –The Health and Disability Act (1993)

In 1992 The Ministers of Health and Social Welfare produced the government statement document entitled *Support for Independence for People with Disabilities: A New Deal.* This document signaled a significant shift in the way that the government approached the delivery of services to disabled people. It signaled the intention of the government to transfer service funding for disabled people from the Welfare to the Health sector. Philosophically, it adopted the principles of inclusion as a basis for policy and service development, making the right of people with disabilities to participate in society on the same level as other citizens a main thrust of the Act. The key themes of the Act were:

- A strong emphasis on human rights, empowerment and advocacy
- Strong emphasis on coordination of services
- Consistent access to services with greater account taken of individuals' and their families' view
- A collaborative approach where the disability sector has participatory power
- Emphasis on habilitation and rehabilitation to maximize participation and independence.

(Briefing to Incoming Minister, 1999:14)

Prior to the publication of the *'New Deal'* and the subsequent passing of the Health and Disability Act the system of providing disability support services had developed in an ad hoc manner and had resulted in differing criteria for both the funding and provision of services, and an uneven distribution of resources through a number of different departments (Tennant, 1996). As has been noted, in the 1980s there had been a shift in philosophy in relation to the care of people with disabilities – much of the care was based in institutions when often home-based care was preferred and often more appropriate. The *'New Deal'* policy document was an effort to provide a more coordinated approach towards the needs of disabled people through a single funding agency.

Prior to 1993, there were two main pieces of legislation that directed the provision of services to people with disabilities. The first was the implementation of the Accident Compensation Corporation Act 1972 (ACC) in 1974, and the second was the Disabled Persons Community Welfare Act (DPCW) Act in 1975. Under the DPCW Act an advisory committee made recommendations to the Minister of Social Welfare on services for disabled people. It provided financial assistance to disabled people (through provisions such as suspensory loans to modify homes and to purchase vehicles), to people caring for a disabled person, and to organisations providing support and counseling (such as the CCS, a former children's organisation, which now supplies services to children and adults with physical impairments, and the IHC, a similar organisation for those with intellectual impairments). Part of this Act was concerned with the provision of disabled access to public buildings and represented a significant shift in recognizing the need for environmental change rather than the emphasis always being on disabled people needing to change to 'fit in' (Tennant, 1996). Responsibility for service funding was divided between the Health and Welfare sectors, and for many disabled people, this led to confusion as to which sector was responsible for which service. Funding was available through the following provisions:

- The ACC
- The Disabled Persons Community Welfare Act 1975 (administered by what was then the Social Welfare Department)
- The Social Security Act 1938 (individual benefits administered by Social Welfare)
- The Ministry of Education (Special Education provisions)
- The District Health Boards (previously called Area Health Boards) (such as rehabilitation services, the provision of equipment and other domiciliary support services).

Under this system to obtain the right to park in a disabled person's car park one applied through CCS; to apply for funding for a vehicle one went to the Social Welfare Department, and to receive help with rehabilitation one went to the local area health facility, for example their local hospital. The fragmentation of services was further

complicated by many service providers targeting services to people with a particular impairment (eg. The Royal New Zealand Foundation for the Blind only providing services to those classified as legally blind). The Health and Disability Act of 1993 brought the budget for the needs of disabled people under one sector, Health, and made one person, the Needs Assessor and Service Coordinator (NASC), the intermediary through which the disabled person was able to have his/her needs assessed. It is important to note here that the budget was 'ringfenced' meaning that it was protected for use in the disability area alone, but also 'capped', which meant that there was a finite amount and thus a limit to how much could be spent in the area.

It was clear from the consultation that the government had undertaken with the disability community, that a change of attitude was required in relation to the provision of services to this section of the community. For some years there had been a growing protest from disabled people that they were often treated as "sick" when applying for services and were put in a position where they had no control over the type of service they received. Moreover, these services were determined by well-meaning health professionals, with little input from the disabled people themselves. The *Support for Independence* document was an attempt to implement a new strategy that attended more sensitively to the needs of disabled people. In the mid 1990s there was a proliferation of documents on the policy and provision of disability support services. In one of these, entitled *Self Help and Empowerment: People with Disabilities Challenging Power, Promoting Change,* it was noted that the expectations of people with disabilities in terms of service provision were not in line with the rights they had recently gained under the new Human Rights legislation, which came into effect in February 1994. This document acknowledged that service delivery needed to reflect the 'social' model of disability, not the 'medical' model. 'We must move away from the 'medical' model, to services that reflect the 'social' model of disability' (p.3). This report (*Self Help and Empowerment*) reflects the movement of people with disabilities as receivers of services to disabled people articulating the terms on which services should be available. The report also identifies the consequences of the 'charity model' of funding for services and concludes that this is another area where 'change needs to occur' (National Advisory Committee on Core Health and Disability

Support Services 1993:3). This is important, as it accepted the definition of disability as a social construction and places problems in a social context rather than in the individuals themselves (Finkelstein, 1981; Oliver, 1983). A fuller discussion of the medical and social models of disability is found in Chapter Two.

At the same time as the report was indicating 'an alignment of expectations between what the disability community want and the current mechanisms for funding and service provision' (p.3) the Core Services Committee ignored the greatest concern of the disability community. The disability community saw the allocation of the funding for disabled people being given to the health sector as a retrograde step. To many this was seen as a remedicalisation of disability, where those in the health system had power and influence over the rights of disabled people, and hardly reflected a move towards the social model of disability. Indeed, the Disabled Persons Community Welfare Act of 1975 was seen as much more influenced by the social model, because a number of services, for example loans for vehicles, respite and family care, consultation expenses and home alteration loans were there as of right, and not part of a capped budget where budgetary rights depend on funds being available, and consequently create waiting lists. It was also pointed out that the Health and Disability Bill was about health and disability:

> to the detriment of both. While health and disability overlap to some degree, they are substantially distinct. Disability does not equate to ill health. However in this Bill they are treated on a similar basis.
>
> (Wicks, 1992:30)

Another issue of concern for the disability community is the use of language. There is a disjunction between how disability is conceptualised in the social model and the expression of that conceptualisation not only in policy documents but also in everyday language. What is not clearly understood is that there is a distinction between impairment and disability, and this distinction lies at the basis of the social model. The distinction between these two concepts was first made by the Union of the Physically Impaired Against Segregation, or UPIAS, in 1975. For UPIAS, *impairment* meant 'lacking part of a limb, or

having a defective limb, organism or mechanism of the body' and *disability* was 'the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from mainstream activities' (UPIAS, 1976:3-4). From this perspective UPIAS is quite unequivocal in locating disability outside the body:

> In our view, it is society which disables...Disability is something imposed on top of our impairments...
>
> (UPIAS, 1976:3)

Thus the social model stands in contradistinction to the medical model and provides a highly politicised account of disability. The disability community argues that the medical model isolates, oppresses and controls the lives of disabled people and it does this by saying that to be impaired and to be disabled is the same thing (Sullivan, 2000:38). Disability is located in individuals who must change and adapt to the mainstream, disabling society. The social model says the opposite, that societal structures must change and adapt to allow the full functioning of all its citizens.

It is clear that many in the disability community would see the assessment process carried out by a health professional using the social model as paradoxical. They would say that it is very unlikely that a health professional could assess a disabled person without using health criteria as their basis. Indeed part of the tension for those health professionals attached to District Health Boards is to apply the social model, while at the same time working in a system that embodies the medical model.

Needs Assessment and Service Coordination

While there is still considerable debate, the Health and Disability Act does represent an attempt to move towards the social model of disability and this was reflected in a number of ways. Firstly, there was a fundamental change in the way that assessments for service provision were to be done. In the past, the purpose of assessment was often to determine people's eligibility for existing services and a separate assessment was required for each

service need, whereas the new approach is focused on the needs of the person and their caregivers, and one assessment could cover a wide variety of service needs. The purpose of the assessment is to 'decide what a person needs to achieve independence and participate fully in society, in accordance with their abilities, resources and goals' (Ministry of Health, 1994:4). The areas of need were clearly outlined, indicating a much more holistic and multi-faceted approach to the assessment process. Alongside the traditional areas of support, such as personal care, household and mobility needs, assessments now included vocational and employment needs, training and education needs, and rehabilitation needs, which not only focused on the physical and social areas but also on the spiritual, emotional, cognitive and cultural needs of the person. The assessment is also to take into consideration the client's environment – their home, the workplace, social venues and community facilities – and caregivers' support needs, such as respite, information and training. Underlying this process is a commitment to provide assessments in such a way that the client's safety and dignity is preserved, and is compatible with their cultural beliefs, values and aspirations.

Secondly, there is an understanding that the assessment process is based on one of 'partnership' between the disabled person and the service provider, one that 'recognizes and respects the person's knowledge and experience of disability' (Ministry of Health, 1994:5). This shift indicates that the assessment process itself is seen to be client-driven, based on the felt need of the client rather than the need that the worker perceives. The meaning given to the role of the assessor has changed from one of being the 'expert' to one of 'working with' the client, of participating in the assessment in a collaborative way that gives pre-eminence to the client's own experience. In other words, they are acknowledged as their own experts, and the assessor engages in a role that facilitates the expression of need.

Thirdly, the policy clearly separates the assessment process from the provision of services. This signaled a significant organisational change. Assessment functions that had previously been undertaken by service delivery organisations such as IHC, CCS and the former 60s+ services were now transferred to the newly established Needs Assessment and

Service Coordination (NASC) teams. Those organisations that had previously provided their own assessments for service now had to make way for a new set of relationships, based around the client, the NASC assessor and the service provider.

Fourthly, in the case of service coordination, the client was to be given a choice of service provider and more control over how the service was going to be implemented. In this relationship, the consumer is an active participant rather than a passive receiver of the service. The role of the Service Coordinator becomes one of case manager, providing information to the client concerning the different providers, and discussing different possibilities. The Service Coordinator then brings a number of different services together into a package for the client which they then negotiate for with the providers.

In the context of this policy budget management enables the funder to manage the distribution of funding across ages according to assessed and prioritized client need. The case management model sets the scene for budget management, where the service coordination role lends itself to having an overall responsibility for how funds are allocated, especially in the environment of a capped budget. Issues of equity can only be addressed if the service coordinator has access to information surrounding funding. In fact the reporting guidelines developed by the Health Funding Agency in October 2000 commented that 'the role of the NASC manager in providing the service coordinator with current budget updates and forecasts is crucial guidance' (NASC Information Reporting Guidelines, October 2000:37). Equally, having responsibility for funding also acknowledges a gate-keeping role. Managing this tension is one of the skills that is always required under this structure. Nevertheless, the new policy was designed to allow people with disabilities to access appropriate services much more easily and was committed to a process that ensured a high level of consumer participation and control. The key to this participation is the level of negotiation that clients are able to engage in with regard to the range and number of services available.

In some instances there is provision for individualised funding where the disabled person him or herself is funded by the NASC to arrange and pay for their own services. The client

is given the means to directly employ their own personal assistance or contract for services with a provider. However, this area of the policy is not yet fully developed and is not a fully constituted support option.

Finally, there is a separation of the assessment function from the function of coordination of services. This is in order to avoid any conflict of interest, as it is felt that combining the two roles compromises the focus of the assessment process, which is to identify unmet need and real need. Having both functions in the same person carries the risk of making assessments against the knowledge of what services are available. This has major ramifications for what skills are required of the worker. The role to date had included advocating for clients to access existing services. This advocacy role rose more out of the entitlement model where the social worker's role was often to advocate their client's entitlement to a service. In a needs model the role requires the worker to firstly identify the gaps in provision of services, then to become the advocate for services that meet the needs of the population. In this model the worker only indirectly advocates for the individual client. An example of the difference is evident when one considers a request for respite care for a child with an impairment. Prior to the implementation of the Health and Disability Act, this request would have been directed to the social worker who would have determined the eligibility of the client, informed the parents of the process and the existing service, and advocated access to the care. In this process the choices were limited, and the power remained in the hands of the social worker, who was much more clearly defined as a gatekeeper.

The NASC worker, on the other hand, identifies the need and then looks at the range of possibilities with the client that may include a mix of different responses to the respite care, both within and outside the home. Under this system the NASC worker must report any identified unmet need to the provider and to their agency and give the provider an opportunity to change their service to meet the need. The NASC worker must also make the funder aware of areas of unmet need, which raises the possibility of moving funding around so that services respond to client need rather than being static. In this situation, the NASC worker aggregates the information they receive for greater use. It moves them

beyond the sample of one, and merely responding on an individual level. Social work has never had that responsibility or expectation.

This does not mean to say that individual clients do not need individual advocacy. The NASC service, however, may not be in the best position to offer this role as the client may, for example, be in dispute with the service coordinator. This service needs to be offered by someone who is independent, and it could be argued that here the social worker could have a role.

Implementation of the policy

At the time when the policy was implemented, the structure for purchasing health services in the country was through the four Regional Health Authorities. However, because there was no standardization of how services were to be purchased among them, they all implemented the new strategy differently. In Auckland, the new NASC functions were purchased from existing services, older people and children's from the then Crown Health Enterprises (CHEs), and the adults (16-65 years) from the Disability Resource Centre. In the first instance, as far as the older people's and children's services were concerned, there was no obvious intent to purchase a NASC service in terms of teams. Rather they set out to purchase the functions and left the CHEs to decide how they were going to implement it. Thus, from its very inception, the Northern RHA (one of the Regional Health Authorities covering Auckland and Northland) did not appear to develop purchasing strategies that supported the social model of disability. Service providers were sitting in the institutions that embodied the medical model and they were unlikely to behave differently just because they had a new role. In fact, as part of a training day for service providers, trainers taught participants how to juggle to make the point that, just as in juggling, the individual skills were all in existence, it was how they put it together that mattered. Initially then, it was acceptable for the Needs Assessment function to be placed in the existing Assessment, Treatment and Rehabilitation Units, a medical service attached to the CHEs, as there was no real understanding that the clinical assessment and the needs assessment should be differentiated. The Service Coordination role was in the first instance placed with the social workers in the Community Health Service.

Within Community Health the role of the social worker has been closely aligned with the transition of patients from the acute setting to their homes. Part of the social work function was to coordinate services and resources in the community to facilitate that event. The NASC functions are similar, but are not directly related to discharge planning. The role needed to be seen as being firmly based in the community accessible to the disability community as a whole, rather than being attached to a hospital and being used mainly to facilitate the transition from the acute system. The first principle in the *Standards for Needs Assessment* document states: "information about the Assessment service must be widely available and promoted throughout the community" (Ministry of Health, 1994:8). Despite the fact that there seemed to be a duplication of roles, NASC teams were developed that were separate from social work, in response to pressure from the funding agency to create a more transparent, accessible service.

Interestingly, at Auckland Healthcare, the NASC team that services older people, while separate from the social work function, is still made up entirely of social workers. Their philosophy is that the knowledge base and the skill set required for NASC is completely congruent with social work professional training. At Waitemata Health, however, there has been a completely different approach. Here the team is multi-disciplinary in the belief that different professions, including social work, occupational therapy, teaching, counselling and physiotherapy, among others, bring some of the skill-base, but none in themselves have the full grounding for the skills required. There is also a belief that a team consisting of different professions brings a richness of diversity to the role that is not available in a single discipline team. Nevertheless, it is not clear whether this multi-disciplinary team is operating from a new body of knowledge derived from the role, rather than from their separate disciplines. Historically, many of the disciplines are closely allied to the medical profession so it remains to be seen whether they are able to consider assessments outside the medical model.

Disability Support Link, (the community organisation in the Waikato contracted to supply the assessment and coordination service to the adult population) is, on the other hand, much more closely aligned with the philosophical underpinnings of the policy. For the adult

population, the needs assessments carried out are likely to be much more diverse with more emphasis on educational, recreational, and vocational aspects, and there is not the same interaction between the disability and health sectors. In this adult sector a different set of skills may be required (and this could be reflected in the professions of their work force,) although there is an argument that if health professionals are not included in the NASC team for this population as well, then you do not necessarily get the right skill mix. For example, a needs assessment carried out with a young person who has continued interaction with the medical system, may appreciate occasional contact with a worker who has an understanding of the complexities of the impairment *and* the health system.

Case management

The practice base for the NASC role is individual case management. Case management as coordination of services has existed in various forms since the early days of social work (Weil & Karls, 1985). It has evolved from the needs of an increasingly complex society and correspondingly complex human services systems. It involves the dual concerns of providing quality service coordination and of delivering human services in an efficient and cost-effective manner.

Today the decision-making process, goal planning, and contracting with the client are integral to the delivery of case management services. Overall the model is seen as having two central functions: one providing individualised assessment and information and the other linking clients to needed services and supports in the community. The practice, in professional terms, is both micro and macro in nature. It is a process that combines elements of classical casework and therapeutic intervention. Case managers must affirmatively deal with environmental barriers to client success, but also must be involved with symptom management. A thorough assessment of the client's needs, both material and clinical, must be combined with an evaluation of the environment's responsiveness to those needs.

Weil and Karls (1985:2) define case management as 'a set of logical steps and a process of interaction within a service network that assures that a client receives needed services in a

supportive, effective, efficient and cost-effective manner'. This definition emphasises accountability but it also focuses on developing a personal relationship. Much early case management centred on the movement of people with mental health problems from hospitals to the community. The techniques spread to other related services for children, older people and their families, people with learning difficulties and disabled people. Case management is a model used mostly with highly vulnerable clients.

Case management is both a concept and a process. As a concept, it is a system of relationships between direct service providers, agency administrators, and clients. As a process, case management is an orderly, planned provision of services intended to facilitate a client's functioning at as normal a level as possible and as economically as possible (Weil & Karls, 1985:3). At the core of case management is the question of what is the most effective, most expeditious, and most cost-effective method of restoring a client to a state of equilibrium, that is, ideally to a state where the client can arrange for his or her own care through the existing health and social services.

Several role functions are consistently noted as essential to case management: assessment, care planning, implementation, and evaluation (Kane, 1988; Rose, 1992; Sullivan et al., 1992). Assessment is the bedrock of the helping process that ultimately informs the care planning and implementation stage of practice (Hepworth & Larsen, 1990). Over the last decade there has been increased emphasis on the assessment of strengths as well as deficits (Rapp, 1991, Saleeby, 1992). However, in practice, assessments still appear to be decidedly deficits-focused and are predominantly geared to gain that information believed necessary to effectively attack an individual's identified problems and pathology. This is particularly true in work with older adults, where needs and problems need immediate attention (Sullivan & Fisher, 1994:65).

The care plan has been described as "a professional judgement of the most appropriate way to provide help for this individual client, given the constraints of the client's situation and the system" (Schneider, 1988: 16). How a care plan is individualised is largely dependent on the professional judgement of the worker, and perceived constraints of the system. One

of the difficulties inherent in the care plan is the possibility that the uniqueness of the individual is not what drives the care plan, but the commonalities of the problems, and the limitations of the services on offer. Over a period of time it is possible to see a range of people who will generate a similar response when it comes to preparing for a care plan. Consequently one can obtain a highly idiosyncratic view of each situation that might limit the worker to scan purely for the services on offer. Conversely, the generalised response may in itself be a response to the constraints on the availability of services.

Interventions in strengths-based case management are driven by the goals as defined by clients and are designed to promote the maximum personal and social functioning of consumers (Rapp, 1992; Sullivan et al., 1992). It is the case manager's responsibility to decipher these needs and ensure that the necessary supports are in place to help the client succeed. Attention must be paid to the social environment, as well as individual need, as interacting with the wider environment is just as important to individual health. However, in reality, concentration is placed on individual pathology with scant attention given to wider environmental barriers.

In the USA case management is seen as a form of implementing social work rather than as something separate (Miller, 1983; Weil et al., 1985). In New Zealand, case management is also seen as an integral part of the social work profession. However, it is not a model utlised by social workers alone. Here a more generalist approach applies. Thus, it is a service model that has been adopted by a number of different health professions including nursing, occupational therapy, dietetics, and speech language therapy, to name a few. It has also been applied to a number of different organisations, such as Accident Compensation Corporation and Work and Income New Zealand. The skills of each profession are adaptable to different agency settings, and each profession brings its own emphasis to the work. Every profession has its own body of knowledge, methods, value system, and professional organisations that safeguard its members' standards and interests. Standard setting and certification roles of professional associations or licensing bodies are safeguards to both the employer and to the client group. But, as such, there is no such

profession for NASC workers. The assumption has been that the creation of this new, specific role will bring a common understanding of the work.

A feature of the role in some areas of New Zealand has been to attempt to separate the assessment role from the service coordination role. This has been the case in the Waikato and Wellington. The reason for this is to assist the assessor to assess for real need and to identify the gaps in the provision of services rather than being 'contaminated' by the knowledge of what services exist and, therefore, assessing according to these constraints. This particular form of the model does not work well with the frail elderly, where the assessment, care planning, and service coordination are not separable phases. The incremental, cumulative nature of assessment, which sharpens as the worker-client relationship deepens, and the planning, re-planning and coordination of services in relation to the client's changing conditions and preferences tend to require continuous face-to-face contact throughout the active phases of the case (Dyson, 2001).

Case management as a model of practice lends itself well to social work and it is not surprising to find that social workers are well represented as NASC professionals in this country. A successful case management system must be grounded in a philosophy that delineates the relationships between clients and workers and between clients and the system, and a philosophy of how and why agencies should and can work together for the benefit of clients. A traditional value of social work is the worth and dignity of the client. Because many clients of case management programmes have suffered severe hardships, impairments or disabilities, it is very important that workers be able to articulate and believe in the integral worth and dignity of each client and the client population. A second basic value is the need for workers to subscribe to a concept of mutual responsibility, that is, responsibility to human beings for each other (Dromi and Weil, 1984). From these two primary values are derived supporting values for case management practice: participation of clients in decision-making processes, self-determination, and the empowerment of clients (Dromi and Weil, 1984).

What is also clear, though, is that the role of the case manager is not the same as the role of the social worker (Steinberg & Carter, 1983:144). The case manager is not a therapist but a clinician who is able to form a relationship with clients in order to carry out accurate assessments and to facilitate the coordination process. In the NASC role that I am researching, two important components of the social work skill base have been explicitly omitted. These are the advocacy role and counselling. It is not considered possible to assess for need and to negotiate for service provision while maintaining an advocacy role. The NASC worker does indirectly advocate for clients when they negotiate for an appropriate service, but if the client is demanding a particular service that the service coordinator is unable to provide, then the advocacy role is undertaken by independent providers of this service.

Similarly, counselling is not considered part of the case management service offered by NASCs. This does not mean to say that interpersonal skills are not at the heart of the case management skill base (Coulshed, 1991; Davies, 1994). In the NASC service case managers have to be able to relate (talking, listening, sharing, giving, receiving, tolerating, understanding, empathizing, inspiring trust), not only to clients and their networks, but to all those with whom they have dealings. Whereas interpersonal skills are said to be advantageous in many occupations, for case managers their job is utterly dependent upon them – that, quite literally, you cannot be a successful case manager unless you can relate to other people in a fruitful and personal manner (Davies, 1994). Indeed, brief counselling may be part of the interview process. However, as an ongoing process, counselling is one of the many services that the service coordinator would consider for a package of care rather than provide this him or herself.

Within case management there is a more transparent conflict between individualised, responsive care and the containment of costs. There are new skills to grapple with: how to coordinate a service based on client need within a restrictive budget that may not be able to take that need into account, mediating between client and provider, and negotiating packages of care with a provider. How do they offer a monitoring service, both to the client and to the quality of the service being offered? What is the quality of the support

that they offer? Similarly, what is the role of advocacy in this model? Considered a core skill of social work, it involves different strategies and techniques within case management. As I have stated, skills of advocacy for clients at a personal level are not seen to be pertinent here, but rather advocating for more complex service provision at a policy level. Much of the literature talks about the functions of case management, for instance, assessment, setting goals, resource identification, planning and coordination of services, monitoring and reassessment. But few, if any, consider the skills that are needed to carry out these functions.

Empowerment

Empowerment is a word and a concept that is easily misunderstood by health professionals generally. Here there has been an assumption that empowerment is a process by which those in society who have power can dispense some of this to those who don't have any. To assume health professionals in their daily work can empower someone else is naïve and condescending and has little basis in reality. However there has been a lack of guidance for workers on how to actually relate to people as empowered users rather than disempowered clients. One of the paradoxes of empowerment is that it has both liberatory and regulatory potential (Baistow, 1994/95:35). According to Baistow, empowerment discourses imply that the power is actually power over oneself, not others. Furthermore, these discourses promote a type of individualised non-reflexive responsibility – empowerment is done *to* you *by* others, or done *by* you *to* others (1994/5:38-39). In this sense, it is professionals who have colonised empowerment and this, by definition, means that empowerment is taken out of the hands of those who are being empowered.

Baistow's ideas are a development from Foucault's conception of the 'normalising power' which in modern society is about separating people from each other, labeling some as deviants to be subjected to the 'carceral network' – a network that has extended to take in the whole of society (Foucault, 1977). The way that health and welfare services are delivered in Aotearoa New Zealand currently requires health professionals to activate this 'normalising power'. In carrying out an assessment, identifying a problem, we categorise the people involved, and target them for provision of service. This in itself can be seen as

stigmatizing – health professionals can be seen as contributing to the client's sense of being seen as 'other', as being normalised as 'other'.

One way in which professionals can engage in empowering activities is not by consulting clients through the use of individual treatment plans, but accepting the client's framework that is necessary for determining the intervention. This is truly client-centred intervention (Pardeck et al., 1994:120). Pardeck argues that client-centredness and contextualisation potentially undermine the traditional hierarchy in that status-based or absolute truth claims are subverted, and traditional expertise can be challenged. The ability to create client-based realities becomes possible (1994:128). The Health and Disability Act (1993) is in part an attempt to improve disabled people's position in relationship to the process of gaining access to services, particularly in the emphasis put on the role of the client as participant in the process.

Central to an empowerment perspective is the role and place of assessment in the practice process. How clients define difficult situations and how they evaluate and give meaning to the dynamic factors related to those situations set the context and content for the duration of the helping relationship. If assessment focuses on deficits, it is likely that deficits will remain the focus of both the worker and the client during remaining contacts. This has been the major criticism of the way assessments have been carried out until now. Concentrating on deficits leads the worker to judge the client against a 'norm', and reinforces the view of the client as 'the other'.

Assessing for need

The implementation of the Health and Disability Act marked a shift in focus from a service-led approach to a needs-led approach offering choice and empowerment to the individual. In the context of this research, need is determined by the 'felt' needs of the individual. The needs assessment is the process of determining the current abilities, resources, goals and needs of a disabled client and identifying which of those needs are the most important. It is a process carried out by the client in conjunction with a needs assessor. The process is driven by the client, and the role of the assessor is to decide *with*

the client what the client needs to maximise independence and participate as fully as possible in society in accordance with his/her abilities, resources, culture and goals. A client's needs will also include where appropriate the needs of the family/whanau and carers; their recreational, social and personal development needs; their training and education needs; and their vocational and employment needs (National Service Specification, 2001).

a) Concepts of need

Need is at once a simple idea about which everyone has an understanding (even if not necessarily a shared one) and a complex concept around which academic reputations are made (Middleton 1997). One of the most enduring theories on need is that of Jonathon Bradshaw whose article in New Society, March 1972 set a useful baseline for an understanding of need in a social welfare context. Bradshaw suggested there are four different ways of defining need: normative, felt, expressed and comparative.

- **Normative need** is that decided on by the professional, expert or administrator on behalf of the community at large. The professional works on some desirable standard. The two principle ways are to aim for a minimum standard or aim at an ideal. The problem with this system is that there is no incentive for its operators to rise above the minimum.
- **Felt needs,** which Bradshaw equated with want, are limited or enhanced by the perceptions, knowledge and experience of the individual.
- **Expressed needs** are felt needs actually translated into a demand for service.
- **Comparative need** is arrived at by a comparison of two areas of need with each other in terms of services available to similar groups, areas or individuals. The gap between them is comparative need. This approach can be used in an attempt to standardize provision but may not necessarily relate to need. (Bradshaw in Middleton, 1997:23)

b) Special need

The notion of need as expressed in the role of the needs assessor is that of 'special need', a term that Bradshaw did not include in his theory. Indeed, it seems to be a term that is related to stigma as assessment is certainly not something that occurs when things are going well. In welfare terms it appears to be a process that visits marginalized groups of the population rather more than it does those in the mainstream of society. As such, it is less associated with gaining rights than identifying problems. Middleton maintains that special needs is a category that is more about maintaining the quality of provision for those who are not special rather than providing benefit to those who are (Middleton, 1997:23). She gives an example of disabled children as a group particularly disadvantaged in this way. She states that:

> the concept of 'special need' has been extremely misleading in promoting a notion that disabled children somehow have different needs from the rest of children. What is different is the barriers which relate specifically to disabled children, and make them 'special'... An assessment relating to a disabled child should not focus on the deficiency of the child, but on the barriers to their hopes and aspirations, within their own context. It follows that any assessment must start with the aim of finding out what these hopes and aspirations might be. Funnily enough, this is the same good practice as an assessment for any other child, or for an adult for that matter. There is nothing special about it.
>
> (Middleton, 1997:24)

Oliver also argues that any hopes for the greater social and political inclusion and empowerment of disabled people will continue to be thwarted by continued attempts at making provision for empowerment on the basis of need. Specifically, he argues that it is one particular conception of need, *ascribed* need, that in fact actively disempowers them (Oliver, 1996:52). The act of ascription lies with persons considered to be expert in their respective fields and who are thus qualified to

undertake such assessments. He suggests that disabled people are being sidelined from a process that is purporting to be client led. The outcomes have been ascribed to them and the consequences are having the greatest significance for their daily lives (Oliver, 1996:32).

c) Self-defined need

The needs assessment process as outlined in the Act is weighted towards needs as they are defined by the client and, indeed, the ideological standpoint of the disability movement both here and overseas has been based around needs as rights, rather than as being defined by 'experts' (Oliver, 1990; Shakespeare, 1993; Barnes, 1995; Sullivan, 1996). There are problems, however, with the attempt to make self-defined needs the basis of rights claims. It is difficult to know when self-defined needs end and preferences take over. Oliver states that, "it is rights to appropriate [welfare services to meet] *their own self-defined needs* that disabled people are demanding, not to have their needs defined and met by others" (Oliver, 1996:74, emphasis added). But as Jerome Bickenbach points out, "Needs overlap imperceptibly with preferences, and preferences know no boundaries" (Bickenbach, 1993:199). In practical terms it may prove difficult to separate and identify want or preference from self-defined need clearly. If everyone demands the satisfaction of their self-defined needs by right, then how are we to sort out the almost inevitable conflicts that this will generate? How are we to prioritise all of these competing claims, and who will arbitrate between them?

d) Organisational constraints

Despite the dictates of legislation to be proactive and inform people of their rights, public service departments are generally not in the business of encouraging people to express their desires or aspirations, especially where there is no matching service. The purchaser/provider split is intended to address this by separating the assessment for service from its provision. Nevertheless, both the assessment and the coordination roles are carried out within a finite budget – rationing is necessary where resources are limited and indivisible. The equitable allocation of finite and often indivisible resources is the conundrum with which all public welfare services have to wrestle.

This means that professionals walk a tightrope between, on the one hand, undertaking assessments based on their relationship with the client and their own knowledge and experience, and knowing that the provision of services are limited. Managing this tension well is part of the skill base that will be considered in this research.

Conclusion

The new Disability Support Service (DSS) framework represents a change from an ad hoc and mainly institutionally based approach to meet people's disability support needs, to a more cost effective, planned, targeted and community focused system. This approach is designed to provide a service which enhances consumer quality of life and which provides a more flexible system of service delivery to meet the needs of people with disabilities. The move to a needs assessment is an attempt to balance the need for a consistent quality of assessments and to allow flexibility in the development of more appropriate, effective and efficient assessment services. Service coordination is the process by which people are helped to identify the package of services required to develop a plan of action which will best meet their needs and to implement that plan. It also determines which of those needs can be met by publicly funded services and explores option for addressing other needs (Ministry of Health, 1994). Efficient allocation of resources is dependent on the effectiveness of service coordination. While the process is consumer-oriented, it must ensure that the identified needs are met within eligibility criteria and available resources. The NASC worker must operate within the competing demands of a consumer-driven assessment and the organisational demand for efficiency within a capped budget.

Chapter 3 – The theoretical framework

The purpose of this chapter is to consider some of the theoretical frameworks that have contributed to our understanding of our attitudes which have impacted on the disabled community. In order to achieve this, and so that we may better understand the position that disabled people have traditionally held in our society, I have used the writings of Michel Foucault to illustrate the ways in which power relations can and do operate. His ideas about the nature of power relations and the production and operation of discourse – the way we think and act on certain ideas – can help in our understanding of how relationships, such as doctor/patient, social worker/client for example, are produced and maintained. To understand why certain discourses dominate we need to examine the power relations which function to legitimise certain discourses and suppress others. Understanding power relationships is critical in developing our understanding of how those with 'authority' maintain certain practices, and what those 'without authority' do to resist them. For disabled people a large part of their lives, and their parents' lives, is spent negotiating with health and welfare professionals to gain access to services. Foucault's ideas can be used to explore how individuals live their lives and how these are given meaning by either being valued or devalued (Sheridan, 1980).

The 'disability community'

It is important to state that disabled people do not form a homogeneous group. Indeed critics often focus on the representative nature of the disability movement and accuse it of not speaking for all disabled people. This is certainly true but then no representative organisations represent their entire constituency. This point is developed by Altman (1989) in making a distinction between what he calls 'movement' and 'community'. He develops this further in the context of gay politics:

> We can think of the gay world as consisting of a number of concentric circles: at the centre are those people who openly identify as gays, and whose social and communal activities exist largely within a gay milieu. Then there are those who are openly gay, but not in all areas of their work and social life. Then there are those who accept

> themselves as homosexual but do not feel part of a larger gay community as a result. Lastly there are very many people who are behaviourally homosexual but do not consider this as part of their identity. The gay movement will draw almost exclusively from the first two categories, but these are themselves in part the product of the movement. Both identity, and conscious affiliation to the gay community, are processes which change over time in an individual's life.
>
> (Altman, 1989:47-8)

The distinction between movement and community is a useful one in considering the politics of disability. Not all people see themselves as part of the disabled community, let alone as supporters of the aims or the tactics of the movement (Oliver, 1996:150). The deaf community, for example, do not identify themselves as disabled, even though hearing people can and do (Wilcox, 1989:44). What is true however is that issues that the movement has placed on the political agenda such as rights, access, choice and control are issues relevant to the wider community (Oliver, 1996).

Oliver also points out that increasing numbers of disabled people within the community are identifying with and joining the movement (Oliver, 1996:150). This is not surprising, as no other groups speak for the interests of disabled people. And the disability movement exists in a society that institutionalises racism, sexism, homophobia and disablism. Oliver goes on to say that:

> All institutions and organisations are bound to reproduce oppression while oppression remains a feature of society. Oppression can only be totally eradicated from organisations when it is eradicated from society and it will only be eradicated from society as part of our struggles to eradicate it from our organisations. And it should be remembered that many of the more traditional voluntary organisations and even some statutory service providers do not even acknowledge that such issues exist.
>
> (Oliver, 1992:151).

Power relations

The theories of Foucault have been helpful in assisting us to understand the disabled community's relationship with the systems with which they have to interact. In particular they have been helpful in our understanding of how such relationships as doctor/patient and health professional/client are produced and maintained. Foucault's concern is with how power relations operate to control individuals and groups:

> ...the judges of normality are everywhere. We are in the society of the teacher-judge, the doctor-judge, the educator-judge, the social worker-judge; it is on them that the universal reign of the normative is based; and each individual, wherever he may find himself, subjects to it his body, his gestures, his behaviour, his aptitudes, his achievements...The carceral texture of society assumes both the real capture of the body and its perpetual observation...
>
> (Foucault, 1979:304)

Foucault's focus is on power relations at the level of the individual and his or her daily experiences in institutions such as the family, school, hospital or prison. The problem lies "in the steep rise in the use of the (se) mechanisms of normalization and the wide-ranging powers which, through the proliferation of new disciplines, they bring with them" (ibid:306). One of Foucault's main interests is in the ways in which individuals are constructed as social subjects, knowable through disciplines and discourses. The goal of Foucault's work has been 'to create a history of the different modes by which, in our culture human beings are made subjects' (Foucault, 1982:208). In *The Birth of the Clinic* (1973) and *Madness and Civilization* (1967), Foucault traces changes in the ways in which physical and mental illness or abnormality were spoken about. Foucault's later work, *Discipline and Punish,* (1977) focuses on the techniques of power that operate within an institution and which simultaneously create ' a whole domain of knowledge and a whole type of power' (Foucault, 1977:185). The effects of the mechanisms of power, he contends, are to construct individuals as subjects in two senses: as subject to someone else, through control and restraint, and as a subject tied to their own identity by their conscience and self-knowledge.

In the context of disability support services, the needs assessment procedure can be characterized as an example of this type of power. Despite the intent, which says that a needs assessment is "a way of putting together information about the support you need in different aspects of your life," and that "once you have worked through an assessment with an assessor and agreed on the support you need, support services can be arranged to meet those needs" (Ministry of Health, undated), the reality can turn out to be very different. For example, for people wishing to stay in their own homes rather than moving into a group/rest home, the needs assessment can be a critical process. The extent to which the disabled person is powerless or powerful in the assessment process is very largely dependent on the skills of the assessor to give up their role as 'expert', and to engage in a process in which the client is not seen so much as the 'other'. Too often the disabled person is subject to an assessment that is dependent upon a favourable judgement to be allowed support services, and tied to and limited by his identity as a person with a disability. This aspect will be a key element of my research.

Surveillance

A central theme of Foucault's work is the way in which the 'gaze' constructs individuals as both subjects and objects of knowledge and power. In the *Birth of the Clinic,* Foucault illustrates how the medical gaze opened 'a domain of clear visibility' (Foucault, 1973:105) for doctors, by allowing them to construct an account of what was going on inside a patient, and to connect signs and symptoms with particular diseases. The space in which the gaze operated moved from the patient's home to the hospital. This became the site for the teaching, as well as the acquisition of medical knowledge, the object of which was the body of the ill patient. The body of the madman, according to Foucault, was viewed as 'the visible and solid presence of his disease' (Foucault, 1967:159). Hence the medical gaze focused on the body and "normalization" or treatment of the insane involved 'consolidation', 'purification', 'immersion' or 'regulation of movement' (ibid 1967:159-172). If this theme is applied to the disability arena then Needs Assessors and Service Coordinators have a similar opportunity to apply their own 'gaze', and define their clients only in relation to their disability. Similarly, the focus of intervention has a danger of being limited to the label of the disability where need for support services and goals for

rehabilitation are assessed against the 'able-bodied' norm, rather than being assessed against the client's perceived need.

Where these workers are part of large health institutions this danger is even more real because the 'gaze' and the consequent labeling is an accepted part of the way the work is carried out. Rehabilitation service providers need to be attuned to how individuals perceive their impairments, the extent to which they control or master social structural constraints, and their ability to utilise social support networks, which may include rehabilitation service providers themselves. Failure to do so encourages the view that medical and rehabilitation agencies foster social oppression by embracing paternalistic notions of empowerment, and by identifying individual, rather than social problems (Oliver, 1996; Jamrozik & Nocella, 1998; Imrie, 1997). Most rehabilitation workers have assessed how well individuals with disabilities have performed a range of physical activities with the framework of biomedical disease models (Oliver, 1996). The unique or personal meanings that individuals ascribe to their psychosocial experiences have been largely ignored (Crisp, 2000:356). Wendell also claims that living with disability provides social experiences different from that of persons without disabilities; and that she and others with disabilities "have accumulated a significant body of knowledge...and that that knowledge, which has been ignored and repressed in non-disabled culture, should be further developed and articulated" (Wendell, 1996:73).

In his analysis of discipline and punishment, Foucault describes how 'techniques of surveillance' which occur in what he terms the 'local centers of power/knowledge' (for example in relationships between doctor and patients), have an individualising effect:

> In a disciplinary regime...individualization is 'descending'; as power becomes more anonymous and more functional, those on whom it is exercised tend to be more strongly individualized...In a system of discipline, the child is more individualized than the adult, the patient more than the healthy man...when one wishes to individualize the healthy, normal and law-abiding adult, it is always by asking him

how much of the child he has in him.

(Foucault, 1977:193)

Margolin (1997) in his book, *Under the Cover of Kindness: The Invention of Social Work,* develops Foucault's ideas further. He asserts that social workers in the health field have developed a method of surveillance that depends on the illusions of non-observation and non-accountability. This is, he says, in part historical: as early as the 1890's, when Mary Richmond became the general secretary of the Baltimore Charity Organisation Society she launched a campaign to find out why some health visitors were more successful than others. She found that their demonstration of sympathy and friendliness, not authority, station or physical force, were the keys to the progress made. The visitors were encouraged to move alongside their clients, and submerge their differences. In this way they gained entry into private places and access to the most personal, secret information:

> The agent's deep unfeigned, educated sympathy leads the family to discuss things not spoken of to others. They reveal not only the amount of the supplies on hand, but also the remote cause of the physical want, and the family resources as well. There is no severe questioning. As a rule the family thinks he does not ask enough questions about flour and fuel and too many questions about life habits – not moral habits alone, but life habits. He delivers no lectures,...and his sympathy, fairness and thoroughness command their respect.
>
> (Gutridge, 1905:359)

In this system, observation could move anywhere, become flexible and adaptable. And because investigators gradually came to know what went on in the homes of the poor, just as one friend comes to know about another friend, they were privy to confessions and anecdotes of the most personal kind and were able to make observations on the smallest, most shameful details:

> ...the clothing they wear; the work they do; the wages which the bread-winners receive; the care with which the family income is spent; the various ways in which it

> is spent, the thrift, the cost of rent; the influence of intelligence and character, or the lack of it, upon the family.
>
> (Woods, 1911: 7-8)

For this power to be exercised, for the poor to be transformed into a field of perception, observation itself had to be concealed. In other words, this is not a surveillance that features the equivalent of the panopticon guard tower, in which the observatory's size and central location lead prisoners to imagine they are being observed even when they are not. This surveillance is not analogous to observation in which the observed are led to believe that everything they do can and will be held against them. Social workers, like the charity visitors before them, attempt to convey they are *not* observing, and even if they do see, they will not tell. One mode of surveillance depends on the illusions of ceaseless observation and accountability; the other – the social work method – depends on the illusions of non-observation and non-accountability. For example, during the home visit by the social worker, there is always the *fact* of surveillance, but there is also a concerted effort to divert attention away from that fact in order to increase the opportunities for surveillance. Friendship dramatically improves social workers' capacity to investigate by convincing the observed that surveillance is not occurring. In addition, it makes clients want to speak and act in the designated ways, the ways they imagine conform to social workers' wishes. Friendship, in other words, makes it possible to exercise direct supervision, without anyone being aware that supervision is being exercised (Margolin, 1997: 25).

The examination

This technique, argues Foucault, combines hierarchical observation, (a 'disciplinary gaze' where each level of the hierarchy looks over the lower ranks), and normalizing judgement, (a continual analysis of whether the disciplined one deviates from normality), and 'establishes over individuals a visibility through which one differentiates them and judges them' (Foucault, 1977:184). The examination becomes a 'normalizing gaze, a surveillance that makes it possible to qualify, to classify and to punish' (Foucault 1977:185). Foucault sees the examination as at the center of the techniques that render an individual an object of power and knowledge. It imposes a principle of compulsory visibility, holding subjects in

a 'mechanism of objectification' (Foucault, 1977:187). Individuality is introduced into the field of documentation that makes it possible to classify individuals, form categories, determine averages and fix norms; and each individual is established as *a* case and may be "described, judged, measured, compared with others, in his very individuality". This individual may also have to be "trained or corrected, classified, normalized, excluded, etc". (Foucault, 1977:191) In medicine it has taken a ritualized form, where the medical gaze allows doctors to construct an account of what goes on inside a patient, connecting signs and symptoms with disease. The disease is what is important, the individual patient being incidental. The more unusual the disease, the more interesting the patient. In today's world, the 'gaze' is extended even further, with little reliance given to the patients' own account of their illness (Stacey 1989). Now, clinical instruments such as the stethoscope, the MRI machine, the CAT scan and X-rays are used to 'see' and understand the nature of illness. Indeed, modern technology is such now, that it is possible to diagnose diseases without even meeting the patient. This distancing from the patient is central to the doctor's power over their patient, and cultivates a mystique about their professional expertise.

Needs Assessors and Service Coordinators also employ the 'gaze' when they become involved in the assessment process. They, too, take part in the examination, and value their highly personalised relationships with their clients. They develop relationships with skills of rapport-building, trust and confidence, in order that their clients will want to speak to them, and while their professional ethics acknowledge the power dynamic inherent within this, they have an opportunity to further oppress by working with individual pathology, rather than attending to the structural and economic causes of power imbalance. In fact, as agents of the state, it is extremely difficult to manage the tension that exists in applying the assessment process to our clients. The very nature of the assessment process excludes as well as includes, depending on the availability of resources, so that while the assessment process might acknowledge a need, it does not necessarily follow that that need is going to be met. Needs Assessors must acknowledge the power they possess over clients even while they are attempting to minimise it through their personal relationships with them.

These points are relevant for the aging population as well. If disability is removed from the medical framework, then you risk seeing disability as an inevitable result of aging, when it is in fact often the result of a medically reversible condition. According to Havighurst and colleagues, one of most influential models of ageing has been disengagement theory. This theory suggests that the life course is marked by stages such as 'young old age', 'middle old age', and 'old old age'. Here, the main emphasis is on 'social roles' rather than personal psychology. From this perspective, ageing is characterized by various patterns of 'disengagement' whereby:

> ...as people grow older their behaviour changes, the activities that characterize them in middle age become curtailed, and the extent of their social interaction decreases.
>
> (Havighurst et al., 1968:61)

These developmental approaches to ageing have a certain usefulness in that they focus on individual experiences over the totality of the life course. But they take little or no account of social factors which are external to individual psychological states or interpersonal behaviour such as the levels of pensions paid or the social attitudes to ageing. Moreover, ageing is usually conceptualised in terms of an inevitable and pathological process; consequently, older people are viewed as victims lacking control over their own lives. These theories do not, therefore, take account of individual differences in attitudes, expectations and resources. All of these factors may have a significant effect on how any one individual may experience ageing – either positively or negatively (Brearley, 1982).

Much of the existing research evidence indicates that the experiences of many older people simply do not match the kind of experience predicted (Oliver, 1996:135). A major research study of ageing in three countries (Shanas et al., 1968) showed that the majority of older people – given good health and adequate financial resources – do not experience a significant reduction in the scope of their activities, as disengagement theory would predict. More recent studies have also indicated that, where it does occur, any reduction in social involvement is much more closely associated with infirmity and poverty, than with age itself (Harris, 1983). If some older people are less socially active, it is due to these external

social factors which vary independently of chronological age. Because the individualistic approaches to ageing do not take sufficient account of factors external to the individual, they make the basic error of assuming the observable association between such problems and old age are actually caused by ageing itself.

The paradox for the elderly is that to assess in a holistic way means that assessors need to link the needs assessment with the clinical assessment. The task for the assessor is to make a constructive connection to the medical assessment, which does not deny the lived experience of the older person, nor diminishes the experience and consequences of infirmity.

Disability as an individual problem

For disabled people, the normalising gaze and the examination become a powerful dynamic. Until relatively recently, the roles and perceptions of disabled people have been viewed predominantly from a medical framework. First and foremost disability, and this includes having a disabled child, is seen as a medical concern, their problems all being associated with their impairment, and their adjustments are all related to able-bodied functioning. As Munford and Sullivan explain:

> to assist individual adjustment the logic of medical science prescribed surgical and pharmacological interventions in and upon the bodies and minds of disabled people to effect either a cure or to ameliorate the worst aspects of the 'condition'. In many instances, those whose disability was either incurable, or perceived as offensive to normative standards of mind and body, were removed from the mainstream for 'care and protection' in segregated institutions.
>
> (Munford and Sullivan 1997:18)

The dominant view that disabled people and disability belonged rightfully to the medical and related professions was firmly entrenched until the mid 1970s. In his article entitled *Healthism and Disabling Medicalisation,* Zola argues that the medical profession has assumed a considerable amount of power over disabled people's lives, largely because

society has allowed the labels of 'healthy' and 'ill' to be applied to more phenomena in our day-to-day lives. The medical profession, he cites, has first claim to jurisdiction over the label of illness and anything to which it may be attached, irrespective of its capacity to deal with it effectively (Zola 1977:42). He goes on to illustrate this by giving examples of how medicine has retained absolute control over some 'taboo areas,' such as drug addiction, alcoholism, and pregnancy, certain technical procedures, such as surgery and drug prescription, and how medical science's definition of health is becoming all pervasive in our lives. In this article, Zola is signaling his concern about the power that medicine has come to play in our lives, and that since it is the doctor's role to save life and eliminate disease, this has huge ramifications for disabled people, especially as technology advances with such rapidity. Already, women are able to have tests to detect abnormalities in utero, and are invited to consider termination of pregnancy as an alternative to a continuation of pregnancy in which such a diagnosis has been made. As Zola points out, once society starts choosing *not* to have children with certain genetic defects, then 'the next step is selection to heighten certain characteristics or at least protect the individual and society against certain negative ones' (Zola 1977:60). As Zola argues, until we remove disability from the medical framework, the dominant discourse will continue to regard disability as an individual problem. This has considerable ramifications for social work practice, in that our work with patients in hospitals in particular have, until recently, tended to be modeled on the medical profession. In order to challenge this we need to understand the role that power plays in the assessment process.

This individual model of disability locates the 'problems' of disability within the individual and sees the causes of this problem as stemming from the functional limitations or psychological losses which are assumed to arise from disability. This is what Oliver calls the 'personal tragedy theory of disability', where disabled people are seen as victims, and this attitude is reflected in social policies, which force disabled people to see themselves as outside the norm, that is, as part of the 'deserving poor'. Their bodies are continually examined and documented. Medical files describe them in detail, so that they become increasingly objectified. It is their disability that marks them, and makes them what Foucault calls a 'case'. As their files grow, so their voice becomes increasingly irrelevant.

To gain access to the means to meet their needs in any area, be it housing, education, or acquiring a vehicle, means to subject themselves to an examination, and have their bodies and their needs defined by others. A case in point is the Accessible Bus Campaign in Wellington in 1998 in which the rights of disabled people to public transport were subjugated to the provision of exclusive mobility taxis. This policy functions to re-inscribe the disabled body as a recipient of welfare and charity rather than being viewed as a subject worthy of generic rights such as public transport. Oliver and Campbell (1996) discuss how the individual model has impacted on the self-identity of disabled people, so that they saw themselves as being ill, especially as in the past they were often found to be living in institutions which upheld that view. Nevertheless, even now the medicalisation of disability pervades all parts of a disabled person's life until:

> non-disabled people feel that our differentness gives them the right to invade our privacy and make judgements about our lives.
>
> (Morris 1991:29)

There is a general acknowledgement that there have been substantial gains through the medicalisation process. Survival rates for disabled people have increased, and there is a prolonged life expectancy, as well as an eradication of some disabling conditions. However it is the distorted emphasis on clinical diagnosis, that leads to a very partial view of the disabled person, which is most criticised:

> In order to understand disability as an experience, as a lived thing, we need much more than the medical 'facts', however necessary these are in determining medication. The problem comes when they determine not only the form of treatment (if treatment is appropriate), but also the form of life for the person who happens to be disabled.
>
> (Brisenden 1986:173)

One of the most oppressive features of the playing out of the individual model is the assumption that disabled people want to be other than they are, in other words they want to

be 'normal'. In the past, many of the yardsticks used for the successful rehabilitation of disabled people have been measured against the extent to which they had regained their former functioning, and resembled able-bodied people. These experiences are not limited to the physically disabled. In Ballard's (1994) book, *Disability, Whanau and Society,* a number of writers show how intellectually disabled people are treated in Aotearoa New Zealand. They have been 'labeled as damaged or inadequate...and subsequently viewed almost exclusively in terms of their problems or deficits' (Ballard, 1994:8). Society's response has been to impose a degree of 'normality' on them, by placing them in sheltered workshops and special schools, in an effort to make them more 'like us'. A case in point currently is the procedure of placing cochlear implants in the ears of young deaf children, which enables them to 'hear' like 'normal' people. As I have previously stated, the Deaf community only tenuously identifies itself as disabled. Rather, they see themselves as belonging to their own culture, where they communicate in their own language. In the Deaf community the birth of a deaf child is much celebrated, a fact which many professionals, particularly those who specialize in researching a cure for deafness, find inconceivable (Townshend, 1993). The birth of a deaf child means maintaining the Deaf community by transmission of Deaf culture and reflects Deaf parents' positive self-identity. Wilcox (1989) argues that the label 'disabled' is not a primary term of self-identification used by Deaf people, 'it is one that requires a disclaimer' (p.44). Deaf leaders have a history, although an uneasy one, of aligning with disability groups because the public understands concerns of this population better than those specific to the Deaf community. I will examine the health professional's role in rehabilitation more closely in detail in Chapter Four.

The social oppression theory of disability

Over the past two decades there has been a growing swell of protest, both in the disabled community and beyond, leveled at the dominant discourse of the individual model. Writers such as Finkelstein (1981), Oliver (1986,1990,1996), (1981), Morris (1991, 1992), Sullivan (1991, 1995, 1996, 1998), Ballard (1991, 1994), and Munford (1992, 1994a,b,c, 1995) have all been to the fore with their critiques of the medical paradigm. Finkelstein and Oliver in particular have been instrumental in developing a theory which effectively redefines the

meaning of disability. This theory rejects the notion that disability can be seen in terms of impairment and deficit. From the perspective of these writers, disability is "more properly located in, and created by, the social and political structures which function to exclude and marginalize disabled people"(Munford and Sullivan, 1997:18). Disability then, according to the social model, is:

> all the things that impose restrictions on disabled people; ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on. Further, the consequences of this failure do not simply and randomly fall on individuals but systematically upon disabled people as a group who experience this failure as discrimination institutionalized throughout society.
>
> (Oliver, 1996:33)

Oliver argues that change for disabled people will only come about through a process of political empowerment, rather than through social policies delivered through the establishment, or treatment programmes provided by the medical and allied professions. This illustrates the sense of growing 'resistance' that Foucault argues takes place wherever there is power operating. Disabled people are challenging not only what is done to their bodies, but also the structures that serve to exclude them. Resistance, according to Foucault, is:

> mobile and transitory...producing cleavages in a society that shift about, fracturing unities and effecting regroupings, furrowing across individuals themselves, cutting them up and remolding [sic] them, marking off irreducible regions in them, in their bodies and minds...the swarm of points of resistance traverses social stratifications and individual unities.
>
> (Foucault, 1979:96)

There is an ongoing debate within the disability community about the relationship of the social model to the experience of impairment. As well there is disagreement about the

language used. For example, one effective strategy was to adopt the term *non-disabled* as opposed to *able-bodied,* as disabled people set about redefining themselves and their condition in a more positive way. In a similar way to the Gay Pride movement, a sense of identity has been developed by the disabled community 'speaking a true word' as Freire put it (Freire, 1972:11). An important level of resistance by disabled people involves their conscious naming of the world in order to transform it. As Morris says:

> We reject the meanings that the non-disabled world attaches to disability but we do not reject the differences which are such an important part of our identities...By claiming our own definitions of disability we can take pride in our abnormality, our difference.
>
> (Morris, 1991:17)

Oliver (1990) argues that a social theory of disability must be integrated into existing social theories and must be located within the experience of disabled people themselves and their attempts to not only redefine disability, but also to construct a political movement amongst themselves. The emergence of the disability movement is an example of how disabled people have begun to construct such a political movement.

Illness vs impairment

There is a common perception that disabled people are 'sick' or 'unwell'. The medical model of disability has been used extensively to organise and control the lives of disabled people, and because it pathologises disabled people as problems the distinction between impairment and illness has become blurred. This is one of the reasons why disabled people vociferously protested against disability funding to be placed under the health portfolio in this country, as it does nothing but reinforce this impression.

The problems that disabled people face are highlighted in a survey that Begum carried out with GPs examining attitudes towards disabled women's impairment. She found that they placed a heavy emphasis on the impairment, seeing that as the problem rather than

considering the disabling attitudes of themselves and the environment as having any bearing. This results in the:

> all-pervasiveness of doctors' power over disabled people's lives, of which the power to make decisions about fitness for work and entitlement to welfare benefits are but examples. This does not necessarily mean, however, that the medical aspects of their lives are unimportant for disabled people.
>
> (Lloyd, 1992:211 quoted in Begum, 1997:159)

One result of this is that some of the women interviewed downplayed their illnesses so that they did not have to go to the doctor (Begum, 1997:165). Sometimes this was because, so often, their illness was perceived to be part of their impairment, (ibid: 166) or because they were not believed or supported in their diagnosis or treatment (ibid: 167).

The social model seeks to redress this perception, in promoting disability as a civil rights issue and in developing schemes to give disabled people autonomy and control in their own lives. In keeping with the social model the Disabled People's International defines impairment as the functional limitation within the individual caused by physical, mental or sensory impairment, whereas illness refers to everyday ailments and other biological, physical, psychological issues that people would not define as 'normal' for them. The relationship between illness and impairment is a complex one. On the one hand, impairments in themselves do not constitute a medical problem but are merely a fact of life that a disabled person has to live with. On the other hand, some disabled people may be more vulnerable to illness because of impairment, or effects of illness on impairment.

Lloyd (1992) goes on to argue however, that inappropriate uses of power and control, insensitive and patronising behaviours, and stereotypical attitudes are not confined to *disabled* people's encounters with the health care system. They *are* particularly experienced by women, however, both as patients and as workers. She poses the question as to whether the automatic linking of the rejection of the medical model with the minimising of medical aspects is the most helpful construction for disabled women of the

relationship between disability and ongoing health care (Lloyd, 1992: 212). She points out that the same devaluing denial of rights and exclusion from information and choices, to which disabled people are subjected, is the common experience of women anyway:

> That disabled women are more regularly and intensively subjected to intimate procedures, insensitively handled, than are their non-disabled sisters is not disputed. It may be, however, that the way forward is to acknowledge the centrality of good health care in their lives and direct attention towards the redefining of need and the reshaping of services.... Although for a disabled woman the negative effects [of the medicalisation of disability] are a consequence of the way in which she is perceived as a disabled person, they are *also a consequence of the way in which she is perceived as a woman.*
>
> (Lloyd, 1992:212)

For old people the link between disability, impairment and illness can become inextricably linked, as is described by Parker:

> I found myself puzzled by arguments that held that disability had nothing to do with illness or that belief in a need for some form of personal adaptation to impairment was essentially a form of false consciousness. I knew that disabled people argue that they should not be treated as if they were ill, but could see that many people who had impairments as a result of ongoing illness were also disabled. My unease increased as I watched my parents coming to terms with my mother's increasing impairments (and disability) related to arterial disease which left her tired and in almost continual pain. I could see that people can be disabled by their physical, economic and social environment but I could also see that people who became disabled (rather than being born with impairments) might have to renegotiate their sense of themselves both with themselves and with those closest to them.
>
> (Parker 1993:2)

The relationship between illness and impairment is complex, and has resulted in considerable debate in the health arena (Begum, 1997; Finkelstein, 1993; Oliver, 1996; Williams 1991). Williams (1991) has suggested that there are dangers in rejecting the medical model:

> Sometimes, in seeking to reject the reductionism of the medical model and its institutional contexts, proponents of independent living have tended to discuss disablement as if it had nothing to do with the physical body.
>
> (Williams, 1991: 521)

However, Oliver and others insist that disablement has nothing to do with the body. They do not deny the reality of the impairment, nor that it is closely related to the physical body. But disablement is the consequence of the failure of social organisation to take account of the differing needs of disabled people and remove the barriers they encounter, and impairment is merely a description of the physical body. Some theorists are focusing on both the impairment and the disabling nature of society, pointing out that the lived experience of disabled people is such that disability and impairment effects interact, and meld together in a holistic fashion. This means that, in a society in which the dominant discourses attribute all restrictions of activity to the 'tragedy' of impairment, it is of great political significance to conceptually separate out disability from impairment effects (Thomas, 1999).

In the New Zealand setting, there are currently arguments that support taking the care of the aged disabled community, (over 65) out of the disability framework. The argument is that as one ages there is often a more causal link between impairment, illness and consequent disability, and because of this, the Ministry of Health is considering removing the funding for the Assessment, Treatment and Rehabilitation of older people from the ring-fenced disability area into the personal care fund. Those working in the field are advocating for a service that is age-related and specialist in nature, as reduction in specialist AT&R services, such as has happened in the Waikato (National Health Committee, 1999:12), risks adverse outcomes for older people, as opportunities for appropriate

assessment for people whose medical condition may be reversible are often missed, and the generic assessment process is often inappropriate to the complex, iterative and changing needs of older people. In this scenario, the argument is that there is a clear relationship between impairment and illness, and that by including the elderly in the same model as the younger population is actually disabling for them. However, there is a risk here of just accepting that old age, frailty, illness, and impairment all go together. In this scenario, the social model is assumed to be less relevant, and an older person is more likely to be treated within the medical model, which is seen to be more applicable. However, this is not to say the social model does not have relevance when one works with the frail elderly, where impairment is acknowledged as part of the equation, and society's barriers have a similar impact, but knowledge of the relationship between the impairment and (chronic) illness is a vital part of the assessment and treatment process, in the same way as a recognition of the structural factors that work to disempower older people's functioning in the community.

The role of biography, continuity and meaning is essential when assessing the needs of older people. This was highlighted in a study by Nilsson *et al.,* (1998), who found that quality of life had little intuitive meaning for older people, since it is a concept imposed on them by researchers and policy makers (quoted in Nolan *et al.*, 2001:14). On the other hand what makes for a 'good life' in older age is readily understood and older people are able to identify the essential elements. These are not related primarily to objective circumstances but to:

- Personal relationships – a feeling of embeddedness, usually, but not exclusively, within a family context
- Activity – engagement in meaningful activity and a feeling of being needed
- Links between past and present lives, where the past is viewed positively, as is the future, no matter how short
- A philosophy of life based on religious or other strong personal beliefs.
  (Nilsson et al in Nolan et al, 2001:14)

Similar explanations can be found in related fields, such as chronic illness and learning disability. For instance, Charmaz (1983) suggested that a 'loss of self' was the fundamental form of suffering in chronic illness, and that this was created and sustained by the overriding focus on physical functioning:

> In a society which emphasized doing, not being, those who cannot perform conventional tasks and social obligations lose the very means needed to sustain a meaningful life.
>
> (Charmaz 1983:191)

More recently Barnard (1995) has argued that autonomy represents one of the most destructive aims for people with chronic illness, and that interventions must instead focus on understanding individual values and aspirations if they are to assist people to relate to life in a way that is responsive to their efforts. He suggests that professionals who thrive on dramatic results and pursue autonomy not only will be disappointed but also do people with chronic illness a disservice.

Conclusion

For the Needs Assessment and Service Coordination Service, the discussion in this chapter is highly relevant. Many of the NASC workers (but not all) are attached to health institutions, which naturally have sick people as their focus. In this environment it is difficult for them to step outside the prevailing medical model, and view the impairment of their clients separately from disability, just as it is difficult for doctors to view illness as separate from the impairment. Moreover, many of the NASC workers are nurses by profession, whose very training is in the medical model.

The social model requires one to view the environment as disabling to the impaired individual. While the NASC policy purports to be based on the social model, a large number of the workers are drawn from those who have trained under the medical model. The question is whether these workers see impairment as an extension of illness and view the client from their professional knowledge base, or whether they are adequately able to

apply a framework to their work that puts the client's perceptions of their problems to the fore, identifies goals that are client-defined, while at the same time enables them to identify disabling environments.

Chapter 4 - The role of the professional

The philosophy that underpins the Health and Disability Act (1993) has determined that the new role of the Needs Assessor and Service Coordinator has the right and the power to engage in a needs assessment process with disabled people. In the former Northern Regional Health Authority region no new funding was allocated to implement the new policy, therefore it was considered pragmatic to place the role into the hands of existing professionals. The NASC workers engaged in working with the elderly and children that were involved in my study are based in health agencies and include social workers, nurses, occupational therapists, dieticians, and physiotherapists – all from large specialisms and accorded status as professions and as such bring with them the power that the role gives them and their own particular knowledge base. For disabled people, engaging with these professionals should be, according to the standards, ' a partnership which recognizes and respects the person's knowledge and experience of disability' (Ministry of Health, 1994). But because the nature of the interaction brings with it a significant power differential it can in practice prove to be a disabling experience for the client.

In examining the meaning of this power differential it is necessary to examine what constitutes a profession and the nature of professional power, especially in the 'caring professions', as this leads to some insight surrounding the dilemmas of health professionals in their work with disabled people. I will confine my discussion to social work as this occupation is well represented in the NASC role. However that is not to say that my discussion does not apply to other occupational groups.

What is a profession?

The idea of a profession emerged from the universities in the late 19th and early 20th centuries, which saw the creation of the professions of law, medicine and the clergy. These three still tend to be seen as the ones against which other claims to professional status are measured. Their general characteristics include a monopolisation of particular forms of expertise, the erection of social boundaries around the received ideas through entrance qualifications and extended training and an ideology of public service and altruism, in that

they claim to serve higher goals than mere economic self-interest. Professions are not simply jobs, but a construct. Professional autonomy is justified by the self-policing mechanisms constructed through their own internal criteria of standards maintained by the profession itself (Abbott & Wallace, 1990:2). A consequence of these mechanisms is that they provide the basis for political power in the market place, allowing the holders of the profession to command higher status and higher economic and social rewards for their services.

Much has been written about the role of professions in our society. Friedson has suggested that it is useful to look at the idea of 'professionalism' as used in practice (Friedson, 1986), whilst Parry and Parry (1976) argue that the key question is how occupational groups achieve the status of 'professional' and in the process gain ascendancy over other occupational groups. Johnson (1972) argues from a Marxist perspective that professions form a particular institutionalized form of client control. Their professional status stems from the ignorance of the client as against professional specialist knowledge, thereby rendering clients relatively helpless. Professionals are accepted as 'specialists' and they often have legal backing for this, making their clients socially and economically dependent. In addition, clients are often socially distanced from their advisers in other ways – by social class, ethnicity, educational background and by gender, for example.

This has relevance for the Needs Assessment and Service Coordination workforce. In the NASC service we see the role determined by policy, which gives it external legitimacy. Furthermore, because services are linked to a capped budget, the NASC worker becomes a gatekeeper to services. If a disabled person requires any services from the health and welfare field they must first gain access to a Needs Assessor, who will, with the disabled person's input, determine the extent and legitimacy of their need. This helps define the NASC as a 'specialist'. As the majority of them are able-bodied, this may distance them from their client group by reinforcing the able-bodied state as the norm. For disabled people there will always be the necessity to build relationships with those 'in authority', and even when those relationships are based on mutual respect and integrity, both parties are aware of the power dynamics that come into play. This has indeed been one of the

major criticisms of legislation that surrounds disabled people. Oliver makes the point in his book *The Politics of Disablement* that the delivery of professionalised services can also create dependency not only in the way that services are offered, but also in the language that is used. He claims that power and control continue to remain with professional staff, and that the ranges of tasks that the professionals can perform are limited because of professionalist boundaries and employer requirements (Oliver, 1990: 90).

The emergence of the professional role was particularly important for medicine. Up until the nineteenth century, the entire system of medical investigation – the development of knowledge and its application in medical practice – was dominated by a relationship of patronage which bound leading practitioners to the 'whims and desires of a narrow circle of the upper class' (Jewson, 1974). With the emergence of the professional form of occupational organisation, control moved from the wealthy patron to the wider community of colleagues. It was they, not the patron, who ensured that such knowledge was spread through the wider professional community. This type of colleague control can be seen in its purest form in the hospital with its salaried career structure which frees practitioners entirely from dependence on clients, and its close community of colleagues employed in the same institution and interested in similar areas of clinical medicine. (Davis, 1981)

The emergence of the profession must also be seen against the background of the growth of the service sector in industrial society. Although the great bulk of this growth has taken place in less highly qualified white-collar and clerical occupations, it is against this background that the growth in stature of the professions must be viewed. The growth in the 'semi-professions' has been particularly rapid in the last few decades. In the health sector the growth in importance of the auxiliary and allied health occupations has been a significant change. While the medical profession in the nineteenth century had to contend with some alternative practitioners, such as midwives and healers of various sorts, these did not have the numbers in the system that nurses, pharmacists, social workers, occupational therapists and medical administrators have today. These groups have all managed to develop their own occupational independence rather than carrying out work delegated to

them from the medical profession. In this way they are weakening the dominance of the medical profession in the health care system.

The 'new professionalism'

The occupational structure in the health sector, then, is a dynamic and evolving division of labour that is shaped by technical advance, by the relationship between medical and other specialties, and by forces in the wider society. Among some of the non-medical professions, alternative philosophies to the curative, technique-oriented skills of medicine have developed. Nursing's emphasis on 'care' rather than 'cure', for example, has to some extent distanced the occupation from medical, or at least, clinical, direction. The more 'holistic' specialties, such as public health nursing, occupational therapy and social work, are all probably somewhat freer of medical direction than those occupations that have a more technique-oriented definition of their task. The literature on the professionalising strategies of these occupations, (that have been regarded as 'semi-professions'), advocate the adoption of a 'new' or 'democratic' model of professionalism based on a form of partnerships between professional and client (Stacey, 1992).

The critics of 'old' professionalism argue that it supports hierarchical relations that deny the knowledge and experience of the client or service user. In prioritising a scientific/rational epistemology it positions professionals as 'experts' whose power and status is maintained by their claim to specialised knowledge. The emphasis is on a one-way transmission of knowledge from the professional as expert to the client as lay person. This is the nature of what Foucault calls the 'normalising gaze' and, as a result, professionals are accorded a great deal of power in their dealings with clients. Illich (1977) argues that professionals exercise power in a way that is disabling – that is that they take away individuals' ability to take care of themselves. Professionals, they say:

> tell you what you need and claim the power to prescribe. They not only recommend what is good, but actually ordain what is right...It is (the professional's) authority to define the person as client, to determine that person's need and to hand the person a prescription.
>
> (Illich 1977:17)

Advocates of 'new' professionalism argue that the 'old' approach treats knowledge as certain, absolute and value-free when it should be recognized as socially constructed and value-laden (Williams, 1993: 11-12). They propose an alternative to professionalism based on a 'partnership' between the professional and the client. This 'partnership' involves the professional and client together identifying what the client wants and needs to know.

Person-centred care

In highlighting the knowledge potentially held by frail older people the literature on chronic illness provides important insights, in which theorists have long argued that 'top-down' models of professional practice fail to recognize the differing types of 'work' required in managing long-term illness, thereby ignoring the genuine expertise held by lay people (Strauss *et al.* 1984; Strauss and Corbin, 1988). This can have a profoundly detrimental effect on the quality of communication between professionals and disabled people. For example, in a study examining consultations between doctors and patients, Tuckett *et al.* (1985) identified four main foci for their conversations:

- The diagnosis
- Treatment and advice
- Perceived consequences of the above
- Patients' understanding of their treatment

During detailed observations they found that consultations were one-sided, with little emphasis being given to the latter two areas above. Patients' attempts to clarify their understanding were often ignored and the advice they were given was rarely individually

tailored. Tuckett *et al.* suggested that patients were in many ways already experts about their condition but that doctors generally did not seek out their theories. Moreover, as doctors believed that the biomedical knowledge they held would be too complex for patients they provided only superficial explanations. As Williamson (1992) contends, the aim should be to have professional participation in patient decision-making rather than patient participation in professional decision-making.

The 'new professionalism' discourse constitutes professionals as 'reflective users of knowledge and experience' (Williamson, 1992:58) whose central task is to develop an understanding of the client's perceived needs and to share their expert knowledge and skills in so far as they serve these needs. The professional-client relationship is reconstituted as a 'partnership' in which each partner contributes to the negotiated outcome. Professional practice from this perspective has more to do with the development and use of interpersonal skills than the application of esoteric knowledge. This approach is what is being asked of the NASC worker in their work with disabled people. It is important that the NASC role stands outside the medical arena so that the assessment process can be based on the social situation and needs of the client rather than the deficit approach of the medical model.

Distancing from the medical profession is important for consumers to regain their power. For the NASC worker, distance is also important, but for different reasons. They need to establish a different relationship with their clients based on mutual respect and 'partnership'. Kivnick and Murray (1997) suggest that relationships between disabled people and professionals should be based on 'interpersonal mutuality'. Similar arguments are advanced by Williams and Grant (1998) who believe that person-centred care required knowledge of people as individuals, exploring and recognizing their ideas, beliefs and lay knowledge. Mulrooney (1997) extends the criteria for person-centred care, identifying three attributes:

- Respect for personhood
- Valuing interdependence

- Investing in caregiving as a choice

These dimensions capture the dynamic and reciprocal nature of person-centred care and largely undermine the notion of 'professional distance'. Clearly while relationships with professionals are different from those with others, for example family and friends, a detached and relatively uninvolved professional stance appears antithetical to a person-centred approach.

It follows that if person-centred care is to underpin professional practice meaningfully (Rodwell, 1996) there is a need for a marked shift in emphasis, so that the client is viewed as an active agent and analyst of their own experience. Such an orientation exposes the limitations of the argument in favour of professional expertise. While Thorne and Paterson (1998) believe that more emancipatory models of care are to be broadly welcomed, these authors caution that the role of an 'outsider expert' should not be entirely denigrated. They argue that there is a need to:

> ...explore the intricate, complex and highly sophisticated skills that comprise professional expertise rather than rushing towards a model in which the professional role is merely to ensure access to services.
>
> (Thorne and Patterson 1998: 176)

They posit that the relative contribution of the 'outsider' expert and 'insider' expert varies over time, depending on the nature of the support required. They suggest that professionals need to work in partnership with disabled people, and must move beyond technical competence to consider the skills and knowledge that they require to deliver person-centred care.

Probably the most detailed consideration of person-centred care is to be found in the nursing literature, with numerous authors promoting such an approach (Fossbinder, 1994; Benner and Gordon, 1996; Benner *et al.* 1996; Tanner *et al.* 1996; Halldorsdottir 1997; Janes *et al.* 1997; Liaschenko 1997). A number of these authors suggest that knowing the

patient as a person allows practitioners to synthesise their understanding of patterns of response to certain illnesses with their knowledge of the individual, in order to identify the 'salient' aspects of a situation. This synthesis is seen not only to enhance the clinical components of care but also to limit vulnerability and promote dignity. Saliency, that is the ability to identify key aspects of a situation, is seen as one of the core attributes of person-centred care.

Liaschenko (1997), argues that while numerous authors focus on knowing the patient or the person, most of these conceptualizations are still implicitly underpinned by a largely biomedical orientation. In other words, knowledge of the person is viewed primarily as a route to a better understanding of their response to illness. Liaschenko believes that other knowledge is required in longer-term relationships; knowledge that alerts practitioners to what it is like to live a particular kind of life. She identifies three broad types of knowledge that might inform health care workers more widely. These are:

- *Case knowledge* This comprises biomedical, disembodied knowledge of a particular condition, for instance stroke.
- *Patient knowledge* This is best viewed as a 'case in context'. In other words information about a person's social circumstances, level of support and so on provide a better understanding of the impact of the 'stroke' and the resources that can be mobilized.
- *Person knowledge* This is based on understanding 'biographical life' which for Liaschenko comprises three components: agency, the capacity to initiate meaningful action; temporality, which is related to an individual's pattern of life rather than 'clock time'; space, in terms of how an individual relates to their physical, social and political environments so as to create a sense of 'belonging' somewhere. (Liaschenko in Nolan, M.*et al.*, 2001:25)

Eliciting person knowledge takes time and trust and thus case and patient knowledge may be more relevant in situations where the primary aim is to cure a condition and 'move a person out' (Nolan *et al.*, 2001:25). Person knowledge is not therefore intrinsically

desirable and may be unacceptably intrusive in certain contexts. Conversely, person knowledge is usually essential where there is an ongoing relationship, for example, in the case of people with learning disabilities, and its value, as well as its potentially resource - intensive and time-consuming nature, has to be recognized. This raises political questions about the type of health care we envision. Person-centred care cannot be manifest unless the skills required are seen as not only legitimate but also important.

Halldorsdottir (1997) contends that modern day health care has witnessed a separation of competence, that is the delivery of complex technical care, from caring as an affective process, the former being seen as the preserve of the professions and the latter delegated to others. She argues that simply being warm-hearted and having common sense are inadequate and that good care must combine competence with caring if quality is to be maintained. This requires a model of competence that extends beyond the delivery of excellent technical care to one that is based upon a more sophisticated understanding of the skills required for a person-centred approach. The first place where these skills will become evident is at the assessment.

The assessment

The assessment tool is the major process whereby each profession stamps its authority in the health arena. It is an analytical process which provides a basis for planning what needs to be done to maintain or improve a person's situation, although it is not the plan itself. Assessment involves gathering and interpreting information in order to understand a person and their circumstances; it involves making judgments based on information (Middleton, 1997). In Foucauldian terms, the assessment is the point where professionals apply the 'clinical gaze'. Originally applied to the way in which doctors analysed the problems of their patients through the application of medical knowledge and practices, the notion applies equally well to other professions involved in the health arena such as occupational therapy, social work and nursing, as in working alongside doctors they have applied the same technique to gain their information. To a large extent, allied health professionals have also been captured by the medical model and carried out their assessments with a similar concentration on the problem or the deficit, ascribing their own professional

expertise to the assessment rather than taking sufficient account of the client's views and opinions.

As has been pointed out previously (see Chapter Two), disabled people have claimed that they have been analysed in terms of their impairment in assessments with the purpose and the outcome being defined by the assessor rather by the disabled person. Abberley (1995), explores this in his survey which examines occupational therapists' attitudes to the idea of partnership when doing assessments and working out goals with disabled people. Often, he said, the Occupational Therapists (OTs) would arrive at therapist-centred goals, occasionally purely medical: 'a measured return of strength and movement', (p.223) but more often with a wider task-based focus: 'you assess what the problem is, your short-term goal is reached. You set another goal. Your final aim is the achievement of realistic goals. Your ongoing task is to set goals and targets that are attainable. We can't allow people to fail' (p.226). A limiting factor emerges here; if the patient 'can't be allowed to fail' then reality is defined in terms of what it is in the power of the OT to deliver. As one other of the OT respondents put it: 'You arrive at where the therapist and client wish to get to. But success for the patient depends on how realistic their expectations are' (Abberley, 1995:226). Again, assessments often fail to look beyond the individual with the impairment, focusing their services on the identified 'client':

> Many services will focus on the needs of the identified member with a disability alone, ignoring the impact of the decisions made and actions taken on the rest of the family. Families are the groups that support children and people with disabilities yet service providers appear to be in retreat from families; this needs to change. Human service workers need to understand their own values when it comes to working with families.
>
> (Turnbull and Turnbull, 1990)

In social work, a profession that is well represented in NASC employees, there has been continued discussion as to what constitutes a good assessment. Milner and O'Byrne talk about the 'lack of clarity about the necessary skills involved in assessment', (1998:8) with

the result that social workers have become more preoccupied with the better-explained methods of intervention. Methods have tended to influence the assessment, becoming a sort of 'practice theory' (Curnock and Hardiker, 1979: 8). Denney (1992) found in his study of probation reports that many of the assessments seemed to contradict the form of work advocated. The most commonly used interventions were largely individual rather than social, although there have been some protests:

> If we are to maintain the integrity of 'community' care, 'social' service and 'social' work, we have to confront the constant tendency that we all have to *regress to the individualisation of individual problem.*
>
> (Smale et al., 1993:30)

Similarly, Barber (1991) also expressed dismay at the tendency towards 'reductionism' in which social work became equated with casework, and individual solutions were found within the psychopathology of individuals and their interpersonal relations.

Barber (1991), also claims that the pressures of professional status affect and restrict social work assessments; the relatively low status of social workers compared with other professionals leading to 'social work's perennial infatuation with professional status' (1991:25) and a resulting preoccupation with psychotherapy and family therapy as exalted activities among case workers. This means that there is a tendency for social workers to want to offer 'sessions' of therapy without necessarily undertaking a thorough assessment of its suitability. The recipient of the therapy may 'not always know, let alone agree with, the social worker's arguments and conclusions' (Davies, 1981: 69).

It is clear from the efforts made to devise and introduce assessment forms, procedures and dedicated staff that assessment is an organisationally valued activity (Middleton, 1997). This is particularly true for NASCs, where the constant procedure changes brought in to improve the assessment process has been the single biggest complaint about the job. Sometimes the agendas of the organizations may not always match those of the professionals within them - or those of their service users. However, part of the skill of the

assessor is understanding and managing this mismatch, in order to get the best deal they can for the service user.

Good assessment should be undertaken by experienced and skilled staff, with the understanding of and ability to work within the organisational context (Middleton, 1997). The assessor is both representing the organisation to the person being assessed, and translating their views back to the organisation. Middleton argues that in this latter sense, there is something of the advocate in the role, although it is arguable that someone who is employed by an organisation cannot reasonably be expected to act as an advocate. Moreover, there are strong voices that argue that advocacy must be independent of the organisations that assess and allocate resources. It is a model which informs the theory behind the purchaser/provider split. Part of the difficulty of this is that it can assist in the process of fragmentation, with the possibility that organisations do not employ the sort of professional who can see both sides of the picture. This has the potential to ultimately disadvantage the service user (Middleton, 1997:30).

There appears to be an increasingly defensive attitude creeping into assessments as organisations rely more on paper or computer-based systems in an attempt to produce a more standardised assessment. This defensiveness can also be observed in the medical profession where the fear of being sued about making the wrong decision about treatment results in, for example, a growth in the number of babies born by Caesarian sections. There is a growing belief in the ultimate scientific rationality of medicine as a process, which is rendering human judgement unnecessary. The expression of this is very clear in the NASC assessment system where the plethora of forms is an attempt to place the subjective needs of an individual into a tool that tries to objectify the assessment and make the judgement of the operator less necessary. This can be seen in the Support Needs Assessment protocol in which the complex needs of frail older people are translated into a number or level, which in turn can open up or restrict the services available. This is an organisational tool that tries to measure need on the one hand while trying to contain budgets by the other. The skill however is not in achieving a measuring tool or set of tools that fits everyone, but in being able to reach an accommodation with individuals which best fits their aspirations and the

resources that can be made available. An assessment that is less influenced by resource limits, and intervention methods which the social worker feels confident with will probably point to the need for quite different resources and interventions to be developed. This requires social workers to respond uniquely to each situation:

> To empower the particular people they work with and respond to the unique circumstances that confront them on a day to day basis, professionals have to *reinvent* their practice and their perceptions of particular problems and solutions in each different social situation that they find themselves in.
>
> (Smale et al., 1993:41-2)

Conclusion

For professionals working in today's health care market, they are required to work in an increasingly complex framework. On the face of it, it would appear that the very nature of professionalism is in conflict with the intent of the NASC framework. On the one hand professionalism encompasses a specialist knowledge base and with it the power to disseminate it to a dependent client group. The occupational groups from which the majority of NASC workers have been drawn such as nursing, social work, occupational therapy and teaching, are all considered professions; they work with specialized knowledge, enjoy status in the community, and are trained in institutions which employ hierarchical relationships as a way of disseminating information.

The NASC framework, on the other hand, is moving away from the 'old professionalism'. Disabled people are demanding not to be assessed in the medical model, rather that professionals work with *the client's* knowledge and experience, and empowering the client so that they move from dependence to interdependence. This position requires the worker to adopt the 'new professionalism' of more person-centred skills, and distance themselves from the medical framework, while at the same time having an understanding of it. As Margolin observes, however, the illusion of non-observation continues even working with the 'new professionalism'. While budget constraints exist, there will always be a need to employ the 'gaze', even if in a more sophisticated fashion. These are the ambiguities that

the worker must negotiate. It is not that their knowledge base and expertise is irrelevant, but they must combine these with equally important skills of relationship building and incorporation of the knowledge base and expertise of the client. The reciprocity of the relationship is an important key, but what must also be acknowledged is the power imbalance that remains while the disability community must negotiate their needs from a limited fund. The assessment is the critical point where the success of the relationship is determined.

Chapter 5 - The research framework

Research focus and objectives

The focus of this research is twofold: one to examine the skill base, both actual and desired of the Needs Assessors and Service Coordinators employed in two distinct areas of service, and two, to explore what they thought their training needs might be for this role. One group will be located in a district health board, which serves an over 65 population and the other is located in a community organisation, which serves the adult population between 16 and 64. Specifically, the research involves holding two focus groups, one each of workers involved in the two different age groups, and interviews with six consumers drawn locally from the area the researcher lives in. Based on the data collected from these groups and from an analysis of the Health and Disability Act, which formed the role of the NASC, the study aims to identify the skills required for the role and to see if they fulfill the spirit of the intention of the Act. The objectives of the research are:

- To determine an understanding of the role and the skill-base of the Needs Assessor and Service Coordinator
- To explore the perceived training needs of NASC professionals
- To determine the perceptions of consumers in relation to the process of needs assessment
- To compare professional/consumer perceptions of the skill-base required.

Focus groups are particularly useful for exploratory research where there is little known about the topic of interest (Morgan, 1997). Needs Assessors and Service Coordinators have been a function of the disability sector for the past seven years. However, in that time little research has been carried out to determine the knowledge base and skills required for the role. It has been assumed that existing professionals hold the skills and, moreover, there has been an assumption that there is some common understanding of the knowledge base required for the role. Any training offered has been largely internal and in response to workers' requests when they come across areas where their skill or knowledge base is lacking. I therefore chose the focus group as the most suitable tool for my research and the

one that would generate the most useful data. They also offer an opportunity for dialogue and interaction between the participants which can generate a useful exchange of ideas. As a supplement to the focus groups, I also carried out interviews with the managers of both teams in order to establish their views on the direction and structure of the service.

The purpose of this chapter is to discuss the methodological design of the research. The setting up of the focus groups will be examined in depth, as they are the central tool used to gather data. Attention will also be given to the advantages and disadvantages of this approach, and an exploration of some of the difficulties encountered.

Methodology

The theoretical framework for this research is embedded in qualitative methodology, more specifically, the use of focus groups. Thus, the focus is on the *meaning* that the research participants attribute to their understanding of the role of the NASC. This was enhanced with individual interviews of key stakeholders (consumers) and interviews with managers of both organisations.

At present, the two principal means of collecting qualitative data in the social sciences are participant observation, which typically occurs in groups, and open-ended interviews, which typically occur with individuals (Morgan, 1997:7). As group interviews, focus groups occupy an intermediary position between these other qualitative methods but also possess a distinct identity of their own. Focus groups provide access to forms of data that are not obtained easily with either of the other two methods. The main advantage of using focus groups is the opportunity to observe a large amount of interaction on a topic in a limited period of time. In relation to this topic, focus groups are a useful mechanism to employ when interviewing professionals who were discussing their skill base. In this instance I was interested in their opinions in order to get a sense of their ideas as a whole. The group process helped to spark discussion, and allowed me to observe interaction on the topic. The group discussions provided me with direct evidence of the participants' similarities and differences in their experiences and opinions as opposed to reaching such conclusions from post hoc analyses of separate statements from each interviewee, such as

an individual interview of views would have generated. This was particularly evident in the second group, where the differences in the skills required by the assessors and the service coordinators were highlighted in a way that quite possibly would not have happened in an individual interview.

Other approaches to collecting the data such as surveying, telephone or one to one interviews were not considered because of their disadvantages. Surveying, in the form of questionnaires provides a large amount of information that other methods cannot provide, and are one of the most popular methods of data collection used in social sciences (Sarantakos, 1993:158). However, they do not allow probing or clarification of questions, nor do they provide an opportunity to collect additional information while they are being completed. For the purposes of my topic, it was the opportunity to probe more deeply into the questions that made a questionnaire less appealing.

Telephone interviews were not considered because as a tool it was considered unsuitable for the topic. Telephone interviewing is generally employed when the interviews are simple and brief, when quick and inexpensive results are sought, and when it is not considered necessary to approach the respondent face to face. It does offer anonymity, but at the same time it also excludes additional ways of collecting data. For the purposes of my research, telephone interviewing would have been inappropriate as greater success is likely if the interview is brief, whereas I wanted to generate discussion and examination in some depth.

One to one interviewing using open-ended questions is a useful way of gathering data and was the approach used with the consumer group. The qualitative interviewing process offers interviewers considerable freedom in presenting questions, and the interview can be adjusted to meet the goals of the study being undertaken. Like focus groups, qualitative interviews employ a readiness to change direction, and there is an expectation of the interviewer to engage in open discussion with the respondent while maintaining a passive and stimulating, but not dominating role (Sarantakos, 1993:188). Their main drawback, however, is that they are much more time-consuming than focus groups and I would not

have considered this approach if a consumer focus group was possible. Nevertheless it did turn out to be a useful way to enhance the information gained in the focus groups. This enabled me to explore some aspects in more detail on topics that were only broadly discussed in the original focus group. This will be discussed in more detail later in this chapter.

Focus group interviews

A focus group interview is a particularly useful tool when the researcher does not have a depth of knowledge about the participants. Stewart and Shamdasani (1990:140) maintain that focus groups provide 'a rich and detailed set of data about perceptions, thoughts, feelings, and impressions' of people in their own words. Focus groups 'represent a remarkably flexible research tool in that they can be adapted to obtain information about almost any topic in a wide array of settings and from very different types of individuals' (ibid:140).

Focus groups are particularly useful when a researcher wishes to explore people's knowledge and experiences. They can be used to find out not only what people think but also how and why they think the way they do (Kitzinger 1994). This is particularly important when the researcher needs to find out about the perspective and experience of people who have different social and cultural backgrounds from theirs or when, as in this case, there is little information about the group of people under investigation.

A focus group is a group of people gathered together to discuss a 'focused issue of concern'. As Morgan (1997:2) puts it, 'the hallmark of focus groups is their explicit use of group interaction to produce data and insights that would be less accessible without the interaction found in a group'. Kitzinger asserts that the intention of focus group discussions is to:

> encourage interaction between research participants as much as possible. When group dynamics work well the co-participants act as co-researchers taking the research into new and often unexpected directions and engaging in interaction which

> is both complementary (such as sharing common experiences) and argumentative (questioning, challenging, and disagreeing with each other).
>
> (Kitzinger, 1994:106)

With this kind of interaction, focus groups:

> reach the parts that other methods cannot reach – revealing dimensions of understanding that often remain untapped by the more conventional one-to-one interview or questionnaire.
>
> (Kitzinger, 1994:107)

Jarrett (1993) argues similarly that, in the focus group interview:

> the primary interaction takes place between respondents. Indeed, it is the presence of others that enhances the intensity of the interaction and, ultimately, the richness of the data. The interchange – a dynamic give and take - stimulates respondents to analyse their views more intensely than in an individual interview.
>
> (Jarrett, 1993:56)

It is important to note that there are also possible limitations to this methodology. The fact that they are driven by the researcher's interests can be a source of weakness. Morgan (1997: 14) asserts that the researcher creates and directs the group, so there is always some residual uncertainty about the accuracy of what the participants say. In particular, there is a very real concern that the moderator, in the name of maintaining the interview's focus, will influence the group's interactions.

Recruiting the participants

The research involves analysing the data from two focus groups of NASC workers and interviews with six consumers who had experienced the NASC service. The purpose of the workers' groups was to collect data on their understanding of the knowledge base and the skills for the role which had been outlined in the Health and Disability Act (1993). The

purpose of interviewing consumers was two fold: one was to gain insight into what they thought the skill base should be and in what areas they thought training was required and the second, was to seek some feedback in relation to what skills they *experienced* in receiving the service of assessors and service coordinators.

Stewart and Shamdasani (1990) assert that two critical elements in successful focus group research are the recruitment of participants and the design of the interview guide. The interview guide establishes the agenda for the discussion of the group. The nature of the discussion is determined in large measure by the composition of the group and the interaction that ensues among its members. Thus the development of the interview guide and the selection of group members may, in one sense, be viewed as the construction of the research instrument (Stewart & Shamdasani, 1990:51).

There are a number of ways to recruit focus group participants. Krueger (1994:94-6) makes a number of suggestions:

- Random telephone screening: participants are randomly selected from a telephone directory.
- Snowball: participants are asked to bring a friend to the discussion.
- Piggyback: participants suggest others who meet the characteristics for focus groups.
- Existing lists: lists of people, such as consumers of health services, are used.
- On the spot: people using a particular service are invited to participate.

As my research involved a discrete service I was able to focus on a particular target group within a health service. However, organising the groups proved to be more difficult than I had envisaged. Despite the fact that I had done a scoping exercise at the end of 2000, when it came to the time to actually set the groups up one organisation, which had previously given me permission to gain access to their workers, found itself in a very busy and difficult period and clearly engaging in a focus group was too hard for the workers. Consequently, quite unexpectedly, I found myself having to quickly find another group that was similar in makeup and willing to be contacted. There were differences too in the

homogeneity of the groups. One group was employed by a District Health Board and was the easiest to set up for a number of reasons. They were a 'natural' group, in that they regarded themselves as a team, had a team leader, saw each other on a daily basis and were therefore well known to each other. They also all held the dual roles of needs assessor and service coordinator. I had a prior professional relationship with the manager who had always held an interest in the topic I was pursuing; she allowed me to broadcast my intent at a staff meeting. In this group, also, there was a strong culture of commitment to professional development, and the intended focus group was presented in this light.

The second group of workers presented some difficulties in the setting–up phase. This group could be described as a 'constructed' group, although they had some features of a 'natural' group. While they were all contracted to the same organisation to carry out their function, they were actually employed by a number of different organisations. Two of them were independent workers, while three were employed by either not-for-profit or statutory health organisations. While they all knew each other, they did not necessarily work from the same, shared professional cultural background, and in this group the roles were separate – some were needs assessors and some were service coordinators. Because this group was operating outside the Auckland area I did not have a relationship with them and, in fact, the request for people for the group was organised through their manager with whom I had a phone conversation. Consequently, it took longer to obtain names, and the physical setting up of the group was largely done via email and fax. Because I was not known in the area I found there was difficulty in getting a quorum for the group. However for those who did come, (five) there was a sense that they were very committed to their own professional development and training.

Focus groups have traditionally been composed of people who do not know each other – for years it was considered ideal if participants were complete strangers (Krueger, 1994:18). While this has recently been regarded as being unnecessary and impractical, Krueger cautions researchers about using close friends, relatives, or work groups who know each other well. People who interact regularly, either socially or at work, can present special difficulties for the focus group discussion because they may be responding more on

past experiences, events, or discussions than on the immediate topic of concern. Moreover, familiarity may tend to inhibit disclosure. The fact that the participants in my groups knew each other reasonably well seemed to encourage participation rather than inhibit it. In one group in particular, there appeared to be considerable accord amongst the members, and discussion flowed freely. In this group I did notice, however, that because they were so familiar with each other's work, it was easy for them to slide into related areas, and I sometimes had to work hard to get them to stay on the topic presented. In the other group, I did sense a certain tension among some members of the group which may have led to some reticence.

A related, yet equally important issue is the familiarity between the interviewer and the participants. If the interviewer is readily identified with the organisation or for that matter identified with any controversial issue within their community, the quality of the results could be jeopardized (Krueger, 1994:18). While I believe my anonymity made the selecting of participants more difficult, I did feel that my distance from the organisations concerned, allowed discussion to flow more freely.

In general there should be about six to ten participants in one focus group session, but some sessions may have up to twelve people (Morgan 1997; Stewart and Shamdasani, 1990). Dawson and others (1993) point out that focus groups work well with four to twelve people. Generally these numbers are based on the argument that if the number is less than six and if the participants have a low level of involvement with the issue, it may be difficult to generate interest and maintain an active discussion and hence one or two may try to dominate the discussion. The information gained may not be adequate or rich enough since there are fewer people to interact. On the other hand, a group of more than eight may be difficult to manage. Some participants may find it difficult to talk in a big group where everyone else is trying to talk. Others may have to wait a long time for their turn and hence may lose interest before their turn finally comes.

I discovered that gaining access to a community and recruiting participants does not guarantee that they will attend focus group sessions. There are other circumstances that

may prevent attendance, for example emergencies, illness, or transportation problems. The best way to avoid this is to over recruit for each session. I had the sense when recruiting for the focus groups that I was fighting against the participants' heavy workloads, and even gaining what I saw as a reasonable number was quite difficult. For the Auckland group I managed to recruit seven willing participants quite quickly, however on the day, only five were able to attend. One was committed to another meeting, and another decided not to proceed with her participation in the group. For the Waikato group, I managed to recruit only five people after considerable effort, however all turned up on the day.

Incentives

I decided that providing incentives was an important part of the process. I was aware of the busy schedule of the participants and felt the need to acknowledge this in some way. While in market research participants are paid, in health research there are debates about this (Rice & Ezzy, 2000:84). Some researchers argue that payments are necessary if the researcher needs to recruit those who are 'hard to find' because of their busy schedules. Other researchers argue that payments should also be made to low income people who may need the money for their survival. The NASC workers' groups were both held in work time, so payment was not considered.

For one group I organised a meeting over breakfast. This was the easiest time of day to gather the participants together, and went some way to make up for the early start to the day. For both groups some form of refreshment was offered. People tend to feel more relaxed if they have the chance to eat and drink together; this also allowed me to show that I valued their time and commitment to the group. Stewart and Shamdasani (1990) warn us, as researchers, that we need to be sensitive to the sacrifice that participants make for our research. The incentives they receive mean little compared with the effort they have to make to meet our requirements. This has to be remembered when planning focus groups:

> Researcher arrogance may be the single most important factor in the failure of a focus group: participants are doing the researcher, and his or her sponsors a favour, regardless of the compensation and other incentives provided.

(Stewart and Shamdasani, 1990:59)

On the basis of this, I did elect to pay the consumers. There were a number of reasons for this, not the least of which were to do with the above sentiments, that we, as researchers, often ask disabled people to give us their opinions without thinking of the efforts they may have to go to. In an article written in 1992, Michael Oliver argues, as feminists have done before him, that the research being done on disabled people was an alienating process, as disabled people's voices were not being heard. Oliver quotes Rowan in describing research that is done that does not take into account the position of the person being researched. Rowan states that research:

> ... treats peoples as fragments. This is usually done by putting a person into the role of 'research subject' and only then permitting a very restricted range of behaviour to be counted. This is alienating because it is using the person for someone else's ends – the person's actions do not belong to that individual, but to the researcher and the research plan.
>
> (Rowan, 1981:93 in Oliver, 1996:140)

This leads us to another challenge that disability theorists have placed before researchers and that is that there needs to be some ethical considerations when doing research. Questions need to be asked as to who benefits from the research. Routine studies of disadvantaged groups may be undertaken with noble intentions but their ultimate effect may be better social management and control rather than increased power and emancipation. I was mindful of these assertions when I was trying to form the consumer group, as they may see no direct benefit from the research.

Consumer interviewing

Interviewing a consumer population turned out to be the most difficult part of the actual fieldwork. Originally I had intended to use a similar focus group approach as I had with the workers. However, finding willing participants proved to be a big hurdle. As I had no personal or professional relationship with disabled consumers, I discovered my advertising

efforts met with no reward. As time became a constraint, I rang a local organisation that provided NASC services to the adult sector of the disability community and asked them for permission to gain access to a random number of their clients from their database. They agreed to contact and pass on the names of 10-12 clients, who would form the base of my focus group.

Interestingly there was obvious reluctance to be involved in this research as was evident from the difficulty they had in getting any agreement. Over a two-day period they contacted 45 of their client base for a total of 8 who agreed in principle to take part. The worker involved in collecting the names was positive and encouraging in her approach but many of the client base were wary of the commitment involved and felt that they had nothing of importance to say about their experiences. Perhaps also the distance of the researcher from those being researched impacted on their decision. Because I was unknown in their world I may have been perceived as an 'expert' imposing my ideas on their world. This position of the 'expert' has been commented on by others. Oliver (1992), states that traditional social relations of research has cast the researcher as the holder of specialized knowledge and skills who decides on research topics and controls the research project. Stone & Priestley (1996) consider that if researchers present as experts, it implies that the knowledge and experience of disabled people do not count.

As I rang each of them individually to arrange a meeting, it became clear that a focus group was not going to be possible as the range of impairments in the group meant that it was too hard for most of them to get out without incurring great discomfort and cost to themselves. I decided very quickly to engage in individual interviews, which met with agreement from all eight. Prior to the interviews taking place two dropped out, one for personal reasons, and the other because he had totally misunderstood the purpose of the research and no longer wished to be involved.

Individual interviews

An in-depth interview is like a half of a very good conversation when we are listening. The focus is on the 'other person's *own* meaning contexts' (Schutz 1967:113). Good

interviewing is achieved not only through technique and method, but also out of a fascination with how other people make their lives meaningful and worthwhile. 'The hardest work for most interviewers is to keep quiet and to listen actively' (Seidman 1991:56). Listening can be divided into two main tasks. First, the interviewer must listen to the content of what is being said. Second, the interviewer must be aware of the process of the interview as well as the content (Seidman, 1991). Questions about process include: What topics on the interview schedule are yet to be covered? How much time is left? How tired do they feel? The consideration of time became an issue for me when I ran out of time for one interview because I needed to catch a ferry back to Auckland! This was a salutary lesson in keeping an eye on the watch and not becoming too engrossed in the content of the interview.

The interviews with the consumers were tape-recorded. Tape recorders have many advantages (Taylor and Bogdan 1998). They provide a level of detail and accuracy not obtainable from memory or by taking notes. They also allow for greater eye contact than is possible if the interviewer is taking notes. However, tape-recorded interviews are costly, both in terms of equipment and transcribing. The mechanics of the tape recorder are crucial as well. Rice and Ezzy (2000), suggest that it is an advantage if the tape recorder has a clear 'on' light that indicates battery level. I lost my last interview because I did not realize that a battery had run out in the microphone, consequently losing the entire conversation. Checking the equipment prior to arriving at the appointment (and carrying spare batteries) became a costly lesson for me.

Questions in the individual interviews were open-ended. The questions established the topic to be discussed, but I tried not to influence the response. The participants were encouraged to talk about their experiences in their own terms. Questions that were avoided were those that appeared to be a test of knowledge (Morse and Field, 1995). Three of my participants were in their early sixties and, despite my best efforts, these were the ones who felt that the interview was some sort of test even though these were also the participants who were most eager to be involved. This arose when I mentioned the term Needs Assessor or Service Coordinator. They were not familiar with either term, and immediately

felt they were not able to be helpful. It was a lesson to me to not use language unfamiliar to the participants as it instantly had a distancing effect (Tagg, 1985). I also tried to avoid questions that asked participants to rely on their memory. They are less likely to remember things if they are specifically asked to remember (Rice & Ezzy, 2000). As far as possible, questions were asked using the participant's own language. Taylor and Bogdan (1998:99) point out that 'in-depth interviewing requires an ability to relate to others on their own terms'.

Ethical issues

There were specific ethical issues to acknowledge and consider in formulating and conducting this research, some of which have already been discussed in this chapter surrounding the research of disabled people. These issues were thought out and considered in the proposal put forward to the Massey University Human Ethics Committee. Other issues included the nature of participant recruitment; ensuring anonymity and confidentiality; and acquiring informed consent. These factors are pertinent because of the inevitable intrusion into people's lives that qualitative research brings. Nevertheless this intrusion must be minimised, while still allowing the researcher to have access to the information required. This section will outline the ethical steps and considerations noted throughout the research process in conjunction with the methodological tool of focus groups.

The initial contact with the potential group members was made by the managers concerned, and only when the NASC workers themselves agreed were their names passed on to me. At that point I sent them an information sheet, a consent form and a covering letter informing them of the purpose of the research. At the beginning of the focus groups I reminded them of the right to withdraw from the research at any stage and the process that would happen following the group. Consent to record the interviews was gained before the groups began. Issues of anonymity and confidentiality were not considered primary issues as the workers were known to each other and the information shared was not of a personal nature. However, in terms of the thesis and any other publications related to it, anonymity

and confidentiality were assured through the used of pseudonyms and any identification of their work base deleted.

Consent from the six consumers was initially gained by the organisation which I had contacted. Once agreement was gained, I also sent these participants an information sheet, a consent form and a letter informing them of the purpose of the research. At the interview appointment I reassured them of anonymity, asked verbally for consent to record the interview, and reminded them of the process following the interview. I also informed them that their tape would be destroyed following the completion of the research.

Research issues

The worker focus groups turned out to be easier to organize than I anticipated, possibly because I was already known in one area and was received collegially in the other. But when it came to the consumer group I failed to anticipate the difficulties that emerged. As I had no reputation or credibility in the area of disability I found it very difficult to begin the process and, therefore, this part of the research was completed very late. One of the lessons I have learned in this process is to make contact with the researched community early so that relationships and understandings can be established and worked through. In this way I might have avoided some of the problems that occurred.

Conclusion

In this chapter I have outlined the construction and operation of the focus groups and individual interviews, the methodological tools used for this research. I have detailed the setting up of the groups and the consumer interviews, the difficulties encountered, and how these were resolved. I have also examined ethical dilemmas that I may have encountered, and how I resolved these to minimize their impact on the research outcomes. There are a number of potential areas of concern when conducting research, from the development of the research question through to the evaluation of the outcomes. Detailing the significance of setting up and running focus groups provides others with clear examples of the methodology in action and assists in their understanding of potential limitations, thus improving the construction of methodological procedures in the future. The setting up of

the individual interviews and the difficulties encountered is a reminder to me of the minimal understanding I had as an able-bodied researcher undertaking research in the disability community. It is possible that had I begun the process of establishing a relationship earlier I may have engaged with a more representative group in respect of age and ideas.

Chapter 6 - Research findings: Needs Assessment and Service Coordination

As outlined in Chapter 2, the data collected for this research has been organized into five themes for analysis. These reflect, in general, the themes of the legislation. They are: needs assessment; service coordination; separating the assessment function from the function of provision of services, user participation and professional knowledge base. These themes encapsulate the data collected from the focus group interviews and the individual interviews held with the consumers.

A large amount of the data analysed is dedicated to the experiences of the NASC workers, as these findings represent the experiences of the practitioners, and most appropriately illustrate some of the key issues. Having said this, NASC workers would not have jobs without the existence of the disability community, and it is the views of the consumers that inform the skills of the workers. This research is really only useful if seen in light of what benefits can be gained by disabled people.

Skills of needs assessment

According to the National Service Specification (February 2001) the role of the assessment facilitator is to work with the client to identify his/her prioritised needs arising from their impairment and to refer to appropriate specialised assessment services. Part of their role may also include making recommendations on how specific needs of the individual can be met (e.g. communication support, mobility assistance), and providing advice on how support services can assist in furthering the rehabilitation process.

The Health and Disability Act states that the assessment is to be a participatory process. This necessarily involves trust and understanding if meaningful information is to be obtained. In order to gain that trust, workers must be able to build positive relationships within a short space of time. Literature in this area, (Trevithick, 2000; Milner and O'Byrne, 1998; Nolan et al, 2001) agree that the skills of rapport building, active listening and questioning skills are essential ingredients to making a successful assessment.

a) Rapport building

According to the professionals and the clients, building the relationship is the most important part of the interview process. Creating an atmosphere of trust where clients can feel at ease in telling their stories is the beginning point of the relationship and all the workers I interviewed recognise this as critical to the success of the assessment.

For the worker, it is important to build a sense of confidence in their clients so that they feel safe to disclose personal information. This is particularly important for those workers where the function of assessment was separated from coordinating services. Often they saw their clients for a single visit only. Therefore, obtaining a complete picture that accurately reflected the issues of the client and their family was important. As I succinctly put it:

> The first 15 minutes is establishing the rapport, and if you don't do that you're on the back foot. If you don't do that you may as well give up because they're not going to be forthcoming. You can still do an assessment but they won't be forthcoming with the information. (I)

For those workers whose functions were combined, rapport building was not only about building a trusting relationship but also ensuring that the client felt sufficiently comfortable with the worker to contact them if 'things were not working for them'. There was not quite the same sense that they only had one opportunity to ensure their success:

> Building rapport means firstly being available, listening to everything that is important to them, ensuring that they feel comfortable enough to contact you should things not be working...I often say to new (and existing) clients that I am happy to review services at any time, that it has to be right for them, that I am happy to review and alter plans three times in one week if that is what they require. (G)

From the client's perspective, the most important aspect was the approach of the worker. Clients needed to feel at ease, that what they had to say was treated with respect and considered to be important, and that the worker did not convey any judgement about the client's needs. More than once I heard consumers say that they had been made to feel like they were 'bludging' in other situations, and that being assessed was like 'passing a test'. Therefore, being reassured that their situation was regarded as genuine was considered an important part of the rapport building process:

> She was very friendly and very helpful. I felt she was interested. In fact, she left me with a very good impression. It's important to me that they don't make me feel that I'm 'bludging' as I've had an instance of that. (L)

> You're a bit nervous when they come. It's important that they put you at your ease and chat to you, because you feel like you have to justify what you need. It's a bit of a test, I think. (L)

Both NASC professionals and clients talked about other qualities that they saw as being part of relationship building. Qualities such as honesty, integrity and timeliness were considered to be absolutely essential ingredients in any contact with clients and, indeed, the ones on which relationships of trust were founded. Clients also found that it helped if workers had an understanding of people with disabilities, that this aspect helped clients feel more relaxed, and that workers had empathy with their situation. As these workers commented:

> It's about being honest, and saying, 'Look I don't know about this, I'm going to have to go away and talk to people about this. And not setting up unrealistic expectations. (I)

> Absolute integrity, if you don't know something you're not hiding behind a screen of omnipotence. You're actually being totally, totally honest, and if something's not available, you don't pretend that it's available. Timing is

> important, if you say that you'll call tomorrow then call tomorrow. It's just what you would expect if you were sitting in their position. (G)

And from a client perspective:

> It's important that they have some empathy, some understanding of people with disabilities. Also that they take the time to show the common courtesies, being respectful and patient. (N)

Establishing a rapport involves creating a climate where the interviewee can begin to gain confidence in the worker's personal and professional integrity. This is important because it creates the favourable conditions necessary for people to be able to discuss and reveal problems or difficulties, successes or failures, and strengths and weaknesses in ways that aid understanding and allow for a realistic plan of action to be created (Trevithick 2000:76).

b) Listening skills

All the participants emphasised the importance of good communication skills as being essential to doing a 'good' assessment, particularly listening skills. Different authors stress different aspects of the listening process. For Egan, *active listening* is about the other person being 'present psychologically, socially and emotionally' (1990: 11). Thus, active listening describes a special and demanding alertness on the part of the listener (Lishman, 1991:63), where the aim is to listen closely to the details of what is being conveyed and to ensure that the client is aware that this is happening. *Non-selective listening,* sometimes called non-directive listening is where listening occurs at several levels: to what people say, how they say it; at what point they say certain things, whether certain themes recur and also to what people do not say. This is sometimes described as 'listening with the third ear'. This form of listening allows us to be sensitive to the wider social and cultural context from which an individual speaks. This theme emerged consistently in the focus groups with the professionals:

> Telling their story is a huge part. I have fairly long calls with some, and I hear about the Chihuahua and the cows in the paddock, the family and the government and it's important to them, it's what's going on in their life. (F)

While some of the listening involves hearing a lot of extraneous information, the skill lies in listening to the feeling that lies behind the words, the listening with 'the third ear'. One worker mentioned also the necessity of a cultural match, so that the ability to accurately interpret what was being said was not being lost:

> So much of it comes back to good listening skills, and to listening to what's going on behind the words, going in and observing and being able to read that. (I)

> It's important to have a good listening ear; not only to listen to things that they say, but also to draw them out...Cultural appropriateness is really important too. (K)

For those NASCs whose functions are separate, the ability of the assessor to use their listening skills is particularly critical. For the service coordinator receiving the assessment, they need a complete picture so that they too can gain a useful and accurate appraisal of the client/whanau's situation. The service coordinator does not have the benefit of interviewing the client face to face but is limited to telephone contact. Therefore, the assessor's listening skills are vital to commit the assessment to paper:

> I can tell when you get assessments and they are not listening, and you just know that they've gone in with that focus in mind that they know what the outcome will be, like home help or personal cares without anything else in between. So you have to, as a coordinator, pick out what's not there, you have to dig a bit deeper. And I feel disadvantaged by that, and I think the client's disadvantaged. (G)

c) Judgement

Central to the assessment and decision-making process is forming judgments. However, forming judgments is sometimes confused with being judgmental: that is being critical or oppressive, or holding prejudicial or stereotypical views:

> There is a very important distinction however, between 'making a judgement' and 'being judgmental'. Social workers must face the challenge and responsibility of the former in order to be helpful; they must avoid the prejudice, closed-mindedness and blaming implicit in the latter. The avoidance of making a moral judgement remains in itself a moral judgement.
>
> (Milner and Byrne 1998:165)

The NASC workers agreed that in making an assessment it was important to distinguish between making a judgment and being judgmental. Holding different values can be acknowledged as long as clients are not judged by them, as is evidenced in this comment:

> Your values might be very different from someone else's, and you can't jump in there and impose that on people. (I)

Making a professional judgement in an assessment is based on the framework of the profession that we come from, and the workers acknowledge this. For example, I found that nurses tend to see independence as an ability to undertake self-care, whereas social workers see independence more as a client's ability to make his or her own decisions around issues such as safety in the home, and where they want to be. Nursing models such as Orem's self-care deficit theory of nursing and Roy's adaptation model reflect this way of thinking (Chinn & Kramer, 1991). B had this to say when she began her work as a needs assessor:

> One of the things I found I really struggled with at the beginning is letting people live how they wanted to. Coming from the profession that I do [*nursing*]

> you want the very best for that person, and I did struggle with that for the first few months, actually going out and seeing clients living in a mess and wanting to make it better for that client. Now if a situation isn't ideal, sometimes it takes a crisis for a situation to fall down, and the person to realize that they need that help. I guess that's come from peer reviewing a lot with people from other backgrounds, and them saying that it's OK for people to be living like that. (B)

Social workers, on the other hand, tend to see independence as a person's ability to make decisions for themselves regardless of what opinions are held by friends and relatives:

> It's also working with families' judgements as well. Sometimes a person's choice is to not shower at all or eat bread and butter three times a day, and it's working with them to accept that yes maybe they would like their family member in a rest home receiving three square meals a day and a shower every morning, but maybe it's OK. Maybe it's not a major risk to them and it allows them to have other qualities, so it's really working with them to get them to accept that. (D)

If an assessment is made where the worker's professional judgement is not acceptable to the client then it becomes important to work at the client's pace. Keeping the relationship alive and continuing to build the trust is important for clients to be able to accept a level of intervention that may necessitate a compromise of their independence:

> Sometimes it takes three or four contacts with that person to accept some showering for instance. You know they're unsafe. The family knows they're unsafe. But you can't just go in there and say, 'How about it?' They refuse it. And just chipping away, just ringing every so often to ask how it's going, it's the rapport building, and it's the skill of not being forceful, just walking alongside somebody, until they get to the level that they are ready to accept. (A)

This raises an interesting question as to whose needs are being served. Health professionals not only act with good intentions, but are also actually employed to make judgments around client care. Ensuring that the client is 'safe' is an important part of the work, and needs client understanding and agreement. The process of making a professional judgement here has been carried out with the best intentions of creating a better situation for the client. However, at the end of the day it creates a double-edged situation for the worker who uses her expertise to engage the client in safe decision making but, at the same time, the client can be left feeling disempowered. That 'professionals know best' is a very powerful paradigm. Despite workers' efforts to work in an empowering manner, it is sometimes necessary to 'gently persuade' clients that another more realistic decision has to be made.

d) Questioning skills

A further common theme to emerge from the focus groups was the skill in asking the right question in the right way. Participants stated that the way they asked questions helped to determine the worker as a collaborator rather than as an 'expert'. Clients are usually the experts on their own situation and workers can make a serious mistake when their knowledge is subjugated to official views. It is very easy for professionals to ask clients questions in such a way that they become, in Foucault's words, 'the judges of normality'. Power relations within individual relationships with clients will be set with the style of questioning used by the worker. To reduce the power difference, the worker needs to use language and a questioning style that is going to engage the client in their own story and identify their own self knowledge, rather than responding to a number of questions that subjugates the client's world to the worker's expert knowledge and world view. T summarised the feelings of one group:

> A lot of older people can't lead an assessment as perhaps a family could, but what it comes down to is listening skills and asking the right questions, and that person feeling comfortable to expand on those. That creates the big picture. If you asked an older person, 'What are your goals?' they would probably look at

> you and think, 'What is this new jargon!' But if you ask it in the right way, 'what do you want in order to remain at home? What do you feel you need from me in order to make things happen for you?' So it's the way in which you put that across, and to empower that person to make those decisions for themselves. (A)

The questions here are based on a strengths perspective which are solution focused (Saleeby, 1992). In this style of questioning, clients are more likely to feel that they are participating in a discussion where they are the central concern, and are offering valuable insights and information, rather than just responding to a series of questions from a health professional and, thereby, participating in professional decision-making. Asking strengths based questions is more likely to lead to the emotion behind the question, and thus inform the worker more accurately of the whole situation.

Different authors highlight the qualities that practitioners need to demonstrate in order to frame questions in ways that are helpful, illuminating and empathic (Lishman 1994:24-5; Seden 1999:30; Nelson-Jones 2000: 183). Most stress that before asking a question we must be interested in the answer. This goes back to the point made earlier about active listening. Most people intuitively know whether they are being listened to and whether their thoughts and feelings are being given the importance they deserve:

> And often it's the type of questions that lead to another, 'Do you shower independently, do you feel safe when you're showering?' It comes down to asking the right questions, and making the client feel comfortable answering those questions, and that's the key, really. It's about being able to observe [*what's happening*] and being able to read that accurately. (E)

Emphasising and orienting the work of helping around clients' strengths can help avoid 'blaming the victim' (Ryan, 1976). This tends to happen when the problem is

determined within the individual while ignoring elements in the environment and how the individual has managed to survive.

e) Writing skills

Clarity of writing and accurate recording skills are considered to be an important part of a health professional's skill base, and an area that was particularly commented on by managers. Much of what is written is used by other health workers to inform their assessments, therefore their accuracy is crucial to clients' lives. Good writing skills were identified particularly by the under 65 group where the assessment and coordination functions are carried out by different people. The Service Coordinators did not visit families to carry out their function but coordinated the required services by telephone. Not surprisingly, therefore, they relied on an accurate and well-painted picture from the assessment, as the following comments illustrate:

> It's really important for an assessor to have good writing skills, to be able to put what they see, what they know, what they feel, all that stuff on a form. That can be very, very difficult for assessors, and it has to be done in a way that the client is comfortable with because they read this. So if you're trying to tell the service coordinator that, actually, this family is absolutely dysfunctional, like Dad's over here and Mum's here, you need to be able to write that down, because it's all got to be recorded, and in language that is acceptable to everyone. (G)

A copy of the assessment document is given to the client/family before they leave. Therefore, what is written on the document must be in an acceptable form for the family to read. This is somewhat different to how health professionals have been used to recording in the past. Previously, they have been able to write their observations in files that have rarely been read by clients and, therefore, subjective observations have been allowed to surface that have gone unchallenged. In this environment, the skill is in recording accurately what the situation is for the client/whanau while at the same time trying to convey to the service coordinator some of the issues that may be involved. At all times this requires the collaboration of the

client being interviewed, and consequently prevents much of the professional subjective opinion being committed to paper. Interestingly, the importance of writing skills was brought up by service coordinators rather than by the assessors. Their comments were that they could tell a good assessment that was client-driven, rather than assessor-driven, by the detail that was in it:

> As a service coordinator, I can tell when an assessment has been done by an assessor who has listened and gathered the information the client has offered compared to an assessment which has been driven by an assessor. And I can tell every time. The one that is driven by the client has all the little things about the client's life that's important to them. You know, it might talk about family pets or the relationship with the neighbour, or those sorts of things, that obviously the client has shared with the assessor that have been important to them. Whereas, an assessment that has been driven by the assessor, those [*sorts of*] things aren't important to the assessor. What's important to the assessor is 'Do they need help with a shower, or can they vacuum their floors, and are they well, or are they not well'. (F)

> You know a good assessor, because you get a real flavour, it's almost like you've been in there yourself; you get a real feel and flavour. It may not be just in the words, but you get that real picture and feel about it. (G)

Language, too, is important. An assessor needs to have a reasonable command of English as well as an ability to be specific and unambiguous, so that the service coordinator has a grasp of what sort of services the client might require:

> An ideal assessment contains the whole picture, and the language that's used is comprehensive. Sometimes I struggle when assessors say 'they mostly' or 'they almost' or 'occasionally' they can make a sandwich. So does that mean four times a day or once a week? So it's knowing that I've got the whole picture.

> The assessor's been in, the client's told their story and their whole story is there and it's in a language that isn't open to too much interpretation. (G)

Equally, the assessors used the actual writing up of the interview as a means of ensuring that the client or family was engaged equally in the assessment process. One talked of sitting beside the client, and actively asking her of how to best express things:

> Sometimes you can say (to the client) 'how can I write that down, how do you want me to write that down', and they will give you the words themselves. (I)

Engaging clients in recording their information is another way of ensuring client cooperation and collaboration in the assessment process. According to the NASCs working with older people, many of their clients choose not to be so actively involved. But for younger adults, the process is an important part of retaining control of the decisions in their lives.

f) Conducting a needs-led assessment

The assessment tool is an analytical process that provides a basis for planning what needs to be done to maintain or improve a person's situation, and involves gathering and interpreting information in order to understand the person and their circumstances. The assessment is based on the person's need and, in the past, disabled people have claimed that they have been analysed in terms of their impairment in assessments with the purpose and the outcome being defined by the assessor rather than the disabled person. Similarly, when a referral arrives with a request for a specific service, there is a danger of accepting this and focusing on the outcome, which may also include the desired outcome for the client.

Part of the tension of this role is indeed managing the tendency to assess against services which the assessor knows are already in existence and not steering clients away from their own perceived needs. Both groups mentioned the fact that many

referrals came to them with a specific request, such as carer support or home help, and they had to be clear that a holistic assessment followed not one that was resource-led. The following comments demonstrate this issue:

> The assessor might get a referral that says, 'please assess for carer support', and so there is already an outcome focus. Now, a skilled assessor will not take that outcome into their assessment process, but an unskilled one will. (G)

> I would have to say that probably 8 out of the 10 referrals come through as basic home help. For example, I went to one yesterday for a lady just to do home help and ended up assessing the husband at the same time, because she was just totally...He was wandering at night, she was worn out, and I've ended up doing the assessment on the two of them, referred to the dietitian, the geriatrician for both of them. So even though the referral was just for home help, when I got there she said 'I just need someone to do the vacuuming'. But as we went through there was all this stuff about, [*how*] she's getting up three or four times a night with husband, he's falling, he's had bruises, she's exhausted and she's not eating because she's so tired. And it just went on, so I ended up doing it on the both of them. And that came through as a basic home help referral, just not managing the vacuuming. (D)

A request for a simple assessment for home help resulted in a complex assessment for this couple based on actual need. Participants in the group working with older people reported how much of their role was based around giving information, that older people often struggled on without knowing what help was available in the community.

For this age group too, the distinction between 'need' and 'want' was less clear and perhaps the distinction was more of a reflection of the services offered than an identification of actual need. Existing services do not necessarily respond to those

who are at home and lonely. Unmet need is often redefined as a 'want' when services are not developed to respond to the actual need, perhaps because of the cost involved:

> Needs and wants have to be separate. You go in and you'd love to have night cares every night, but it's just not a reality. (A)

> Some of the wants are families having expectations that we can provide someone to pop in to see that Mum or Dad are OK seven days a week. But we don't have a budget for that. We don't have a monitoring service unfortunately. And it's often quite different to what the needs are when we go out and do the assessment. (E)

The focus group involved with older people stated that managing the distinction between family anxiety and actual need was a significant part of the assessment process. In these situations the family often speaks for the client and it is an important function of the assessor to create a space for the client to be able to speak for her/himself. One participant spoke about the reduced world of the client; that they don't wish to engage with new and different people and that loneliness is, perhaps, defined by the family or by the assessor, rather than the client:

> I had a phone call the other day and they were wanting someone to sit with Mum for four hours a day to see that she was all right. That was the family's expectation but at the end of the day we just couldn't do that so we'll do an assessment to see what the actual needs are and why that person's needing four hours drop-in service every day, when we could put in, say, equipment or get an O.T. out and see what the needs are. And often the person wouldn't want that – someone invading their space for four hours a day – but it meets the family's need and takes the responsibility away from them. Perhaps getting a personal alarm will give them peace of mind, or may be accessing a neighbour, so it's a matter of separating the need from the expectation. (D)

There are two separate issues here. The first is separating the client need from the family need. The reduced world of the frail older person can produce an anxiety within families, who often want to provide company for their parent/relative because they are unable to be there themselves, usually due to work commitments. However frail older people may be unwilling to engage in new relationships and the worker's skill requires separating the need of the client from the anxiety of the family. Loneliness is sometimes a concept defined by families rather than the client him/herself:

> By the time you are 85 and frail, you actually haven't got what I term the 'social energy' any more. You haven't got the energy to invest in new relationships and, because of either physical or mental frailty, they can no longer go to the groups they've gone to before. They drop out and they haven't got what is necessary to form a new relationship. (E)

There is also another issue at stake. Sometimes it is possible that a need becomes an expectation because the need cannot be met from existing services. This does not make it any less of a need, but is one that must be identified as a gap in service delivery yet to be addressed. The worker must be careful not to redefine the expressed need as an expectation if s/he is frustrated in his or her ability to source a provider of the required service.

Conclusion

There was a general agreement among the practitioners of both groups and managers concerning the skills required for this role. Overall it is the ability to engage appropriately and meaningfully with a client that is important. Managers, in particular, emphasised the need for NASC workers to be mature, that is to bring with them a sound practice base from which to operate, and acute observation skills.

The range of activities involved in carrying out an assessment includes the relationship building processes already described above. For the client, 'telling their story' is clearly

part of the rapport building process, and in this type of assessment this form of narrative is regarded as a helpful way to understand how service users see their lives and the difficulties they have encountered. 'People live stories, and in the telling of them reaffirm them, modify them, and create new ones' (Clandinin and Connelly 1994:415). What is attractive about this intervention is its 'client-centredness' and the fact that people often greatly appreciate the opportunity to describe themselves in this unhurried way. It is part of what makes the assessment a collaborative approach.

The practice evident here, is guided first and foremost by a profound awareness of, and respect for, clients' positive attributes and abilities, resources and aspirations. Practitioners must be genuinely interested in, and respectful of, clients' accounts and narratives, the interpretive slants they take on their own lives. Clients want to know that workers actually care about them, that what they do makes a real difference to them, that they will be respected no matter what their history. It is the quality of that relationship that creates a successful assessment process.

The skills of service coordination

This section will examine the skills required for the role of service coordinator. This role has been separated from the assessment role, in order that the assessment is carried out according to actual need rather than being 'contaminated' by the knowledge of what services exist and being assessed against these constraints. The skill base for this role is concentrated around negotiating and planning a care plan both with the client and with the provider. While the skills involve the ability to build respectful relationships with clients, the emphasis within this part of the role is on the worker's ability to plan, negotiate, and, in some cases, mediate, between client and provider in order to supply the best package of care. This also requires a sound knowledge of community resources.

According to the National Service Specification the role of the Service Coordinator is to:

> Identify, plan and review the package of services required to meet the prioritized assessed needs and goals of the client and, where appropriate, their family/whanau

and carers. Service coordination will also determine which of those needs can be met by government funded and other services, and will explore all options and linkages for addressing prioritized needs and goals.

Service coordinators work within budget restraints, and in their work a tension exists, particularly where demand for resources exceeds supply or where the need exists yet services do not. Because of this the Service Coordinators that I interviewed found that their skill base was often quite different from assessors as they focused more on managing client expectation, negotiating packages of care with providers, and managing conflict and anger. The differences in the skills required were more clearly enunciated by those service coordinators whose functions were separate from the assessment process. They emphasised the necessity of having knowledge of the resources available in the community and being able to negotiate packages of care with clients that were flexible and sometimes involved compromise because particular services were just not available.

a) Negotiation

Negotiation is primarily directed at achieving some form of agreement or understanding. In direct work with service users, negotiation skills are the tools that establish the climate of shared decision-making and collaboration that lies at the heart of the concept of partnership. It is through negotiation that we arrive at a common agreement across different parties in terms of how problems are understood and how these might be overcome. Negotiation skills are also important in situations of disagreement (Trevithick, 2000). There may be no obvious way to overcome underlying differences but, where a degree of flexibility and compromise exists, this can be a foundation on which to negotiate an acceptable solution to both parties. Part of the task may involve negotiating a shift in the balance based on an understanding, respect and acceptance of people's perception of events. Service coordinators in particular emphasised the need for good negotiating skills, as they either negotiated packages of care with families or, in a less familiar role, negotiated the range and hours of care from a range of providers. Negotiation involves discussion with other members of the multi-disciplinary team, which means having not only knowledge of

their role and function but also an appreciation of the boundaries of each role to avoid unnecessary conflict:

> You have to have the overall view, it's not just the assessment, it's the providers, the occupational therapists, you've got to be able to talk to the GP, get information, there's a lot of stuff you've got to be able to do that's about negotiation, and you've got to know who the stakeholders are. (J)

It also requires the worker to have sufficient knowledge of the resources in the community and an ability to negotiate with providers an appropriate package of care that responds to the needs of the client. This may require the NASC worker to negotiate with the provider to develop a more flexible and responsive service to their market, as A expresses:

> One of the things I had to learn was balance. To be able to change my mind, to acknowledge that I got things wrong, to learn about empathy not sympathy, and then I had to go and negotiate hardball stuff with the providers, and say 'well no I don't want this I want this' and you had to put another hat on which said, 'well I hold the dollars and if you can't provide it I'll find it somewhere else'. (G)

The group working with older people also identified the importance of being able to work in with other professionals to obtain the best deal for the client and being more directive towards providers than they had previously been used to. They also saw that negotiation skills were key to the service coordinator's function, but at the same time identified that being able to do the assessment as well meant that they had a clear understanding of the sort of services they were attempting to coordinate:

> Having that knowledge in boundaries and working with people, that's really important. And then the rest of your role is called coordination but you're sort of directing everything into all these other areas. There's a huge amount of negotiating and working with a number of other services, and it's having that

> skill to negotiate, and be really directive in a way. But you might have to follow up, so there's a lot of stuff that you have to be really clear and accurate on, and negotiate for and around. (F)

Part of the negotiation skills, is the ability to manage the expectations of clients and their families. This involves being able to distinguish between 'want' and 'need' and requires the skills of judgement discussed earlier:

> Managing expectations has been one of the things I've learnt – certainly you're doing their needs assessment but some of their goals are way off. One of their goals might be to be a policeman, and that's way off, but that's neat to still say that's one of their goals. But there are some needs that are just not going to be met. I will say to people we are not going to be able to meet all your needs but certainly let's get them down on paper, and let's sit and talk about them, and maybe there are other areas people can think about, I mean they can be quite creative too, it's not just your standard carer support or home help, especially with the younger people with disabilities. (I)

b) Knowledge of resources and managing expectations

One consistent theme that emerged from the focus groups was that in order to engage in negotiation, the worker needs to have a sound knowledge of the resources in the community. Coordinating packages of care also requires NASCs to have a thorough knowledge of the resources available within their own health team, which in turn means that they must have a clear understanding of the skill base of their colleagues as well as their boundaries. This ability to work within a wider team is a particularly important function of service coordination, and it relies heavily on interpersonal skills and an ability to communicate the complex care needs of the client:

> Because of having to connect with all these providers, you really have to have good teamwork skills, because you might send a referral, but you often have quite a bit of interaction with your PT or OT, or care providers, so your ability

> to work with a large number of other disciplines is important. It's intensive, there's more interaction than on a ward, you don't just make a referral and get on, you tend to talk to them more, and you have to understand what the other disciplines can provide and support the client with. (D)

> I guess the coordination is really working as part of a multi discipline[*ary team*], because you're taking from other disciplines what you need, to get that person's needs met, and that may be a referral down to social work to sort out some family dynamics, or a referral to OT to look at safety within the environment so I guess it's knowing what networks are out there, and getting the client access to those areas to get those needs met. (E)

What was clear from both groups was the necessity of having good local knowledge, and being able to tap into resources that were not necessarily from mainstream providers. Both groups of professionals emphasised how much time was spent in coordinating the best range of services for clients, while at the same time being mindful of budgetary restraints. This was particularly so in the group working with the under 65s where the demand for specific services sometimes tested the community's ability to deliver:

> It's all a matter of balance; you have to be mindful of what the client wants and the dollars. And local knowledge is important. For example, the other day I thought I had to fund transport and fund some day care, but by ringing around we actually got this amazing day care where the client just pays $2.00, and they get a meal, and day care and picked up...And that was all through local knowledge. (F)

The time and energy involved in mobilising resources is considerable and can require our having to use collaborative, competitive or combative tactics depending on the situation and our response (Coulshed 1991:62-64). Combative skills, (engaging assertively with organisations to provide an appropriate response or resource) are not

generally seen to be part of the skill package that is required of workers in the social services, however they are often particularly important when we are dealing with inequalities in resource provision. Success may depend on workers' ability to withstand rejection and failure. Resilience, determination and the skills of persuasion are the hallmarks of a successful negotiator, as well as a sense of balance. Sometimes workers, as well as clients, need to have realistic goals and like clients, have to accept the disappointment that inevitably arises with gaps in service provision.

c) Budget management

Budget holding is not part of the current NASC role, as all of the money for disability support is held by the Ministry of Health. However, all workers do have a knowledge of the indicative budgets for the flexible funding option offered through the Ministry. This allows NASCs to have some autonomy in arranging creative care packages that are not provided through existing services particularly for clients with complex need. The Ministry also holds this budget, but the workers do have a figure to work to and have to consider the cost of their particular package in relation to the total amount of money available for the given year. This means that workers are acutely aware of the budget restraints and issues of equity and fairness have, to a large extent, replaced the advocacy role.

Most NASCs regarded this aspect as taking on a new skill as the role of advocate so commonly adopted in situations of resource provision is not available to workers in this role. For those workers who held both functions of assessor and service coordinator, there was a particular tension in assessing for need while at the same time knowing that there was a budgetary restraint:

> Our service has an indicative budget for home care, so we are aware of the hours. So we have to understand the concept of managing that there is only a certain resource that's available for everybody. (A)

Another new skill that has taken on importance is the ability to see the bigger picture. In other roles, such as nursing and social work, advocating for the needs of the client is a central concern. However, in the NASC role the skill is in meeting the needs of the client while at the same time taking into consideration the wider needs of the population. Workers must be able to grapple with issues of equity and fairness while still being concerned about their individual client. This requires an understanding of ethics as well as having trust in your colleagues. As G reports:

> Equity is important, but it is a very difficult issue. You really need to be able to understand the resources available and equity issues and all the ethical issues that come up when you're holding indicative budgets, and need to know how to be sure that there's equity in what you do, and that every person in your service, all your colleagues are actually coming from the same point, because otherwise everyone has got a bit of an individual twist to their assessment. (G)

Managers also acknowledged the area of fiscal responsibility as one which required skills that practitioners did not necessarily learn in any courses or bring with them. Internal training increases workers' understanding of their role in relation to budgets and how to work within guidelines. They, too, talked about workers having to have maturity to manage the tension of service coordinator with an overall awareness of costs. As one manager said:

> Increasingly the skill that isn't catered for in any courses is around what is called fiscal responsibility, not only the ability to work with a budget, but the ability to understand the significance of cost of services and link those with human need in a way that actually fits, and hold both the roles of being a professional and being perceived and having to act as a gatekeeper – holding both those at the same time. (P)

For clients, particularly those under 65, budgeting restraints became an issue as well, and they often felt they had to have good negotiation skills as well in order to get

what they needed. While some clients expressed awareness of funding issues in terms of 'health cuts', others were very clear about funding issues that affected them on a personal level. M spoke about how assertive he had to be in order to get what he wanted, and how he felt he had to justify his need because of the expense involved:

> When you're dealing with a funding issue, you feel you have to justify your need. The first time it was nerve-racking because you didn't know the ropes, but this time, it was touch and go whether we were going to get the kitchen, and everyone was saying, 'Well, they won't spend more than $20,000 on any one home, and you're already up to $9,000 with the ramp and the bathroom so it's a bit touch and go. And I said, 'Well, hang on, there's two of us in this place with the same condition. I said, 'Put the application in, I want you to put the application in because otherwise they'll be having to support two of us in care somewhere shortly at this rate. So yes, you do have to justify all the time, but in the end, you stamp your feet and say, 'Hey, hang on this isn't right! (M)

However, for some clients, there is much more scope for participation, as N expresses:

> It's far better for me as a consumer. There's more scope to work with me rather than for me. I'm managing a lot more myself. I find my own care workers, negotiate my own package, and the service just gives me the boundaries. It means I can do my own interviewing, can interview in a safe environment, and can also include my wife in the process. I just have so much more control. (N)

Conclusion

The role of service coordinator provides information to the client concerning different providers, discusses with the client different possibilities, and then negotiates a package of care with providers. This is designed to allow people with disabilities to access appropriate services much more easily and ensures a high level of participation and control. As has been indicated, in some instances consumers themselves manage the budget that has been

allocated to them. This gives them a lot more control over the process of employing carers, and gives them responsibility for meeting *their own needs.*

For other clients, however, it has not been an empowering process. Where the budget is still held in the hands of professionals, and the client is reliant on professionals for their eligibility to services there is still considerable tension, with the consumer still in the position of having to justify his or her need. Whether workers want it or not, they are still regarded as the 'expert'. Their power and their choice, however, is constrained by how much is in the budget and the consumer has limited participation in the decision-making process.

Chapter 7 – Research findings: consumer perceptions and experiences

This chapter continues to examine the data with a focus on consumer participation and how the functions of assessment and service coordination respond to the needs of clients. In the two worker focus groups the role is expressed differently. In the group that works with the older population the functions of assessment and service coordination are carried out by the same person. However in the group that mainly works with the younger disabled population, the functions are separated. This has brought out some interesting differences in the perception of the worker's role, especially in relation to the consumer group they work for.

Consumer participation

Partnership and the principles of participation and 'user involvement' inform current legislation in relation to health and social services. Positive practice must involve service users if it is to achieve agreed objectives (empowerment and personal responsibility) and that within this process service users must be seen not only in terms of the 'problems' they bring, but as 'whole people' and 'full citizens' (Dalrymple and Burke 1995:64). Service users have an important contribution to make in terms of their knowledge and perception of the situation, personal qualities, and problem-solving capabilities.

The Ministry of Health document, *Standards for Needs Assessment for People with Disabilities,* (1994) makes a very clear statement concerning the need for client participation in the assessment process:

> A needs assessment is about 'partnership' between a person with a disability and the assessment service; a partnership which recognizes and respects the person's knowledge and experience of disability. The assessment service will encourage full participation by the person, their caregivers, family/whanau and friends, if the person wishes those people to be involved.
>
> (Ministry of Health, 1994:5)

This represented a fundamental shift in philosophy in relation to assessments. Previously guided by available resources, now the assessment process is to be needs led and guided by a much more participatory process. In saying this, it needs to be recognized that there is a tension between assuring rights-based access to services and making the best use of public funding within budget limits. Pure needs and rights-based approaches do not take account of limited funding and competing demands and this tension is one in particular that the NASC worker has to manage.

In the groups I interviewed there were considerable similarities in approach to the assessment process, despite the different age groups. For the workers involved in assessing those under 65, there was a very clear perception that the process was client-driven. Participants in this group talked about emphasising to the client that the process belonged to them, that what they said was important, and translating what they said to the assessment form needed their collaboration:

> I think in terms of your assessment, working with your client in their home, their needs and their perspective of their lives, it's really important to work with them as to where they want to be and what their needs are. I think some disciplines have an approach of knowing what's best for the person, and it's very much having to accept the person where they are and as they are because it's their choice, and they're entitled to that choice, and I think that's a major part of your assessment is to acknowledge that it's the person's assessment and we're working out with them what's going to be best for them, from their perspective not from our perspective. (J)

Many talked about the importance of being able to hold a conversation with the client and their family rather than ask a series of questions. It was clear that while they were there to gather information for a specific purpose, their role was to participate as a part of a team rather than being viewed as the expert. Being able to engage clients in such a way involves good engagement skills and the ability to put clients/whanau at their ease so that the client's story will unfold naturally:

> You have to keep in mind that it's their assessment, it's not yours, it's their assessment of their perceived needs...And you're gathering that information by talking, rather than by asking a direct question, you're actually gathering information right through...Even just observation too, from when they first open the door, you're observing continually. (H)

Younger clients were also quick to point out the difference in approach. T was appreciative of maintaining control of the interview process. A major difference he pointed out was that he felt that he was given full information rather than having to ask for everything, and that he felt confident about making decisions that affected him based on that information rather than having the decision taken out of his hands. He also pointed out that participation was enhanced if the assessor had a good knowledge of the difficulties that disabled people faced, so that they could have a conversation about it, rather than he having to educate the worker before the conversation could take place. This makes the relationship more equal:

> She let me lead everything. She didn't try and foist anything on to me. So that was really good. I felt really confident with her. I sensed that she had all the knowledge, that it wasn't a case of me having to press all the right buttons, like it is with WINZ, where if you don't ask the right questions you're not told anything. (T)

Another consumer commented:

> Obviously they have got to have good people skills, and then they've got to be on the same wavelength. They've got to understand the difficulties you have, otherwise they simply would not be able to do their job. If I say I'm having problems in the kitchen then I expect that person to have enough nous to go in there and pull out a few draws, and see for themselves that they're really hard to guide. I'd expect an assessor to prompt me, to ask the right questions. (M)

The two clients I interviewed who were younger (i.e. under 50), and who had been disabled for a number of years both commented on how the new approach to assessing disabled people had impacted on them personally. Both felt that they now had more control over the process, and there was not the same feeling that information was being withheld. One stated:

> I spent so many years under Social Welfare saying please, please, thank you, thank you, and feeling I had to beg. But this is a totally different way – I still say please and thank you but I'm in control – I feel like they're listening to me and not telling me what I can't have. (N)

In work with older people, this ownership of the assessment process was also clear to the workers. However, there did not appear to be the same need by these clients to have control over the process. For many clients in this group, there was not the same identification with being disabled. The workers commented that many older people saw their impairments as part of the ageing process and many had no interest in taking control of the process because of their physical or mental frailty. Regardless of this, however, for the workers it is an important part of their approach to make it a participatory event, even though this age group are more likely to accept the 'expert' status of the professional involved:

> When I go out and do a first assessment, I always talk about the process of the assessment that I am going to do, and really talk to the client about it being *their* assessment. They own it and I'm going to be guided by their needs. And that's an introduction to them being quite empowered because they own it and they belong to it. (A)

> I will lead the assessment, but I'm letting them know that they own this piece of paper that I'm holding and writing on, and I'm just ticking boxes and letting them know that this is theirs and I need to be guided by them. (E)

Three of the consumers that I interviewed were in their early sixties and had become disabled later in life. For these people there was significant confusion in trying to distinguish between the assessor, the service coordinator, and, indeed, the service provider. When I explained my intentions for the research, four remembered names of people who had visited them but were unable to identify that they were an assessor. One even commented positively on how wide ranging the assessment process seemed to be when she 'just wanted someone to do the vacuuming'. She did not appreciate the purpose of the initial assessment process, and indicates that the model is varied in its response to different consumers.

Conclusion

Amongst the workers and the consumers I interviewed there was a general appreciation of the greater participation of consumers in the assessment process, but that this can bring with it a greater range of emotions that both workers and clients have to manage. For some clients there was an expression of greater expectation of worker expertise in relation to knowledge about disability generally; for the worker, there was an acknowledgement that client-driven assessments require workers to engage in conversations that extract information while at the same time maintain client control. This differs from the approach of the 'top down' hierarchical bureaucracy within which many of the workers are employed.

For some older clients, however, who are more recently disabled, and perhaps do not even regard themselves as so, there was confusion as to the roles of the various health professionals and service providers. For these clients participation was not so much the key as getting the service. This was particularly true for those consumers who required only a single service, such as home help.

User participation also has limits where funding is an issue, as has been explored in the previous section. Participating in an assessment as a client and identifying and receiving the service you want are not necessarily the same thing. Managing this tension is a skill that service coordinators in particular mentioned as being one that they had to develop. It

requires the worker to negotiate with clients in a positive spirit that maintains the integrity of the relationship. This in itself requires a mature and respectful approach to clients.

Separation of assessment from service coordination

As has been noted in Chapter Three, the Health and Disability Act clearly separates the assessment function from the function of coordination of services. This was to avoid any conflict of interest, as it was felt that combining the two roles could compromise the focus of the assessment process, which was to identify unmet need and real need. The rationale was that combining the two functions led to assessments that were clouded by the knowledge of what services were available. In the Waikato focus group, (those involved working with the 16-65 age group) the functions were separated, but in the Waitemata group, (those working in the over 65 sector), the functions were combined in the same person. The differences in the perception of the functions highlighted how the model was implemented in the different age groups.

For those working in the 16-65 age group the separation of the functions was seen as being essential to the role because they saw the skills required for each function as being quite different. Service coordinators identified their skills being centred around negotiation, particularly with providers, and managing tension and conflict constructively with clients where there was a difference in expectation:

> I truly believe the assessors' skills are way different from mine. As a service coordinator I need to be a good negotiator. I need to be able to manage conflict. I need to be able to get a win/win situation at all times and that might mean going way around here and then get there. I need to be equitable with funding. The funding issue's a big one, I've got to know that I sit within the guidelines and regardless of how bad that person regards their situation, that if they don't meet a level that attracts funding, then I can't go there. So I need a bit of a hard edge to me, and a strong edge, and I need to be the person who is driving it...gently. Whereas if I took those skills into an assessment, I wouldn't get an assessment. They're quite different; they're at different ends of the scale, I believe. (G)

Another new skill highlighted here is the ability to see the client in context of a wider funding issue, where issues of equity need to be considered. This worker talks about needing to have a 'hard edge', having to be strong in order to make decisions that may not necessarily please the individual client, but does respond to the wider organizational funding issues that require the worker to take account of the needs of the population as a whole. The 'hard edge' is also required to negotiate with community agencies to provide services that respond to actual client need. This, too, is a new part of the service coordination function not experienced in other roles.

Assessors, on the other hand, feel that they would not be able to do justice to an assessment if they were constrained by budgetary concerns. There were concerns that the process would be contaminated by the conflict inherent in both functions. They identified their essential skills as rapport building, active listening, and engaging the client in the assessment process, so that a total picture is obtained:

> If the role was in one person, I think my assessment would be clouded with [the] thinking of budget, and I don't have to think like that. In the very early days I did assess and coordinate services, and it was difficult, because when you started to build the rapport, they wanted to know, 'do you make the decision? Are you going to tell me how much?' And I had to be honest, and say well, yes I do, but not right now. And always you only got the story that they wanted to tell you, whereas I read [assessor's] assessments all the time, and she gets the story of their lives, and they're not going to tell you that if they think you're the person making the decision. Whereas she can encourage them to tell them all the things, write it down, like 'I want to be a policeman or whatever' and they won't tell her that if they think she is going to make the decision. (I)

However, while the functions of assessment and service coordination might be held in separate people, many assessors working in the Waikato also carry out this work in combination with other roles in the health arena. For example, all district nurses carry out assessments for those aged over 65, and specialists are employed to bring particular skills

and knowledge in assessing older people with dementia. This requires the worker to be very clear about which role they are carrying out, and can become very confusing for the client and their family, as W explains:

> I have to distinguish between my two roles of Field Officer and assessor, to clearly delineate that at the beginning, and if it is a client that may be wanting to use our services after the assessment's done, then I do that at a separate time. It's too confusing for clients. (H)

This confusion between roles is also apparent for district nurses who distinguish between using the terms 'clients' when doing assessments and 'patients' when visiting as district nurses. In an effort to keep the roles separate, they have dedicated days for assessments. They also see clients becoming very confused particularly if they are transferring from acute to long term care:

> The elderly get very confused. They might have acute care where they have a district nurse, then they get a coordinator with the home help, and then they have an assessor for long term care, and another provider, and so it goes on. (O)

Workers from the over 65 focus group attached to Waitemata Health were equally sure that not separating the functions worked better, particularly because of the age group with which they were dealing. There was a general feeling within this group that introducing a number of different people to the very old was particularly confusing for them, and it was disempowering to work with a model that encouraged that. The majority of the client group for these workers were generally the 'very old' (over 85) and often physically and mentally frail:

> I think the benefit is consistency for the client. For an older person and the family, one person as a contact is better than two. Often things can get confusing and muddled. Personally I would never want to see it as a split, but in saying that I haven't actually worked in a split model. (J)

Workers in this area commented how the needs of this group can change very quickly, particularly when they can have several illnesses present at one time. Because of their 'shrinking world' they often do not have an understanding of the organisations they need to deal with. Therefore contact with one person enhances their ability to contact the help they require:

> Having one person for the client is important, because they're old, sometimes their memory's not too good, and just to have that consistency, they know that they can get on the phone, they've got your card, they can ring up and say what's going on and they've got that one person all the time to phone if they're in strife or if they need another assessment. (A)

Managers' opinions tended to reflect the structure in their own area. Where the functions were both in the same person, the manager felt that there was more value to the client in not splitting the functions into two people, especially high needs clients, where having contact with a number of people with different roles becomes confusing for the client. There is also a clear expectation that workers will consciously finish one process before they start another, and explain that to clients. Alongside this was an appreciation that the separate functions should be protected:

> As long as the different functions are protected, then for the client having one person doing that is valuable. For people living in rural areas doing assessments, those people say that they have tended to do the straightforward service coordination because they were there, so I'm not sure how necessary it is to have the function in separate people. I think the separation of the *function* is necessary but in other roles we expect professionals to hold that as part of their professional responsibility and I don't see why that shouldn't happen here. (P)

For the area where the functions are carried out in separate people, the skills are seen to be different, and protecting the purity of the assessment process is an important focus for this area:

> Having the functions in separate people protects the assessor to actually do a good assessment without having to worry about what's happening next. A lot depends on the quality of the assessment for the service coordinators. (Q)

A generic NASC model does not necessarily meet the needs of all disabled people. For older people, not only do they often have several illnesses present at one time, they also are more likely to have adverse reactions or unexpected responses to drugs. Timely intervention is imperative to prevent irreversible losses that lead to increased dependence:

> If you have a split role between service coordination and needs assessment then you have an inevitable time delay, and so if everything does 'turn to custard' we have the ability within our combined role to deal with it now, rather than several hours or days later. (J)

For one worker, being able to complete the 'whole job' meant that she had a greater understanding of that person and their world which gave them a better appreciation of the services that they required. There was concern that without the ability to do both parts of the role, then the needs of the client might get lost:

> Having one person doing both parts of the service is invaluable to the client for the continuity, and if you've done an assessment, then you have a huge understanding of that person, and if somebody else does the coordination then they don't have that understanding, so I think there's a lot lost if there are two people going in. Yes, I agree, that an assessor can go in and do a great assessment and then pass on that information to a coordinator who then does the setting up bit, but it sort of loses the client. (B)

For the workers whose role included both functions, it was still clear to them that the functions had to be done in two distinct phases. There are guidelines for each process (for which they had to keep data) which helped them in this. Training workshops also helped them to distinguish the requirements of each function:

> The message is really clear that needs are not service driven. And that's about those clear boundaries. It's like you switch off, you've done the needs assessment and OK, now what can we give to support those needs. (D)

While the assessment focuses on 'people skills', eliciting information and obtaining a sense of a client's situation, these workers also identified negotiation skills and 'directing' services to meet need as part of their skill base. But as the following indicates there is more of a balancing act between the need and the service provision. There is more likelihood in this scenario, that the definition of the need might be influenced by the worker's knowledge of what resources are available:

> And when you do the assessment, basically it might come out that they can't manage showering for instance, and you're talking to them about *how often is [having a shower] best for you*, some of them might want one twice a week, some might shower every day. You may when it comes to the coordination have to discuss with them that perhaps at this stage *we could manage this*, but when you're talking to them in their assessment you're picking up what their pattern is, what their need is, but in the coordination you might have to discuss with them what might be possible. (B)(*Author's emphasis*)

There is a clear distinction here between what the need is and what might be possible in terms of providing a service. The danger in having the two functions combined in the same person is that the distinction between the need and the ability to provide becomes blurred and the need becomes redefined. For the functions to be combined in the same person there needs to be rigid adherence to the guidelines, so that the expressed and unmet need is recorded.

Conclusion

The purpose of separating the assessment from the service coordination function was to avoid any compromise of the assessment focus which was to identify unmet and real need. However, the model does not necessarily suit all age groups. Anecdotal evidence suggests

that frail older people appear to be confused by the number of people involved in their care and are less likely to be informed about different providers or indeed interested in who is providing their care, while younger people and their carers are reported as taking a much more active role in the process. Nevertheless, not separating the function may lead to the boundaries between assessment and service provision being more obscure.

Professional knowledge base

One of the features of the NASC worker is that they have had to respond to the boundaries of new legislation. The medical model and the role of the expert are no longer considered the best way of intervening in the lives of disabled people and workers are required to adopt a more participatory approach to their client base. For those workers who have been trained to use their expertise in a more traditional professional manner these changes are considerable. The professional expertise of the worker is no longer paramount, rather it is a collaborative partnership where the client is viewed as the expert in their own lives.

Most of the NASC workers that I interviewed came from a health background and are made up of trained nurses, social workers, occupational therapists and counsellors. Most were familiar with the medical model, indeed the NASC workers who worked with the elderly were based in a hospital, and therefore were trained within a very hierarchical setting. For some, letting go of the more traditional professional role was difficult:

> I think the biggest change for me has been instead of going into a person's home and telling them what services I think they need, is turning that around, and listening to what services they think they need. I'd hate to see some of my first assessments. (I)

The new role was an acknowledgement that they had to do things differently. Even so, most considered that their initial professional training gave them a good grounding for this role, particularly in the area of assessment. D was typical of those interviewed:

> Particularly with nursing, right from the beginning you're taught good assessment skills, because that's what your basis of everything works upon. You're assessing

> that client as soon as they come in, be it medical or social. So certainly I think from my nursing training and my background it plays a huge part on how I professionally carry out my work...you carry that with you the whole way through, what you've learnt. (B)

Generally workers saw their original professional training as providing the framework for the skills needed for their current role, but that they had to take on new knowledge, and learn how to apply their skills in a different way. In a sense they no longer carried out the particular tasks related to their professions, but carried a much broader knowledge around disability related to the particular age group they were working with. This enabled them to become valuable dispensers of information in the area of community resources:

> What we learn within each of our professions is what we take and use as the assessment process. But the boundaries are different in that we're not actually providing that service of counselling, or sorting out benefits, or whatever, we're referring them off, so that the client gets to where they need to be. (A)

Some found they had to *unlearn* some of their skills to adapt to the NASC role, which they identified as being 'more defined'. This was particularly so for counselling and social work professionals where the work and the relationship with the client was so closely intertwined. The skills of rapport building, active listening, and creating an ease with relationships were directly transferable to the present role, but the ongoing relationship was not available to them:

> I think as a counsellor I actually had to do quite a lot of unlearning because this is a different role to counselling. Although there is a lot of overlap, particularly in terms of establishing a rapport with people and making them feel comfortable, listening behind the words, but, it's a tighter role than the counselling role. I had to learn not to say to people, 'and how do you feel about that?' and that was a big learning for me on the job, because I do find it quite easy to talk to people, to encourage them to talk to me. This has more defined guidelines. (E)

The social workers on the team also found they had to leave much of their former role behind. For social workers, relationship building is part of the role, and one that is expected to grow over a period of time. Opportunities for doing work at a deeper level were no longer available to them. Former tasks that they would normally help with, they now had to refer on to their colleagues:

> I was doing social work before I came here, and I had to leave a lot of stuff behind as well, and change my way of thinking. I needed to be very specific about what I could do and couldn't do in my new role...I couldn't go out and do counselling, like in-depth long term counselling...a lot of advocacy work and benefit work as well, that's not our role any more either. (D)

All the participants I talked to acknowledged that while they still identified with their profession of origin, they saw this role as a way of expressing those skills and knowledge base differently. In carrying out the NASC role, they are bound by specific boundaries and guidelines, and this in itself helps them to identify as a distinct group within the health arena:

> It's a role as a facilitator. It's on its own, because of the boundaries and the guidelines that we have to work within. What we learn within each of our professions is what we take and use in the assessment process, but the boundaries are different, in that we're not actually providing that service of counselling, sorting out benefits, but referring that person to where they need to be. That's what makes it the role on its own. (A)

The appointment of a variety of disciplines to this role reflects management's view that the skills required do not belong to one discipline alone. As one manager said, (who is a trained social worker):

> It is a different role. It draws from the skills that are traditional social work skills but I would have to say they are skills not owned by social work alone, and I think that has to be acknowledged...Different professions bring with them different cultures. Bringing together a shared understanding and shared value base takes time, but does happen through peer review. (P)

What is looked for in potential employees is a combination of skills in working with people and a specialized knowledge base around disability. Managers acknowledge that workers tend to come from a health background, but that is because that is where the knowledge of disability has traditionally been held.

Knowledge of the patient for health professionals has traditionally been viewed primarily as a route to a better understanding of their response to illness. Disabled people have also been viewed similarly, especially as the professionals involved have come from a medical setting. However there were some distinct differences in each of the professional groups as to how they viewed themselves in relation to the medical model. Those interviewed working with the adult disabled community felt that it was their understanding of the blocks to participation in society for disabled people that was critical:

> The under 65-year-old client needs that 'disability thinking' rather than the health based view. People with disabilities don't want to be assessed by people who have a health hat on. Whether their background is nursing or whatever, I don't think that is particularly relevant, but if the assessment is slanted and all the questions are around health you're told to get off that [*by the client*]. (G)

For many younger disabled clients, the focus on the impairment is not tolerated; rather the assessment is about identifying their needs in relation to their ability to participate. However, working with older people brings a different perspective to disability. Older people's support needs are much more linked to ageing and their declining health, and therefore a closer link to the medical world was needed, as older people's needs could change so quickly. Closer relationships with specialists such as geriatricians are necessary, and services are often directly linked to physical frailty. This was reflected in some of the

comments of the workers in the over 65 group, who acknowledged a stronger link to the medical world:

> The physical frailties, the arthritis, which are a natural development of old age, are not relevant to people with a disability in the 16-65 age group as a whole. There's a flaw in the thinking, I feel, in just carrying on the elderly as a progression in disability, because most of our clients are not disabled in the sense that the younger age groups are. It's just a natural process that comes with ageing, rather than a disability. It does have a disability component in that it impacts on their ability to function. (G)

Workers in the older age group felt generally frustrated that people aged 65 and over were linked to the same funding as those aged under 65. They did not identify their client group as being disabled in the same way as those aged 16-65, and in fact clients themselves did not identify themselves as disabled, but rather were suffering from their particular ailments as a result of ageing. Their ailments do have an effect on their ability to function, but there is less likely to be any long-term stability following assessments.

> In the older age group, the disability also impacts on their whole lifestyle. In the under 65, the disability prevents them from doing x, y, and z, but they can actually function the rest of their lives around that disability at a reasonably high level, whereas the older person's disability has an impact on their functioning for the rest of their lives. They can't manage very much more because they're frail anyway. (A)

This difference has finally been acknowledged by the Ministry of Health, which has recently separated the disability support funding into two streams – one for people aged 65 and over, and one for those aged under 65. The decision acknowledges that the complex and serious health and disability needs of older people are not the same as the more stable needs of most younger people with disabilities. Younger people's support needs typically relate to wider sectors than health, such as housing, income, education and employment (Ministry of Health newsletter, August 2001).

Clients express more confidence in the assessment if the assessor has got some information about the particular disability the person experiences. One worker talked about looking up some information on a particularly rare syndrome on the Internet, so that she would not enter the home completely ignorant of the effects on the client or the family.

> You do get asked: 'What do you know about this disability?' And it is in your best interests, if you don't know, (because you can't know about every disability or syndrome out there), to arm yourself with that knowledge before you go out, because they will say, 'what do you know about this?' If I don't know anything about it, I will ask them: 'how does it affect them?' (I)

Clients also expressed the need of workers to have some particular appreciation of their difficulties as a result of their impairment, so that clients are not left having to explain their trials and trying to convince workers that their need is justified:

> They need to know that with MS we can look well, but our bodies are letting us down, so they need to understand that even the simplest task can be really, really daunting. So they need to assess that there is a *need.* (M)

> It's helpful to know that they have some knowledge of what I need, that they can understand what I'm talking about. They need to have some association with people with disabilities, and they need to be educated about how they could help. (N)

Conclusion

The creation of the NASC role is the result of a change in service delivery to disabled people. Change is a constant feature in the health field, which leads to new challenges for the professions. Claims to expertise are doubly challenged – first, by the questioning of expertise by different social groups, and, second, by the pace of the organizational and knowledge-based change they face. The recognition of pace of change in recent times has

been a major dynamic behind the official recognition of the importance of lifelong learning and leads to a need for professionals constantly to update their learning (Frost, 2001:13). The challenge for NASCs has been to adapt their skills and knowledge base to a model that in itself needs to be flexible to respond to the different needs of the various client groups.

What is clear is that thinking in the disability field has radically changed in the last 10 years. Health professionals who have trained and work within the medical model need to be open to adapting their expertise to meet the demands of the new legislation, which is grounded in the social model. Clearly, however, and somewhat paradoxically, those working with the very old also need some alignment with the medical model to get the best care for their clients.

The modern professional therefore has to become what Schön (1983) has described as the 'reflective' practitioner. Social change places the professional in a position of becoming a continuously reflecting practitioner – learning from the new, changing and diverse situations which face them in their everyday practice. It follows then that current training needs to reflect these changes as well, so that workers can carry out their work, supported by models of practice that reflect the most recent theoretical developments.
In the next chapter I will comment on the main findings in relation to the literature already explored, and include subject areas that I think should be considered for a training programme.

Chapter 8 - Discussion

Introduction

A number of key issues were raised in the presentation of the research themes in Chapters Six and Seven. These primarily focused on an exploration of the role of the Needs Assessor and Service Coordinator in the two different localities and how this impacted on the consumers they serve. This section will identify some of the key issues pertinent to the implementation of the legislation, and provide some recommendations for direction for training needs. The issues that will be discussed here are those that most adequately reflect the issues that emerged from the literature review, the research questions and responses.

Skills required for the NASC role

Over half of the focus group participants participating in this research came from a nursing background, (7 out of the 12) with the rest being made up of 3 social workers, one counsellor, and one who had come from a business background. According to the numbers given by the Ministry of Health, this reflects the professional qualifications of the NASC workers nationwide, with by far the greater number of workers coming from a nursing background. In the focus group for those working with people under 65 only two of the group were service coordinators. Again, this reflects the area where there are a large number of assessors and very few service coordinators.

The skills of rapport building, active listening and asking questions that elicited appropriate information were all identified as essential by both focus groups for the assessment process, and reflected skills that are considered part of the professions they originally trained for. Good communication skills, particularly listening and interviewing skills, are essential within social work (Trevithick, 2000: 53). They require that we can combine being both sensitive and purposeful (Boswell 1997:352) with being able to acknowledge uncertainty that is inherent in looking across into another person's world. We also need to learn to ask good questions in ways likely to provide information that is both relevant and sufficiently detailed, and to watch for clues. It is generally acknowledged that a good

assessment involves client participation, and is a collaborative process (Trevithick, 2000: 62).

Nurses also require similar skills in their relationships with patients. Nursing literature (Kron, 1972; van Dersal, 1974; Sundeen et al, 1994) refers to the skills of therapeutic listening, paraphrasing, reflecting and creating a relationship of trust as being essential to a relationship that leads to partnership. Consistency and reliability are both extremely important (Sundeen et al., 1994:173), and provision of accurate information along with an opportunity to share feelings (ibid) are seen as significant factors in the relationship. All health professionals use assessment as the basis of their intervention so it is not surprising to see that there is some commonality of skills required for the task.

As I have stated earlier, the NASC work force is made up largely of allied health professionals, not only nursing and social work, but also include occupational therapy, physiotherapy, dieticians and counselors. One consequence of working in a multi-disciplinary group is the acquisition of knowledge that has traditionally belonged to separate disciplines. While this may be useful to integrate this knowledge in the assessment process, for clients there are other issues. One of the consequences of chronic illness or long-term care is that the client's body may become very vulnerable to an unnecessary exposure to the worker's 'gaze' (Opie, 1997:7). Extensive discussion of elimination processes and toileting problems, for example, can become embarrassing for the client, and an unwitting violation of privacy on the part of the worker. As the workers' knowledge base grows and becomes more oriented towards disability generally, rather than oriented to their own particular discipline, they need to be careful about the depth and range of the interviews they undertake. Rather than including more questions they may have to shed some of the more intrusive ones, without losing the sense of the whole assessment. This also needs to be reflected in the assessment tool which can be used to collect too much information, thereby creating an unnecessary burden on both client and assessor.

For service coordinators the critical skills were those of negotiation and being able to appropriately identify and employ community resources in a way that fitted the needs of the clients. These are considered core skills of case management, again a familiar role of both nursing and social work. In many ways the skills of nursing and social work are well suited to NASC and it is not surprising to find that these professions are well represented in the makeup of the NASC professional population.

The role of service coordinator is also much more defined and involves much more collaboration with the client. More emphasis is given to providing information to the client concerning different providers, and discussing with the client different possibilities as to how their needs can be met. This is designed to allow people with disabilities to access appropriate services more easily and ensures a high level of participation and control. In some instances (such as I have outlined with client N), consumers themselves manage the employment and payment of their caregivers, giving them the power to meet their own needs. For the worker, this not only highlights the requirement for skills of relationship building with clients, but also well-developed skills of negotiation with clients that allow self-determination. Where services are arranged by the service coordinators, negotiating skills with providers are significant. This is a new relationship, which requires some care, as service coordinators cannot be seen to favour some providers at the expense of others, thereby creating inequitable relationships. At the same time they need to negotiate a relationship that results in appropriate packages of care for clients.

There is perhaps a need to develop some training around the more difficult aspects of service coordination, such as conflict management that emerges when workers need to balance the tension between service coordination and budget management. While the more therapeutic skills of intervention are generally well catered for in social work and nursing education, conflict management is often not taught transparently, but is often a skill gained through experience 'on the job'. Equally, a guide to ethical decision-making within the NASC context needs to be explored, along with the concepts of equity and fairness. For example, there is an important difference between fairness arguments which appeal to people's current status, and those which appeal to people's lifetime status. Some people

argue that fairness requires people to be treated equally if they have equal current need. Others argue, against this, that people have a past and a future as well as a present, and that fairness should be assessed in terms of people's lifetime need (Moore & Tennant, 1997). Concepts such as fairness and equity are emotive and, to a large extent, contested and workers need to examine, both individually and as a group, what informs their ideas.

At this stage, NASC workers manage indicative budgets only which means they are aware of the overall funding for the area, but are not restricted to a dollar amount when arranging services for clients. Nevertheless, they do have to work within guidelines and are responsible for arranging packages of care for complex need through the flexible funding option. Therefore workers need to be cogniscant of issues of equity and fairness when it comes to coordinating services for their given population. This often involves ethical decision-making and requires maturity on behalf of the worker. Most health care professionals would not have learnt about health care economics in detail in their academic programmes. Even now, health is regarded as an essential good, and health professionals continue to grapple with the idea that it comes at a finite cost. Case managers today face serious ethical challenges: maintaining personal and professional integrity and working to maintain quality outcomes within a cost containment environment.

There are tensions too in trying to work within a framework that embraces the social model of disability while at the same time having to communicate with and sometimes work within the medical model. In recent times, the medical model has been the target of bitterness because it has been seen, particularly when the concept of normalization was popular, as a force only to change disabled people into some more normal beings (Hutchison, 1995; Oliver, 1996; Sullivan, 1998). As a result of increasing emphasis upon the importance of social factors in the maintenance of disability, the inadequacies inherent in clinical models of disability have been thrown into focus. This does not mean that the model has been disproved, but rather evidence has accumulated that it does not sufficiently encompass the disabling attitudes of society. Within a social model of disability it is argued that individuals who are different by virtue of an impairment find that they are oppressed by societal views of normality. In other words, disability only exists in so far as

it is socially constructed and imposed on people with impairments (Hutchison, 1995). The social model of disability puts the problem back into the collective responsibility of society as a whole and there is a de-emphasis upon the individual.

To work within the area of disability, an appreciation of both models and their limitations is needed in order to appreciate how they impact on the client group. Nearly all of the NASC workers interviewed for this research have trained within the health area and have, therefore, had to adapt the skills and knowledge gained within the medical model to an environment where the 'truth, perceptions and beliefs' of the client are central to the assessment process rather than the position of the professional 'expert'. New concepts are emerging around the notion of building partnerships with clients, such as coaching, collaboration and facilitation. The evidence shown in the research indicates that these concepts are better understood by some than others, and was determined in part by what the managers of the teams saw as relevant to their skill base, and in part by how much importance workers themselves attached to them.

Separation of the assessment and service coordination functions

As was evidenced in the research discussion, the NASC model as designed in the Health and Disability Act is not applied consistently geographically or across age groups. Those working with older people were both assessors and service coordinators, while those in the Waikato have the functions carried out by separate people. For the former, it would appear that there are potential risks of the process of assessing for need being blurred by the implications for the coordination process. For example, because the workers carry out both roles, it is possible to assess against available services rather than to assess the need itself. Equally risky however, is the separation of the functions. In the Waikato region, many assessors carry out dual roles of assessor and service provider, such as field officers for not for profit organisations, or district nurses, and it would appear just as difficult to maintain clarity between these roles.

Perhaps the model does not need to be expressed in the same way for each age group, as clearly the needs are different. As has been shown, the NASCs involved with the over 65s,

can become more aligned with the medical model, as the majority of the clients they work with are often experiencing ill-health and often have more than one illness at any one time. Consequently, they often need specialist assessment, and services often need to be reviewed quickly. A relationship with one person that is able to carry out both functions is likely to be more client friendly than introducing a number of people, and this issue becomes even more critical for the very old and frail. Similarly, for an older person who needs only help with housework, it would seem cumbersome and unnecessary to have two people involved in a simple task.

An interesting outcome of the discussion was the need to pay attention to the reduced world of the older client. While our services are more geared to supporting the frail older person in their homes, less attention is paid to how services may assist them to engage in a meaningful existence. The type of 'shrunken world' that frail older people living in the community can occupy was captured by Lawton et al. (1995). Employing a 'yesterday interview', in which family carers described the previous 24 hours, they revealed that older people were passive for over 80 per cent of their time, with only 7 per cent being spent in 'enriching activities' compared with approximately 23 per cent for a similarly aged but less frail cohort. As recent government health policy is focusing increasingly on maintaining people in their homes, attention to a 'meaningful existence' must become of central concern if the assessment is to remain 'client-centred'.

For younger people, on the other hand, it is important that the assessments are multi-faceted and include needs in such areas as education and training, employment, housing and recreation, areas where traditionally the needs of the younger disabled community have not been well catered for. Nevertheless, the result of separating the functions brings with it another potential problem. In some areas, (including the Waikato) the need to include specialist knowledge has meant that the assessment function is carried out by a health professional who has another specialist role in the community (e.g. Multiple Sclerosis Field officer and assessor for under 65 physical health). This can be equally confusing to clients, and potentially can create a 'contamination' of the assessment process, as the worker can attempt to provide a service while at the same time carrying out an assessment.

The views expressed by those NASCs who work with older people have in part been reflected by government, which has made changes to the funding structure for older disabled people. In a letter to the District Health Boards in July 2001, Ruth Dyson announced that the 'planning and funding for Disability Support Services (DSS) for older people with disabilities will be separated from funding for younger people with disabilities, with a view to devolving older people's DSS funding responsibilities to District Health Boards in future years' (Dyson, 2001). A key factor in deciding to split DSS funding was the desire to facilitate the development of a more integrated continuum of care for older people, across health and disability support services, and certainly the fieldwork carried out in this research supports this policy shift. Whatever variation of the model used, the boundaries between the functions are important new developments and a consistent understanding across disciplines is critical to its successful implementation.

Concepts of need

Ultimately, the roles of assessor, case manager and service provider are all distinct ones, and are ones which have traditionally been carried by one professional. However, the separation of the functions of assessment and service coordinator within the Health and Disability Act is an attempt to ensure that the assessment identifies need and is not measured against the availability of services. In other words, assessment is needs driven rather than service driven, and more likely to lead to individualized services for clients.

The concept of need is a complex one, and one that is particularly difficult for consumers to establish in the face of professional expertise and a limit in the number of services provided. Bradshaw's theory of need (Chapter Two) is helpful in providing a useful baseline for an understanding of need in a social welfare context, but does not include the notion of special need. The research has shown that there is an understanding among workers that the need expressed is that of the client. However, as Middleton (1997:23) points out, the assessment process itself is one that is visited upon marginalized groups of the population, for whom special need has been invented. Assessment in this context is less for the benefit of this group than to maintain the quality of provision for those who are not special. As such, it is less associated with gaining rights than identifying problems.

Nevertheless, the more inclusive, collaborative relationships with disabled people now involve a more deliberative approach to the assessment of need where there is negotiation to the extent that the disabled individual feels as if their self-defined needs have been duly taken account of.

It is also apparent that a need expressed does not necessarily mean that a need is going to be met. Part of the reason for separating the assessment process from the service coordination process was to identify unmet need in service provision, and the reporting of this is a requirement of the Health and Disability Act. In one of my interviews with managers of NASC services, there was a comment that, despite faithful recording of service gaps, little change had occurred. Areas of urgent need, such as provision of night nursing, can at times be met through the flexible funding option, but the cost of such care prevents it from being added to the public purse. At times, then, it is not surprising that workers can have a tendency to redefine need as want under a system that clearly does not respond to its own processes.

What is clear is that in this environment the complex concepts of need, want and availability warrant examination and understanding. As I have already stated, the needs assessment process as outlined in the Act is weighted towards needs as the client defines them. But where is the boundary between needs and preferences? In practical terms it is difficult to separate and identify want or preference clearly from self-defined need and, indeed, there was evidence in the research to show that clients' expressed need was occasionally redefined to link with the known availability of services.

Professional knowledge base

The participants in both focus groups and their managers have stated that the NASC role is a different role to those currently employed within the disability and health sector, and therefore requires an adaptation of skills and knowledge base.

There are two points to be made here. The first is that, while the role suits health professionals generally, the skills and knowledge base required are not limited to one

profession alone, but are available across a number of professions. Participants stated that they have not only had to adapt their skills, but have also acquired new knowledge, to meet the needs of this client base. For example, the skills of advocacy and counselling, considered at the core of the social work role, are not part of the NASC role. Equally, the basic training of nursing is based around the medical model which is not appropriate to the client base of NASC. Both these professions are present in high numbers in the NASC role. New skills that have required development include budget management, and negotiation skills, particularly with providers. This adaptation process has become more apparent as the role has developed, and has further clarified with the continued development of standards and guidelines.

As with all professions there is a need to operate within a sound theoretical framework. For the health professional, much of their acquisition of knowledge about a person has been underpinned by a biomedical orientation, and disability has been interpreted as a deficit within the individual in keeping with the medical model. The development in thinking in the area of disability has changed dramatically over the last ten to fifteen years, and this development has to a large extent influenced the changes made in the Health and Disability Act (1993) to the way services are offered to disabled people. Participants in the focus groups were not universally aware of the social model of disability as a term, but that is not to say that they did not operate within the spirit of the philosophy, as is evidenced in the research findings.

Clients expressed a need for workers to have an understanding of the particular needs of disabled people and to not be judged against the ability of able-bodied people. Any training package would therefore need to include an examination of the more recent literature surrounding both the medical and social models of disability, including experiences of disabled people and their application to the NASC role.

Traditionally, the knowledge base for issues around disability has been found in the health professions, as doctors have, until recently, been considered the rightful carers of disabled people. Naturally this knowledge has devolved to the allied health professionals such as

social workers, nurses, and occupational therapists who, within their own professional frameworks, have also assumed the 'role of the expert' with their client base. In this process the knowledge belonging to the consumer has largely been discounted in preference for the more medicalised and 'expert' knowledge of the medical profession. In Foucauldian terms, the 'doctor-judge' and 'social work judge' have assigned their definitions of normality to the disabled 'body', and any rehabilitation has focused on a 'return to normal'. This research focuses on the more recent assertions from the disability community that *their* knowledge be respected and used as the basis for assessments, and that professionals involved in their lives use their expertise in way that encourages partnership.

What the research has made clear is that commonly used terms can have different meanings for different professions. Independence, for example, can mean ability to self-care for nurses, return of strength and movement to limbs for occupational therapists, and a capacity for decision-making for social workers. Assessments in each profession can take on widely differing journeys. This has ramifications for the client for assessment of need, and highlights the necessity for the relationship with the client to be collaborative so that client interpretations are not lost. Not only do professionals need to have a more collaborative and facilitative relationship with their client base, they also need to have an understanding of the role of different health professionals so that their assessments can indeed be holistic. While a referral for a more specialized assessment may be an outcome of the assessment, NASC workers need to know to ask what one participant called 'the right questions' so that the actual need of the client can be met. The NASC worker today needs a knowledge base that broadly encompasses the needs of their client base. For the older age group (and children) this may require a more linked connection to the medical system, while in younger adult disabled people, a knowledge of the issues in other areas which affect their lives, such as the reality of disableism, education, employment and transport, will be necessary.

Finally, the knowledge base gained by workers must be framed in a way that benefits consumers rather than further disempowering them. None of the NASC workers that I

interviewed were disabled themselves and, therefore, the need to work in partnership with clients and use their knowledge about themselves is paramount. Despite good intentions, non-disabled professionals can be patronizing as they fail to admit ignorance, lack practical information, and fail to acknowledge the expertise of the disabled person in front of them. Traditionally, they are seen as the holders of specialized knowledge and skills (Bricher, 2000:786). In order to include disabled people in more active roles in the relationship, it is important that NASCs receive high quality disability equality training, that they understand the meaning of disability as disabled people define it, that they are informed about the important role disabled people have played in the development of services, and that they present information to disabled people in accessible formats. 'The challenge for workers at all levels of community care is to make sure that the service user is in control of his own lifestyle *and* in control of the services surrounding him which are designed to support that lifestyle' (Munro and Elder-Woodward, 1992:41).

Consumer participation

In the policy document entitled *Self Help and Empowerment (1992)* it was stated that the expectations of people with disabilities in relation to service provision were moving towards having the articulation of their own needs acknowledged and accepted. The NASC role outlined in the ensuing Health and Disability Act (1993) stressed the need for a commitment to a high level of consumer participation and control. The key to this is the level of participation of clients in their own assessments, and their ability to negotiate with service coordinators in regard to the range and number of services available.

The extent to which consumers wish to have participation in and/or control over the assessment process varied amongst the consumers I interviewed and, indeed, it may be unfair to generalize from such a small sample group. However, the interviews showed that the younger disabled people, especially those who had lived with disability for a long time, were more concerned about building relationships with NASC workers that involved mutual respect and understanding that would ensure best outcomes over a prolonged period. N, for example, felt he had a collaborative relationship with his assessor and felt totally in control of the process of employing his caregivers. This element of self-control

was important to him, and the ability of the assessor to power-share was critical to its success.

The older people I interviewed (two aged 62 and 63) did not express those needs in the same way. They saw the interview with the NASC worker as a necessary part of gaining access to the service they required, and more reliance was placed on the expertise of the worker to gain that service. This does not mean to say that workers should approach these clients any differently. There is an opportunity here for workers to coach clients to participate more fully in the decisions that affect them, so that an awareness of self-determination is developed within a professional relationship. Coaching is a skill that NASC workers could develop to create a more empowered client base.

This idea of coaching is not new. The Institute of Medicine's Committee on Quality of Healthcare in America states in its recent publication, *Crossing the Quality Chasm: A New Health System for the 21st Century* that in the current health system, control over decisions, access, and information is typically in the hands of caregivers and is ceded to patients only when caregivers choose to do so. For example, patients are often required to obtain permission to see their own medical records, to have visitors, or to participate in treatment decisions. They suggest a new rule, which asserts that, except in unusual circumstances, control should reside with the patient. This they say is consistent with the direction in which clinician-patient relationship has been evolving (Bastion and Richards, 1999; Harrison, 2000) and with widely understood concepts of informed consent. Informed patients participating actively in decisions about their own care appear to have better outcomes, lower costs, and higher functional status than those held to more passive roles (Gifford et al., 1998; Lorig et al., 1993).

Work by Kaplan and others on patient empowerment (Greenfield et al., 1985, 1988; Kaplan et al., 1989) has demonstrated that it takes time for patients to be included as partners and that in many cases they need to be coached to assume such a role. Kaplan et al. (1989) found that patients who had been coached to ask questions during office visits reported fewer functional limitations and had better control of blood sugar and blood pressure than did patients in the control group. This has relevance for the NASC role. Accomplishing

the goal of shared decision-making is part of the NASC role, and is one where the NASC worker has an opportunity to be pro-active. It is not only a case of asking the right questions *at* the interview, but perhaps providing clients with a question prompt sheet with a list of suggested topics *before* the interview that are likely to be included in a comprehensive assessment. Access to relevant research and development of new approaches is one of the purposes of training. Workers need an opportunity to meet across areas, both geographically and age groups, to develop ideas and to promote consistent approaches to client empowerment.

The use of language also needs to be considered. Language is never value-neutral and in disability discourse has the potential to be oppressive and discriminatory. Terminology and the labels that society gives disabled people affect not only the way disabled people are perceived, but also how they perceive themselves (Zola, 1993). The key to appropriate use of language appears to rest with the meaning that is ascribed to the word. Terms to describe the user tend to be employed very loosely in the literature, but as Barnes and Wistow (1991) argue:

> the key terms 'customers', 'consumer', 'user', 'citizen', and 'survivor' all imply substantially different kinds of relationship between those who provide and those who 'receive' services (p.3).

Within both the individual and social models, different words have been used to describe disabled people. Most within health professions describe their consumer base as clients, but one participant who worked as an assessor and as a district nurse went even further and called people 'patients' when she was a district nurse, and 'clients' when she was acting as an assessor. Not many of the participants referred to their client group as consumers or users. Clearly, however, N (mentioned above) felt in control of his situation because he was an employer, a user of a system. This embraces the concept of empowerment which involves giving more power to service users over decisions and hence involves taking power away from service providers (Taylor et al., 1992)

How we view the disabled person is important, and what meaning we ascribe to descriptive labels is critical to our understanding of the use of power. Within the individual model, the thrust has been to restore the disabled person to a 'better' state. Traditionally, this process has tended to emphasise an authoritarian relationship where a dominant service provider acts upon a passive and submissive consumer. This relationship reinforces a status-power differential which is a barrier to collaboration. Within the customer model service providers view the person with a disability, and their families, as a consumer of their services (Lavery, 1996). This means that the customer has the right to decide and select what services they believe are appropriate for them. Decision-making is ultimately in the consumer's hands. The service provider's key role is to be a resource provider, consultant and instructor. User empowerment needs structures, knowledge, resources, commitment and training on the part of power holders and requires advocacy, skills, confidence on the part of the users. Thus, the language that NASCs use and what they understand by it and whether it is perceived in relation to its medical origins, or as a component of a wider sociopolitical structure has significant implications for the way NASCs work with disabled people.

Cultural responsiveness

Traditionally, the Maori and Pasifika nations client groups have not been high users of disability services and the Health and Disability Act has designed policies which encourage services that respond to cultural difference. This included the employment of NASC workers that reflected the make-up of the client population. The Ministry of Health's *Standards for Needs Assessment* has as its third standard that 'the assessment service will ensure the needs of Maori are met throughout the assessment process'. Where possible, Maori people are to be assessed by other Maori and should be able to use their own language during the assessment.

Of the twelve professionals interviewed only two were Maori, and only one was employed specifically for her responsibility to Maori clients. No consumers interviewed were Maori. Consequently it is difficult to draw any definite conclusions from my data. Nevertheless it is generally accepted that the health system in the past has not responded well to the needs

of Maori. One example of the difficulties faced expressed in the findings (Chapter Six) was the reluctance of Maori to allow strangers into their homes. It is not their custom to tell their stories to outsiders, and it is extremely difficult for them to link with different services, when that means that they have to admit different people into their homes.

In the past, health providers have proved extremely reluctant to consult with tangata whenua and Maori consumer groups in an effort to change the way services are offered. However this is slowly changing, particularly in those rural areas where Maori predominate. For example, Disability Support Link has consulted with the local Maori community in one of their rural areas in an effort to provide appropriate caregivers to older Maori people. Older Maori are very particular about who looks after their personal cares, and the dilemma for Disability Support Link has been that while the person can get the care, they will often not accept the person available to deliver the service. Now, in partnership with the Maori Women's Welfare League, they have asked the local community to nominate the person they would find acceptable as each situation arises.

Assessment tools also do not necessarily reflect different cultural viewpoints and both organisations used in this research have made efforts to develop a tool that responds to cultural needs. For example, there are many areas that are considered tapu around which questions will not be tolerated. These tools are usually developed within local areas to respond to local needs, and training is given to all workers in their use.

The question of whether this model responds well to the needs of other cultures was not one that was specifically posed by this research, but that is not to deny its importance. Some of the difficulties have been highlighted above, however the predominant culture of the participants and consumers was Pakeha and therefore substantive conclusions could not be drawn. Participants in the focus groups and management in both organisations emphasized the importance of having good awareness of and knowledge about both Maori and Pasifika cultures, so that entry into homes would be respectful. It was also acknowledged that over time, more contracts have been awarded to iwi and pasifika providers, to provide assessments to their own people.

Conclusion

The field of health and disability has been under significant transformation over the last decade, which has seen the formation and implementation of new policy. The restructuring embedded in the Health and Disability Act (1993) has considerably influenced these changes and has created a competitive environment for the funding and provision of services. This restructuring has also affected the services received by New Zealanders and the level of input that they have the potential to contribute in decision-making processes. For health professionals these changes have brought challenges to the way they interact with their clients, bringing their expertise and knowledge together with the client's expertise and knowledge to facilitate a holistic assessment and negotiate a relevant package of care. Existing skills have needed to respond to these changes, and new skills have been identified as requiring development, so that full expression is given to the spirit of the Act.

Chapter 9 – Concluding comments

The research

The purpose of this research was to determine the skills and knowledge base required for the functions of needs assessment and service coordination and to examine whether the role of the NASC worker in practice was consistent with the aims of the Health and Disability Act that created it. This was facilitated through the use of two focus groups with practitioners, drawn from different geographical localities and with emphasis on different client groups, as well as in-depth individual interviews with six consumers.

Chapter Two examined the historical development of health and disability policy in Aotearoa New Zealand, with a key focus being the reforms to the health and disability sector in recent decades. This introduced the formation of the current legislation, examining its purpose, and the reasons for the changes sought that led to its enactment in 1993. The history of the formation of the legislation was pivotal as it expressed the identified need for the Act and, specifically, the development of the Needs Assessment and Service Coordination role.

Once an account of the legislative landscape had been established, a discussion of the theoretical perspectives relevant to the legislation ensued in Chapter Three. These perspectives looked at the major themes of power and empowerment, models of disability, and the concepts of illness and impairment. Chapter Four examined the development of professionalism and how this has impacted on disabled people.

The design and methodological implementation of the research was outlined in Chapter Five. The theoretical framework for the research was qualitative methodology. This chapter provided a detailed description of the setting up and conduct of the focus groups, the setting up of the individual interviews with the consumers and the evaluation of the data.

Chapters Six and Seven provided an analysis of the material gained from the focus groups and individual interviews. This was divided into five key themes which emerged as a result of the interviews, and are most pertinent to the research enquiry. The analysis of the data permitted the research to engage with the topic at a deeper level of inquiry and explore how the legislation functioned in practice in two discrete areas, namely with younger disabled people (under 65) and with older people, (over 65) especially the very old.

The remainder of this chapter will identify the learning made as a result of the research process, especially in my relationships with the disability community. Specifically I will highlight areas of potential future research especially relevant for NASC practitioners, and summarise the training needs for this sector of the health industry.

Limits of research

Due to its size and nature, this research has been limited in investigating all of the possible consequences of the development of the NASC role. It focused on the participation of a small number of consumers and NASC workers in two geographically distinct groups, who employed the model in different ways. The methodological techniques adopted, particularly the composition of the focus group meetings, inevitably impacted on the data generated. The composition and size of the focus group interviews was commented on in detail in Chapter 5, when discussing specific research interviews. The most noteworthy point was the limited number of participants in the focus groups. This needs to be the subject of further scoping when looking at the development of any training.

In the course of the research I was unable to create a consumer focus group that was fully representative of the age groups. Access and reciprocity are two key challenges in all qualitative research (Opie, 1998; Tolich & Davidson, 1999). Engaging with one worker focus group was not difficult at all as I had a prior relationship with that organisation. However, my initial requests to the other organisation were rebutted, as work pressures and managerial protection prevented my entry. As I was not known to this organisation, (even though I had visited and placed my request in person), there was not sufficient willingness to engage in the research. Gaining access to consumers was also difficult for me. In order

to gain access and create a reciprocal relationship, one needs time and a number of meetings to engender the trust required. In future I would embark on this part of the research much earlier.

Implications of research for training

The allied health professions, especially social work and nursing, are well represented in the NASC workforce. Making an assessment of the client's situation is considered a part of the professional role and therefore it is not surprising to find that the skills of assessment are well developed and well articulated within the workforce. Professionals do understand the importance of being able to build relationships with clients that are based on trust and respect, however it is possible that the ways in which professionals express their expertise is dependent on the degree of assertiveness around the relationship expressed by the client. For example, a young disabled person taking part in an assessment where there is much at stake may demand a more collaborative and negotiated relationship than an older person, whose assessment may not impinge so actively on their life. An examination of Foucault's work is helpful for professionals to come to an understanding of their own use of the 'gaze', and the impact that this has on their client. There is a continuing need to develop techniques of interviewing that do not disempower clients, but rather focus on building relationships that truly respect each other's journey and contribution to the process.

Developments in service coordination around the area of the funder/provider split have required workers to gain new skills, and it is here that the training needs are greatest. Negotiating packages of care from existing services is not new but where the worker needs to negotiate with clients as well as agencies to provide new and flexible services, negotiation skills are required that are built around an understanding of the issues for both provider and client. Sound skills for resolving conflicts and reaching a compromise are now required for this part of the role. An exploration of the terms 'fairness' and 'equity' alongside an understanding of the constraints of budgetary requirements in relation to government policy would be a necessary component of any training.

Much of this training is already carried out internally within each organisation. However the way the NASCs operate is expressed differently with each age group throughout the country. There is a need for a national training framework, which would not only help set the standard for the required skill set and knowledge base, but also allow workers from different areas to discuss differences and commonalities. And in itself this may encourage the development of a new professional identity that is built primarily around mutually respectful relationships with clients.

Further research opportunities

The key emphasis for this research was to give voice to a group of professionals that had taken on a new role in the disability area, and to explore consumer response. Little prior research in this area has taken place, and I see this project as being a beginning not a definitive statement. The perspectives of more workers and consumers need to be taken into consideration. The scope and nature of future research can broaden the parameters of this thesis by looking at workers' response to cultural issues, and relationships with caregivers. This would significantly further explore relationships within the NASC role that impact on service provision.

Another avenue for research is a further examination of the impact of the employment of different health professionals in the role of NASC worker, particularly around the notions of independence and client empowerment. The research here has indicated that there are different interpretations of these terms from the different professions. This requires further investigation, as such inquiries would benefit consumers, and would enhance a common knowledge base across professions.

In a broader context, this research has highlighted the challenge that is presented to the assessment/service coordination model by the notion of consumer participation. This research has shown that the role of the NASC worker is developing into one of partnership, negotiation and facilitation, which is in keeping with the philosophy of the Health and Disability Act. However, a fuller evaluation of the effects of these policy initiatives on service users would be beneficial in identifying some of the limitations of the current

structure and operation of the Act. If future roles are to include facilitating people to participate through coaching then we must look beyond present methods of delivering services. Further research and literature is required to investigate the position and function of consumers within this context, particularly the opportunity to self-manage budgets, the next logical step in consumer empowerment.

Concluding comment

The findings from this research show that specific training for the roles of needs assessor and service coordinator is desirable, and that not all the required skills are necessarily at hand for the workers employed in this area. From the comments of the participants it is clear that there is a variation in perception of such concepts client empowerment, the meaning of disability, and working from the social model. Future developments in this role need to emphasise the importance of client participation and professional power sharing, and to this end it would be desirable to include high quality disability equality training so that workers understand the meaning of disability as disabled people define it.

The model contained within the Health and Disability Act (1993) that NASC workers are required to work with is not the full answer to the questions posed by service users, and it is expressed in different ways in different areas. The model will need to be flexible enough to encompass changes as the role of the NASC worker develops and consumer participation becomes more sophisticated. We cannot underestimate the impact the legislation has had on workers and consumers alike. The legislation has highlighted the need for transparent accountability, consistent professional standards, and relationships with clients that are built on clear communication and respect. It is envisaged that as the role of the NASC worker matures, the benefits to service users will be enhanced as skills and processes for delivery of services evolve. This piece of legislation has focused on the development of the consumer voice in relation to needs, and is encouraging the development of a skilled workforce that will respond to it. It is time for educators to play their part.

References

Abberley, P. (1995). Disabling ideology in health and welfare - the case of occupational therapy. *Disability and Society, 10* (2), 221-232.

Abbott, P., & Wallace, C. (Eds.). (1990). *The Sociology of the Caring Professions*. Bristol, Pennsylvania: Falmer Press.

Altman, D. (1989). The emergence of the gay identity in the USA and Australia. In C. Jennett & R. Stewart (Eds.), *Politics of the future: The role of social movements*. Australia: Macmillan.

Ballard, K. E. (1994). *Disability, Whanau and Society*. Palmerston North: Dunmore Press.

Ballew, J. R., & Mink, G. (1996). *Case Management in Social Work: Developing the Skills Needed for Work with Multiproblem Clients*. Springfield, Illinois.: Charles C Thomas.

Barber, J. G. (1991). *Beyond Casework*. London: Macmillan/BASW.

Barnard, D. (1995). Chronic illness and the dynamic of hoping. In R. Toombs & D. Barnard & E. Carson (Eds.), *Chronic Illness: From experience to policy*. Bloomington, IN: Indiana University Press.

Barnes, C., & Oliver, M. (1995). Disability Rights: rhetoric and reality in the UK. *Disability and Society, 10 (3)* 111-116.

Barnes, M., & Wistow, G. (1991). *Consumers, Citizens or Survivors: User involvement and cultural change in community care*. Leeds: Nuffield Institute for Health Services Studies.

Bastion, H., & Richards, T. (1999). Australia's consumer champion. *British Medical Journal, 319*, 730.

Begum, N. (1997). General Practitioners' role in shaping disabled women's lives. In L. Barton & M. Oliver (Eds.), *Disability Studies: past, present and future*. Leeds: The Disability Press.

Benner, P., & Gordon, S. (1996). Caring practice. In S. Gordon, J. Benner & N. Noddings (Eds.), *Caregiving: Readings in knowledge, practice, ethics and politics*. Philadelphia, PA: University of Pennsylvania Press.

Bickenbach, J. E. (1993). *Physical Disability and Social Policy*. Toronto: Toronto University Press.

Bloom, A. L. (2000). *Health Reform in Australia and New Zealand*. Melbourne: Oxford University Press.

Boswell, G. (1997). The role of the practice teacher. In M.Davies (Ed.), *The Blackwell Companion to Social Work.* Oxford: Blackwell.

Brearley, C. P. (1982). *Risk and Ageing.* London: Routledge and Keegan Paul.

Brechin, A., & Swain, J. (1988). Professional /Client Relations: Creating a "working alliance" with people with learning difficulties. *Disability, Handicap and Society, 3*(3).142-149.

Bricher, G. (2000). Disabled people, health professionals and the social model of disability: can there be a research relationship? *Disability and Society, 15*(5), 781-793.

Brisenden, S. (1986). Independent Living and the medical model of Disability. *Disability, Handicap and Society, 1*(2).53-62.

Charmaz, K. (1983). Loss of self:a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness, 5*(2), 168-195.

Chinn, P. L., & Kramer, M. K. (1991). *Theory and Nursing, a systematic approach.* St Louis, MO: Mosby.

Clandinin, D., & Connelly, F. (1994). Personal experience methods. In N. Denzin & Y. Lincoln (Eds.), *Handbook of Qualitative Research.* London: Sage.

Clarke, J., Cochrane, A., & McLaughlin, E. E. (1994). *Managing Social Policy.* London: Sage.

Committee on Quality of Health Care in America, (2000). *Crossing the Quality Chasm: A New Health System for the 21st Century.* Washington: Institute of Medicine.

Connelly, N. (1988). *Care in the Multi-Racial Community.* London: PSI.

Connelly, N. (1990). *Between Apathy and Outrage:Voluntary Organisations in Multi-Racial Britain.* London: PSI.

Coulshed, V. (1991). *Social Work Practice.* (2nd ed.). London: Macmillan.

Crisp, R. (2000). A qualitative study of the perceptions of individuals with disabilities concerning health and rehabilitation professionals. *Disability and Society, 15*(2), 355-367.

Curnock, K., & Hardiker, P. (1979). *Towards Practice Theory: Skill and methods in social assessments.* London: Routledge & Keegan Paul.

Dalrymple, J., & Burke, B. (1995). *Anti-oppressive Practice: Social care and the law.* Buckingham: Open University Press.

Davidson, C., & Tolich, M. (1999). *Social Science Research - Many paths to understanding*. Auckland: Pearson Education New Zealand.

Davies, M. (1994). *The Essential Social Worker*. Aldershot: Arena.

Davis, P. (1981). *Health and Health Care in New Zealand*. Auckland: Longman Paul.

Denzin, N. K. (1989). *Strategies of Multiple Triangulation. The research act: A theoretical introduction to sociological methods*. New Jersey: Prentice-Hall.

Deutsch, A. (1949). *The Mentally Ill in America: A history of their care and treatment from colonial times*. New York: Columbia University Press.

Dromi, P., and Weil, M. (1984). 'Social Group Work Values: Their Role in a Technological Age'. Paper presented at the 6th Annual Symposium of Social Work With Groups, Chicago.

Dyson, R. (2001). Cabinet Decision on Disability Support Services Funding. Letter to Chief Executive Officer, Waitemata District Health Board, Auckland.

Egan, G. (1990). *The Skilled Helper: A systematic approach to effective helping*. Pacific Grove, CA: Brooks Cole.

Feltham, C., & Dryden, W. (1993). *Dictionary of Counselling*. London: Whurr.

Finkelstein, V. (1981). Disability and the helper/helped relationship: an historical overview. In B. A & P.Liddiard & J. Swain (Eds.), *Handicap in a Social World*. Seven Oaks: Hodder and Stoughton.

Fossbinder, D. (1994). Patient perceptions of nursing care. *Journal of Advanced Nursing, 20*, 1085-1093.

Foucault, M. (1967). *Madness and Civilization: A History of insanity in the age of reason*. London: Tavistock.

Foucault, M. (1973). *Birth of the Clinic; An archeology of medical perception*. New York: Pantheon Books.

Foucault, M. (1979). *Discipline and Punish: The birth of the prison*. New York: Pantheon Books.

French, S. (1994). Disabled health and welfare professionals. In S. French (Ed.), *On Equal Terms: Working with disabled people*. Oxford: Butterworth-Heinemann.

Friedson, E. (1986). *Professional Powers: A study of the institutionalization of formal knowledge*. Chicago: University of Chicago Press.

Frost, N. (2001). Professionalism, change and the politics of lifelong learning. *Studies in Continuing Education, 23*(1), 5-17.

Gifford, A. L., Laurent, D. D., & V. M. Gonzales, et al., (1998). Pilot randomized trial of education to improve self-management skills of men with symptomatic HIV/AIDS. *J. Acquired Immune Deficiency Syndrome (Human Retroviral), 18*(2), 136-144.

Greenfield, S. Kaplan, S. H., J., & E. Ware , J. (1985). Expanding patient involvement in care: effects on patient outcomes. *Journal of International Medicine, 102*, 520-528.

Greenfield, S., Kaplan, S. H., & John E. Ware , J., et al. (1988). Patients' participation in medical care: effects on sugar control and quality of life in diabetes. *Journal of General International Medicine, 3*, 448-457.

Gutridge, A. W. (1905). 'Investigation'. Paper presented at the Proceedings of the Naional Conference of Charities and Correction, Portland, Oregon.

Halldorsdottir, S. (1997). Implications of the caring/competence dichotomy. In S. E. Thorne & V. E. Jaues (Eds.), *Nursing Praxis: Knowledge and action*. Thousand Oaks, CA: Sage.

Harris, C. (1983). Associational participation in old age. In D. Jerrome (Ed.), *Ageing in Modern Society*. London: Croom Helm.

Harrison, A. (2000). Choice is a gift from the patient to the doctor, not the other way around. *British Medical Journal, 320.(2)*.1075-1085.

Havighurst, R., Neugarten, B., & Sheldon, S. (1968). Disengagement and patterns of ageing. In B. Neugarten (Ed.), *Middle Age and Ageing: A reader in social psychology*. Chicago: University of Chicago Press.

Hay, I. (1989). *The Caring Commodity*. Oxford: Oxford University Press.

Hepworth, D., & Larsen, J. (1990). *Direct Social Work Practice.* (3rd ed.). Belmont CA: Wadsworth Press.

Howe, D. (1996). Surface and depth in social work practice. In N. Parton (Ed.), *Social Theory, Social Change and Social Work*. London: Routledge.

Hutchison, T. (1995). The classification of disability. *Archives of Disease in Childhood, 73*, 91-95.

Illich, I. (1977). *Disabling Professions*. London: Marion Boyars.

Imrie, R. (1997). Rethinking the relationships between disability, rehabilitation, and society. *Disability and Rehabilitation, 19*, 263-271.

Jamrozik, A., & Nocella, L. (1998). *The Sociology of Social Problems*. Cambridge: Cambridge University Press.

Janes, N. M., Wells, D. L., & Daly, J. (1997). Elderly patients' experiences with nurses guided by Parse's theory of human becoming. *Clinical Nursing Research, 6*(3), 205-224.

Jarrett, R. L. (1993). Focus group interviewing with low-income, minority populations: A research experience. In D.L.Morgan (Ed.), *Successful Focus Groups: Advancing the state of the art.* Newbury Park, California: Sage.

Jewson, N. (1974). Medical knowledge and the patronage system in eighteenth century England. *Sociology, 8*, 369-385.

Johnson, T. J. (1972). *Professions and Power*. London: The Macmillan Press.

Johnstone, P. E. (1969). How medical social work developed in New Zealand. *New Zealand Social Worker, 5*, 35-37.

Kane, R. (1988). Introduction. *Generations, 12*(5), 5-6.

Kaplan, S., Greenfield., S., & John E. Ware, J. (1989). Assessing the effects of physician-patient interactions on outcomes of chronic disease. *Medical Care, 27*(3, Supplement), S110-127.

Kitzinger, M. (1994). Focus groups: method or madness. In M. Boulton (Ed.), *Challenge and Innovation: Methodological advances in social research on HIV/AIDS*. New York: Taylor & Francis.

Kivnick, H. Q., & Murray, S. U. (1997). Vital involvement: an overlooked source of identity in frail elders. *Journal of Aging and Identity, 2*(3), 205-225.

Kron, T. (1972). *Communication in Nursing* (2nd ed.). Philadelphia: WB Saunders.

Krueger, R. A. (1994). *Focus Groups: A practical guide for applied research* (2nd ed.). Thousand Oaks, CA: Sage.

Lavery, S. M. (1996). 'Disability and employment: the move to market power'. Paper presented at the 18th World Congress Rehabilitation International, Auckland.

Lawton, M. P., Moss, M., & Dunamel, L. M. (1995). The quality of life among elderly care receivers. *Journal of Applied Gerontology, 14*(2), 150-171.

Le Grand, J., & Bartlett, W. (1993). *Quasi Markets and Social Policy*. London: Macmillan.

Liaschenko, J. (1997). Knowing the patient. In S. E. Thorne & V. E. Hays (Eds.), *Nursing Praxis:Knowledge and action*. Thousand Oaks, CA: Sage.

Lishman, J. (1991). *Handbook for Practice Teachers in Social Work.* London: Jessica Kingsley.

Lloyd, M. (1992). Does she boil eggs? Towards a feminist model of disability. *Disability, Handicap and Society, 7*(3), 207-221.

Longmore, P. K. (1987). Uncovering the hidden history of people with disabilities. *Reviews in American History, 15*, 355-364.

Lorig, K. R., Mazonson, P. D., & Holman., H. R. (1993). Evidence suggesting that health education for self management in chronic arthritis has sustained health benefits while reducing health care costs. *Arthritis Rheumatism, 36*(4), 439-446.

Macdonald, K. M. (1995). *The Sociology of the Professions.* London: Sage Publications Ltd.

Manoleas, P. (1996). *The Cross-Cultural Practice of Clinical Case Management in Mental Health.* New York: The Haworth Press.

Margolin, L. (1997). *Under the Cover of Kindness:The Invention of social work.* Virginia: The University Press of Virginia.

McKnight, J. (1977). Professionalized Service and Disabling Help, in Illich, I. (Ed). *Disabling Professions.* London: Marion Boyars.

Middleton, L. (1997). *The Art of Assessment.* England: Venture Press.

Milner, J., & O'Byrne, P. (1998). *Assessment in Social Work.* Basingstoke: Macmillan.

Minford, P. (Ed.). (1987). *The Role of the Social Services: A view from the new right.* London: Sage.

Ministry of Health (1994a). *Disability Support Services: The New Zealand Framework for Service Delivery.* Wellington: Ministry of Health.

Ministry of Health. (1994b). *Standards for Needs Assessment for People with Disabilities.* Wellington: Ministry of Health.

Moore, A., & Tennant, M. (1997). *Who is Responsible for the Provision of Support Services for People with Disabilities?* Wellington: National Health Committee.

Morgan, D. L. (1997). *Focus Groups as Qualitative Research* (2nd Edition ed.). London: Sage Publications.

Morris, J. (1991). *Pride Against Prejudice.* London: Virago.

Morris, J. (1992). Personal and Political: a feminist perspective on researching physical disability. *Disability, Handicap and Society, 7*(2).81-94.

Morse, J., & Field, P. (1995). *Qualitative Research Methods for Health Professionals.* (2nd ed.). Thousand Oaks, CA: Sage.

Mulrooney, C. P. (1997). 'Competencies needed by formal caregivers to enhance elders' quality of life: the unitility of the 'Person-and Relationship-Centred Caregiving (PRCC) Trait' Paper presented at the Sixteenth Congress of the International Association of Gerontology, Adelaide.

Munford, R. (1994). Reclaiming our rights to citizenship. *Social Work Review, 6*(3), 5-11.

Munford, R., & Nash, M. (1994). *Social Work in Action*. Palmerston North: Dunmore Press.

Munford, R., & Sanders, J. (2000). Getting to the heart of the matter: Making meaning - three challenges for family researchers. *Qualitative Health Research, 10*(6), 841-852.

Munford, R., & Sullivan, M. (1997). Social theories of disability: The insurrection of subjugated knowledges. In P. O'Brien & R. Murray (Eds.), *Human Services: Towards Partnership and Support*. Palmerston North: Dunmore Press.

Munro, K., & Elder-Woodward, J. (1992). *Independent Living*. Edinburgh: Churchill Livingstone.

Nelson-Jones, R. (2000). *Introduction to Counselling Skills: Text and activities*. London: Sage.

Nilsson, M., Ekman, S., & Sarvimaki, A. (1998). Ageing with joy or resigning to old age: older people's experiences of the quality of life in old age. *Health Care in Later LIfe, 3*(2), 94-110.

Nolan, M., Davies, S., & Grant, G. (Eds.). (2001). *Working with Older People and Their Families: Key issues in policy and practice*. Philadelphia: Open University Press.

NZASW, (1971). *Social Welfare at the Crossroads: Report on social welfare in New Zealand*. Wellington: New Zealand Association of Social Workers.

O'Brien, P., & Murray, R. (1998). *Human Services: Towards partnership and support*. Palmerston North: Dunmore Press.

Oliver, M. (1983). *Social Work with Disabled People*. Basingstoke: Macmillan.

Oliver, M. (1992). Changing the social relations of research production. *Disability, Handicap and Society, 7*(2) 76-82.

Oliver, M. (1996). *Understanding Disability, From theory to practice.* London: Macmillan Press Ltd.

Oliver, W. H. (1977). The origins and growth of the welfare state. In A.D.Trlin (Ed.), *Social Welfare and New Zealand Society.* Wellington: Methuen.

Opie, A. (1997). *Teams as author: narrative and knowledge creation in case discussions in multi-disciplinary health teams* (Vol. 2, no.3). Sociological Research Online.

Opie, A. (1998). "Nobody's asked me my view": Users' empowerment by multidisciplinary health teams. *Qualitative Health Research, 8*(2), 188-206.

Orchard, L. (1998). Public sector reform and the Australian way. In P. Smyth & B. Cass (Eds.), *Contesting the Australian Way: States, Markets and Civil Society.* Cambridge: Cambridge University Press.

Pardeck, J. T., J.W., M., & Min Choi, J. (1994). Some implications of postmodernism for social work. *Social Work, 39*(4), 343-346.

Parker, G. (1993). *With this Body: Caring and disability in marriage.* Milton Keynes: Open University Press.

Parry, N., & Parry, J. (1976). *The Rise of the Medical Profession.* London: Croom Helm.

Patton, M. Q. (1990). *Designing Qualitative Studies* (2nd Ed. ed.). London: Sage.

Rapp, C. (1992). The Strengths Perspective of case management with persons suffering from severe mental illness. In D. Saleeby (Ed.), *The Strengths Perspective in Social Work Practice.* (pp. 45-58). New York: Longman.

Reinken, J. (1988). Health: A brief historical overview. *Royal Commission on Social Policy, IV*(April).

Rice, P. L. & Ezzy, D. (2000). Qualitative Research Methods: A health focus. Melbourne: Oxford University Press.

Robb, J. H. (1974). Medical social work. In D.W.Beaven & B.H.Easton (Eds.), *The Future of New Zealand Medicine: A progressive view.* Christchurch: Peryer.

Rodwell, C. M. (1996). An analysis of the concept of empowerment. *Journal of Advanced Nursing, 23*(2), 305-313.

Rose, S. M. (1992). *Case Management: An empowerment/advocacy design.* New York: Longman.

Rothman, D. (1971). *The Discovery of the Asylum: Social Order and disorder in the new republic.* Boston: Little Brown.

Saleeby, D. (1992). *The Strengths Perspective in Social Work Practice.* New York: Longman.

Sarantakos, S. (1993). *Social Research.* Melbourne: Macmillan Education Australia.

Schneider, B. (1988). Care Planning: The core of case management. *Generations, 12*(5), 16-18.

Schofield, V. (2001). Health social work. In M. Connolly (Ed.), *New Zealand Social Work.* Auckland: Oxford University Press.

Schutz, A. (1967). *The Phenomenology of the Social World.* Evanston, Illinois: Northwestern University Press.

Seden, J. (1999). *Counselling Skills in Social Work.* Buckingham: Open University Press.

Seidman, I. (1991). *Interviewing as Qualitative Research.* New York: Teachers College Press.

Shakespeare, T., Gillespie-Sells, K., & Davies, D. (1996). *The Sexual Politics of Disability.* London: Cassell.

Shanas, E., Townsend, P., & Wedderburn, D. et al., (1968). *Old People in Three Industrial Societies.* London: Routledge & Keegan Paul.

Sheridan, A. (1980). *Michel Foucault: The will to truth.* London: Tavistock Publications.

Shipley, T. H. J., & Upton, T. H. S. (1992). *Support for Independence for People with Disabilities.* Wellington: National Government.

Smale, G., Tuson, G., & Brehal, N. a. M., P. (1993). *Empowerment, Care Management and the Skilled Worker.* London: National Institute for Social Work.

Stacey, M. (1988). *Sociology of Health and Healing.* London: Unwin Hyman.

Stacey, M. (1992). *Regulating British Medicine: The General Medical Council.* Chichester, UK: John Wiley & Son.

Steinberg, R. M., & Carter, G. W. (1983). *Case Management and the Elderly.* Lexington, Massachusetts: D.C. Heath and Company.

Stewart, D. W., & Shamdasani, P. N. (1990). *Focus Groups: Theory and Practice* (Vol. 20). Newbury Park, CA: Sage.

Stone, D. (1984). *The Disabled State.* Philadelphia: Temple University Press.

Stone, E., & Priestley, M. (1996). Parasites, pawns and partners: disability research and the role of non-disabled researchers. *British Journal of Sociology, 47*, 696-716.

Strauss, A. L., & Corbin, J. M. (1988). *Shaping a New Health Care System: The experience of chronic illness as a catalyst for change*. San Francisco, CA: Jossey Bass.

Strauss, A. L., Corbin, J. M., & Fagerhaugh, S. et al., (1984). *Chronic Illness and the Quality of Life*. St Louis, MO: Mosby.

Sullivan, M. (1998). Contemporary policy developments in disability support services: social work practice under difficult circumstances. *Social Work Review, X*(2).

Sullivan, W. P., & Fisher, B.J. (1994). Intervening for success: Strengths-based case management and successful aging. *Journal of Gerontological Social Work, 22*(1/2), 61-74.

Sullivan, W. P., Wolk, J., & Hartmann, D. (1992). Case Management in alcohol and drug treatment: improving client outcomes. *Families in Society, 73*, 195-203.

Sundeen, S., Stuart, G., Rankin, E. A. D., & Cohen, S. (1994). *Nurse-Client Interaction: Implementing the nursing process* (5th ed.). Missouri: Mosby.

Tagg, S. (1985). Life story interviews and their interpretations. In M.Brenner & J. Brown & D. Conater (Eds.), *The Research Interview*. London: Academic Press.

Tanner, C. A., Benner, P., Chesla, C., & Gordon, D. (1996). The phenomenology of knowing the patient. In S. Gordon & P. Benner & N. Noddings (Eds.), *Caregiving: Readings in knowledge, practice, ethics and politics.* Philadelphia, PA: University of Pennsylvania Press.

Taylor, M., Hodges, L., Lart, R., & Means, R. (1992). User empowerment in community care: Unravelling the issues. *Studies in Decentralisation and Quasi-Markets, No 11*.Bristol University.

Taylor, S., & Bogdan, R. (1998). *Introduction to Qualitative Research Methods*. New York: John Wiley & Sons.

Tennant, M. (1996). Disability in New Zealand: An historical survey. *New Zealand Journal of Disability Studies, 2*,3-33.

Thomas, C. (1999). *Female Forms: Experiencing and understanding disability.* USA: Open University Press.

Thorne, S., & Paterson, B. (1998). Shifting images of chronic illness. *Image:Journal of Nursing scholarship, 30*(2), 173-178.

Trevithick, P. (2000). *Social Work Skills: a practice handbook.* Buckingham: Open University Press.

Tuckett, D., Boulton, M., Olson, C., & Williams, A. (1985). *Meetings between Experts: An approach to sharing ideas on medical consultations.* London: Tavistock.

Turnbull, A. P., & Turnbull, H. R. (1990). *Families Professionals and Exceptionality: A special partnership.* New York: Merrill.

Upton, S. (1991). *Your Health and the Public Health: A statement of Government health policy.* Wellington: Ministry of Health.

van Dersal, W. (1974). How to be a good communicator - and a better nurse. *Nursing, 4*(58).

Walby, S., & Greenwell, J. (1994). Managing the National Health Service. In Clarke, J. Cochrane, A. & E. McLaughlin (Eds.), *Managing Social Policy.* London: Sage.

Weil, M., Karls, J., & Associates. (1985). *Case Management in Human Service Practice.* San Francisco, CA: Jossey-Bass Inc.

Wendell, S. (1996). *The Rejected Body:Feminist philosophical reflections on disability.* New York: Routledge.

Wicks, W. (1993). *Personal commentary*, Open Health Forum Seminar, Wellington.

Wilcox, S. (1989). A different centre. In S. Wilcox (Ed.), *American Deaf Culture: An anthology.* Silver Spring, MD: Linstok Press.

Williams, J. (1993). What is a profession? Experience versus expertise. In J. Walmsley & J.Reynolds & P. Shakespeare & R. Woolfe (Eds.), *Health, Welfare and Practice: Reflecting on roles and relationships.* London: Sage Publications.

Williamson, C. (1992). *Whose Standards? Consumer and Professional Standards in Health Care.* Buckingham: Open University Press.

Woods, R. A. (1911). *University Settlements as Laboratories in Social Science.* Paper presented at the International Congress of Charities, Correction, and Philanthropy, Chicago.

Zola, I. K. (1977). Healthism and Disabling Medicalization, in Illich, I. (Ed) *Disabling Professions.* London: Marion Boyars.

Zola, I. K. (1993). Self, identityand the naming question: reflections on the language of disability. *Social Science and Medicine, 36*(2), 167-173.

Appendix – Ethics Proposal

Massey University

Application to Human Ethics Committee

Name	Sue Foster
Status of Applicant	Masters Student
Department	School of Social and Cultural Studies
Name of Employer	Centre for Social Work Auckland College of Education
Project Status	Masters of Social Work thesis
Title of Research	An analysis of the skills and knowledge base for Needs Assessment and Service Co-ordination
Attachments	Information Sheet Consent Form
Supervisors	Neil Lunt, Department of Social and Cultural Studies Albany Professor Robyn Munford, Department of Social Policy and Social Work Palmerston North

Signatures	Researcher
	Supervisor
Date	18 March 2001

1 DESCRIPTION

1.1 Justification

The creation of the Needs Assessment and Service Coordination role from 1995 is an attempt to respond to disabled peoples' needs for service in a more equal and participatory way. Domestic research and commentary on the role of needs assessors, from both the workers' and the consumers' point of view, is scarce. This thesis will use focus groups, and interviews with key stakeholders, to examine the skill base, both actual and desired, of the NASC workers from two service providers, the Disability Resource Centre, and Waitemata District Health Board. (DHB) This will require input from both professionals and consumers of the services. The information gained will be used to contribute to the training needs for NASC workers for the future.

1.2 Objectives

To determine an understanding of:

- the role and
- skills-base of the Needs Assessor and Service Co-ordinator.
- explore the perceived training needs of NASC professionals.
- To determine the perceptions of consumers in relation to the process of needs assessment.
- To compare professional/consumer perceptions of the skill-base required.

1.3 Procedures for recruiting participants and obtaining informed consent

- Three focus groups will be constituted to gather information and data. These groups will consist of two professional groups and one consumers' group. All groups will meet once (i.e. 3 focus groups). If any members of the groups would prefer individual interviews the researcher will accommodate this. These interviews would then be conducted under the same conditions as those laid out for individual stakeholders interviews.

- Participants will be recruited from two different providers: one group of workers will be drawn from the Waitemata DHB, who hold the contract to provide the Needs Assessment and Service Coordination service to the elderly, (over 65), and the other group will be drawn from the Disability Resource Centre who hold the contract for the 16 to 64 age group. A consumers' group will be drawn from the latter service.
- The Managers of both services will be contacted and asked to participate in the research, by allowing the researcher access to participants. If permission is granted then they will be asked to provide the Information Sheet on the research to the workers. The workers will then be invited to a meeting where the information will be clarified, and at that point will be invited to participate in the focus group. (Both managers have already indicated a willingness to participate).
- The researcher will ask the managers of both services for permission to access the caseloads of the agencies, from which a random sample of potential participants will be drawn. The researcher will write to the consumers inviting them to take part in the research, and giving them an outline of the purpose of the research. If the consumers are willing to participate they will be asked to contact the researcher. When the consumer has contacted the researcher, the researcher will send an Information sheet and invite the consumers to attend a consumer focus group. All consumers taking part in the research will be paid for their time.
- Informed consent will be obtained before the focus groups. The Consent Form will be posted to participants when they have indicated a willingness to participate in the research. They will have the opportunity to discuss with the researcher any concerns they have about participating in the research.
- Further to the focus groups, a number of key informants will be recruited by the researcher, based on the researcher's prior knowledge of the field. These key informants will include 2 managers of the services involved,

and two people involved in the area of training. Informed consent will also be gained from these people.

1.4 Procedures in which research participants will be involved

- Participants will be asked to attend 1 focus group meeting. These meetings will last approximately 2 hours each.
- Should individual interviews be preferred, these will take approximately one hour.
- The researcher will facilitate the meetings, which will take the form of a discussion based on a number of themes that will be sent to the participants prior to the meeting.
- These meetings will be audio recorded for the purpose of transcribing the information gathered. If someone, other than the researcher, is employed to transcribe the audiotapes, then this person will be subject to the provisions of a confidentiality agreement.
- Participants may withdraw from the research at any stage of their involvement.
- The consumers' focus group will be made up of disability consumers. Therefore participants will be invited to bring carers / interpreters / support people if necessary. These support people will be required to sign a Consent Form before the focus group meeting.

1.5 Procedure for handling information and material produced in the course of the research

The information gathered from the focus groups and the key informants will be transcribed from the tapes recorded. This transcription will not identify individual participants and their confidentiality and anonymity is guaranteed. Participants will be identified by pseudonyms. The final research information will be used to fulfil the partial requirements for the Masters of Social Work. The information may potentially be used for subsequent publications by the

researcher and supervisors. No information will be published that will indicate the identity of participants.

1.6 Procedures for sharing information with the research participants

The results of the research will be reported back to both agencies concerned. At the convening of each focus group the researcher will discuss with the participants the best way to keep them in touch with the research.

A written summary of the results will be sent to all individual participants.

1.7 Arrangements for storage and security, return, disposal or destruction of data

Steps taken to secure data will include:

- Secure storage of both tapes and transcripts in separate locations in the researcher's office.
- Separate storage of paper and disk copies of interview transcripts. All interview transcripts will be locked in a filing cabinet, which will only be able to be accessed by the researcher.
- Destruction of the tape recordings of interviews once the thesis has been completed and the examination process concluded (unless interviewees choose to have recordings returned to them).

2 ETHICAL CONCERNS

2.1 Access to participants

- Access to participants is at this stage primarily reliant on the approval of the agencies named and the involvement of their consumers.
- Both groups will be provided with an Information Sheet. In the first instance, the Information sheet will be given to all the workers by the Manager of the service at weekly meeting. The managers of the agencies

will also be asked to address the Information sheet to consumers and ask for their permission to be contacted by the researcher.

- Once contact has been made between the researcher and the participants, they will be provided with the Consent Form.
- The agencies concerned have already indicated their willingness to participate in this research, and to be involved in contacting consumers. However if for any reason the organization did not want to be involved in the recruiting of consumer participants then the researcher would advertise for participants. This would involve taking out advertisements in regional newspapers, community newsletters and on noticeboards at social service agencies, as well as verbally notifying voluntary agencies. The advertisement would simply state the nature of the research and the desire for consumers past and / or present of the agencies concerned to contact the researcher if they are interested in participating. Participants would then be sent the information sheet, consent form and question sheet prior to the arranged meeting time.

2.2 Informed consent

All of the participants will be provided with an Information Sheet on the research. If they agree to participate their consent will be sought. They will be provided with the Consent Form prior to their participation in the focus group meeting. It will be made clear to all participants that they can withdraw from the focus groups/interviews at any stage and that they can ask the researcher questions about the research and their involvement at any stage.

2.3 Anonymity and confidentiality

All participants in the focus groups will be ensured anonymity and confidentiality. The transcribing of the tapes of the focus groups will provide pseudonyms. The data will be aggregated and where quotes are used pseudonyms will be used. Participants will be provided with the text that includes their quote and will be asked to consent to the use of the quote. At no

time will participants' identity be exposed. Furthermore, collected data will be stored appropriately to safeguard the information.

Key informant interviews will also be recorded and transcribed. Again no identifying names will be used, although it is recognised that anonymity may be more difficult to guarantee in this instance. As a safeguard, participants will be provided with the text that includes their material for comment and feedback, however the nature of the research does not include the collection of sensitive data.

2.4 Potential harm to participants

The undertaking to provide confidentiality, anonymity and the safe storage of data will minimise the likelihood of harm.

2.5 Potential harm to researcher

No harm to the researcher is envisaged.

2.6 Potential harm to the university

No harm to the University can be identified.

2.7 Participants' Right to decline to take part

Consumers and professionals can decline involvement. Participants will be informed of their rights when they receive their Information Sheet and Consent Form. All participants have the right to withdraw from the research during any time in the 3-month interval following the focus group, and this will be clearly explained to them in the Consent form.

2.8 Uses of the information

The information gathered while doing this research will only be used for the Masters Thesis and for any subsequent publications and conference presentations that result from the thesis. A copy of the thesis will be sent to the agencies involved and be made available to the participants to access. An executive summary of the research findings will be sent to all participants.

2.9 Conflict of interest / roles

The research is being carried out to fulfil the requirements for the Masters of Social Work and presents no conflict of interest for the researcher.

2.10 Other ethical concerns

No other ethical concerns are identifiable.

3 LEGAL CONCERNS

3.1 Legislation

3.1.1 Intellectual property legislation – e.g. Copyright Act (1994)

All research data, analyses and reports will belong to the researcher.

3.1.2 Human Rights Act (1993)

Participants will be treated with dignity and respect. There is no mechanism within the research for the participants to be discriminated against. All measures that are practicable will be employed to ensure the needs of consumers and workers are met for their equal participation.

3.1.3 Privacy Act (1993)

All of the information collected will only be used for stated purposes, and will not be privy to any other parties in the raw form. Participants

will be asked to give their consent for the information they provide to be used within the parameters of the study.

In accordance with the Health Information Privacy Code, the agencies involved, (DRC and Waitemata DHB), will not provide the researcher with information that identifies consumers or allows the researcher to contact consumers, until consumers have given their consent to the agency.

3.1.4 Health and Safety in Employment Act (1992)

No relevance to the present study.

3.1.5 Accident Insurance Act (1998)

No relevance to the present study.

3.1.6 Employment Relations Act (2000)

No relevance to the present study.

3.2 Other Legal Issues

None.

4 CULTURAL CONCERNS

The ability of the workers to meet the needs of consumers of different cultures will be a focus of the research, and it is expected that both the consumer and the worker focus groups will be multi-cultural. The researcher undertakes to be monitored by both Maori and Pacific Island consultants, and will undertake to be knowledgeable about, and sensitive to, the cultural differences of Maori and Pacific Island members of the focus groups. The researcher has identified a Maori and Samoan social worker, who are both familiar with research processes, and will meet with them prior to the focus group meetings, to review the meeting process, and ensure sensitivity with the collection of material.

5 OTHER ETHICAL BODIES RELEVANT TO THIS RESEARCH

5.1 Ethics Committees

Should it be necessary this proposal will be presented to the Ethics Committee of Waitemata DHB following the presentation to this committee.

5.2 Professional Codes

This research is not subject to any professional codes as such, however the codes of ethics that guide the professions of the NASC workers, (such as NZNO, ANZASW) will be taken into consideration and will not be breached while conducting this research.

6 OTHER RELEVANT ISSUES

None.

INFORMATION SHEET TO PROFESSIONALS

Researcher	Sue Foster
Contact details	Department of Social and Cultural Studies Massey University Private Bag Albany
Phone (Private)	09 8186003
Supervisors	Neil Lunt, Massey University, Albany Professor Robyn Munford, Massey University Palmerston North
Phone	09 443 9700 x 9041

I am writing to seek your assistance in a piece of work I am currently engaged in around needs assessment. The research examines the role and skill base of the Needs Assessors and Service Co ordinators. The purpose of this research is to clarify the skills that are utilised and required in this complex role, and I intend to use the information gained to develop training packages that are specifically targeted to the needs and the development of the Needs Assessment and Co ordination Service in the Auckland area. The information gained may also be used as a basis for articles for future publications.

I want professionals to help me identify these skills. To this end I am organising two focus groups for NASC workers. Each group will meet once. The questions asked will be based around your knowledge and experience, and you will be provided with themes for discussion before the meeting. If everyone agrees, the discussion will be audio taped to help with writing up the information gathered. Each meeting will take approximately two hours, and refreshments will be provided.

If you agree, your formal consent will be obtained before the meeting. I will send you a Consent form, and an outline of the themes that will be discussed at the meeting. You can contact me if you have any questions about the Consent Form or the research. All participants will be kept informed about the work and receive an individual summary of the

report. You will not be identified in the research. If I quote you in the research, I will use a pseudonym. The information gathered will be used for the purposes of the research, and possibly as a basis for subsequent publications by myself and my supervisors.

I would very much value the knowledge and experiences you can share. If you would like to participate in the research or wish to raise any further questions with me before deciding whether or not to participate, then please do not hesitate to contact me.

INFORMATION SHEET TO CONSUMERS

Researcher	Sue Foster
Contact details	Department of Social and Cultural Studies Massey University Private Bag Albany
Phone (Private)	09 8186003
Supervisors	Neil Lunt, Massey University, Albany Professor Robyn Munford, Massey University Palmerston North
Phone	09 443 9700 x 9041

Dear

I am writing to ask for your help in a piece of research that examines the assessment processes for services. This research is part of my studies as a Masters student in social Work. I am currently teaching at the Centre for Social Work, Auckland College of Education where I have been for the last 4 years. Prior to that I spent 15 years working in health social work.

I want to have separate discussions with assessors and consumers. I am going to explore the skill base by holding 3 focus groups, 2 for NASC workers and one for consumers. Each group will meet once. The questions I will pose will be based around your experience as a consumer, and your perception of the role and skill of the NASC workers you have been involved with. I will provide you with the general themes for discussion prior to the meeting. If everyone agrees the discussion will be audio taped to help with writing up the information gathered.

This meeting is expected to take approximately 2 hours, and refreshments (tea/coffee and food) will be provided. I am happy to assist with transport needs if required. Carers and

support people are welcome to accompany you, but it is **your** views I am seeking. Please let me know if an interpreter is required.

I would very much value the knowledge and experiences you could bring to the meeting, and will pay you for the time that you spend in the focus group.

If you wish to participate in the research or wish to raise any further questions with me before deciding whether or not to participate, then please do not hesitate to contact me. Your formal consent will be obtained before the meeting.

INFORMATION SHEET TO ORGANISATIONS

Dear

I am writing to seek your assistance in a piece of research I am currently undertaking as part of the requirements of a Masters of Social Work. The research is an analysis of the skill base of the Needs Assessment and Service Co ordination Service. The purpose of this particular research is to gain information that can be used to develop tertiary training packages specifically designed for this function, but to do this, I need to have a good understanding of the skills that the Needs Assessors and Service Co ordinators identify as being essential, as well as the skills they think they need to develop.

To this end, I would like to interview some members of the Needs Assessment and Service Co ordination group in your service. I intend to organise 2 focus groups, one from your organisation, Waitemata District Health Board, and the other from the Disability Resource Centre in Royal Oak. The intention is to compare the skill base of these groups, as the skills required for working with the older population, (over 65) may well be different from that required to work with the adult population (16-64 age group). The general themes will be based around the knowledge base and experience of the members of the focus group, and will be provided to the members prior to the focus group meeting. I expect the focus group, (6-8 people), to meet for a period of two hours. As well, I would like to include a consumer focus group, (gained from the caseload from the Disability Resource Centre) as I think it is important to gain a consumer perspective on service delivery, and they have an important part to play in the development of training packages.

I would also like to interview you as a key informant, as I consider your perception of the development of the role of the NASCs and the training needs in the area to be an important contribution to the research information. As it may be difficult to ensure anonymity, I will submit material where you are quoted to you for your permission to include, prior to my submitting it for publication.

I would very much appreciate your consideration of this proposal. The NASC participants in the research will not be identified and all will receive an individual summary of the report. I will also furnish your organisation with the completed thesis, which I would be happy to discuss further with you. Should you agree to this proposal, I am happy to meet at your convenience, to arrange the meeting time and place of the focus group.

INFORMATION SHEET FOR INDIVIDUALS

Dear

I am writing to seek your assistance in a piece of research I am currently undertaking as part of the requirements of a Masters in Social Work. The research concerns an analysis of the skill base of the Needs Assessment and Service Co ordination Service. The purpose of this particular research is to gain information that can be used to develop tertiary training packages specifically designed for this function.

I would like to interview you as a key informant to this research, particularly because of your expertise in and knowledge of the Needs Assessment and Coordination Service. Your experience as a consumer of these services, as well as your general expertise in the disability area is invaluable in helping me to gain an understanding of the skills required for this important role.

As well as interviewing yourself I will be organising 3 focus groups, one from Waitemata District Health Board, whose service has the contract for the Needs Assessment Service for the over 65 population, and the second from the Disability Resource Centre who have the contract to provide the same service for the adult population (between the ages of 16-64). The third group will consist of a consumer group, which will be randomly selected from the caseload of the Disability Resource Centre. My intention is to compare the skills of these two distinct NASC professionals, as the skill base required for one may be quite different for the other. It is also important to consider the views of consumers, especially as they play an important function in the development of training packages in the disability area.

If you agree, I would like to audiotape the interview to help with writing up the information gathered. However you will not be identified in the research. If I quote you in the research I will use a pseudonym. The information gathered will be used for the purposes of the research, and may be used as a basis for subsequent publications by my supervisors and myself. Should you agree to participate, I would like to discuss with you at our meeting the

best way I can keep you in touch with the progress of the research. Your formal consent will be before the meeting. I also expect to pay for your time.

If you wish to raise any further questions with me before deciding whether or not to participate, then please do not hesitate to contact me.

Analysis of the Skill base of Needs Assessors and Service Co-ordinators (NASC)

CONSENT FORM

I have read the Information Sheet and have had the details of the study 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 that I have the right to withdraw from the study for a *three-month* interval following the focus group, and to decline to answer any particular questions during the groups themselves. It will not be possible to withdraw from the research following this 3-month period.

I agree to provide information to the researcher on the understanding that my name will not be used without my permission.
(The information will be used only for this research and publications arising from this research project).

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

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

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

Signed _____

Name _____

Date _____

Susan Foster
53 Kaurilands Rd
Glen Eden
Auckland 7