Tensions, issues and challenges in Special Education in Aotearoa New Zealand

Stories of mismatch between the policies and the practice

A thesis presented in partial fulfilment of the requirements of the degree of

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Dedicated to my grandmother

Alison Hardy Dare

(1880-1954)

who had the vision and the strength to give her children and her grandchildren

opportunities that were beyond the gold mines of Karangahake.

ABSTRACT

This study identifies issues, tensions and challenges within education in Aotearoa New Zealand through the responses of nine families who talked about their experiences when supporting their children with special learning needs in regular schools. The policies and practices of the Education Act 1989 and Special Education 2000 underpin a vision of inclusive education that gives all children access to high quality learning programmes enabling them to participate and achieve at school. My interpretations of the experiences of these nine families and their children suggests that these tensions arise from mismatches between the families' expectations and the philosophies, policies and practices of health, government and educational professionals which created barriers leading to the exclusion of their children from regular school placements. This thesis argues that these tensions and issues have an adverse impact on the children and their families.

The study revealed perceptions by families that some schools practised a culture of exclusion by being unable or unwilling to meet the learning or personal care needs of their children. Barriers identified by the families included some schools being unwilling to accept their children's enrolments; the inability of some teachers to provide appropriate programmes of learning; incidents of bullying of their children by students and staff; and issues involving access to therapist support. Barriers were also identified to positive communication between families and health professionals. Issues involving the Special Education case managers were also identified by the families as contributing to the families' decisions to remove their children from their regular schools or to seek alternative education providers at times of transition to secondary school.

This study concludes with recommendations for key stakeholders outlining ways that may enhance the experiences of families and their children with special needs within inclusive education. Children with special needs and their families do have a right to the experience of inclusive education. It is the role of the key stakeholders to ensure this becomes reality for all children and their families.

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Barry's story

Meet Barry. Barry was introduced, by a psychologist, to the unit where I was teacher in charge. The unit was based within an infant school in a Kentish town. The young children enrolled in this unit were labelled 'maladjusted'. This was in the 1960s and labels were fashionable. '*He's nearly 5 and he doesn't talk. He's still not toilet trained, but I think he would fit into your group very well'. 'If you don't take him, we will have to place him in a mental hospital.*' We took him.

Barry arrived. Yes, he did not speak and he was not toilet trained, but he joined our group of seven interesting, challenging and VERY vocal students, a teacher and a teacher aide. There were certainly good language role models for Barry. Days, weeks and months passed by. Barry was soon toilet trained and he participated in all the class activities, but remained silent. The terminology 'autistic' was beginning to be heard within education and Barry's behaviours and lack of speech were placing him within this field.

One day, John asked where cream came from. '*I know cows make milk but how do they lay the cans of cream?*' Now there was a challenge for a Kiwi teacher working in Kent. Off we went to a local dairy farm to see cows being milked and the cream separator in action. Then it was off to the local milk bottling factory to watch the cream bottles being washed, dried, filled with cream and capped with shiny red tops. Throughout this visit, Barry held my hand and watched the bottles rattle along the conveyor belt. End of story: '*John, cream comes from cows*' answered Mrs Baldwin.

No! Not the end of story. That evening I answered a call from Barry's mother. '*Where have you been today? Barry's talking about soldiers marching up and down the hills'*. Barry was talking. He arrived off the taxi transport the next morning '*Good morning Mrs McIntyre, Good morning Mrs Baldwin. How are you today? Isn't it a lovely day?*' Barry was talking, talking in six-year-old sentences. Barry never stopped talking that day. He had six years of experiences to tell his classmates.

Although Barry needed ongoing support through his schooling, he reached very high standards and was granted entrance into Oxford University when he completed his secondary school courses. And this is the boy for whom a mental hospital placement was the second option for his schooling at age almost five.

Barry has been my inspiration throughout my long teaching career. Not every classroom has a cream bottling machine in the cupboard, but the challenge is to provide programmes of learning for all students to enable them to meet their potential.

Thank you Barry.

CHAPTER ONE

INTRODUCTION

> *I went to the Bank and the bank teller said to me 'Well, are they tired? You need to take them home.'*
>
> *'No they aren't. Can't you see there is obviously something wrong? They are always like this.'*
>
> *And she said 'It's OK. I will tell you. There's a place called Magic World and they've got children with all special needs. Would you like to go there? I will give you the phone number.'*
>
> *I was desperate. I took the number and went there.*
>
> (Lynda, mother of Joshua and Katrina, 2011)

1.1 Introduction

This thesis is about the tensions, issues and challenges within education in Aotearoa New Zealand. Tensions arise in any situation where there is a contradiction between the policies and practice, rights and responsibilities, beliefs and values of key stakeholders. The argument central to this research is that these tensions stem from inconsistencies within education in Aotearoa New Zealand, resulting in people, e.g. families, believing their rights are being compromised and the needs of their children are not being met.

Over the past two decades, the Ministry of Education (MoE) has promoted policies and practices that underpin an official philosophy of inclusive education where 'all students will have fair access to a quality education environment that enables them to learn successfully and participate in society' (MoE, 2012b). It is the responsibility of Ministry of Education: Special Education (MoE: SE) to translate this policy into practices that enable those working in the schools to provide programmes of learning that increase the participation of all students within the culture of the communities of regular schools (Booth, 1996, Carrol-Lind & Rees, 2009).

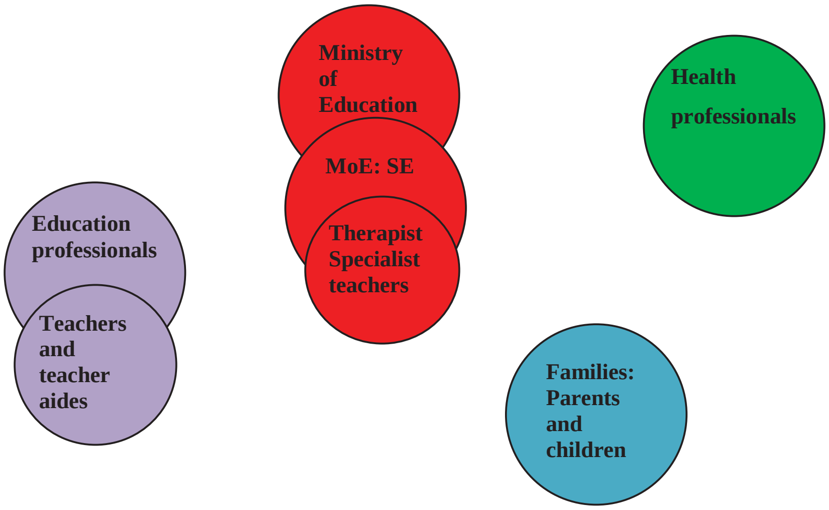
Parents have the right to expect that their children have access to programmes of learning in an environment that allows them to reach their optimum potential. It is also the responsibility of educators such as teachers, support therapists and teacher aides working in schools to meet the learning needs of all the children in their classrooms.

But does the current model of inclusive education allow these rights and responsibilities to be addressed? In this study it is argued that the education policy of the current government is not meeting the needs of students with special needs. The basis of this argument is that there is a mismatch between the rights of parents to enable their children to access and experience programmes of learning in regular schools, and the responsibilities and practices of the MoE, MOE: SE and educators to meet these needs.

The key stakeholders in this study are:

- The MoE who has responsibility for the design and establishment of policy underpinning the education of children with special learning needs.
- The MoE: SE who are responsible for the implementation of special education policy and practice.
- Education professionals and support staff who work with the children in the schools.
- The children with special learning needs enrolled in regular schools and their families.
- Health professionals who work with and support the children with special learning needs and their families.

Figure 1.1*: Key stakeholders in education in Aotearoa New Zealand*



1.2 Background

This research was undertaken in this country where all children aged between 2 and 19 years and who have right of residence in Aotearoa New Zealand, are legally entitled to attend government-funded early childhood centres and schools of their choice. Before the passing of the 1989 Education Act, responsibility for the education of children with special learning needs remained with families, residential and day special schools, psychopaedic hospitals and voluntary organisations such as the Intellectually Handicapped Children's Society (IHC) (Mitchell & Mitchell, 1985). Although, by 1964, regional education boards had undertaken responsibility for children attending the centres established by the IHC, many of these children had access only to special schools. More able children with special learning needs had been granted entry into the state education system through the establishment of special classes in 1917. The Education Act 1964, although appearing to give the right of education to all children to the age of 15, did, in Section 113, identify children who were 'suffering from a disability of the body or mind' who were not eligible to enrol in regular schools as they were perceived as 'requiring education treatment beyond that normally obtained in an ordinary class'. However it was the prerogative of individual principals to decide whether to allow children with special learning needs to enrol in their schools. Children did not have the right of automatic enrolment. There was thus no compulsion on the part of the state to provide 'free and appropriate education' for children with special learning needs (Mortlock, 1985, p. 20).

Allison Franklin tells of the experience of her acceptance into Paparoa Street School in 1964. Allison is a long-term advocate for disabled people and currently serves on the Upper South A Regional Health and Disability Ethics Committee, Meridian Energy's Consumer Advisory Panel, and the Lottery Grants Board's Individuals with Disabilities Distribution Committee.

> *Mr T (the Headmaster), no doubt had his reservations about such a 'handicapped' child as myself attending his school. I couldn't walk, my speech was very difficult to understand, and I needed full assistance with toileting and eating. He said "It's up to Miss S" (the Infant Mistress), and when Mum asked her, she replied in her slow drawl "I'll take her, Mrs Franklin". Five words that afforded me the start of a mainstream education and a great foundation for my life!! I know Mum's (and my father's)*

> *gratitude knew no bounds. It meant that Mum could take me to school on her bike, visit at lunchtime to feed and toilet me, and collect me after school. Within a year I was walking, on wobbly legs, riding my chain-drive trike to school and my future was looking bright.* (Allison Franklin, personal communication, 24 June 2012)

The Education Act 1989 gave children like Allison the right to attend regular schools. Children who were enrolled in day special schools, special units and special classes were also granted access to regular schools. Moore et al. (1999) saw the successful implementation of changes towards the inclusion of children with special needs into regular schools as being a challenging and requiring time. These authors suggested that changes were necessary to address any concerns relating to the attitudes, values and beliefs of those working in the schools if a policy advocating inclusion was to be successful.

One area of concern for principals in relation to inclusive education was the resource support available to those students with high and very high needs who were enrolling in regular schools (Butterworth & Butterworth, 1998). The funding required to meet these students' needs was included in the school's special education grant (SEG), which was in turn based on school enrolment numbers. But what was seen by one principal as a 'sinking lid policy' did not allow the funding needs of regular schools to be met: 'The politicians could not see the subsequent additional costing for changes this would put on mainstream (regular) schools' (T. Howard, personal communication, 30 June 2012). The funding and allocation of resources to support students requiring adaptations to their learning programmes thus became an issue for schools, and therefore for the MoE. In 1993, an increase in funding was granted to meet the resourcing of children with special education needs (Butterworth & Butterworth, 1998), but the shortfall in funding for such support personnel as teacher aides, psychologists and speech language therapists, continued.

To remedy this funding shortfall, Special Education 2000 (SE2000) was introduced in 1996 as a policy designed to fund resources and intervention programmes for children with special learning and behavioural needs (Kearney & Kane, 2006, p. 206). The key objective underpinning SE2000 was the achievement of 'a world class inclusive education system that provided learning opportunities of equal quality to all children and school students' (MoE, 1996, p. 5). These resourcing initiatives entitled individual students identified as having ongoing high and very high learning needs, to additional resources to meet the demands of the curriculum content of their school day, in either regular or special schools.

SE2000, claimed by McMenamin (2011) as being New Zealand's 'first inclusive education policy' (p. 97), introduced four strategies, to be administered by Group Special Education (GSE), providing additional support for teachers and children, to enable the children to participate in programmes of learning in regular schools. One strategy, the Ongoing Reviewable Resource Scheme, now known as the Ongoing Resource Scheme (ORS) was a 'student focussed funding model' (Sigafoos et al., 2010, p. 23), where additional funding to support individual students in their learning in both regular and special schools was provided over and above the funding that was already available through SEG to support children with special learning needs who were not ORS funded.

With access to these additional resources funded by SE2000 and ORS, some families chose to enrol their children with special learning needs in regular schools (MacArthur, 2009). Other families continued to choose special schools over regular schools as their preferred education provider (McMenamin, 2009). Some families, whose children attended regular schools, were concerned that these regular placements did not meet their expectations and they transferred their children to special schools.

This research investigates the experiences of nine families who, having initially selected a regular school placement as their first choice, later made the decision to transfer their children to special schools. It explores some of the tensions that were voiced by the families, and interprets them within a philosophy of inclusive education. These narratives are posited within the context of national and international literature relating to the practical and theoretical issues underpinning the families' choice of education provider for their children.

1.3 The research questions:

- What were the experiences of selected families when supporting their children with special needs in regular schools?
- Why did these families decide to move their children from regular schools to special schools?
- How does this study 'fit' within the educational ideology of inclusion?

1.4 Rationale for this study

It is the family's right to make choices for their children and, as Murray et al. (2007) stated, this right should be recommended and practised in all aspects of education. Parents are the 'driving force in obtaining special education for their children' (Brown & Moore, 2011, p. 189). With the Education Act 1989 giving all children with special learning needs the right to enrol in regular schools, parents exercised this right by making choices between regular schools and special schools.

How families understand the choices available to them and the impact of this knowledge on their choices was seen by Flewitt and Nind (2007) as often the result of conflicting advice and 'informed confusion' (p. 439). Bailey, McWilliam, Busse and Wesley (cited in Flewitt & Nind, 2007) suggested that families were often placed in the position of having to choose between education providers when none provided everything the families perceived as necessary to meet their children's learning needs. Hess, Molina and Kowleski (2006) and Jenkinson (2001) claimed that little was known about the processes families undertook when making choices. Jenkinson (2001) asked 'How do family groups actively contribute to decision making about schooling?' In reviewing the literature, there is apparently limited research in which parents are given an opportunity to relate their experiences of making choices. It is therefore important that families' experiences when making these choices are investigated, in order to gain a greater understanding of their solution of the 'where to learn dilemma' (Norwich, 2008, Shaddock, MacDonald, Hook, Giorcelli & Arthur-Kelly, 2009). Swick and Hooks (2005) suggest the 'decision of placement for children with disabilities is not an easy one for parents' (p. 402).

Between 2005 and 2010, I was aware of the number of families who approached one special school seeking information about possible placements for their children because they were either dissatisfied with their child's current placement or the child had been refused enrolment into regular schools. As described by Higgins, MacArthur and Rietveld (2006), some children were 'still being rejected by their (chosen) regular school or encouraged to attend another school' (p. 31) on the grounds that appropriate programmes of learning to meet their special learning needs were not available or accessible. Many of the parents who visited our school lacked knowledge about education providers within their residential area and this was of concern to me. I had assumed the agencies supporting and resourcing these families would have provided their clients with comprehensive overviews of education placements that were suited to their child's learning needs, but it became apparent that this was not always happening. I was also aware that regular schools in the locality were often reluctant to accept these students, or allow them equal access to learning opportunities because of the schools' perceptions that their programmes of learning would not meet the students' special learning needs.

> *We went to the school to ask them about Olivia enrolling for Year 9. They said they would not be able to let her into some of the classes, such as technology and science because of her special needs.* (Olivia's father, Fred, 2010)

My experiences of the difficulties faced by families seeking appropriate placements for children with special learning needs such as Olivia, suggested there were considerable differences between the expectations of some families who enrolled their children in regular schools and the outcomes they experienced.

1.5 The participants in this research

A selected number of families living in the North Island of Aotearoa New Zealand were chosen as the focus for this research. A number of criteria were used when selecting the family groups. One criterion was that each of the family groups included a child who was receiving ORS funding to support his or her learning because these children had been identified as having high or very high learning needs. Another criterion required that the children had attended an early childhood placement and/or a regular school for 2 or more years, but then transferred to a special school, in order to ensure that the families and students had sufficient experience of regular schools on which to base their discussions. Family groups were asked about their experiences when supporting their children in regular schools and about how and why they chose to move to special schools. Their narratives gave an insight into the issues the families faced when making these choices.

1.6 The place of the researcher

Wadsworth (2011) suggests that researchers bring preconceived understandings, beliefs, theories and conclusions to their inquiries, and because of this, there is a need for researchers to ‘adopt new ways of seeing’ (p. 19) if they are to be successful in their inquiry. It is therefore time for me to reflect and be conscious of the influence my life’s journey may have had on this research.

This study draws on my experience as a teacher who has worked in regular and special schools for 50 years. In my first permanent teaching position in 1962, I worked with a class of over thirty 7-year-old students. One student was profoundly deaf, another was a student with Down syndrome, but the real challenge was ensuring the identical twins whose attention-seeking behaviours challenged all who worked in the school were on task. There were no teacher aides, no withdrawal classes and no specialists providing in-class support for the students or for me, the teacher. This experience gave me an insight into working with students with special learning needs: an experience that gave me the confidence to seek further teaching positions in regular and special schools and units in England, Scotland, Papua New Guinea, Canada and Aotearoa New Zealand. I have also worked in special classes attached to regular primary schools, and established, managed and worked in learner support departments in secondary schools until retiring from classroom teaching in 2010.

In many of these teaching placements I was working in partnership with families to ensure their children were receiving learning programmes appropriate to their unique learning needs. I also worked with families who were selecting learning placements for their children at times of, for example, from primary to secondary schools and from secondary school to the world beyond the school gate. For many families, there were positive outcomes when the choices made were seen to be the most appropriate options available to them. However, I saw that for some families, changing schools could be a time of tension, concern and stress.

In this study I wanted to listen to families talk about their experiences when they found themselves ‘between a rock and a hard place’ (Runswick-Cole, 2008, p. 1) while seeking support and solutions to questions about educational placements for their children, in a context where education policies of Aotearoa New Zealand promote inclusive education in regular schools.

1.7 The organisation of this thesis

This thesis is organised in seven chapters. Chapter One presents the aims and rationale for the study. Chapter Two reviews the literature complementing the study and gives an overview of education, with a focus on special education, in Aotearoa New Zealand from the time of the arrival of the first pakeha settlers to the present day. Chapter Three outlines the methodology underpinning the study and concludes with an exploration of the ethical principles basic to this research. Chapter Four describes the methods used in the study. Chapter Five tells the stories of the families' experiences, some from the birth of their children to the time they transitioned to special school. Chapter Six interprets and analyses the interpretations of the research findings in the context of relevant literature. The final chapter summarises the findings, draws conclusions and presents recommendations for key stakeholders working with children in both regular and special schools.

CHAPTER TWO

LITERATURE REVIEW

Keep asking and asking so that you get information to make a choice.

(Iain, father of Andrew, 2011)

2.1 Introduction

Internationally, education is seen as ‘an important right’ (Ryan, 2004, p. 1). Aotearoa New Zealand’s history of providing programmes of learning for children with special learning needs stretches back to the late 19th century. The literature review is presented in two sections. Following the statement presenting the processes underpinning the research for this literature review, the first section of the chapter opens with a discussion of ‘What is Special Education?’ as defined for this study. Prior to the formal literature review, the next section presents an overview of the establishment of special schools providing education programmes for school age children with special learning needs, from the arrival of the first European settlers in the country through to the present day. The impact of international events and legislation on educational practice in Aotearoa New Zealand will be examined in this discussion. Reference will be made to the discourses that have developed about people with special learning needs, and how these have influenced the legislation that supports programmes of learning for these students. How these paradigm shifts have influenced policy making and the provision of educational programmes for children with special learning needs will be evaluated.

An outline of SE2000 initiatives and their support for education providers and children enrolled in regular and specialist schools, classes and units is followed by an overview of the findings from the 2010 Review of Special Education. The place SE2000 has in inclusive education is discussed and followed by a statement of my place in the education of children with special learning needs within a ‘fully inclusive education system’ (MoE, 2010a, p. 1).

The second part of this chapter presents the literature review pertaining to this study, and the working definitions used when addressing the issues on which this research is based: the family, decision making, and exclusive and inclusive education. Issues such as bullying and teacher and teacher aide education, which are identified in the literature as influencing the quality of education experiences of students in schools, are also reviewed.

2.2 The literature review process

Books, journals, articles, government documents, theses and conference papers provided the foundation on which to base this literature review. Although the emphasis in the literature searches was on publications within the past 15 years, original writings were sourced when quotations and citings in more current publications did not present the depth of information and discussion required for this study.

A list of key researchers and organisations prominent in the education field in Aotearoa New Zealand was used to source literature relevant to the topic under investigation.

A list of key words to be used when implementing electronic searches of the literature throughout the research process was developed. This list included: family, parents, decision making, special education, special school/s, regular school/s, disability discourse, parents, whānau, Māori, Ongoing Reviewable Scheme (ORS), inclusion, Aotearoa New Zealand, New Zealand, Special Education 2000 (SE: 2000).

2.3 What is Special Education?

This research is embedded in the world of special education in Aotearoa New Zealand. But what is meant by ‘special education’? These two words have, in the majority of contexts, referred to the provision of venues separate from regular schools, where students with special needs participate in programmes of learning planned to meet their particular learning needs. These separate learning environments may include: residential and day special schools, special units managed and staffed by either a special or regular school and usually placed on the site of a regular school, specialist classes managed and staffed by the host regular school, satellite classes, hosted by a regular school but staffed and managed by a special school, and programmes of withdrawal with students being removed from their regular school classroom to participate in specialist teaching or therapy programmes designed by specialist therapists.

The programmes of learning for students with disabilities resulting in special learning needs has become wide ranging in order to meet the very diverse learning needs of these students. Within most definitions of special education is a discourse or particular way of thinking about disabled students (MacArthur, 2009) suggesting that these students are different and therefore have different learning needs that can only be met by special education providers in a learning situation separate from regular classrooms. Historically, the term ‘special education’ referred to students enrolled in education programmes in separate settings. However, given the current emphasis on the inclusion of students with special education needs into regular school placements, it is accepted that in the early years of the 21st century in Aotearoa New Zealand, special education refers to all students receiving additional support in their learning programmes in both regular and special school settings.

The implementation in Aotearoa New Zealand, of the 1989 Education Act enabled all young people between the ages of 5 and 19 to enrol in their neighbourhood regular school. Students with special learning needs were now able to enrol in regular schools, thus negating the belief that programmes of learning for students with special learning needs were available only in special schools. The introduction in 1996 of ORS funding as a component of the SE2000 initiative, further encouraged and supported students with special learning needs to enrol in regular schools (McMenamin, 2009). There was, therefore, a need to review and change the terminology ‘special education’ to indicate that not all learning was undertaken in separate establishments or separate classes within the host school.

Jenkinson (2001), working within the Australian education system, uses the term ‘special education’ to refer to ‘the education of students who, because of an identified disability, need some kind of support to attend school and access the curriculum’ (p. 11). In this definition, Jenkinson (2001) has retained the term disability, thus inferring that some students are different and in need of specialist care. Her definition does suggest that the student may be participating in a programme of learning in an inclusive or segregated environment.

The definition of special education as stated in the 2011 Special Education Policy Guidelines of the Ministry of Education, in Aotearoa New Zealand, acknowledges ‘the provision of extra assistance, adapted programmes or learning environments, specialised equipment or materials to support children and young people with accessing the curriculum in a range of settings’ (MoE, 2011a). This definition embraces the range of learning environments from a residential special school to include students accessing programmes of learning in a classroom in a regular school. It also acknowledges the wide range of support programmes that may be implemented to meet the specific learning needs of a student with special learning needs. This support may be provided in any setting: special schools and units, satellite classes, regular classes, and possibly in the student's home.

A working definition of special education for this study should combine the underlying philosophies of the MoE definition and that of Jenkinson (2001). Special education is thus defined in this research as 'the provision of additional assistance to enable children and young people to access the curriculum in a range of educational settings'.

The terminology 'children with special learning needs' is used to refer to students who require additional assistance and support to enable their accessing of the curriculum across a range of educational settings.

2.4 An historical overview of special education in Aotearoa New Zealand

In the next section, an overview of the learning environments that were established in Aotearoa New Zealand to meet the demand for programmes of learning for children with special learning needs is presented.

2.4.1 The establishment of residential special schools

In the earliest days of settlement in Aotearoa New Zealand, provision of education was very uneven (Graham, 1981). There were teachers who helped 'a few boys and girls with lessons' (Cumming & Cumming, 1978, p. 5) during the voyages of migrant ships from Britain, but once settled in their new country, if schooling was wanted, settlers had to teach their children themselves, pay for private tutors, enrol their children in schools established by religious organisations, or build and maintain educational facilities through cooperative efforts. During the Crown Colony period (1841–1852), a major concern for those community and religious groups promoting education was how to find a way out of the vicious circle of parental apathy, underfinanced schools, and poor teaching. The unstable economy and indifferent population (Cumming & Cumming, 1978) saw little progress being made in the education of the young people of the colony. Apart from the Sister of Mercy religious organisation founding an orphanage for girls in

1850, little is known of the provision of education for those children with special learning needs at this time. As had been the practice in Britain and USA, these young people were the responsibility of the family, who would house their afflicted member within the community with the family acting as caregivers and decision makers (Osgood, 2005).

This focus on family responsibility for the education of children with special learning needs changed with the passing of the 1852 Constitution Act, which abolished the provinces of New Ulster and New Munster and replaced them with six new provinces. With this new Act, it became the responsibility of each province to provide for the education of the colonists living within their geographic area. Financial support was offered to the provinces, and provincial governors were given the task of building and funding their own educational systems. The passing of legislation by Provincial Councils establishing the Industrial Schools for Destitute Children, where 'neglected and out of control children' (Mitchell & Mitchell, 1985, p. 4) were taken into care, was the beginning of an acknowledgement by those in political power that not all young people were participating in established educational programmes. These industrial schools were established to 'rescue young boys and girls from the paths of vice and infamy' (AJHR, 1881, p. 20), and provide them with training that would enable them to become useful members of society. The first government Industrial Schools were established under the control of the Justice Departments of the provincial governments.

Vincent (1985), in her study outlining the place of the industrial schools in the education of children in Aotearoa New Zealand suggests these schools embodied the first notions of special education and were the 'foundations for a system of special education and child welfare' (p. 48) in this country. Her findings were based on a definition of social deviance as being dependent on the interests of dominant groups. At the time of the establishment of Industrial Schools in Aotearoa New Zealand, what was required of the citizens of this developing country was productivity. Settler parents often gave priority to the labour a child could contribute to the family economy over having that child attend school (Olssen & Matthews, 1997). These young people, identified as neglected by their parents or uncontrollable, were seen as 'potentially troublesome' (p. 50) and it was in the interests of those in power that they be removed from a society where maintaining order and control was a priority.

By placing neglect and inability to conform as the responsibility of individual children, it was accepted by the lawmakers that these children were responsible for their placement in a residential industrial school. No acknowledgement was made of the environment in which these children were living. At the time of the establishment of the first Industrial School in 1867, the economy of Aotearoa New Zealand was based, in the main, on agriculture. However, with the discovery of gold in Coromandel and later in Otago, the ensuing gold rush saw many women and children being left to maintain themselves as the men working their claims were living in conditions not suited to family life (Vincent, 1985). Beagle (1974) further suggests that the impact of the conditions of hardship on the early colonial settlers often resulted in children being left homeless as a result of death, sickness or desertion by one or both parents.

The removal of children who were seen as not 'normal' from their families was not only practised for those young people identified as being a danger to the community because of their behaviours, but, according to the Hon. Colonel Brett in a motion put to the Legislative Council in 1873, for young people identified as 'being deaf, and dumb, and ...blind' (Mitchell and Mitchell, 1985, p. 4). Although the response in 1874 from the Legislative Council was to pass a resolution that an asylum be established for the support and education of the blind, deaf and dumb children residing in New Zealand, the educational needs of these young people remained the responsibility of their families for another 6 years. Following the abolition of the provinces in 1875, this control passed to the central government's Department of Justice. In 1880, the management of industrial schools was transferred to the Education Ministry.

Although the 1877 Education Act did mandate a national system of secular, free and 'almost compulsory education' (Mackey, 1967, p. x) for children aged 7 to 13, the implementation was left to the discretion of school committees and was 'not generally enforced' (Mitchell & Mitchell, 1985, p. 7). 'Temporary and permanent infirmity' (New Zealand Government 1877, p1V, s 90(2)) was legislated as grounds for exemption from attending school. Children with 'disabilities and impairments' (Davies & Prangnell, 2000, p. 1) were thus denied access to state funded education in the first government legislation relating to education; a practice that was to continue for over 100 years.

Following the pattern established in such countries as Britain and the USA, the onus for the care and education of those children excluded from the state system fell on family and voluntary, charitable and religious organisations (Shuker, 1987), with the government's education policy for the education of students with special learning needs being largely 'uncoordinated and implemented in a fragmented fashion' (Vincent, 1985, p. 7). Some provision was made for hearing-impaired children with the founding in 1880 of the Sumner School for the Deaf, the 'world's first government funded school for the deaf and dumb' (Allen, 1980, p. 11) with an enrolment of five students. Children with visual impairments were required to travel to Australia to receive educational programmes appropriate to their special needs, until the opening of a charitable trusts' residential provider, the Jubilee Institution for the Blind in 1891, with the Department of Education making financial contributions to the 'costs of educating the blind children' (Mitchell & Mitchell, 1985, p. 10).

In the next section, I will examine some of the discourses that underpinned the education policies of the late 1800s and early 1900s.

2.4.2 Discourses within the early years of the education system

Underpinning this early legislation establishing educational opportunities for the young people of Aotearoa New Zealand was the belief and acceptance by those in power that a disability was a defect located within an individual. It was accepted by those persons in positions of policy making that it was the role of individuals, families, and humanitarian and charitable groups, to provide protection and shelter for those with mental and physical impairments. Politicians, and health and educational professionals, made decisions based on these 'collective assumptions' (Neilson, 2005, p. 10). These decisions were accepted by the community in general, possibly because of their acceptance of the power of the positions held by those in these professional occupations.

The ideas emerging as systems of power were acknowledged by Foucault (1991) as the base of his theory of discourse analysis where dominant groups are seen as the holders of power when decisions are made in the community. Gunn (2008) suggests that this is because discourses are normative. They devalue some concepts and ideas while valorising others. It is this norm that 'lays claim to power' (Foucault, 1999, p. 50).

Foucault developed his discourse analysis by categorising people into normal and abnormal groups, with his theory showing that in power relations, those in the ‘normal’ group have power over the ‘abnormal’. This theory reflected the view of the general population that people with disabilities were seen by the majority of the population as abnormal and therefore without power to make changes. This concept of discourse becomes important in understanding issues in education (Gunn, 2008) and the models of disability underpinning legislation and policy within special education. Given that a discourse is a way of approaching and thinking about a problem or concern, it must be accepted that people who by their actions and the laws they have supported through parliament, have contributed to the ‘hidden hurdles and barriers’ (Neilson, 2005, p. 11) that have ensured young people with special learning needs continue to be excluded from regular schools and classrooms.

Language is also an ‘instrument of power’ (Fulcher, 1989, p. 4) that was used in the earliest years of government legislation to raise barriers within the education system to exclude children from the regular school system. This language included phrases such as ragged schools, vagrant and criminal children, lunatics (defined in the 1868 Lunatics Act as being any person idiot, lunatic or of unsound mind and incapable of managing himself of his affairs and where found lunatic by inquisition or not), deaf and dumb, deaf mute, imbecile and feeble minded. These terms, used to describe children who were not ‘performing an activity in the manner or within the range considered normal for a human being (World Health Organisation, 1980), individualised and medicalised disability with no acknowledgement of the impact the issues might have on the person in their daily lives. Physical or mental disability was a problem belonging to the person, and the treatment of children exhibiting these symptoms was based upon this assumption. The person’s failure to learn was located within the person – ‘there was something wrong with them’ (Moore et al., 1999, p. 8). It was the role of the health profession to find out what was wrong (the clinical diagnosis) and use their knowledge to try and fix these deficits (the remediation) to make them ‘normal’: a symptom that needs a diagnosis and a remedy (Vincent, 1985). The focus was to change the ‘victim’ to fit the accepted and ‘established norm’ (Pihama, 1997. p. 289). An alternative solution involving analysis of the environment in which the child was living was neither acknowledged nor considered.

Fulcher (1989) suggests there were four major discourses relating to disability:

- the medical discourse also known as the biological paradigm (Davies & Prangnell, 2000) where disability is seen as a physical deficit, a health and personal problem
- the lay discourse: which regards people with disabilities as inferior and weak who should therefore be shunned and rejected
- the charity discourse: where disabled people are dependent, needy and are expected to be grateful for the gifts they receive, and
- the rights discourse: which fights against discrimination and exclusion and demands equality of citizenship

with the dominant medical discourse 'penetrating the lay and charity discourse' (Fulcher, 1989, p. 26). The medical discourse is described by Davies and Prangnell (2000) as a discourse where disability and special needs are perceived in terms of functional limitations' (p. 2). The language of persuasion of the medical discourse (Fulcher, 1989), suggesting that all actions undertaken are in the best interests of the child, dominated the provision of state education programmes for young people with special learning needs for over one hundred years, beginning with the passing of the Education Act 1877. The legislation introduced in this act was 'widely regarded as the great foundation stone' (Codd & Openshaw, 2005, p.156) of the education system of Aotearoa New Zealand.

2.4.3 Education opportunities for children with special learning needs in the early 20th century

In response to findings by George Hogben, the Inspector General of Schools, who had visited Europe and USA in 1907 to investigate possible educational programmes for subnormal or incorrigible children, the 1908 Education Amendment Act provided education programmes for defective or epileptic children between the ages of 6 and 21 years. For these young people, who by reason of mental or physical disability were perceived as being incapable of receiving proper benefit from instruction in an ordinary school, the Department of Education established two residential special schools in the South Island: Otekaike Special School for 'feeble minded' boys, which opened in 1908, and Richmond Special School for Girls, which opened in 1916. Both special schools were administered by the Child Welfare Branch of the Department of Education, although it was the role of the officers of the Mental Hospitals Department to make the final decision as to whether a child would be granted admission to these residential special schools (Winterbourn, 1944).

Legislation continued to require education for visually and hearing impaired children to be provided by their families or in an institution as directed by the Minister of Education (New Zealand Government, 1901). This institutionalisation of children who were unable to reach the levels of learning required by primary schools was supported by the primary teachers' union, the New Zealand Education Institute (NZEI), who in 1904, passed a resolution urging 'schools and asylums be established for children mentally weak' (Winterbourn, 1982, p. 27). The passing of this resolution again emphasised the continuing dominance of the medical model of disability held in both the education and political arena. It appears that those in authority accepted that the inability to make progress in learning within a school, or even to be accepted into school was, at this time, caused by these young people being unable to take responsibility for their learning, and was not in any way due to the learning environment or the curriculum being implemented within the school.

The 1910 Education Amendment Act reiterated the ruling of the 1901 School Attendance Act by further reinforcing an exclusion policy obligating parents of blind or deaf children to provide education for their young people. The inability of parents to meet this obligation could result in the child being sent to an institution as directed by the MoE. The shortage of finances through most of the 1880s and 1890s (Ross, 1972, p. 20) and the demands of existing schools, saw very little expansion in special education services. Young people with disabilities continued to be cared for within the community, or were placed in residential institutions to live and be educated away from their family and community. Those professionals making decisions about the educational placement of a young person were required to consult with medical officers before making a decision, as it was the role of the medical officer to identify 'remedial defects' contributing to the student's apparent inability to maintain the levels of learning necessary in the regular state schools (Winterbourn, 1944). The focus on disabilities or impairments continued to dominate the decisions made by the professionals in power. The assumption that students with disabilities have more in common with each other than with those who do not have disabilities strengthened the belief by those with the power to control education legislation that segregated education facilities were the most appropriate placements for children with special education needs (Callendar, 1972).

Although the 1914 Education Act established the principle of equal provisions of educational opportunities for girls and boys, it restated the policy makers' philosophy that parents of 'blind, epileptic, deaf or feeble minded children' (Vincent, 1985, p. 81) were deemed responsible for the provision of effective and suitable educational programmes for their family member. Despite continued exclusion of this disabled group of students from state education, the 1914 Education Act did acknowledge and establish a specified learning support opportunity in the form of special classes for children who through 'physical infirmity, absence from school, or otherwise' (New Zealand Government, 1914, n. 36, p. 182, s. 127) were below the average standard of education reached by other children of the same age.

2.4.4 The establishment of special classes

In 1917 the introduction of special classes attached to regular schools, was the first education practice that enabled children with special education needs to attend school while still living with their family within their community. Although these students may have received the majority of their education programmes in their own classroom with a specialist teacher, they were part of the school community and were included, to a greater or lesser extent, in the wider school environment. This education initiative could be viewed as inclusive education in its infancy. The education environment within the special class was adapted to achieve a more effective match between the children's learning needs and the programmes being implemented. The class setting was within the larger school community and the students interacted with their peer group in their out-of-class times. However, it must be remembered that the placement of the students in the special classes was based on the belief that their delay in learning came from within the student. The medical model of disability continued to dominate the decision making of politicians and their education providers (Winterbourn, 1944). Over a period of time, these day 'special classes' replaced the industrial schools, and together with their secondary school equivalent, work experience classes, remained within the education system until the implementation of SE2000 in 1996.

2.4.5 An alternative placement? Residential psychopaedic hospitals

For those students exempted from school because of their 'temporary or permanent' infirmity, there were very limited learning opportunities within the state education system, apart from those children with hearing and vision disabilities who may have been offered places in the specialist residential schools, Sumner Institution for the Deaf and Dumb, and the Jubilee Institute for the Blind. Two residential schools for mentally impaired students catered for the educational needs of a small number of students with special learning needs. Residential institutions under the control of the Mental Hospitals were 'the only places available for those with intellectual and physical disabilities' (Payne, 2010, p. 109). A residential school, Templeton Farm School, opened in 1929 with an enrolment of eight young boys. This was the forerunner of what became known as psychopaedic hospitals. 'Often these families had been distanced from their disabled family member on the instruction of their doctors. Doctors know best' (Payne, 2010, p. 108).

Psychopaedic hospitals, later renamed Training Centres, provided residential care and educational programmes for multi-handicapped, severe intellectually handicapped, and moderately disabled young people. In later years, programmes were introduced for the education of those working in these institutions but the overall responsibility for the management of the hospitals and the care of the young people remained under the jurisdiction of the Mental Hospital Department and later the regional hospital boards.

> *Many babies were, soon after birth, taken to institutions and left. That is what (parents) were advised to do by their doctors in those days. They had very little option as there were no support facilities in the community* (Payne, 2010, p. 64).
>
> *In earlier times and certainly at the time I was born (1959), parents who had a child with a significant disability were actively encouraged to put the child into "care" and get on with their lives* (Franklin, 2008, p. 155).

These personal recollections show that the medical discourse was still the foundation on which decisions were made about the care and education of children with special learning needs.

Supporting the medical discourse of disability was the charity discourse, which viewed people, identified as disabled, as being in need of help, and who should be 'grateful recipients' when they received assistance from private and state welfare agencies (Fulcher, 1989, p. 29). With the origins of the charity discourse being in the Victorian era, where reformers believed they had a 'moral duty to give protection and succour to the poor and afflicted' (Human Rights Commission, 1986, pp. 26–27) there was no recognition of the needs or rights to privacy or choices for people with disabilities.

These negative connotations within the medical and charity discourse were also inherent in the lay discourse, which focused on the 'myths and stereotypes' (Neilson, 2005. p. 16) about people with disabilities that might result in such discriminatory practices as resentment, prejudice and rejection. Negative and inappropriate labels were used to describe the person with the disability and, in some situations, the person with the disability, although physically present, may be excluded from a conversation that is pertinent to his or her well-being.

While positive actions did arise from within the medical discourses, and, indirectly, from the charity and lay discourses, children with disabilities continued to be excluded from regular schools. However, for some children, their enrolment in institutions was challenged by their parents, who were unwilling to place their children in residential settings. There began a spontaneous though uncoordinated establishment of voluntary and professional organisations reacting to the continued segregation of students with special needs (Callendar, 1972). The common factor uniting those people establishing and working within these organisations was the care and concern for children identified with a debilitating and intellectual or physical condition. Families supporting people with similar disabilities had similar experiences, similar concerns, and similar expectations of their communities (Mitchell, 1999). The 'medically derived disability labels' (Mitchell & Havill, 1972, p. 13) enabled the gathering together of families with similar concerns for their family members' well-being. The use of a 'label' enabled these support groups to lobby policy makers to accept responsibility for the education and welfare of their children.

From within these voluntary groups, established originally to support children with disabilities and their families, emerged a rights discourse with the focus on gaining equal opportunities for education (Brown, 1994) and the opportunity to live in their community. For example, in the 1950s, Danish parents had lobbied for reforms for mentally handicapped people, 'to let the mentally retarded obtain an existence as close as possible to normal' (Nirge, 1985, p. 66), arguing that normal living conditions included the legal and human rights to which all people were entitled. In the USA, the integration of students with disabilities emanated from the civil rights movements of the 1960s, being closely linked with the exclusion of ethnic minority students from regular classes. This new emphasis from families, people with special needs and their advocates was in keeping with international statements on people's rights. In 1948 the

United Nations had supported the rights discourse universal access to education with the passing of the Universal Declaration of Human Rights which, in Article 26 (1) stated that 'everyone has the right to education'.

Neilson (2005) describes this time of increasing recognition and respect for human dignity as an 'integration and normalisation stage' (p. 13) in the history of disability. She sees the impact of increasing numbers of people with disabilities resulting from injuries sustained World War II as also being a turning point for the disabled. These newly disabled people, when they returned to their home countries, expected to remain and live as part of their communities.

The rights' discourse places an emphasis on 'self reliance, independence and consumer rights' (Neilson, 2005, p. 10), and represents a shift in values towards greater equity for all and a clearer recognition of human rights issues (Moore et al., 1999). In the education field, the rights discourse challenged the medical model's assumptions that disabled people are 'objects to be treated' (MacArthur, 2009, p. 12). The rights discourse also challenged the education community to change their attitudes and procedures away from internal causation and remediation and to focus on the environment in which the learning was taking place as being one external causation impacting on learning. This demand from those advocating for and working with children with disabilities, and from people with disabilities themselves, has an underlying strategy of 'confrontation and demand' (Fulcher, 1989, p. 31), where the issues causing concern are brought to the notice of the policy and law makers and acceptable solutions demanded.

One role undertaken in 1952 by the IHC, a parent volunteer group, was to petition the policy makers to acknowledge and accept young people with intellectual handicaps into the education programmes within their communities as an alternative option to the two residential facilities established by the Education Department (Ryba & Annan, 2005). The government's response was the forming, in 1953, of the New Zealand Committee on Intellectually Handicapped Children, who were charged with investigating and making recommendations for the educational needs of this group of young people. Those working on this committee saw the IHC definition of intellectual handicap as unsatisfactory as it included 'all grades of mental defect ...together with such physical defects as the deaf, the blind and cases of cerebral palsy with normal intelligence' (New

Zealand Government, 1951, p. 4). The investigation led by Dr Aitken elected to be concerned with those children termed 'imbecile: lower grade mental defectives who, when older, would be incapable of earning their own living by reason of a mental deficiency existing from birth or an early age' (New Zealand Government, 1951, p. 2).

In 1953 the committee's report, the Aitken Report, presented ten recommendations that focused solely on the provision of residential institutions for the majority of intellectually handicapped children and adults in the community. Parents were to be encouraged to place their children in these institutions from the age of 5. The committee saw the role of voluntary parents' organisation such as the IHC as providing cottage homes at the proposed residential homes, and working on a volunteer basis in the occupation centres established as 'holding institutions' (Winterbourn, 1944, p. 286) until places were available in such residential institutions as Templeton Hospital, or assisting other parents in the care of their intellectually handicapped children.

The Aitken Report was not received favourably by those working with intellectually handicapped persons. This change of thinking by the members of the IHC was responsible for a request for further investigation by members of the New Zealand branch of the British Medical Association who, in turn, produced a document 'criticising it [the Aitken Report] as being out of touch with new ideas' (Callendar, 1972, p. 144). The Report's emphasis on residential care was regarded as both impractical and outdated, with the committee seen to be failing to investigate alternative programmes being implemented in other countries. The response from the government was to reassess its role in the education of children with intellectual handicaps.

In 1956 the government accepted partial responsibility for the education of school age children attending the occupation centres established and staffed by the IHC. Government financial support was also made available to the IHC occupation workshops catering for the needs of adults with intellectual handicaps. By 1964 the responsibility for the 'formal' education of the intellectually handicapped was undertaken by the regional education boards, although provision and maintenance of the buildings remained the responsibility of the parent groups. These occupational centres were to become the foundation of many day special schools for students with intellectual disabilities, and intellectual and multiple disabilities.

2.4.6 Day special schools are established

In the final act in 1956, when the responsibility for the occupational centres founded by the IHC, was transferred to the control of regional education boards, these centres became day special schools and were completely under the management of the state. Students with special learning needs had the opportunity to enrol in programmes of learning that were fully funded and managed within the education system of Aotearoa New Zealand.

Moore et al. (1999) regard the period from the late 1950s to mid-1970s as a time of rapid expansion of segregated and separated special education providers. Many children who had attended day programmes organised by voluntary organisations were transferred to the special schools. Support networks were established between regular and special education providers. Teachers working in regular education supported the special schools with the provision of resources. In return, the special educators would ‘take over the troublesome and the troubled students’ (Brown & Moore, 2011, p. 185) who were enrolled in the regular classes. Throughout this period of ‘most rapid expansion in special education services’ (Ross, 1972, p. 30) the emphasis continued to be on classification and remediation, based on the medical model in which causes of failure to learn were located within the individual.

The segregation of children who, because of physical or mental handicap, required educational treatment beyond that normally obtained in an ordinary class in a school was further formalised in the Education Act 1964. Children of school age ‘suffering from a disability of body or mind of such magnitude as to require special education’ (New Zealand Government, 1964, s. 113) were excluded from government education programmes. The responsibility for providing education programmes for these excluded students remained with their parents. Section 114 (1) of the Act outlined the conditions of compulsory enrolment of ‘certain children’ who, after an examination by a medical officer, might be required to attend a special school, class or occupational group. Parents who failed to enrol ‘any such child’ would be liable for a conviction and find not exceeding £100’ (New Zealand Government, 1964, S 116).

Following this historical pattern of segregation, the 1969 Mental Health Act consolidated existing mental health legislation by defining classes of mental impairment and admission procedures to psychiatric hospitals. Persons over 10 years of age, and alleged to be mentally disordered, might be ‘committed to the care of a hospital, in the public interest’ (Department of Health, 1969, s. 8), thus confirming the current policy of two providers for the education of young people with special education needs, education and medical. Within the politics of Aotearoa New Zealand the focus remained on the medical model of disability where the health professionals and those in power made decisions leaving individuals with disabilities with little control over the resources themselves (Oliver, 1996).

Internationally, however, there was increasing public pressure by ‘people ahead of governments’ (Grant, 1981, cited in Brouillette, 1993, p. 33) for the specific inclusion of persons with special needs in human rights charters (Herr, 1993, p. 39).

The United Nations Declaration on the Rights of Mentally Retarded Persons (1971) stated that ‘the mentally retarded person has…the same rights as other human beings …the right to an education that will enable him/her to develop his/her ability to a maximum potential’ (p. 1).

2.4.7 The rights discourse

The response to this legislation from the USA was the passing of the ‘most comprehensive and significant piece of legislation’ (Sigmon, 1987 p. 26), PL94-142 The Education for All Handicapped Children Act of 1975 (EAHCA). This far-reaching act mandated free, appropriate public education for all children aged 3–17. PL94-142 had a zero-rejection policy, regardless of the nature and severity of the child’s handicap. It introduced compulsory Individual Education Programmes (IEP) focussing on both educational needs and support services to maintain and assist the students to benefit from education programmes in ordinary school settings ‘in least restrictive environments’ (Ashman & Elkins, 2005, p. 19). PL94-142 also mandated parental rights to all school information pertaining to their children and participation in meetings such as the IEP (Meyen, 1995). For the first time in the USA, parents were not expected to provide educational programmes for their child with special learning needs. The cornerstone of this legislation was the link between the funding to the schools and the provision of education to students regardless of the ‘type and severity of the handicapping condition’ (Ashman & Elkins, 2005, p. 82). As stated by Kirk, Gallagher, Coleman and Anastasiow (2012), the law was to ‘become part of the educational landscape’ (p. 34) in USA, with the Federal Government taking a major legislative role in the provision of programmes of learning for children who have disabilities so as to enhance their educational outcomes.

But PL94-142 was not inclusive of all children of all ages as indicated in its title. The legislation was intended to support children aged 3–17 years, and it was not until the passing of the amendments of 1986 that the federal funds allocated for the development of plans and programmes for children with disabilities were extended to include ‘children and their families from birth on’ (Kirk, Gallagher, Coleman & Anastasiow, 2012, p. 35).

A similar development was also developing in Britain with the passing of the British Education (Handicapped) Act of 1970, which legislated for the entry of children with severe learning difficulties into the British education system. This legislation, together with the ground-breaking legislation PL 94-142 (Sandow, Stafford & Stafford, 1987), showed the direction in which ‘New Zealand education should go’ (Sleek & Howie, 1987, p. 60). However it was some time before all children with special learning needs would, with the support of their parents, have right of access to regular class programmes of learning within the state education system of Aotearoa New Zealand. There was a continued increase in the number of voluntary parent/child-based organisations, focussing on the welfare of the children with special learning needs. A growing awareness among Mental Health providers that identification of learning disabilities should not be restricted to medical measures but that consideration should be given to environmental and sociological factors indicated the beginnings of a change in focus for the care and education of children (Pankhurst, Pankhurst & Elkins, 1987).

The International Year of Disabled Persons (IYDP) in 1981 drew world attention to the needs of disabled persons. In Aotearoa New Zealand, the IYDP National Committee’s recommendations to the government included amendments to be made to the Education Act 1964 to ensure disabled persons were given access to educational programmes in regular schools. These recommendations echoed submissions made to the Department of Education in the 1980 Social Issues report from the New Zealand Psychologists Society (NZPS). The NZPS had also focussed on the Education Act 1964, and recommended amendments that would ‘ensure appropriate education for all handicapped children’ (Mitchell & Mitchell, 1985 p. 79) irrespective of the type and degrees of their disability, or their geographic location. The recommendation that the education of all handicapped children, including those in psychopaedic or psychiatric hospitals, should be the responsibility of the Department of Education, was supported by a further recommendation that when ‘categorising handicapped children, consideration should be given to their learning needs’ (Mitchell & Mitchell, 1985, p. 80), rather than general disability levels.

Voluntary organisations maintained their ‘rights orientated’ approach, underpinned by the international rights legislation ratified by Aotearoa New Zealand, to demand equal educational opportunities for all their members in age-appropriate placements in their local community and ‘in the same class as their same aged neighbourhood peers’ (O’Brien & Ryba, 2005, p. 24). One example of this action was the presentation to the government of recommendations made by working parties attending the Disabled Persons Assembly in 1983 (Mitchell & Mitchell, 1985).

The response from the Department of Education to the ‘quest for a realised right to an appropriate education’ (Herr, 1993, p. 49) by families and voluntary organisations supporting children with special learning needs, was the commissioning in 1982, of the New Zealand Council for Educational Research (NZCER) to undertake a survey of the services offered to students with special educational needs.

2.4.8 Changes to legislation are implemented

The report from the NZCER coordinated the findings of a comprehensive survey of parents, educators and teachers’ unions. A wide-reaching overview of issues and policies identified as ‘important for the advancement of special education services in New Zealand’ (Pankhurst et al., 1987, p. 15) was presented. Underpinning the issues was the anticipation that legislative change would make it mandatory for the state to provide free and appropriate education for every child in New Zealand, particularly for the severely handicapped children who were receiving their education in hospitals or special care centres administered by voluntary organisations such as the Crippled Children’s Society (CCS) or the IHC. Pankhurst et al. (1987), in a footnote comment, indicated that relevant amendments to the Education Act were expected to come before the Parliament in 1986.

The Department of Education had also commissioned an examination of special education for departmental purposes, to ensure the widest possible examination of existing resources and established practices was obtained. Within the conclusions reached by these reviewers, presented as The Draft Review of Special Education, was the adoption of a socio-political approach in which resources would be allocated on a needs basis within a major administrative reorganisation (Department of Education, 1987). The vision of inclusive, lifelong education being available to people 'with significant handicaps or learning difficulties' (Department of Education, 1987, p. 18) led the objectives for the proposed comprehensive educational reform.

The Draft Review (1987) introduced the term 'mainstreaming' into Department of Education language in the context of the philosophy of normalisation where all handicapped persons would have the opportunity to live independently within their neighbourhood community. The education component of this process involves the integration of students into a regular school setting for learning, called 'mainstreaming' in the review. This concept of 'mainstreaming' mirrored that embodied in the United States Act PL94-142, although not mentioned by name, with the terminology 'least restrictive environment' being the preferred language to describe the placement of students in a setting that was as close to that of a regular classroom as possible (Ashman & Elkins, 2005). In Aotearoa New Zealand, this least restrictive terminology was replaced, 'almost universally' (Chapman, 1988, p. 124), with the word 'mainstreaming', although educators in Britain and Australia adopted 'integration' to describe a similar policy that promotes the education of students with special learning needs into a regular school setting. The decision not to use 'integration' in the Draft Report was to avoid any misunderstandings as this term was used in association with the integration of private schools into the state education system of Aotearoa New Zealand.

Although the Draft Review of Special Education was overtaken by major administration changes at the time, it raised a focal point for debate (Chapman, 1988) among educators in New Zealand. It offered a vision for those people demanding acceptance into the community and the education system. It introduced educators and policy makers to the need for a change in their policy making to enable young people to learn and interact in an education community from which they were previously excluded by legislation.

The next stage of the policy development for special education was achieved through the commissioning of the Picot Report, which subsequently became Tomorrow's Schools (Lange, 1988). Underpinning these reports was an ideology based on 'New

Right principles' (Greaves, 2003, p. 59), where education was visualised as a market economy with relationships between the education system and its participants similar to that between a vendor and customer. The emphasis was on restructuring the existing system, and the 'creation of schools that would be responsive to their communities' (Davies & Prangnell, 2000, p. 3). Within this legislation, special schools were acknowledged and would be 'run in the same way other state schools' (Lange, 1988, p. 31), but would be managed under a separate funding formula to that of regular schools.

2.4.9 The Education Act, 1989: Doors are opened

The culmination of these reports was the 1989 Education Act, which gave all children aged between 5 and 19 equal rights to enrol in a state school and receive free education:

> *People who have special education needs (whether because of disability or otherwise) have the same right to enrol and receive education at state schools as people who do not* (New Zealand Government, 1989).

However, Section 9 of the Act retained separate educational providers by stating that

> *if satisfied that a person under the age of 21 should have special education, the Secretary of Education shall agree with the person's parents that the person should be enrolled or direct them to enrol the person at a particular state school, special school, special class or special clinic, or, agree with the person's family that the person should have educational help from a special service.*

The contradictions within the 1989 Education Act are obvious. The Act gives children the right of enrolment, but in Section 9, refers that right to a decision made by the Secretary of Education, as to whether a child with special learning needs is entitled to have choices of education placement. The MoE, through the powers of the Secretary of Education, has a 'gate keeping' role that impacts on the rights of children and in turn their parents to freedom of education choice in Aotearoa New Zealand. It must also be noted that the Education Act 1989 underpins the current legislation of 2012.

Under the legislation of the Act, every school had to prepare and maintain a school charter (New Zealand Government, 1989, Section 61 (1), stating the aim of achieving, meeting, and following the national education guidelines. This placed the responsibility with the schools to ensure students with special education needs were receiving an education appropriate to their needs. The focus of the Act was on identifying and removing barriers to learning, and ensuring students with special learning needs received appropriate teaching, specialist resource, and support.

Although the 1989 Education Act gave children with special learning needs the right to attend regular schools, it also gave these schools the ability to refuse such enrolments on the grounds that the school was not able to provide appropriate programmes of learning for these students. These children could, under the power granted to the Secretary of Education in Section 9 of the Education Act, be directed to enrol in the already established residential and day special schools for young people with hearing, visual, physical and intellectual disabilities. Meyen (1995) describes this paradox as being 'between stories' (p. 30), the beliefs and assumptions of the medical model of individual's deficits, and the rights model where parents have the right to choose the setting in which their child is to be educated. Tensions were emerging between paradigms underpinning education in Aotearoa New Zealand. The demand from parents for their children with special learning needs to have access to programmes of learning in regular schools and the implementation of Section 9 of the 1989 Education Act was resulting in tensions within and without the education system.

2.4.10 A clash of paradigms

Mitchell (1999) sees these shifts from a medical to a rights focus in educational thinking and policy as a 'paradigm clash' (p. 204) where there has been a change in the conceptualisation of students' special educational needs. The term 'paradigm' was brought to prominence by Kuhn (1962) as a means of explaining the process of change in the scientific world. Kuhn used the term to describe a model, a view that reflects peoples' most basic beliefs and assumptions: 'What is true? What is the nature of things?' (Brown & Thomson, 2005, p. 162). Paradigms are challenged when values and attitudes in society change. If an existing paradigm is unable to accept or incorporate the new ideas, a shift to a new model or paradigm is necessary.

The original paradigm of special education was implemented to justify the placement of a student in a special or regular programme of learning. The new paradigm, the ecological or inclusive paradigm, moved the focus to the interaction between the students and the environment in which the learning was taking place. This paradigm focused on the students' individual needs and the removal of barriers within their learning environment to enable enhancement of their learning opportunities and outcomes. It was necessary for those people working in the education field, designing and implementing learning programmes for students with special needs, to make a paradigm shift enabling a new way of thinking about the education of these young people (Moore et al., 1998, p. 13). The role of those working within an ecological or inclusive environment is to 'alter, adapt and improve' (Davies & Prangnell, 1999, p. 3) both the environment in which the learning takes place, and the philosophy and practices of those responsible for the overall implementation of education in Aotearoa New Zealand.

Mitchell (1999) also identified a third paradigm a 'socio political paradigm' where disability is seen, not as an outcome of a condition that people have, but as created by the social attitudes and actions of a society that fails to meet the needs of all its members (Ballard, 1996). This third paradigm is evident in the enrolment of children and young people into education providers in Aotearoa New Zealand. Parents enrolling their children in a regular school have only to approach their chosen school and present documentation verifying the child's date of birth and proof of residency in New Zealand. If all documentation meets the requirements of the school and the school is willing to accept the child, enrolment procedures are implemented. On the other hand, parents who wish to exercise their right to enrol their family member in a special school, are met with a barrier in the form of Section 9 of the Education Act 1989. These parents, often supported by teachers, therapists and health professionals, are required to present evidence to a panel to justify their application for their child to enrol in a special school. If the application meets the panel's approval, it is necessary for a further assent to be given by the MoE. Thus equal rights to enrol in a state special school are not available under this much praised education initiative: the Education Act 1989. As a principal of a special school explained in a personal communication:

> *We had all the documentation completed and signed: by the parents, the school where the student was currently enrolled and my school (the special school accepting the student). But GSE would not approve or sign the application. They said the student should remain at (the regular school) and would not agree to the transfer.* (D. Hankins, personal communication, 24 February 2011)

This clash of paradigms is again prominent in the Human Rights Act (New Zealand Government, 1993). Although Sections 57 and 60 of the 1993 Human Rights Act make it unlawful for education providers to ‘refuse or fail to admit a person as a student’ according to Section 57 (1a), an exclusion based on the medical model may be implemented should the necessary special services or facilities required to ‘enable the person to participate in the education programme of that establishment’ not be reasonably available (New Zealand Government, 1993, Section 60).

The clash of paradigms continued in the draft document *Education provision for learners with special needs: A review of policy* (MoE, 1991a). The statement ‘No matter their different levels of ability, all children in education are pupils and learners first’ (MoE, 1991a, p. 24) is an acknowledgement by the authors that, for a small group of learners, education in regular settings would not be possible and these students would require the implementation of IEPs with the major aim being ‘social integration of the pupil into the daily life of the school’ (MoE, 1991a, p. 47) to enable access to regular education provisions. Integration and segregation values continued to clash. Where would this small group of learners participate in learning programmes until they were socially ready to enrol in a regular school? In a special school? Certainly not in special classes because they were disestablished when SE2000 was implemented and the MoE stopped funding and staffing for special needs classes within regular schools in 1999.

Special Education in New Zealand – Statement of Intent (MoE, 1991b), the document responding to the draft proposal Education Provision for Learners with Special Needs (MoE, 1991a), outlined the Government’s intentions for special education policy. The main purpose of this document was, according to O’Brien and Ryba (2005), to investigate the decentralisation of the existing special education services to ‘free up administrative resources’ (p. 27). The Statement of Intent echoed the proposals introduced in its parent draft document that the primary focus would always be on the learning needs of the student (MoE, 1991b, p. 11) with families being able to make informed choices about their children’s education. But in the same set of principles underpinning the proposed changes to special education, it was stated that special schools and units for students with disabilities would remain an option for families ‘as long as they were supported by enrolments’ (MoE, 1991b, p. 11), inferring that the families of students with special needs were responsible for the retention of special schools. Segregation and inclusion were still options within the MoE’s policy making. The use of the terminology ‘physical, intellectual and/or sensory disabilities’ (MoE, 1991b, p. 12) to describe students requiring special learning programmes indicated that despite all efforts, the medical model was still an integral component of the MoE's special education philosophy.

Greaves (2003) suggests the 1990s were a time of 'growing pressure from parents and educators' (p. 61) for a review of the criteria for the allocation and distribution of resources for students with special learning needs. There were challenges in coordinating health, education and welfare services necessary for the well-being of these students. Policy development was also perceived as being 'seemingly piecemeal' (Greaves, 2003, p. 61) by parents and educators who were experiencing difficulties in coordinating health, welfare and health services. The response to the need for reforms was the development of SE2000, introduced in the 1996 Budget as an education system that provides learning opportunities of equal quality to all students (MoE, 1996, p. 5).

2.4.11 SE2000: A world class inclusive education for all students (Fancy, 1999, p. 1)

One of the rationales underpinning the SE2000 policy was to improve the resourcing of education programmes and services for those students with the highest need for education support in the early childhood and school sector. This policy, described by Bourke (1999) as 'one large basket filled with a multitude of initiatives' (p. 3), saw a shift from a deficit model of disability to an ecological paradigm that posited the student's learning and behavioural difficulties as a 'social construct' (Davies & Prangnell, 1999). The responsibility for students reaching their educational potential was inherent in the quality of interaction between the student and their learning environment, which was seen as influencing their ability to learn: a school-based and curriculum deficit rather than 'a child deficit' (Riddell & Brown. 1994, p. 8). Mitchell (2000) described the policy as a set of complex, interlocking paths designed to address all aspects of the education of students with special educational needs. The fundamentals on which SE2000 was constructed intended to ensure that resourcing was equitable and consistent, irrespective of the students' school or geographic settings.

The reforms underlying SE2000 were based on the principles of the Education Act 1989 that all students between the ages of 5 and 19 receive their education at the regular school in their community. However, there was no acknowledgement of the role that the already established day and residential special schools would have in this inclusive education system. Wylie (2000), in her review of SE2000, suggests that one of the intentions of SE2000 was ‘to make it easier for students with special needs to enrol at their local school’ (p. 70), with the students’ funding resources enabling the provision of support services deemed necessary to enable successful learning outcomes for the students. The resources available to students were determined by the initiative the Ongoing Resourcing Scheme introduced in SE2000, and by the verification of their application.

An overview of the SE2000 policy is presented in Appendix B1.

2.4.11.1 The Ongoing Resourcing Scheme (ORS)

A major component of the SE2000 policy was a significant increase in funding to provide equitable resourcing for those students with similar needs irrespective of the school setting or geographic location. For SE2000 to enhance the ecological paradigm, the MoE introduced an ‘individual resourcing scheme’ (MoE, 2000, p. 2) that would enable schools to deliver ‘sound education and appropriate educational support’ (ERO 2005, p. 3) to students with very high or high on going educational needs wherever they attended school. A more comprehensive overview of ORS is presented in Appendix B.2.

Although SE2000 was seen by policy makers as a ‘major shift away from past thinking’ (Fancy, 1999, p. 3), a concern was noted by the teachers, support specialists and families making applications for ORS funding. While the major section of the original application form focussed on the skills the student has already gained and the teaching strategies that were required for the child to learn and maintain skills (MoE, 2000), the final section of the original thirteen-page application document requested information regarding the student’s health needs, including ‘name and type of condition/s and effects on student at school’ (p. 10). Despite the emphasis on skills and teaching strategies, a diagnosis was seen as necessary to access the requested support for the students. This request for information, together with the terminology used within ORS when identifying students with high and very high needs, and the categorisation of students as having moderate needs, would suggest that the ‘vestiges of the medical model of disability remained’ (Mitchell, 1999, p. 205) within the policy underpinning SE2000.

Rosalind Bartlett (2009), in her discussion outlining challenges faced by education professionals working with students with special learning needs, highlights a second concern: the need to adopt a 'negative deficit' (p. 125) perspective when completing the ORS application form in order to increase the chance that funding will be granted by the verifiers. When first introduced, the ORS application process was seen as exacerbating attitudes to disability that were inherent within the medical model and not supporting the ecological paradigm it was intended to address. In many cases the application for ORS funding is supported by specialists from within the education field or from those working in support services such as physiotherapists and occupational therapists. Bartlett sees this 'over reliance on specialists to guide the application process' (p. 125) as being in conflict with the rights discourse where there is an emphasis on the environment in which the student is participating in learning programmes. It also removes the rights of parents to make their own application and enforces reliance on educational and health professionals who then assume a position of power.

In the revised ORS application forms introduced in July 2011 (Appendix B3), the applicants have to select one of nine criteria on which to base their application. As with the original application form, the medical model remains a component of the criteria for eligibility for ORS funding which was designed to promote the categorisation of children with special education needs within an ecological paradigm (Davies & Prangnell, 1999). Although the request for information on the 2011 application focuses on the student's interaction with the essential skills of the national curriculum in such areas as oral and written language, cognitive skills and mobility, the section requesting information about the student's diagnosis, the date of the diagnosis and the specialist's designation is retained in this application form. The 'medical model' has been retained, albeit it in the final pages of the application. Given the depth of information requested on the application form relating to the student's interaction in the learning environment and the teaching strategies implemented to support the student, it could be assumed that the verifiers would be able to make an assessment without having to rely on the diagnosis of specialists from within the education and health sectors. As suggested by Mitchell (2010), the medical model retains dominance even when other models that place an emphasis on the environment have 'gained traction in recent years' (p. 2).

A key tenet of SE2000 was that 'all children with special needs would receive their education in regular classrooms in inclusive education settings' (McMenamin, 2009, p. 183).

2.4.11.2 The medical model remains within special education policies

As described by Neilson (2005, p. 15) in 2.4.10 as ‘the most powerful discourse, the medical model posits disability within an individual as a personal problem with that person hoping and waiting for a cure. Forness and Kavale (2001) suggest this model has been most dominant in both the diagnosis and treatment of children with disabilities. Kauffman (2007) infers that this is because the majority of schools serving the general population were established under their country’s legal system, while many of the earliest leaders in special education were medical practitioners, hence the focus on a medical model to support children with special education needs.

Challenges to the use of the medical model in education have lead to a redefining of the term disability in order to apportion some responsibility to the community and the environment in which people live and are educated. The environmental discourse challenges the medical model as the dominant discourse in current education policies and practices in Aotearoa New Zealand. This model assumes that it is environmental contingencies such as the use of the communication resources to support non verbal students that are required to address most learning needs of a population.

Forness and Kavale (2001) in their research with children diagnosed with ADHD (Attention Deficit, Hyperactivity Disorder) found that the learning needs of only a few AHDH children identified in USA may have been the products of an inconsistent environment. Their findings were that the majority of children requiring special education support have been and/or continue to be supported by medical diagnoses and ongoing medical care. As seen in the review of international trends in the education of children with special education needs conducted by Mitchell (2010), most countries have a mix of paradigms in special education policies and provisions for these students, with the medical model retaining and remaining an influence in the practices of special education. In Aotearoa New Zealand, the expectation that a health specialist will ‘sign off’ the diagnosis of a child’s disability on the ORS application form reinforces the statement from Forness and Kavale (2001) that ‘a new version of the medical model seen as complimenting an existing environmental model may be fundamental to the education outcomes of children with special needs.

2.4.11.3 Group Special Education (GSE)

GSE was established within the legislation introducing SE2000. This section in the MoE replaced what had been known as Special Education Services (SES). In 2011 GSE was rebranded to become the Ministry of Education: Special Education (MoE: SE). Because this research was undertaken during the GSE era the terminology relevant then has been retained. GSE had a very public profile in the field of special education. Its focus was on the strengthening and improving of educational opportunities and outcomes for children with special education needs. These support persons, funded by GSE, include psychologists, special education advisors, early intervention teachers, and therapists.

2.4.12 Enrolments in schools

The expectation underpinning the introduction of SE2000 was that there would be increasing numbers of children requiring special education programmes within regular school settings and increasing numbers of parents who wished to have their children receive their education in a regular school setting (MoE, 2005). This would result in a noted increase in the number of children with special education needs enrolling in regular schools. The implementation of ORS funding and the establishing of the Resource Teacher Learning and Behaviour (RTLB) support network resulted in the closing of most special classes in primary schools and work experience units at secondary school level (Wylie, 2000). It was expected that the students enrolled in these units would not be granted High or Very High Needs verification and would therefore be continuing their education in their regular schools.

The closure of the residential psychopaedic training centres, in response to the Department of Social Welfare’s policy of maintaining children in their home communities, also had a considerable impact on the resources available in regular schools. With the majority of these young people being granted High or Very High Needs ORS funding, the regular schools’ programmes of learning available to these ‘fragile’ students were seen by some parents as being of ‘poor quality, albeit well intentioned, or insufficient’ (Wylie, 2000, p. 25). Some parents therefore chose not to support the regular school option available to them.

Following the introduction of the SE2000 reforms, there was a change in the enrolment procedures for students wishing to enrol in special schools. A component of the

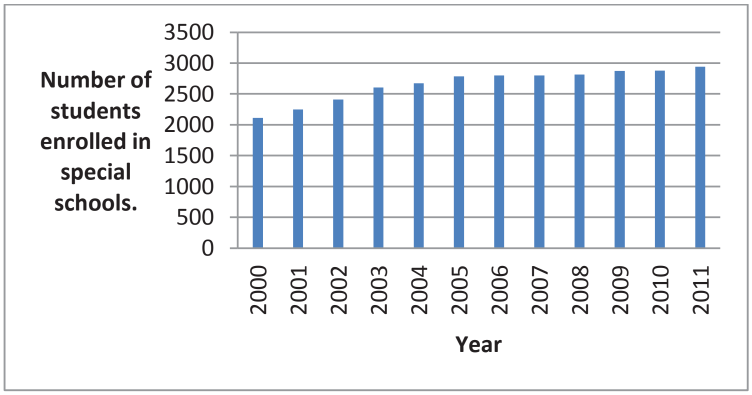
Education Act 1989, Section 9, required families wishing to enrol their children in special school to appear before a panel to discuss their application. The application is approved by the panel, usually chaired by GSE staff, and signed off before the student enrolled in the special school. Under the regulations introduced by SE2000, students granted ORS verification were deemed to have met the requirements of the Section 9 agreement, thus making the enrolment process equitable to that of regular schools the families of students granted ORS could apply to and enrol in special schools as of right. For the first time in the provision of education in Aotearoa New Zealand, students with special education needs had barrier-free access to the education provider of their choice. This paradigm shift by the policy makers was welcomed by parents wishing to enrol their family member in a special school placement, and by those working in these placements: their education provider was acknowledged as having equality in the education system. However, in 2004, the Section 9 agreement was reinstated, with the justification for this move being explained by GSE that the procedures implemented by SE2000 contravened the legislative requirements of Education Act (1989). In 2012 applications from ORS funded students to enrol in special schools are 'rubber stamped', with ORS funding being accepted as meeting the criteria for a Section 9 enrolment; however, the paper work has still to be completed and lodged with the Ministry.

Once again the right to choose a school appropriate to their child's education needs was removed from those parents wishing to enrol their child in a special school. The paradigm shift towards equality in the education of children was not long lived. This new process of enrolment once again moved the control to GSE and therefore to the MoE. Although parents and schools could be part of the initial process, the MoE still remains the 'gatekeeper' as to who may enrol in special schools. Yet another example of the MoE's gatekeeper actions is the procedures for enrolling of students when they first enter a school. Regular schools have access to the national register of students Enrol and are able to enter the information regarding new students directly onto their schools register within the national register. However, any new enrolment in a special school is made by GSE with the individual special schools having no power to complete the documentation for such an enrolment. Why are there no similar gate-keeping practices when students enrol in a regular school? Perhaps this is one means of monitoring the number of students enrolling in special schools and tracking the education journey each student has made before entering special school. Of interest is that the MoE do not keep statistical records of students who transfer from regular school to special school (B. McPherson, personal communication, 3 June 2011). The information is on the students' individual files but not able to be accessed as a separate statistic. This information would and should be of interest to the MoE when discussing the role of special schools in the education system.

Despite SE2000 being 'heralded as a new era of resourcing and organisation for special education' (McMenamin, 2009, p. 183) with the primary focus on nurturing and establishing an inclusive education system in Aotearoa New Zealand, enrolments in special schools increased by 4% between the years 1998 and 1999 (Wylie, 2000, p. 75), with some schools gaining more than ten students in one year. While this increase in roll numbers may be seen as a result of the closure of the psychopaedic training centres and possibly the closure of most special classes, the increase in enrolments was maintained through the next decade as illustrated in Table 2.1.

Table 2.1

Enrolments in special schools 2000–2011



Note. Data information received from Ministry of Education (Alex Nairn, personal communication, Ministry of Education, 1 March 2012).

McMenamin (2009) suggests that this roll growth could be attributed to the programmes of learning offered by the special schools. Parents had confidence in the commitment of the staff to the education of these children with special learning needs. Another factor that may have influenced this roll growth in day special schools is the early identification of young children experiencing difficulties in reaching accepted milestones in such skills as mobility, communication, and socialisation. The SE2000 initiative to have speech language therapists working with children with speech language difficulties is often the first step in the identification of those children requiring additional support in their learning programmes. Support from the Early Intervention Team is also an important component in the early identification and support for students with special education needs and their families. This early identification of children in need of specialist support in their learning programmes may have impacted on the rolls of special schools with families electing to enrol their children in these schools when their early childhood programmes were completed.

Within SE2000 legislation, the MoE had the authority to remove selected education providers from the education system should their programmes of learning no longer be considered necessary. Some special schools were closed and the MoE placed an embargo on any further development of special schools or units (Ryan, 2004). In response to the closure of their special school, a group of sixteen parents legally challenged The Crown acting on behalf of the MoE in Court. The basis of the challenge was the statement in Section 9 of the SE2000 that, where it had been ascertained that students had special education needs, it was the Crown's responsibility to maintain special education provisions for those students. Although the first ruling found in favour of the parent group, The Crown appealed this finding. In a settlement reached between the two parties, the Court found the Crown had acted unlawfully and ordered that The Crown 'no longer pursue the closure of special education units' (Wills, 2006, p, 197). This ruling, in what is known as Daniels v Attorney General (Ryan, 2004, p. 1), enabled some special education communities and schools to remain open.

Gasson (2008) examined the educational experiences of families of severely disabled children who had elected to enrol their students on a special school and 'support the special school model' (p. 107). The students whose parents participated in the research had attended a special school that was identified within a MoE proposal as being surplus to requirements and was to close. It was expected by the MoE that most students would enrol in inclusive educational settings. However, with the support of the school's Board of Trustees, the parents and staff of the school to be closed, and professionals working within educational organisations, the school was redeveloped and families continued their support for the special school by re-enrolling their children in the new school.

The actions of these groups must be seen as yet another example of a paradigm clash in the world of special education. Although the ecological paradigm promoted an all-inclusive education system where all school age students could participate in programmes of learning in their regular neighbourhood school, the ongoing demand for segregated programmes of learning was still very prominent.

2.4.13 Review of Special Education 2010 (RoSE)

In the years following the implementation of SE2000, a number of changes were made to the original funding framework. In 2009 an additional $NZ18 million a year was added to the SE2000 funding to expand support for students with high and very high learning needs. In 2010 RoSE was implemented with the intention of ensuring there was 'genuine choice' (MoE, 2010a, p. 1) about how students with special needs were supported. The review investigated the services available to school-age students and was guided by the vision of 'how special education services and support could work in the future' (p. 7). Responses to the review were invited from all persons interested in the education of children with special education needs.

In a discussion relating to what were perceived as successful schools, RoSE presented a range of school options as possibly providing education programmes for children with special learning needs: the current dual system as at 2010; no special schools; special schools as resource centres; or the 2010 system with open access to special schools

RoSE gave parents and the community the opportunity to voice their concerns about special education to those with the power to make changes in the education programmes offered to children with special education needs. The paradigm conflicts were evident within this review. The segregation of students for education remained in conflict with those who advocated one learning environment for all children. The identification of those in need of specialised learning programmes, although couched in environmental terminology within the documents, still encouraged a medical diagnosis to support any application for specialist support.

The range of views about special education received from parents, students, education-based organisations, community organisations, specialist support persons, and members of the community is summarised in the Review of Special Education 2010. A discussion of the public response is presented in the next section.

2.4.14 The Review of Special Education 2010: Public response summary

One major theme emerging from RoSE was the need for high-quality learning programmes presented by teachers with the right skills and knowledge (MoE, 2010b, p. 9). It was acknowledged by the MoE that there was a bank of rich funds and knowledge held by teaching and support staff already working in special schools and satellite classes. The sharing of this knowledge together with ongoing professional education for the staff of regular schools were identified by 22% of the respondents as essential components for the successful programmes of learning in regular schools. Another theme highlighted was the need for improved specialist services to be available to students with special learning needs enrolled in regular schools. Parents' responses compared the 'in house' specialist services accessed by special school students on a regular basis (daily or weekly) and the itinerant visits (possibly once a term) to support students in regular schools.

Many respondents used such medically derived labelling as cerebral palsy, Down syndrome, and deaf to support their statements. The glossary supporting the Public Response Summary document includes a range of 'medically derived labels' to assist readers understanding of some of the responses. While there is an emphasis on the environment in which learning takes place within the current philosophy of education in Aotearoa New Zealand, the medical model that focuses on the assumption that the deficits impeding learning are located within the individual students is still present, creating a scenario of 'two values' (Norwich, 2008, p. 138) education provisions to meet students' individual learning needs in Aotearoa New Zealand.

The MoE response to the review, Success for All – Every School, Every Child (MoE, 2010c), formalises the government's overall direction for special education for the years 2011–2014. This document outlines a change of focus from preparing children to enter school, to preparing schools for the enrolment of students with special education needs. Underpinning this shift of focus remains the SE2000 overall aim for students in Aotearoa New Zealand to be part of a 'worldwide inclusive education system providing learning opportunities of equal quality to all students' (MoE, 1996, p. 5). What is meant by the term 'inclusion' will be examined on the next section of this literature review.

2.5 Inclusion, inclusive education and SE2000

The term ‘inclusion’ has many different meanings (Bourke, 1999). It can be defined according to the nature of the community in which it is being developed (Ainscow, 2008). While the term is most commonly used when discussing the education of students with special education needs, in many countries it is linked to a response to disciplinary exclusions from education providers. In this context, inclusion is when schools may be requested to enrol students who have been excluded from other providers. Mittler (2000) also sees inclusion as linked with groups of people disadvantaged or discriminated against within the society in which they live. The term ‘social inclusion’ may refer to migrant families in a community, to girls being on the margins of or being denied educational opportunities, or possibly to people living in a low socioeconomic community. Children with special learning needs may also be included in these groups of social inclusion.

The Inclusion as Education for All movement, created in the 1990s, was based on the philosophy of increasing access and participation in education across the world. Coordinated by the United Nations Educational, Social and Cultural Organisation (UNESCO), the two international conferences held in Jomtein (1990) and Dakar (2000) gave the participants the opportunity to rethink the development of education within communities. Although disabled people and their supporters were very concerned that their issues were ‘pushed down the priority order’ (Ainscow, 2008, p. 243) in the Education for All declaration of 2001, this document made comprehensive reference to inclusive education seeing it as a ‘process that involves the transformation of schools and other centre of learning to cater for all children – including...those with disabilities and difficulties in learning’ (Burnett, 2009, p. 4).

Education for All defines an inclusive school as one that offers possibilities and opportunities for a range of working methods and individual treatment to ensure that ‘no child is excluded from companionship and participation in the school’ (UNESCO, 2009, p. 16). This inclusive model of education is seen as a ‘rights based education’ (p. 16) enabling children, supported by their families and communities, to realise their rights to appropriate programmes of learning. The Education for All document also acknowledges the inclusive approach to education as a shift from seeing the child with special learning needs as a problem to seeing the education system as a problem.

While this definition of inclusion in education has relevance in the education setting in Aotearoa New Zealand, MacArthur (2009) suggests a fixed definition of inclusion is not appropriate because inclusion means ‘different things to different groups in different contexts’ (p. 14). For Sainsbury (2002), who describes herself as woman living with Asperger’s Syndrome (AS), inclusive education meant attending a regular school in her neighbourhood. She describes her experiences as ‘a recipe to ensure failure’ (p. 37) in both her academic learning and her social interactions with her peers. By not having contact with other AS students, Sainsbury had a feeling of isolation: ‘Normal is being in the company of others like oneself’ (p. 42), where the making of friends is on a level playing field, where failures are more acceptable or possibly not noticed by those with whom you are interacting. Sainsbury describes the ideal inclusive educational placement for her as being in a specialist school where the focus would be on the particular learning and social needs of AS students.

In contrast, an Aotearoa New Zealand presenter Matt Frost (2009), in a plenary session at the Making Inclusive Education Happen conference, spoke of love and luck as his keys to success in education. Frost, an ‘Aspie’ (he has AS), thanked his whānau, friends and support professionals who gave him the strength to pursue his dreams. He celebrated his luck in finding education providers who were willing to accept him into, and support him in his learning programmes. Frost referred to the experience of learning in an inclusive education programme where he attended the regular school in his neighbourhood, as a time to make friends. ‘Making friends and enjoying their friendship is the key to a successful education’ (p. 1). The learning environments in which Frost enjoyed educational and social success were at the opposite end of the success continuum from that of Sainsbury (2002). Both draw on personal experiences to support their commitment to the education programmes that they perceive as best suiting their particular learning and social needs.

If the aim of inclusive education is to promote quality education for all children, Jarvis (2007), when discussing the education of deaf children in the United Kingdom suggests this does not mean the same education programme for all children. Although technological developments have given many deaf children the opportunity of hearing spoken language, there are still a number of deaf children for whom sign language is their first language. As is with all children, communication is the foundation on which learning, together with social development, is based. For many deaf children studying in an inclusive setting, the inability to communicate with their hearing peers leads to a feeling of isolation from both the hearing and the deaf community. Jarvis advocates that any provision for deaf children should be large enough to enable the creation of a deaf culture community, within in and outside the classroom. This community could be established in a specialising school or unit within an inclusive school setting. This would avoid the inappropriate placement of deaf students in order to meet the demands for all inclusive settings.

Osgood (2005), draws on the finding of research in deaf education in the USA together with those who had ‘personally experienced it’ (p. 177) to support his findings that a philosophy of integration runs counter to the deaf community’s ‘staunch defence of its own sense of unique identity and culture’ (p. 178). In reflecting on the current state of the integration of children identified as hearing impaired more effectively into regular education programmes, Osgood suggests that most of the progress and research records have been with children with mild disabilities. The author sees conflict arising when regular schools are required to meet the educational and social needs of those students who require greater adaptations to the programmes to enable success in their learning. Osgood highlights the need for fundamental restructuring of established education programmes, and education of teachers and students if full inclusion of all students in regular programmes is to be judged as successful. It is only when this restructuring occurs and is practised that a philosophy of inclusive education that embodies the right of every child to be ‘educated in a common setting where his or her individual needs and those of all other children are addressed completely and effectively’ (p. 198) can be successful. This educator states that any child who wishes to be educated in a regular school setting has the right to be there and it is the responsibility of all stakeholders to ensure this happens. But alternative education placements must be available for those children, who, while having the right to regular school education programmes, may prefer not to be there and ‘their voices need to be heard’ (p. 199).

When describing the themes underpinning SE2000, Davies and Prangnell (1999) had a view of inclusive education as ‘a place where everybody belongs, is accepted, supports and is supported by his or her peers and other members of the school community in the course of having his or her educational needs met’ (p. 2). The very broad view of inclusive education could be interpreted in many ways: the school community being the neighbourhood regular school; a special school satellite class within a regular school; a day special school; or a residential special school. Within this view of inclusive education, all students have the right to education, and parents have the right to choose the education provider best suited to their child's special learning needs.

But MacArthur (2009) does not see inclusive education as occurring in segregated settings such as special schools or units. She sees inclusive education as developing only in regular schools where special education thinking and practices have been replaced by a philosophy that it is the role of the school to adapt and attend to the diverse needs of all its students. That all children, regardless of their individual educational needs, should participate in programmes of learning in their regular neighbourhood school, is echoed in the Success for All statement from the New Zealand Ministry of Education (2011b), where inclusion means that all students 'are welcomed and achieve at their regular school' (p. 1).

The conflict surrounding the philosophies underlying inclusive education continues. As long as there are choices of education providers available to parents of children and young people with special learning needs, there will be a 'major point of tension' (Mitchell, 2010, p. 4) between the supporters of segregated special education placements and those promoting inclusive regular schools.

The continued presence of, and support for, special schools within the state education system of Aotearoa New Zealand could be seen as an anomaly existing in an education system that promotes inclusive education. The dilemma of where to learn (Norwich, 2008) faces those making decisions about educational placements for their ORS funded students. If inclusion is about actively removing barriers to learning (MoE, 2005) and supporting individual student's learning needs, it may be more appropriate and inclusive to educate some children in an exclusive setting that provides the high level of support necessary for successful learning.

For the parents of students with special learning needs, the inclusion debate continues. Special schools are seen by some parents as an integral component of a continuum of inclusive provisions for children with special learning needs (McMenamin, 2009). 'Parents with special needs children should be given the same right as any parent to choose a school where they think their learning needs will be best met' (McKay, 2010, p. 1).

For other parents, the continued presence of special schools represents a failure of inclusive education policies (Higgins, MacArthur & Morton, 2008):

> *To think that everyone will be working together in an inclusive manner is a serious move in the right direction. This time, together, we will make a better world for our children. The alternative is unthinkable.* (Manning cited in MoE, 2011b, p. 1)

Inclusion in education is a process of increasing participation of all students within the 'cultures, curricular and communities of neighbourhood centres of learning' (Booth, 1996, p. 35). There is a need for the identification and reduction of barriers that confront all students in their learning programmes. Although the barriers may be more complex and of a greater height for students with special education needs, the issues of inclusion remain the same. In Aotearoa New Zealand all students with special learning needs are entitled to participate in state schools, no matter how high their support needs. Students with special learning needs are funded directly by ORS, or through the SEG to receive the support they need to access the curriculum. The challenge is for education providers to meet the challenges of the diversity within their school communities and address the needs of these students. Inclusion is not an end product. It is an evolving, complex concept based on educational policy, processes and practices grounded on 'key principles of social justice and human rights' (Higgins, MacArthur & Rietveld, 2006, p. 34).

In a statement supporting the Education Gazette publication, A Fully Inclusive Education (2011), a parent expresses what could be seen as the key to an inclusive education world that would be acceptable to all families of children, including those families whose family members have special learning needs:

> *I hope that Success for All-Every School Every Child means that if families wish all their children to attend the same local primary and secondary schools, then the schools will have the support structures in place for this to happen effectively (*M. Leach).

The second section of this literature review examines the meaning of families, and the role of decision making, the issues on which this research was based. An overview of the literature discussing issues that were identified as influencing families' decision making, bullying, and education of school staff concludes the chapter.

2.6 What is meant by 'the family'?

Society is formed by a number of entwined groups and entities and a multitude of individual persons, each with their own specific objectives and purposes. Among these groups, families are the basic social unit (Boyden, 1994. p. 164). As may be expected, 'every family is like no other family, like some other families and like all other families' (Gestwicki, 2007, p. 31). The term 'family' covers a wide range of structures, types, values and functions. In every society, the family is continuously evolving, and changes occur as members pass through different stages of their life cycle.

Gestwicki (2007), when defining a family, states that the family is the most adaptable of human institutions, being 'able to modify characteristics to meet those of the society in which it lives' (p. 20). She suggests that characteristics common to the family are the concepts of sharing common values, having commitments to and accepting responsibility for members of the group, and providing life and support over a time.

Until the early 1990s, in the United States of America, all roles relating to support roles for children focussed on parents (Turnbull & Turnbull, 2001). The change in focus to families as supporting children is seen as a response to increasing recognition that partnerships are not and should not be limited to parents only. In accepting that partnerships involve relationships between other family members, close friends and professionals working with their family members, Turnbull and Turnbull (2001) define the family as 'two or more people who regard themselves as a family' and who perform some of the functions that families typically perform. These people 'may or may not be related by blood or marriage and may or may not usually live together' (p. 12).

Segrin and Flora (2005) suggest there is no one, universally accepted definition of family (p. 4), and very little chance that one will be accepted in the future. They present an outline of three approaches to the definition of a family: members related by blood or law, and residing together in a household; members identifying a common nurturing and socialisation need; and groups of people with 'strong ties of loyalty and emotion' (p. 10).

Segrin and Flora (2005) have included all three approaches in their final definition of family:

> *'any group of persons united by ties of marriage, blood, or adoption or any sexually expressive relationship, in which adults cooperate financially for their mutual support. The people are committed to one another in an intimate interpersonal relationship, and the members see their individual identities as importantly attached to the group with an identity of its own.* (p. 11)

In a discussion relating to the Family Court in Aotearoa New Zealand, Carson (2008) stated that 'no one seems very clear as to how far the definition of a culturally recognised family group extends' (p. 65). This is the challenge for this researcher working in an Aotearoa New Zealand setting. In a paper based in Aotearoa New Zealand Cunningham, Stevenson, and Tassell (2005) confirm the findings of overseas researchers that attempts to create an 'absolute definition for the term family' (p. 13) are burdened with problems.

These authors acknowledge the influence of ongoing social change and the flexibility of family groupings on the challenge to develop an accepted global meaning for the terminology family. In Aotearoa New Zealand, contemporary use of the Māori word 'whānau' refers to a variety of groups: some referring to whakapapa-based definitions with others are 'not based on descent or kinship' (Cunningham et al., 2005, p. 13). The term 'whānau' has, as with the terminology family, broadened to include non-traditional situations where Māori with similar interests but 'not directly blood relationships' (Cunningham et al., 2005 p. 14) form a cohesive group.

Whānau is acknowledged as the basic social structure within Māori society. It is a concept that extends much wider than the traditional nuclear family unit to what is understood as an extended family. Although Durie (2003, cited in Cunningham et al., 2005) discusses Māori terminology that describes different family groupings, Cunningham et al. (2005) conclude that the model of whakapapa whānau, with its links to the land and to shared ancestors, remains at the core of Māoridom.

Because of this range of ethnicity and family groupings, which includes single parent families, nuclear families and extended families, the whakapapa whānau, as defined by Durie (1994), would be most appropriate for research that is based in Aotearoa New

Zealand. I see the combined terminology of family/whānau as used in some documents as suggesting that there is a conflict between the two words, and not reflecting the diverse nature of family groups in Aotearoa New Zealand. In this research, 'family' is defined as 'whānau: a diverse unit where people not necessarily sharing common ancestors form a cohesive group within which certain responsibilities and obligations are maintained'. The role the family has in making decisions is discussed in the following section.

2.7 How are decisions made

This research asks families how and why they made the decisions to move their ORS funded family member from a regular school placement to a placement in a special school. This decision may have been made one day over a cup of tea. It may have been made over a period of time when the family group, together with their family member, was placed in a situation where change was necessitated. When were these decisions made? How were these decisions made? Why were these decisions made? These questions led to the examination of literature surrounding decision making.

Every day throughout the world, people are making decisions: what to have for breakfast, which road to take to a holiday destination, the most suitable name for a new pet kitten. How these decisions are made may depend on information already known to the person making the decision what breakfast food there is in the refrigerator or pantry, how much time has been allocated for the journey to the holiday destination, or whether the kitten is a male or female. But maybe people do not have an understanding as to why they made a decision. As suggested by John F. Kennedy (1971, cited in Fitzgerald, 2002) 'there will always be dark and tangled stretches in the decision making process, mysterious even to those who may be intensely involved.'

Galotti (2007) describes the process of decision making as involving social phases, the most important of which is decision structuring, where the person or persons making the decisions consider all available options and decide on a criterion to be used when choosing among these options. Although lineal models of decision making, where the decision makers investigate all aspects of the importance of all the independent criteria within the decision, underpin many decisions in research undertaken in clinical studies, Galotti (2007) suggests these models are rarely used in everyday world. In real life situations, Galotti's (2007) and Galotti and Tinkelenberg's (2009) research findings showed that decision makers reduce the number of options by setting goals, then gather information, structure the decision, make the final choice and finally evaluate the decision. These phases of decision making may not be instigated in any set order.

In their 2009 research, Galotti and Tinkelenberg investigated parent groups who were choosing a school placement for their six year old children. The findings confirmed that in real-life situations, people use only a small amount of the available information to make decisions. ‘Presumably they adopt techniques and shortcuts’ (Galotti, 2007, p. 323) to minimize the number of options they actively consider.

While Galotti and Tinkelenberg (2009) focussed their research on how much information people do utilize when making decisions they did not investigate how the research participants gained the information, who they asked and why they selected certain options to influence their final decision.

Helga Drummond (2001) cautions on placing focus on the idea of decision without considering the process. She suggests that until the situation is understood, no decision can be made. Once a decision is made, it needs to be implemented. In making the distinction between the decision and the decision-making process, Drummond sees the decision as the final outcome of the process. It is the decision-making process that involves events leading up the moment of choice and beyond.

Decision making is one component of this research. It is the decision that family members have made to move their ORS funded family member from their placement in a regular school that underpins this study. Why and how did the family make this decision? For Drummond (2001), decision making is about asking questions and receiving clear and definite answers. But she sees questions as possibly lacking the necessary precision to elicit answers that give guidance. Another suggested concern is that often those persons giving the guidance say what the questioner wants to hear or expects to hear. The author implies that people are at their most vulnerable if what they are given as advice is what they want to hear, and this information can be rationalized to fit inherent expectations. Drummond suggests gathering information from a range of sources. If similar solutions are reached, the information can be accepted as reliable.

If decision making is about asking questions and receiving answers, those making the decision need to know who to ask and how to access these information providers. For many families, faced with the demands of providing the daily care and needs of their family member with special needs, the task of sourcing information may become very challenging. At these times, parents and families may be working to the 'limits of their mental processing abilities' (Drummond, 2001, p. 9) and this human factor may influence their feelings and undermine any judgements made.

Weick (1979) suggests that all sense comes from a backward glance. Necessary components of a decision maker's package are a lantern to enable the path ahead to be seen, and a mirror to look back at the path already travelled. 'All knowledge, all meaning, all insight and all understanding is the result of looking backwards' (Weick, 1979, p. 37). The implications for this research are that by reflecting on their family member's past educational experiences, this 'look backwards' may give insight into why and how the final decision to transfer their student was made, not what the final decision was. Reflection is seen by Drummond as the key to generating understanding into the decision making process.

Because the family unit is flexible 'every decision a family makes is unique' (Segrin & Flora, 2005, p. 84), but common methods of decision making can be identified. Turner (1970) identified three common decision-making styles: consensus, accommodation, and de facto. In the decision-making model described by Turner (1970) consensus requires all family members to agree before a decision is made and, not surprisingly, this is the least common decision-making process. When using the accommodation decision-making method, one or two of the family members make the decision and the remainder of the group accept the chosen action. This form of decision making is seen by Segrin and Flora (2005) as a power process, with the more powerful members of the family group being in control. In the de facto decision making, the situation makes the decision for the family. Should the family, when faced with the need to make a decision, do nothing or cannot agree, no action is taken. The outcome is that either the decision resolves itself or it is determined by factors beyond the control of the family group.

The roles families have in making decisions that impact on the education of children have changed with legislative mandates such as PL94-142 The Education for All Handicapped Children Act of 1975 (EAHCA) in the United States of America (USA) and the Aotearoa New Zealand Education Act of 1989, which placed an increased emphasis on parental empowerment and decision making. But in research investigating the methods family groups used to obtain the best educational outcomes for their children, Hess, Molina and Kozleski (2006) acknowledged that ‘very little attention (has been) given to the voice of families’ (p. 148) as to who will be making the decisions and how these decision will be made.

Families’ rights to make choices about all aspects of their family member’s life experiences, including health, educational, social, recreational, therapeutic, and community aspects, were the focus for research undertaken by Murray et al. (2007). These decisions, while affecting only one member of the family, impact on all members of the family and may also include ‘friends, community agencies and religious affiliations’ (p. 117). Murray et al. remind professionals working with families that a critical component of their role in the decision-making process was their listening to the families’ voices and respecting their right to make choices.

The decision to place a child in inclusive or self-contained special education programmes ‘is seldom a clear cut decision’ (Hanson et al., 2001, p. 66). In their study based in the USA, Hanson et al. investigated possible influences on decision making by parents as their children moved from preschool to elementary (primary) school programmes. The focus research group were the parents of twenty-five children with disabilities, with a second group of eight parents supporting ‘typically developing children’ (p. 67) providing information on their school experiences. Although inclusive placements were the choice for most families of the children with disabilities, over the 5 years of the research programme many placements became ‘more restrictive’ (p. 74), with the parents’ voices less dominant than that of the professionals when making educational decisions.

The researchers found five themes emerging over the 5-year period of interviews: the influence of advice from professionals on the families decisions; the families’ ability to access information; the influences of advocates; the fit between the families’ needs and expectations and those of the host schools; and the influence of the families’ and schools’ characteristics. However, there was no discussion as to the factors that influenced individual families to make the decisions to maintain the placement of their family member in an inclusive placement or to transfer to an educational programme provided in a setting separate from the regular school.

In a study based in England, Flewitt and Nind (2007) examined how parents made choices for their child's preschool education, given the choice of inclusive or special education providers or a combination of both providers. With some participants in the research living in rural locations, there was a lack of choice due to their geographic location. For families living in urban areas, the funding practices of the local education authorities resulted in restrictions imposed on the placement of their children with significant educational needs. The opinions given by support professionals were, for some parents, central to their decision making. But for all parents interviewed, the final decision for their child to attend a particular education setting was based on a 'balance of many different factors' (Nind, Flewitt & Johnson, 2005, p. 15), including visits to possible providers, consultation with staff of schools, and discussion with extended family and friends, with the latter being the major referral group. The pressures of 'choice making and choice avoiding' (p. 16) were identified as a source of disagreement within family groups with a report of a 'lonely journey' (p. 16) being experienced by some participants.

Robertson, Gunn, Lanumata, and Pryor (2007) researched parental decision making when deciding whether to use Early Childhood Education (ECE) services in Aotearoa New Zealand. Results from the literature research conducted by these researchers reiterated the findings of others that 'there is not a lot of literature' (p. 12) outlining the reasoning processes involved when parents make decisions about the care for their young children with special education needs. A further issue identified in the literature was the lack of research as to how parents find out about the various options available to them. The summary findings of the literature were that parental decisions involved complex interactions between 'family's needs, preferences, knowledge and expectations' (p. 16). However, there was no discussion of the factors that influenced the families when making these decisions. Such questions as: How was the decision made? To whom did you talk? What information did you access? would have provided more information, giving further insight into the families' decision-making process.

Giving parents the rights of 'an equal and fixed partner with educators and school systems' (Turnbull & Turnbull, 1988, p. 265) assumes that all families have the skills to enable balanced and effective collaboration with their child's educational providers. The legal mandate for parental participation in the decision-making process relating to the education of their family member with special education needs is based on an assumption that equity, individual rights and freedom of choices are understood and valued by all families involved in special education. The authors argue that a belief in the rights of the individual and freedom of choice places families from culturally diverse backgrounds, who may not share these values, at an unfair disadvantage. Kalyanpur, Harry and Skrtic (2000) place the responsibility for 'more effective and balance collaboration with families' (p. 121) within the educating of such professionals as teachers, physiotherapists and language therapists preparing to work in the field of special education. The authors suggest that all people, including specialist professionals, have a micro-culture or set of personal characteristics such as ethnicity, gender and religion that they bring to the macro-culture such as nationality or professional affiliations. The combination of the micro- and macro-cultures creates a cultural identity that is multifaceted and highly individualised. However, the educating for those working in a specific field of special education is focused on a particular professional's knowledge, skills, norms, and values, with few opportunities available for the trainees to become aware of barriers that may hinder successful parent and professional partnerships with families from diverse socio-economic, cultural and educational backgrounds.

A wide range of models of professional education reviewed by Kalyanpur, Harry and Scrtic (2000) highlighted the need for professionals to first develop an understanding of their own cultural and ethical values before practising their skills in the education field. The outcome of educating professionals would be an awareness and acceptance of others' options and of possible alternative actions, enabling the development of reciprocal and mutually supportive relationships with parents and students.

The giving and receiving of information between families and professionals must be undertaken in a mutually agreed manner. In a multicultural country such as Aotearoa New Zealand, all participants in any decision-making process must be aware of and respect the culture of all members of the group (Sheehey, 2006), with the identifying and use of culturally appropriate services a priority (Cunningham et al., 2005) when family groups are working with professionals to reach a decision impacting on the education placement for their family member.

It becomes the role of those responsible for the educating of professionals working with students with special learning needs to ensure these people have the skills to meet the expectations of students with special learning needs and their families.

2.8 Teacher education

The statement "Success for all – every school, every child (MoE, 2011b) sets the 'overall direction' (p. 2) for the provision of special education programmes of learning in Aotearoa New Zealand for children with special learning needs. This document presented the vision that by 2014, 80% of schools in Aotearoa New Zealand would demonstrate highly inclusive practices measured through assessments implemented by the Education Review Office. In achieving this aim, the MoE's vision is that all schools will be both confident and welcoming of every child 'regardless of that child's learning needs' (p. 1).

But, as suggested by Mock and Kaufmann (2005), if all students are to participate in learning programmes in regular schools, the regular classroom teacher 'must be prepared to teach all students' (p. 286). This makes the assumption that the classroom teacher will have the skills to meet the learning, physical, and emotional needs of all the students in the class. In a study investigating the relationship between the achievements of students with special learning needs and the various aspects of teacher education, the findings of Li and Sass (2010) show that pre-service preparation of teachers working with students with special learning needs, had positive results in classroom interactions with the students. The findings that 'special education students who receive all of their math instruction in a regular education course exhibit greater achievement gains when their teacher holds an advanced degree (in special education)' (p. 15) supports the findings of Fazel (2011) that when teachers are 'trained and given the proper tools, they are better equipped and more successful' (p. 1) in meeting the learning needs of all students in their classroom.

Findings from Hulston's 2000 research based in Aotearoa New Zealand emphasised the need for teachers to accept responsibility for all students in their classes. Kershner, (2007) suggests that the ability to recognise and meet the different needs of students in a classroom is a significant aspect of good teaching. For teachers to develop classroom practices and curricula that are reflective and inclusive of all students, they require pre-service and in-service education and ongoing professional development that recognises that the generation of knowledge about good teaching is not the exclusive property of universities and research and development centres (Zeichnerm, 1994; Kershner, 2007). An examination by Higgins, MacArthur, and Rietveld (2006) of teachers grappling with 'complex issues relating to inclusion, difference, disability and belonging' (p. 34) when working with children with special learning needs, identified the need for teachers to have knowledge and understanding of practices that are effective for both the teachers and diverse groups of students, including students with special needs.

The Education Review Office (ERO), in their 2010 report *Including children with high needs*, emphasised the link between schools identified as 'most inclusive' and the implementation of effective whole-of-school-based professional development programmes, leading to the use of innovative practices that managed the complex and unique challenges related to the inclusion of student with high learning needs. However, ERO (2010) did acknowledge the necessity for ongoing, whole school professional development to change and maintain the overall quality of learning programmes in a school. This statement is supported by Kershner (2007), who suggests there is a need for those working in education to use a school as a site for the development of 'teaching expertise and the creation of knowledge' (p. 496). Teacher's knowledge about particular types of learning difficulties, teaching strategies or special resources is only one aspect of meeting the learning needs of children. Of equal importance is the teaching expertise that has developed and continues to develop within a social, cultural and historical context that also influences the learning of children within a particular community. This collective knowledge base about meeting the children's special education needs within a particular context is seen by Kershner (2007) as a fundamental component of whole school professional development.

In a submission to the Special Education Review, the PPTA (2010) discussed the need for courses addressing the teaching of children with special learning needs to be available at pre-service and in-service levels. These courses would include 'compulsory special education theory and practicum components' (PPTA, p. 3). In Aotearoa New Zealand the educating of early education, primary, and secondary school teachers is provided by private and state establishments. In a comprehensive report investigating initial teacher education Morton and Gordon (2006) 'were struck by the unevenness of content' (p. 17) of courses offered by tertiary institutes. A review of early childhood and primary teacher programmes at an undergraduate level identified only one provider offering a compulsory course introducing students to issues and research in the fields of inclusive and special education. Other providers include courses examining inclusive practices and studies for diverse learners in their teacher education programmes but there is no obvious course content addressing the learning needs of students with special learning needs. At the post-graduate level, teacher education courses for students intending to work in regular secondary schools were seen by Morton and Gordon (2006) as promoting ‘teaching the subject (is seen) as the most important role of the teacher’ (p. 14). This focus was seen by the PPTA (2010) as raising the question about the extent to which it is reasonable to expect ‘teachers with little or no training in this specialist field’ (p. 3) to manage inclusive programmes of learning in regular schools. In courses introducing the students to the management of classrooms, most tertiary education providers do acknowledge the diversity of the students in inclusive-based classrooms but there is little indication that the specific issues relating to the needs of students with special learning needs are addressed or that these courses are compulsory. The content of teacher education courses designed to prepare students for the role of teaching in regular schools may provide opportunities to observe and participate in classrooms in regular and/or special schools where good teaching practices are implemented. An overview of the differing aspects of disability, sensory, physical and intellectual, would provide students in teacher education programmes with a knowledge base that would be further developed with interaction with children with special needs. It must be hoped that the preparation of teachers for inclusive classrooms and schools continues to be ‘woven across the fabric of the teacher training curriculum’ (Slee, 2001, p. 117).

An overview of topics that I think should be included in teacher education programmes preparing students for working with children with special learning needs in regular classrooms is presented in Appendix C.

2.9 Teacher aide education

Since 1989, in many schools in Aotearoa New Zealand, Teacher Aides (TAs) have become an established part of the everyday classroom life where they support students with special learning needs. In a survey of special education resourcing, Ward et.al. (2009) present findings that in the 245 of the schools surveyed in their study one third of the total number of TA hours was funded by ORS. ORS funded students receive TA hours to support their in class learning activities. Although the role of TAs is presented as learner support staff who work under the supervision of a teacher and support teaching programmes and student learning (MoE, 2002, p. 3), a later MoE document (2011a) suggests that ‘the reality is often quite different’ (p. 97) with the TA rather than the classroom teacher taking the lead role in the management and learning programmes of ORS funded students.

Giangreco, Broer, and Suter (2011) express concern at the inadequacy of educating and supervision of TAs to prepare them for the jobs they undertake. In Aotearoa New Zealand, although teacher aide fee-based courses are offered by some tertiary institutions, there is no prerequisite for pre-entry study or educating for TAs to work in schools. On-the-job education by support persons such as the Supplementary Learning Support teachers funded by the MoE: SE and in-house professional development programmes are seen by Symes and Humphrey (2011) as being essential components of school management plans if TAs are to be effective in supporting children with special learning needs. These researchers also emphasise that if the expertise of others is to be utilised, the ‘creating of an atmosphere where asking for advice is acceptable and even encouraged is of paramount importance’ (p. 159).

In their review of the inclusion of students with high needs in regular school, the Education Review Office (ERO) (2010) indicated that all schools participating in the review noted that it could be difficult ‘finding TAs with the correct skills and knowledge to work with individual students’ (p. 28). ERO also stated thatTAs as well as teachers needed ‘appropriate professional development’ (p. 13). Blatchford, Russell, and Webster (2012) recommend that there is a need to ensure teachers have the necessary skills and preparation to enable them to interact with the TAs with whom they are working in the classroom. The use of professional development time for the education of TAs was seen by ERO (2010) as ensuring they have the ability to support classroom teachers and students with special learning needs

ERO (2010) also identified other areas for improvements at inclusive schools, one of which was reduction of teasing/taunting by other students in some contexts (p.22), later referred to as bullying.

2.10 Bullying

Bullying is an issue in schools that has become widely viewed as a social, health and education concern (Stuart-Cassel, Bell, & Springer, 2011). While students with and without disabilities face significant negative emotional, educational and physical results from bullying, Young, Ne’eman, and Gelser (2012) describe students with disabilities as being ‘uniquely vulnerable and disproportionally impacted by the bullying phenomena’ (p. 1), which is often a direct result of the student’s disability (Stephens & Villano, 2011).

Ervin (2011) describes three factors that increase the risk of children with disabilities being involved in bullying situations: these children ‘bear a stigma relating to their disability’ (p. 6); they are within an inclusive learning environment where they are more exposed to potential bullying from their peers (Gill & da Costa, 2010); and they may react inappropriately to a situation because of their inability to understand the nuances of social interactions and often demonstrate a lack of social awareness, and the bullying is a result of their behaviours. AbilityPath (2012) explains this type of bullying as conditional friendship, where the bullying occurs when a child thinks that someone is being their friend but the times of friendship are alternated with times of bullying.

Gill and da Costa (2010), Ervin (2011), and Young et al. (2012) report bullying involving children with disabilities as being complex as these children often do not have the ability or skills to manage the stress and anxiety that results from being bullied. Many students with special learning needs have communication-related disabilities and are unable to report incidents of bullying. Because this inability of some students to recognise and/or communicate incidents of bullying, families frequently do not learn of these unacceptable behaviours experienced by their family members (Young et al., 2012). It is often only through the reporting of incidents of bullying by those working within the learning environment that families and school staff can become aware of these unacceptable behaviours.

Gill and da Costa (2010), when discussing the bullying of children with visible and non-visible disabilities, found there was little difference in the number of bullying incidents reported, although when a gender analysis was conducted it was suggested that ‘boys were bullied more often than girls’ (p. 151). However research reviewed by Young et al. (2012) indicated that students with disabilities are not only subject to bullying and harassment on the basis of disability, they are frequently more vulnerable to ‘bullying and harassment of a more general nature’ (p. 4).

In a study focussing on education in Aotearoa New Zealand MacArthur, Sharp, Kelly, and Gaffney (2007) report that bullying was an issue identified by children with disabilities as impacting on their school experiences. Children interviewed talked about feelings of isolation both in and outside the classroom, and about a lack of friends. In a study of exclusion, Kearney (2007) also identified teacher to student bullying as an issue influencing the 'exclusion of disabled students from school' (p. 222). Parents participating in the research undertaken by Kearney (2009) reported incidents 'where teachers behaved in inappropriate and, in their view, cruel ways' (p. 114) to their children. The parents had observed one child helping another who was shouted at and told to *'leave him alone'* because, in the teacher's view, the boy had to do everything himself and the social interaction between the two children was not seen as part of the boy's learning.

Bullying has always been within the school environment but has now been identified as a problem of global significance (Ervin, 2011). Without timely intervention, students with disabilities who experience bullying will have increased problems that will likely make it more difficult to meet their special learning needs (*Walk a mile in their shoes report*, nd).

2.11 Individual Education Plans (IEP)

An IEP is a compulsory component of the granting of ORS to students. IEPs are 'living documents' (MoE, 2012a, p. 1) developed by those directly involved in the education of students with special learning needs in both regular and special schools. Those participating in the IEP meetings may include family members, GSE, specialist therapists supporting the student in their learning programmes, teachers, and TAs. The outcome from the meeting is a plan, an IEP, for an individual student that establishes learning outcomes for the student and identifies the extra assistance, adapted programmes and learning environments, and specialist equipment and materials that will support the school experiences of this student. The life of the IEP is dependent on the needs of the students, but most are reviewed every school term. The method of developing an IEP is seen as the promotion of an effective partnership between the students and all persons supporting and working with them. It should not be a 'disempowering, daunting or distressing experience for families' (MoE, 2012, p. 2).

2.12 Resource report: Special school survey 2010

An informal nationwide survey of the day special schools in Aotearoa New Zealand was conducted in 2007 to establish the changes in enrolments identified by Pickering and

Wilton (1996). The findings, which will be discussed in detail in Chapter Four, confirmed that that a significant number of students transferring from regular schools to the day special schools responded to the survey. Responses received from fourteen schools indicated that all these schools had, in the previous 2 years, enrolled ORS funded students who were transferring from regular school placements. One responder indicated that few students transferred from regular schools because '[the area in which the special school is situated] is very pro-mainstream so students and families are not encouraged to seek special schools at this stage' (R. Alexander, personal communication, 12 November 2007)

In order to gain current enrolment data, a survey of the day special schools was constructed, trialled and emailed to the twenty-seven day special schools in Aotearoa New Zealand. Some schools found the sourcing of information from the Enrol programme proved to be a very complicated and time-consuming process. The data received from ten schools confirmed that the movement of ORS resourced family members from regular schools to day special schools was continuing.

Table 2.2

ORS resourced students transferring from regular schools to 10 day special schools

Year	**2007**	**2008**	**2009**	**2010**
Number of students transferring schools	40	34	38	45

Although there was a relatively low response to the 2011 survey, it was possible to compare information from five schools that had participated in both the 2007 and 2011 surveys and were able to be identified. Although the 2007 survey was constructed to enable respondents to remain anonymous seven of the schools self-identified in their return documents with school name cards and comments on school letter head paper. Of these seven schools, five responded to the 2011 request for information.

When comparing the data from these five schools across the 7-year period 2005–2010, it can be seen there was an increase in the 2010 enrolments in four of the schools. The fifth school had enrolled a larger than usual number of students transferring from regular school placements in 2009.

Table 2.3

ORS funded students transferring from regular schools to five special schools in the years 2005–2010

	2005	2006	2007	2008	2009	2010	
School A	0	0	0	0	2	2	4
School B	3	9	7	1	4	9	33
School C	2	2	2	3	0	4	13
School D	4	5	2	2	7	3	23
School E	6	8	7	7	5	9	42
Yearly total	15	24	18	13	18	27	115

Although 2011 enrolment data specific to the day special schools were not accessible from the MoE statistics, enrolments for all special schools, including the day special schools, has increased by 0.1%. This is at a time when enrolments in primary and secondary school enrolments had decreased by 0.4% and 0.2%. (For these statistics, primary school includes both primary and intermediate schools). This increase in special school enrolments has followed the patterns of previous years.

Table 2.4

A profile of enrolments in special schools

2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
+0.2%	+3.3%	+5.4%	–0.6%	+3.2%	+1.4%	–0.5%	+2.1%	+2.1%	+0.2%	+2%

The quantitative data emerging from the survey of special schools and the MoE's statistics support the findings of Coleman (2011) and McMenamin (2009) that the movement of students from regular school placement to day special schools is 'likely to be a continuing option for children with high and very high needs' (McMenamin, 2009, p. 198). This is despite the additional ORS resourcing available to regular and special schools when students granted ORS enrol in a school. The findings also indicated that enrolments are increasing. All the schools responding to the survey indicated the ongoing enrolment of children from regular school placements. Although it was not possible to gain statistics from the MoE giving information of the number of children with ORS funding who had transferred from regular to special schools, the overall number of enrolments in special schools was shown to be increasing at a time when regular schools enrolments are declining.

2.13 Summary

The first section of this literature review opened with a discussion exploring the conflicting literature defining ‘special education’. Historically, special education has implied the education of children in settings apart from regular school learning environments. An overview of the education policies for children with special learning needs that eventually resulted in the establishment of day special schools in Aotearoa New Zealand is presented within a discussion of the influence of the discourses underpinning the educational legislation upon which these programmes were established. The review suggests tensions between the practices of the medical- and the environmental-based discourses remain in education policies of SE2000 and the Review of Special Education in 2010.

The concepts of inclusion and inclusive education are discussed in a national and international perspective. The acceptance in the Review of Special Education of both regular and special schools as placements for students with special learning needs presents a challenge for the MoE’s key aim of supporting all children in attending their local school.

The second section opened with a discussion about the concept of family’ and highlights the challenges inherent in defining ‘What is a family?’ The findings from within the literature give support to the acceptance of an operational definition of family for this research. When reviewing the eclectic range of literature discussing decision-making processes, the emphasis is on the processes implemented by the family groups, revealing there is limited evidence of research into the processes undertaken by such groups to reach decisions, and there is a need for further investigations into why and how these final decisions are made.

A review of pre-entry education of teachers is followed by a discussion of TA education programmes where research findings suggest that on-the-job education is the most effective means to ensure TAs have the skills to support teachers and students in their programmes of learning.

Bullying was identified by ERO (2010) as an area of school and classroom management that must be addressed if schools are to be a safe learning environment for students. A brief overview of current literature discussing bullying is followed by a statement outlining the role and implementation of the IEP. A resource report presenting the results of the survey of special schools in 2010 concludes this chapter.

A general overview of education in government funded schools in Aotearoa New Zealand as at 2012 is presented in Appendix A.

Chapter Three discusses the methodology implemented in this research.

CHAPTER THREE

METHODOLOGY

You read every book and you talk to every person and you belong to every group.

(Kathy, 2011)

3.1 Introduction

This chapter outlines the methodology selected to investigate the experiences of a selected group of families with children supported by ORS resources. A discussion of the theoretical paradigms underpinning this research is followed by an overview of the ethical considerations relating to the study.

3.2 Qualitative research

In the 1960s and 1970s, qualitative research emerged from within the discipline of the sociology of education, which had previously been mainly quantitative in nature (Bogdan & Bilken, 2007). With its emphasis on the 'slice of life' approach to research, this qualitative research method of investigation was seen as being reliant on first hand-data gathering of data as a vehicle for giving voice to people previously marginalized in their society.

The audience for qualitative research in education grew in the 1960s (Bogdan & Biklen, 2007; Burns, 1998). The demand from educators and funding agencies was to know more about the school experiences of those who were on the front line, those who were on the outside, and those who never felt valued or represented (Bogdan & Biklen, 2007).

There is no singularly defined scientific approach governing qualitative research (Borbasi & Jackson, 2012) – it can mean different things to different people. It can also mean different things depending on the historical time or context in which the research was instigated. Glaser (1992) sees qualitative research as being used to 'uncover the nature of people's actions, experiences and perspectives' (p. 12) as yet unknown to the researcher and the audience. Creswell (2009) describes qualitative research as an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. Within the implementation of qualitative research, Creswell assumes, the researcher will build a complex holistic picture of the study that is conducted in a natural setting where the researchers will have face-to-face interactions with people within their own context. Within this context, qualitative methods of research can be used to gather intricate details about phenomena such as feelings, thought processes and emotions that are difficult to learn about through more conventional methods (Creswell, 2012).

In acknowledging that qualitative research has a range of philosophical underpinnings and methodological techniques and practices, Mason (2002) identifies three elements of qualitative research, although not all works described as qualitative may have all three traits to an equal degree. The first characteristic identified by Mason is concerned with how the social world is interpreted, understood, experienced, produced or constituted. The events researched are seen in context, in authentic settings, and where nothing is taken for granted. This implies a direct concern to understand the participants' experiences in the settings in which they occurred. The second characteristic of qualitative research, as described by Mason, is that the methods implemented in the data collection are both flexible and sensitive to the social context in which the data are produced. There is no general method of data collection, although the data are not collected in numbers but rather in words or other visual images such as pictures or photographs. The third characteristic is based on methods of analysis, explanation, and argument building that involve understandings of complexity, detail, and context. The researcher aims to produce rounded and contractual understandings on the basis of rich, nuanced and detailed data.

Davies and Logan (2012) see qualitative methodology being used when 'little is known about a topic' (p. 9) or where quantitative research has raised unanswered questions. This research project was designed to have an insight into the educational experiences of a selected group of families who were talking about educational placements for their children with special needs. Qualitative research was selected to examine the experiences of these families as it allowed and encouraged contextual dialogue between the families, the students, and the researcher. From the 'rich complex picture that emerges' (Creswell, 2012, p. 18), these dialogues explain the effect environmental contexts have had on the decisions made by the families.

3.3 The research process

Denzin and Lincoln (2008) suggest there are three interconnected generic activities that define qualitative research theoretical paradigms, methodology, and methods. Behind these three activities stands the 'biographically situated researcher' (p. 21). The final stage of the research process is identified as the 'art, practices and politics of interpretation and presentation' (p. 23). The process or phase of explanation and analysis, the process of judgement by others, and the process of the possibility of ongoing research emerge from the findings and presentations. This judgement can, however, be influenced by the person initiating the research – the researcher.

3.3.1 The researcher as a multi-lens subject.

In their discussion supporting the inclusion of the researcher as a component of their research process model, Denzin and Lincoln (2008) state that any research is always 'filtered through the lenses of language, gender, social class, race and ethnicity' (p. 21). While the researcher may unconsciously bring a particular view to the research, at the same time there is a need to have an understanding of the worlds of and between the researcher and the participant. It is important that these perspectives are articulated and made visible to those persons participating in the research process and the readers of the completed documents.

Fine, Weiss, Weseen, and Wong (2003), in their discussion of social responsibilities in qualitative research, see the relationship between the researcher and the subject should be one of protecting privilege and securing distance. But producing texts from which the 'self has been sanitised' (Oakley, 2009, p. 5, cited in Fine et al., 2003, p. 170), has the potential to distort collected data, as does an over-emphasis of the researcher's subjectivities. There must be trust between the researcher and the participants in any research. In this research, the families needed to have confidence that the information they have shared would be transcribed as true interpretations of their stories. I was very aware of this criterion of trustworthiness (Lincoln & Guba, 1985) in the interviews. There was a need for me to monitor my questioning and responses to ensure there was no element of bias. In order to maintain this high level of trust, all documents relating directly to the families were returned for scrutiny and any necessary corrections were accepted and actioned. A more comprehensive overview of this process is discussed in Chapter 4.3.5.

Researchers must undertake responsibility for their personal biography when entering the research process. There is an obligation for reflection and questioning of all their actions, beliefs, and assumptions as the researcher moves through the stages of the research. In this research project it is necessary to acknowledge and accept my personal biography and the lenses through which I have reviewed my research. I am a fourth generation New Zealander of English, Scottish, French and Australian heritage. My father was a teacher in Native Schools and my early childhood years were spent in remote areas of Aotearoa New Zealand where the settlements were based around the local marae. The family settled in a small town to enable me and my siblings to attend a secondary school. In my teaching career I have worked in both regular and special schools in New Zealand, Canada, England Scotland and Papua New Guinea. It is also necessary to acknowledge and accept my past and present involvement in the education of young people with specific learning needs. There is a responsibility to acknowledge this personal biography when undertaking research in an educational field that is 'close to the heart'. Following Fine et al. (2003), it is also necessary for me to challenge this research as it moves through the stages of this particular social analysis; with such questions as:

- Have I connected the 'voices' and 'stories' of the participants back to the set of historic, structural, and economic relations in which they are situated?
- Have I included the mundane and the exotic for these aspects of an interaction can give a more intense insight into the experiences of the participants.
- Have I hidden my own authority behind the narrations and interpretations of the participants? My knowledge and personal experiences in special education must not influence the narrations and interpretations of the participants' interactions. If they do have an influence, I must make the reader aware of this.
- Have participants been given the opportunity to review the data, and interpret dissent and challenge the findings?
- Have I considered how the final data could be used for future social and educational policies?
- Have I considered who the readers of the findings and recommendations may be?

  (adapted from Fine et al., 2003, pp. 199–201)

By questioning both the processes implemented in research and the potential and possibility for my personal experiences to have an influence on the questions asked, and the information gathered, the lenses through which this research has been viewed must always seek to have more understanding of the participants' worlds of experience that I am studying (Denzin & Lincoln, 2008). Throughout the research field work and the transcribing of the families' interviews, I have returned to the challenges of Fine et al, (2003) to reflect on my practice: Are my lenses clear and am I accepting and understanding the stories I am hearing and writing? I was also very aware of my role to give the families the opportunity to have their stories heard, not only in the room where we were sitting but in the world beyond.

But research needs to be underpinned by a rigorous theoretical perspective on which to base the 'finding out' and the 'knowing' (Wadsworth, 2011, p. 188).

3.3.2 Theoretical paradigms and perspectives

Ontology is the study of 'being': epistemology is concerned with how we gain knowledge of what we i.e. the researcher and 'the researched' know (Creswell & Plano Clark, 2011), and what it means to know something. Therefore in research, there is always an ontological base that gives the world view of the researcher. This shapes and defines the epistemology, that is, the beliefs, values, and priorities that underpin and order how the research should be implemented, and therefore determines the methods. Therefore both the ontological base, and the methods chosen reflect the 'truth' and 'beliefs' about knowledge held by the researcher.

Ontologically this study favours a pragmatic view (Tuli, 2010) that seeks an understanding of the participants' perceptions and meanings of the research questions through methods, techniques and procedures that best meet the needs of the researcher and the participants.

Ontology therefore sits within an interpretive paradigm which meets five criteria, according to Lincoln (1995, cited in Denzin 2010 p26): it

- displays the author's positionality
- addresses the community in which the research was carried out
- engages and gives a voice to silenced or marginalized persons

- explores the author's understandings during, before and after the research experience and
- demonstrates an openness between researchers and participants.

In this research the primary importance of the study are the questions asked (Creswell & Plano Clark, 2011) and the importance of assessing the varied input from these questions into the knowledge gained.

Methodology, the third component of this paradigm is the theoretical perspective of how the inquiry should proceed. It includes the assumptions of what is important to the study, what constitutes legitimate knowledge and what evidence there is for making knowledge claims (Glesne, 2006). As summarised by Borbasi and Jackson (2012), theoretical perspectives should be consistent with 'the underlying belief systems that inform the research' (p. 126).

The paradigm chosen by individual researcher is dependent on what their perceptions of the real world truth are (ontology) and how they know it to be the real truth (epistemology) (Tuli, 2010). Crotty (1998) sees these ontological and epistemological issues as 'tending to merge together' (p. 10) to become components of a theoretical perspective, a paradigm or worldview (Creswell & Plano Clark, 2011) that establishes an interpretive framework of beliefs that guides the research action. Mason (2002), when discussing ontology, sees the researcher asking what is the very nature and essence of things in the social world. This author highlights different versions of components of social realities and where these ideas may be located. Underlying ontological properties could include such elements as the attitudes, beliefs, and views, social or cultural practices, experiences and accounts and words, codes and communications of both the researcher and the research participants.

The essence of this research project is to study the world from the point of view of the interacting individuals (Schwandt, 2003). Interpretivists are concerned with understanding the social world people have produced. Blaikie (2009) suggests an interpretive approach to research sees people as primary data sources with the researcher seeking out their 'inside view' rather than imposing an 'outsider view'. A researcher, when using an interpretive paradigm, involves an understanding of the participants' day-to-day experiences and the meanings of those experiences in the settings in which they occurred.

By discussing their experiences when selecting an education provider, the families had the opportunity to understand and to give meaning to their decisions within the context of their individual environments. The implementation of interpretive research practice was seen as giving the participants the opportunity to discuss and reflect on their own personal experiences to enable them to have an understanding as to why they made certain decisions. It also enabled the research participants to have an understanding of the significance of their actions within the context of their social communities (Clark, 1997).

3.3.3 Case study

A research design is a plan or strategy for assembling and integrating data and its results in a specific end product: the research findings (Burns, 1998). The selection of a particular research strategy is determined by how the problem is shaped and by the questions it raises (Merriam, 1988). 'Case study is a study of the particular' (Borbasi & Jackson, 2012, p. 130): 'an empirical inquiry that investigates contemporary phenomenon set within its real life context, especially when the boundaries between the phenomena and content are not clearly evident' (Yin, 2009, p. 18).

Case-study research, an investigation of one entity, can answer the question 'What is happening or what has happened?' Case study is also concerned with 'How and why something happened?' 'What is going on?' with no attempt to control the events (Yin, 2012). Case study research examines individual units such as social groups, and communities, and investigates what goes on within the unit and the unit's relationship horizontally with other units, and vertically with other orders of units. It attempts to understand meaning within the units and to understand the individual, unique construction of reality. This 'bounded system', seen by Paul, Kleinhammer-Tramill, and Fowler (2009) as an instance of action, has been selected for this research project because of its ability to enable the sourcing of rich data from a single study encompassing multiple cases. The multiple cases are the families interviewed to gain an insight into their experiences of regular schools meeting the learning needs of their family members. In investigating multiple cases within this research, there is a reassurance that the events in only one case are not 'wholly idiosyncratic' (Miles & Huberman, 1994, p. 172), which enables a deeper understanding through more powerful descriptions and explorations.

A unique strength of case study research is its ability to deal with a variety of evidence: documents, artefacts, interviews, and observations (Merriam, 1998). The research design is adaptable and offers many techniques for collecting information. It allows every selected case to serve a purpose within the overall scope of the inquiry (Paul et al., 2009). Case-study methodology is eclectic and is an umbrella term for a family of research methods having in common the decision to focus an inquiry around a bounded unit (Adelman, Jenkins, & Kemmis, 1977; Hocutt & Fowler, 2009).

Case-study research is carried out in real situations in which the participants studied have responsibilities and obligations that may interfere with or impact on the study. It is therefore a social and cultural process in the sense that these interactions are phenomena of social life; their pursuit is a social act, and they are absorbed into this social life. In general, the researchers become participants in this social life of the participants.

With its grounding in real life situations, case-study reports may use prose and literary techniques (Merriam, 1988) to describe and analyse situations. Because the report may include the documentation of events, quotes, samples, and artefacts, it brings new meaning to the researcher's understanding of the bounded system being studied. Stake (2008) believes this use of the less formal or abstract language results in the knowledge gained being more concrete, vivid and sensory because of its relationship with reader's more personal experiences. In this research, the presentation of the stories of the individual families as their unique life journey within a group format has been deliberate. The use of this format allows each family's narrative text and their non-verbal messages to 'speak for itself' and produce 'an insight descriptive pattern' (Yin, 2012, p. 16) that enhances the formal interpretation of the data.

The great strength of case-study research is that it allows the researcher to concentrate on a specific interest or situation, and to identify, or attempt to identify, the various interactive processes at work. The validity of case-study research is more important than its generalisations (Bell, 1996). For the experiences of the nine families participating in this research to be listened to and heard, there was a need to use a research method that was process orientated, flexible and adaptable to change in particular circumstances, and was an evolving context. For such a situation, case study method was deemed appropriate (Paul et al., 2009).

3.4 Quantitative research

When addressing the research question seeking information about the enrolment of students in regular and special schools there was a need to implement a methodology that enabled the collection of numerical data. With the use of both surveys and interviews to gather data, this research is more robust (Paul et al., 2009). Creswell (2012) labels this combination of methods as the ‘embedded design’ design in which the one form of data plays a supportive or less dominant role to the other form of data. In this research, qualitative data collection was the dominant method, with quantitative data collection the less dominant component of the study.

Quantitative research has been used to gather and analyse information that is measured by an instrument that relies heavily on numbers. Taylor (2000) describes quantitative research as taking an ‘outside’ perspective where personal contact with the subjects is kept to a minimum.

One of the primary purposes of quantitative research is to analyse trends that are developing as well as current situations (Taylor, 2000). Cause and effect relationships may also emerge from within quantitative research designed to understand how one variable has influenced another.

In this research a quantitative approach to data collection was implemented to generate a more comprehensive understanding of the data gathered in an informal survey undertaken in 2007. The findings from the 2007 data had considerable impact on my decision to undertake this research. The data showed that there was student movement between regular and special schools but the survey did not ask the question ‘Why?’ This information was used to support the design of the quantitative component of the research design. As there was limited research about the chosen topic, a survey was an acceptable tool to access further data, with the goal being to discover how frequently the transfer of students was occurring (Davies & Logan, 2012).

For both the qualitative and quantitative research aspects of this research, ethics have an important role when interacting with families, and listening and retelling their personal experiences.

3.5 Research ethics

Research usually involves a community of people who share common assumptions and values (Snook, 2003). When research involves the gathering of data from people, the researching community is responsible for the ethical standards of the programme. The principle consideration must be that the participants are respected and enter the research voluntarily with a comprehensive understanding of the nature of the study and any inherent dangers and obligations (Bogdan & Biklen, 2007). Warren (2002) is concerned that, at times, the researcher's understanding of the principles underpinning the research may not match that of the participants. It is the role of the researcher to revisit the nature of the study to ensure all those involved in the programme have an understanding of the principles inherent in the study. Munford and Sanders (2001) state that adherence to the fundamental principles of ethical research impacts positively on the outcomes of a research programme. To ensure that research is conducted for the promotion of good, a minimisation of harm, and that all participants are treated with dignity and equality, key ethical principles must be considered.

Because this research programme included the conducting of interviews in a family setting, with parents, children and family members contributing to the discussions, a full application was made to the Massey University Human Ethics Committee (MUHEC).

This research adhered to the *Massey University Code of Ethical Conduct for Research, Teaching and Evaluations Involving Human Participants,* (Massey University, 2010).

Ethics approval was received from MUHEC: HEC: Southern B Application 09/52.

The ethical principles that were considered in this study were:

- Informed and voluntary consent
- Respect for privacy and confidentiality
- Minimal risk of harm to participants, researchers, communities, and Massey University: Beneficence
- Social and cultural sensitivity.

Because no personal data were collected in the second component of the research, a nationwide survey of special schools in Aotearoa New Zealand, this component was judged 'low risk' when completing the questionnaire in the guide lines set out in the Massey University Human Ethics Screening Questionnaire.

Low risk approval was received from MUHEC 30 September 2010.

3.5.1 Informed and voluntary consent

A most fundamental principle for ethical acceptability is that of informed consent (Bailey, 2007). Participants in research must be informed of the nature and purpose of the research, and its risks and benefits, and be given the opportunity to consent or decline participation. The *Massey University Code of Ethical Conduct Involving Human Participants (*MUCEC) (Massey University, 2010) states there are four elements required for formal consent:

- Information on which to make the decision
- Comprehension of the information
- Competence to make a decision and give formal consent
- Absence of pressure or coercion.

Participants in research projects have the right to receive adequate and appropriate information about what their participation will involve. This information must be in a format that is comprehensible to potential participants. Although MUCEC (2010) states that this information should be in written form or in a format appropriate to the participant, oral consent may be obtained where culturally appropriate (Snook, 2003) or where the participant is unable to provide written consent because of a disability. All consent documentation should be presented in the participants' first language, that is, the language used by the participants in their everyday activities in their home.

In seeking consent from 'less powerful participants in research' (Diener & Crandal. 1978, p. 216), such as young children who experience difficulties with cognitive functioning, special care is required to ensure the explanation of the research is understood by the participants without misrepresenting the nature and outcome of the research (Oliver, 2003). The consent of young people must be sought in a format that they are capable of understanding. Researchers must be aware of not making assumptions about their intended participants' ability to make informed decisions. They must take responsibility for ensuring the participants understand the nature and extent of the research and take advice as to whether it is ethical to continue (Oliver, 1993). Snook (2003), in acknowledging that vicarious consent may be an alternative option available to the researcher, argues that this action is only acceptable if there are significant benefits for the research and no risk to the participants. Munford and

Sanders (2001) suggest it is the role of the researcher to find appropriate means of giving young people or those people with impaired cognitive skills, 'meaningful opportunities' (p. 104) to enable them to make decide for themselves whether they participate in the research programme. The United Nations Convention on the Rights of the Child (2008) states that children have the right to be heard and to participate in decisions affecting them. Researchers should always provide information to the young participants in the most appropriate manner and secure genuinely informed consent (Munford & Saunders, 2001).

Snook (2003) suggests it can be argued that informed consent is seldom possible. To be fully informed the participant would need to know as much as the researcher and this is rarely possible. However, by treating the participants with respect, ensuring they are aware and informed of the nature and purpose of the research and its risks and benefits, and have given consent to participate without coercion, the research principle of ethical informed consent should be achieved.

In this research programme, the information for the students participating in the research was presented in two formats: a conventional font and as Widgit Symbols. In the conventional font letter the language used in the information and consent forms was targeted to a student with a reading age of 8–9. The Widgit Symbols letter was written to the level of an emergent reader.

It is important that consent to participate in research is granted voluntarily and without coercion or manipulation (Massey University, 2010). At the time of the first meeting with the family group, explanations of the research intentions were presented and the participants were given the opportunity to decline participation. When students were present, additional time was taken to ensure these young people fully understood what was going to happen during the interview. My experience working with students with special learning needs enabled me to adapt the giving of this information to a format best suited to their level of understanding. The information was presented in single statement sentences: one piece of information in each sentence. The language used to convey the information was appropriate to the students' cognitive levels of understanding. In all cases the students asked questions about the research before signing their own consent forms.

By treating the participants with respect, ensuring they were fully aware and informed of the nature and purpose of the research and its risks and benefits, and had given consent to participate without coercion, the research principle of ethical informed consent was achieved to the best of the ability of all participants.

3.5.2 Respect for privacy and confidentiality.

All researchers are on the 'inside' of their research (Clough & Nutbrown, 2002). It is therefore essential that participants have the right to confidentiality of information of both data and identity of participants (Massey University, 2010). This right to confidentiality implies that the participants should decide what information should be communicated or withheld from others, thus avoiding the linking of data to the concerned respondent (Anderson, 1995). Confidentiality is at risk from the time the researcher is 'told or allowed to see something that normally would be hidden' (Barnes, 1970, cited in Burgess, 1984, p. 10). The protection of participant's privacy is vital. MUCEC (2010), in citing legal actions regarding protection of identity and confidentiality of data, acknowledges that an absolute guarantee of confidentiality of recorded data is not possible. Every effort must be made to protect the participants and their information.

When working with family groups in interview settings anonymity and confidentiality are not practical or possible. Munford and Sanders (2001) advise that methods of protecting participants must be established before any interviews commence. In this research, procedures were established before any interviews commenced.

All participants in the interview had prior knowledge of who was attending, and that they could elect to participate or withdraw. Although the parents who agreed to take part in the interviews were given to opportunity to ask family members to support them, it was the researcher's role to ensure that all participants in the interviews were aware of who was attending and that no person felt compromised by the membership of the group. At the beginning of the interviews, ground rules were established to ensure information discussed in the interview would not be discussed in other forums without all participants' consent. All recordings taken from the meeting were transcribed by me and returned to all participants to ensure it reflected the information given at the time of the interviews.

All confidential information should be handled in a way that protects the confidentiality of its participants and ensures the information is kept confidential and secure (Massey University, 2010). The most likely source of harm in research is that the disclosure of private knowledge can be damaging (Christians, 2005). It must be accepted by all persons involved in research projects that the data and findings will be available to others. It is the responsibility of the researcher to make known to all participants the purposes for gathering data, who will have access to the data and the findings, and how the data will be stored (Snook, 2003).

The introduction of a 'note taker' to the interview series was discussed with one family group who did not wish to have a recording made of the interview. To ensure confidentiality was maintained, the 'note taker' was required to complete a confidentiality agreement (Appendix G) before the commencement of the meeting with the participants.

For the purposes of this research, the term anonymity was interpreted to imply that any data gathered during the research could not be linked with names, education providers or any other factors that could identify the research participants. All documents and recording relating to this research were kept in locked filing cabinet.

Except for one family group, no real names were used in any printed material arising from the research. The participants in the research were given the opportunity to nominate pseudonyms for both their family name and the first names of the family members referred to in the research. These pseudonyms were confidential to each family group and to the researcher. Care was taken to ensure any background information relating to the participants could not be used to identify them, their school, or the geographic area in which they lived. The family who selected to retain their given names in any printed material were made aware of the options available to them, but they elected not to select pseudonyms for their family's statements.

3.5.3 Beneficence

Collecting information about family life can become an unhappy, painful, and possibly threatening or frightening experience for the participants (Munford & Sanders, 2001). Under the principle of duty of care, researchers are required to secure the well-being of the participants (Christians, 2005). It is the researcher's responsibility to anticipate any undesirable consequences that may emerge throughout the research process and may harm or reveal harm to the participants (Oliver, 2003). Potential harm to participants can be physical, psychological, social, and emotional (Massey University, 2010). The risks of harm are greatest when the participants are vulnerable. Researchers working with children, especially young children, need to ensure no harm comes to their young psyche (Snook, 2003). It is the responsibility of the researcher to ensure all unnecessary risks to the research participants must be eliminated (Glesne, 2006).

Three general ethical principles have particular significance for the beneficential conduct of research – the promotion of good and minimisation of harm, being fair to all, and the recognition of human dignity (Soltis, 1989). Within these guidelines, the researcher must be encouraged to be ethical in the purpose as well as in the process of doing research.

When discussing the possibility of harm arising as a result of a component of the research process, the researcher and the participants have the option of continuation or withdrawal before or during the interview. However, Oliver (2003) suggests that if researchers were always to avoid investigating issues that might 'remotely be sensitive to so someone' (p. 32), research could become so bland that the generation of useful data would not occur.

Munford and Sanders (2001) highlight their ongoing concerns for the management of relationships developed within the research process, especially when working with young people. They suggest the expectations young people have towards those who show an interest in them are often different from those of adults. The nature of feedback processes may be interpreted as an ongoing interest in the young person's activities, rather than a concluding part of the programme. It is therefore essential that a defined conclusion is reached with these young people. This may require concluding messages to be rephrased, or presented in a different format: the use of a written format, the use of Widgit, or the use of a pictorial format of presentation.

It is the role of the researcher to maintain a watching brief over the participants, especially young people, to ensure they are safe, and to have contingency plans in place that will guide both the researcher and the participants should unexpected issues arise. It is also the role of a research ethics committee to provide protection for all participants in research programmes (Massey University, 2010) for the most likely source of harm in an inquiry is the disclosure of private knowledge that can cause harm. These disclosures may be of a personal nature such as health information or unknown family affiliations.

In this research, there was the potential for harm to the participants in the family interviews. The research programme included the conducting of interviews in a family setting. The presence of parents, children and family members could raise issues that are seen by Munford and Saunders (2001) as being 'fraught with ongoing ethical issues (p. 99). The definition of family for the purposes of this research is as *'whānau: a diverse unit where people not necessarily sharing common ancestors form a cohesive group within which certain responsibilities and obligations are maintained'* However, participating family groups may invoke a definition of family that falls outside this definition. It was important to establish that, for these interview groupings, the definition of family met the criteria of dependent children and adults in caring roles. During the interviews, with focus on the recalling of incidents experienced in the student's earlier years, there was the possibility of the family members becoming distressed and possibly psychologically harmed. This risk was minimised by ensuring that the participants in the research knew they could withdraw from the study at any time and decline to answer any particular questions (Appendices F1, F2, F3 and F4). An information sheet outlining information and support available for parents and their family members (Appendix E5) was made available to all family members.

The breaking of confidentiality and anonymity was also seen as a possible potential cause of distress and concern for the participants in the interviews. This was discussed, and the procedures instigated to reduce potential harm to all participants in the research are outlined in the respect for privacy and confidentiality section of this discussion of ethics.

3.5.4 Social and cultural sensitivity

Research in itself is a powerful intervention (Tuhiwai Smith, 2005) but at all times, people initiating research must be aware not only of the ethical requirements of the responsible governing body, but also of principles in a particular society at a particular time (Snook, 2003). Should the researcher be of a different culture from that of the participants, it is necessary that the neither the data collection instrument nor the discourse between the participants be seen as indicating any view that the participants' culture is less significant than that of the researcher (Oliver, 2003).

In Aotearoa New Zealand there must be an awareness of cultural sensitivities, the Treaty of Waitangi, and gender and socioeconomic differences within the research participants' community. Researchers working with participants from indigenous or ethnic groups must have an appreciation and understanding of the attitudes, values articles and actions that underlie the cultural property and traditions of particular groups before beginning the research. It is important that the participants do not have a feeling of intimidation by the research process (Oliver, 2003). Cultural protocols should be inherent components of the research and be implemented at appropriate times during the research process. Cultural sensitivity is the recognition by the researcher that participants in the research may operate through a set of measures, accountabilities, reliabilities and validities that are unique to their community or culture. This is to be acknowledged, respected, and celebrated.

Within the guidelines for the selection of research participants, ethnicity was not the primary focus. However, there was a possibility that members of the participating family groups might be of Māori ethnicity or belong to an ethnic or social group other than that of the researcher. Preparations had been made to consult with a personal friend, who is a competent speaker of Te Reo Māori, to ensure all protocols were known before embarking on interviews where some of the participants might be of Māori ethnicity. There was also a possibility that some family group members might be of an ethnicity other than Pākehā or Māori. Should the need have arisen, contact would have been made with cultural advisors with extensive knowledge of the protocols pertaining to the particular group, through the Ministry of Education Advisory Services.

The participants in the interviews were of a range of ethnicities and cultures, including Canadian, English, Māori, and New Zealanders of European heritage. Two of the family members interviewed identified as Pākehā and one family as Kiwi. All the family groups displayed very competent use of the English language, and there was no necessity to make contact with cultural advisors before the first meetings with the family groups or throughout the interviews.

3.6 Summary

This chapter has established the rationale for selecting a qualitative research paradigm upon which to base this research study. An explanation of the theoretical paradigms of ontology and epistemology are included in the discussion outlining the selection of

Interpretivism and case study as the methodology appropriate for this research. The chapter concludes with a discussion of ethical considerations relating to this study.

Chapter Four presents a discussion outlining the selection and implementation of the methods used to gather the data to support this study.

CHAPTER FOUR

RESEARCH METHODS

There was a change of principal at (the local primary school). He was a totally different kettle of fish, had a totally different attitude towards special needs and that set us up for a very successful time at primary school.

(Margaret, mother of Hamish, 2010)

4.1 Introduction

This study is an inquiry with an interpretive perspective that seeks to gain an understanding of the experiences of families of children when making the decision to move their child from a regular school to a special school setting. Central to the methodology discussed in Chapter Three are the techniques or procedures researchers use to listen to the families' stories and interpret them within the research questions. The use of interviews for this study of families' experiences enabled the family groups to give what van Manen (1990) describes as a memory and voice to their lived experiences. The method of selection of participants invited to participate in the interviews is followed by a discussion outlining the format of the interviews used when meeting with the families.

The second component of the information gathering was a survey of all special schools in Aotearoa New Zealand, to obtain current data relating to the number of ORS funded students who, in 2010, transferred to a special school, having completed at least two years education in a regular early childhood placement or primary school. This survey was designed to provide quantitative data to complement the case findings (Yin, 2011) and address the question 'What has happened to the enrolments of children with special learning needs in regular and special schools since the introduction of SE2000? The implementation of this survey is discussed in the final section of the chapter.

4.2 The research sample

Qualitative samples are purposely chosen for their ability to provide the richest in depth information on the topic being studied (Davies & Logan. 2012). In this research I decided to focus my research on ORS funded students currently enrolled in special schools. The nine families participating in the research were drawn from the school population within six of the twenty-eight day special schools in Aotearoa New Zealand. The decision to focus on students granted ORS funding was deliberate. These students have been identified by their family members, and professionals working with the families in the home and in educational settings, as requiring additional support to enable and enhance their accessing of learning. The applications for ORS funding had been made and approved by MoE verifiers, with the students being granted support for High or Very High learning needs. This formal identification of students enrolled in learning programmes ensured there was a consistency in the selection of families participating in the interviews. An overview of the resources funded by ORS is outlined in Appendix B2.

Travelling time was a consideration when selecting the schools to be approached. As the researcher it was necessary for me to travel to meet the families. It was not practical to travel the length of New Zealand, and because of my home location, I decided a range of 200 to 250 kms return journey would be the guide to the selection of schools. Physical locations and decile rating of individual schools were also factors guiding the final selection of schools to be approached. Decile ratings give an overview of the community profile from where the schools draw their students. However, because students often travel across school zones to attend the special schools, the correlation between the decile rating and the geographic location of the schools is not as true to the decile rating schedule as in regular schools. In order to cover a wide range of school decile ratings, the decile rating of the six special schools attended by the family group sample ranged from 8 to 2, with 10 being the highest possible rating and 1 the lowest rating. (Decile rating is explained in the Glossary).

Given the relatively small number of special schools in Aotearoa New Zealand, there is often only one special school serving a very large geographic area. In order to maintain the confidentiality of the participating families, geographic location has not been included in this report, but it was a factor in the selection of schools. Consideration was given to geographic location to gain a balance of urban/rural range of school locations with the final selection including an inner city school, three schools in provincial towns and one school serving a mainly rural based population. All schools were in the North Island. The special school where I taught was excluded from the selection of schools.

The principals of the six selected schools were initially contacted by telephone and appointments were made to meet at a time best suited to them. Before this meeting, an introductory letter (Appendix E1) was emailed to the principals to enable them to have an understanding of the research being undertaking before the meeting.

4.2.1 The selection criteria

At the face-to-face meeting, the research was further discussed. Throughout the discussions with principals, emphasis was on the selection criteria for possible candidates. These criteria were:

- ORS funding
- Completed at least 2 years of their education in an early childhood and/or a regular school setting
- Be enrolled on a special school roll, although the students might be attending a satellite class.

By selecting children who had been granted ORS, there was no requirement for justification of the selection of students. They had been identified through a verification process as having met the criteria for this funding.

Selecting students, who had completed at least 2 years of their education in an early childhood setting and/or a regular school setting, meant these students would have participated in regular school setting for sufficient time for their education programmes to be established. It also allowed assessments to have been completed to show the students' achievement of their IEP goals, giving the students' families sufficient insight into their child's participation in a regular school learning environment.

After discussions with three principals, it was decided to use the principals' knowledge of their students and their families to guide the selection of possible participants. Two principals provided a list of names of students and the contact details of their primary care givers. Before the list was released to me, these principals made prior contact with the primary care givers to obtain permission for their details to be included in the list. After a lengthy discussion about the criteria for inclusion in the research, the principal of the third school made an initial contact with possible participants and, when agreement from the families was received, forwarded the contact details to me by email.

It must be acknowledged and accepted that the principals of the schools were not acting as gate keepers and restricting access to the families of students enrolled in their schools. Special school communities are very diverse and very vulnerable. The school community is usually drawn from a wide geographic area. Family groupings are often very complicated and unique to a particular student, with students often living between family and respite caregivers' homes. The health and behavioural factors inherent in many students' conditions are both extreme and fragile. The principals of special schools know their school communities, their family groups and their students very well and often have to make decisions on information that is confidential only to them. Having access to all the families in the school population who met the criteria for this research would have been the ideal means of selecting families to contact. However, my supervisors and I accepted that I should be guided by the principals in making the selection of families for my research.

With the initial criterion being met, selection of participants was then based on the student's age, gender and, if known at the time, the date of enrolment at a special school. The intention was to have an age and gender range of students participating in the interviews. At the time of initial selection, little was known about the students' educational background, apart from the completion of at least 2 years in a regular school setting. I had no prior knowledge of the students' educational experiences that had resulted in the application for and granting of ORS funding. This information would be on the student's school file, but access to these documents was neither requested by the researcher nor offered by the principals. Privacy issues were known and acknowledged by both parties.

When six family interviews were transcribed, it was noted that the ORS funding for all six students was based, in the main, on their Autistic Spectrum Disorder (ASD) diagnosis. However, there are students enrolled in special schools whose ORS funding is based on a condition that was diagnosed before birth, at birth or in the early months after birth. Included in this group would be students diagnosed with Down syndrome, spina bifida, and cerebral palsy. When comparing the journey described at the pilot interview, where the student's educational needs were diagnosed at 2 months of age, students working within the ASD continuum were seen to have life stories that were markedly different. (These stories will be discussed in more depth in Chapter Five.)

After discussions with both supervisors, the decision was made to add a fourth criterion when selecting the final candidates for the interviews in order to include a range of families more in keeping with the enrolment pattern in most special schools:

- ORS funding linked to an educational need based on a neonatal, birth or early months after birth diagnosis. An example of a student meeting these criteria would be a student diagnosed with Down syndrome.

Telephone contact was made with two special schools in different geographic areas from the schools previously contacted. The principal of one school approached a family within the school community and emailed the contact details to me. The second principal placed a 'PhD Research' request in their weekly newsletter (Appendix D) and a response was received from a parent of a student attending this school. A return phone call resulted in email contact being established for the transfer of information.

Contact with the final participating family group was made through a 'snowball' effect with this family group being aware of my research and being willing to be a participant in the interview programme.

4.2.2 Meeting the family groups

My first contact with each family was by telephone. At this time arrangements were made to post the introductory letters to the family outlining the research being undertaken and the role of the family group in the interviews. The postal package (Appendices E2, E3, E4 and E5) included an information letter for parents, and an information letter for the students. This letter was presented in two formats: the first as a document with a regular print format; the second document being presented in Widgit symbols format. Widgit is a communication language used for students not yet able to read but who have an understanding of conventional print formats. As shown in Appendix E4, graphic symbols support written text to aid communication and understanding of events for people with learning difficulties. Five families indicated they did 'read' the Widgit information letter with their family member who did not read conventional text. Although these young people did not participate in the interviews, their parents appreciated of their inclusion in the 'giving of consent' process. At the time of the initial contact with the family, a commitment was made to contact the family after a week, giving them time to reflect on the information they had received and make a decision about participating in the interviews.

The second phone call was to further discuss the research with the contact family member, and to clarify any questions the family might have about the research. This was also the time when eight of the family groups gave a positive decision to participate in the research. The ninth family group member asked that contact be made at a later time (2 months) as it was not an appropriate time for a decision to be made. This request was accepted and at the time of the contact at the later date, the participant agreed to take part in the interviews.

The family contact person was reminded of the need for consent forms to be completed, as outlined in the introductory letters, and the discussion clarified which consent forms would be relevant to their unique family group: a parent's consent form; a student consent form; a consent form for any family member taking part in the interviewing; and a consent form with a student giving consent for a family member to sign the form on his or her behalf. This last consent form would be used when the student has the cognitive ability to understand the process of the interview, and would be able to give verbal consent but not a written one. These documents (Appendices F1, F2, F3, and F4) were posted to the families. At the time of the second telephone conversation, mutually agreed meeting venues and times were discussed. Contact with four families was transferred to email format with the 'conversations' becoming a series of emails.

Higgins, Nairn and Sligo (2007), reporting on Aotearoa New Zealand based research, discuss the subculture of place within research based on interviews for data gathering. These writers suggest that all persons have a 'culture capital' (p. 106) that gives them the knowledge and skills to work with ease within the dominant culture of his or her social space. These authors further suggest that different venues for interviews 'privilege the exercising of different capitals' (p. 109) and this may impact on the data collected and the participation of both those being interviewed and those conducting the interview.

A home represents the 'cultural capital' of a family. By inviting the researcher into their home, the participants are making private spaces open for view and assessment. Higgins et al. (2007) see some risk in the family having a sense that their 'cultural and/or sub cultural capital' (p. 109) may be in conflict with that of the research visitor. These authors see this risk being reduced with the meeting being held in a non-personal space. Should the family groups be given the opportunity to suggest meeting in a mutually agreed space, they would be accepting the use of a shared sub-cultural capital. However, for these seven families, their home was accepted as their 'safe place', the place where they could relax and feel comfortable discussing issues that were personal to them.

When discussing possible meeting places, the use of a 'neutral' or non-personal space such as a room at the local library was discussed. However, seven of the nine families decided that the mutually agreed meeting place would be their family home. The remaining two interviews were held in cafes. The two cafe meeting places were seen as the most convenient venue because of the family members' commitments for the remainder of the day together with time and travelling factors. Neither of the cafe meetings was in the home town of the researcher or the family group. The selected cafes had a large seating area, and the timing of both meetings was such there were very few other customers in the cafe. At no time was there any concern about the interview being overheard by other customers in the cafe.

The timing of the meeting for all family groups was again mutually agreed, with consideration being given to the travelling time of the researcher, and in the case of the cafe meeting place, the participants' travelling time, and the families' work, family and social commitments. Six of the families chose to meet in the mornings, two in the afternoons and, because of work commitments, one family asked for the meetings to take place in the evening, after the family had finished their evening meal. Two of the families preferred to meet in the weekend, when all members of the family who wished to participate, could be present. Because I was travelling considerable distances to meet with the families, there was always a need for some flexibility in the meeting times, allowing for possible delays in my arrival time. Mobile phone details were exchanged to enable any changes to arrival times to be notified.

Being invited into the participants' homes was a privilege. Gathered around the dining room table, and sharing snacks, cups of tea and coffee, played a key role in shaping the interview. Although some family and professional history had been shared in the telephone contacts, this first face-to-face meeting with its 'conversation opening'

(Stanfield, 2010. p. 5) of introductions, and such topics as travel and finding the venue, the weather, and how everyone's day was progressing, established a rapport between those at the interview, and enabled the conversation to flow. At no time did I have an awareness of the 'cultural conflict' described by Higgins et al. (2007). The knowledge and skills learned and practised when working in a wide range of socio-economic situations enabled me to acknowledge and accept the sub-cultural capital into which I was being welcomed. These skills, together with my knowledge of both regular and special education procedures, ensured my transition into each unique family space was free of cultural mismatch and possible conflict.

4.3 The interviews

'An understanding of experiences of disability and impairment can only emerge when disabled people and their families are listened to' (Macartney, 2011, p. 18). When a respondent is empowered in an interview encounter 'we establish a space for the respondent's voice to be heard' (Gubrium & Holstein, 2002, p. 21). In his discussion outlining interviewing as a basic mode of inquiry, Seidman (2006) sees the ability of people to symbolise their experiences through language as being the centre of what it means to be human. He suggests that through recorded history, recounting their stories has been the major way people have made sense of their experiences.

In this research, the purpose of in depth interviewing was to gain an understanding of what Warren (2002) describes as 'the meaning of the participants' experiences and life worlds' (p. 83). van Manen (1990) suggests that interviews provide a means to explore and gather narrative material that may be used as a resource for developing a richer understanding of an experience of other persons. Yin (2012) supports the use of interviews because the data gathered is 'richer and more extensive' than that gathered from surveys or even from 'open ended portions of survey instruments' (p. 12).

The format for the interviews for this research combines the 'life history' interviewing drawn from van Manen (1990) and the Three Step Interviews Series (Seidman, 2006). Following Seidman's guidelines, open-ended, in-depth questions were used to lead the discussions, with the aim of having the participants reconstruct their experiences, and discuss the phenomenon of decision making within the context of their experiences. It also enabled the building on and exploring of the participants' responses to the opening question by placing it in the context of their lives and the lives of those around them

(Seidman, 2006). Without this contextual placement, Patton (1990) suggests there can be little possibility of exploring the meaning of the experience. In acknowledging that the initial use of open-ended questions may suggest a looseness or lack of focus within the emergent nature of the interview, Seidman (2006) emphasises the need for an inherent structure within the inquiry that allows the maintaining of a sense of focus. The researcher must have an understanding of the intended outcome and place of closure for the first and second interview.

The opening question for the first interview was:

Tell me about (student's name) early years before he/she was enrolled in his/her first preschool or school.

The question prompts used in this first interview were:

How did your family make the choices for the first preschool/school placement for (student's name)?

Where was the first place that (child's name) started a learning programme?

Who did you discuss this with?

What other options were available to you? Why did they not become your first choice?

The natural closure for this first interview was when the discussion had reached the stage where the family members were beginning the talk about investigating possible alternative educational providers for their ORS funded student. By concluding the first interview at this time of transition, the families had time to reflect and review what had been discussed. It also gave the family groups time to prepare their thoughts and memories for the second interview.

The second interview was a time to discuss how the family made the decision to move their family member from a regular setting to one offered by a special education provider.

The opening question for the second interview was:

Now (student's name) is enrolled in a special school. Why did your family decide to move (student's name) to this school?

Did you discuss this 'possible' move with anyone at the school/GSE?

The question prompts used in the second interview were:

What was happening in (regular school) that made you contemplate a move of schools?

How did you make the decision to move (child's name) to this school?

Who helped you make this decision?

How did (child's name) feel about the move to his/her new school? (If the child was at the interview, this question will be addressed to him/her.)

The second interview reached its natural conclusion with a discussion about how the students and their families understood their child's present educational and personal life in the context of their and their family's life experiences. This discussion was introduced with the question:

What does it mean for your family and for (student's name) to be going to this school?

Where do you see (child's name) completing his/her schooling?

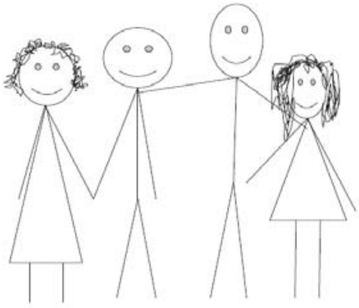
There was also a time to reflect on the experience of the series of interviews and talk about the findings that emerged from the discussion. The point of closure for the second interview was the discussion relating to the student's future education placements and life beyond the school gate. For many families the transition from school to the 'world beyond the school gate' is a time for discussion and planning. Students enrolled in special schools are entitled to attend the school to the end of the year in which they reach their 21st birthday. Being given the opportunity to discuss this time of transition enabled the students and their families to talk about their plans for the next stage in their child's life journey

The outcome of these interviews was a reflection of the education experiences for the nine families and children. The discussion in Chapter Six will give an in-depth analysis of the data that emerged from the interviews.

4.3.1 Pilot interviews

A pilot interview with the Samuels' family was completed before the interviews with the selected family groups. Because of my travel times and the unexpected time commitments for the family, this interview was a 'one off' meeting but followed the pattern of the Two Series Interviews, with a break when the discussion reached the transition of Olivia (the student attending a special school) from a regular school to a special school.

4.3.1.1 The Samuels family



Olivia lives with her parents and elder brother in a rural area of the North Island. From an early age it was evident that Olivia was not reaching significant milestones expected of an infant. She was diagnosed as having a developmental coordination disorder that affected both her fine and gross motor skills. Her medical diagnosis also identified a pattern of myclonic seizures that responded to medication.

When Olivia was enrolled in an early childhood placement, it was suggested by the staff that teacher aide (TA) support would allow Olivia greater access to the activities in the daily programmes. Her family provided the funding for this additional support for Olivia. At the time of her transition to primary school, an application was made for ORS funding, but this was unsuccessful. Throughout her primary schooling, Olivia continued to be supported by a TA, funded from within the school's SEG and by her family. A further application was made for ORS funding as the gaps between her levels of achievement and those of her peer group in both classroom activities and general mobility skills were widening. Again Olivia was not granted verification.

At the time of transition to secondary school Olivia's family discussed the options available to their daughter. Although her older brother was aware that Olivia should be attending the school he attended, his parents were concerned that this school would not have the resources to meet Olivia's special learning needs. They were concerned that Olivia did not have the skills to manage a high school timetable with the changing of classes. They were also concerned that the programmes of learning offered at this high school would not be accessible to Olivia as the school did not offer its students access to a 'learner support programme'. However, the major concern for Olivia's family was the expectation within the secondary school community that her brother would be responsible for her when she enrolled at this school. This was unacceptable to the family and an alternative education provider was sought. Because of their rural location, an alternative secondary school placement would have resulted in the family having to move to a different location. This would have meant a change of occupation for Fred (Olivia's father) and schooling for Olivia's brother. Although a secondary school in the wider geographic area did offer students with special learning needs places in their learner support unit, Olivia was not eligible for placement as she was not funded by ORS.

The special school in the area was known to the family as Olivia had attended aqua therapy classes that were conducted as an after-school programme at the special school's swimming pool. The school was approached and agreed to accept Olivia although she did not have ORS funding.

4.3.1.2 Discussing the pilot interview

In the discussion at the end of this interview, Fred suggested that it would be less stressful if there were two interviews, each with a distinct purpose. A 'natural' time for the end of the first interview would have been when the family had made the decision to investigate alternative education providers for their daughter, Olivia, who was, at that time, enrolled in a regular primary school. Fred also suggested that a break in the interview would have given the family time to reflect on the discussion from the first interview and prepare for the second meeting. Having completed one interview, the families would know 'what to expect' and would not be so apprehensive about the interview process.

It was also necessary to be aware that participating families and the interviewer might have travelled some distance to the selected venue, and have made arrangements for the care of other children for the duration of the interview. A further factor to be taken into consideration was that the duration of the interview might be longer than first intended, and the researcher should be aware of possible conflicts of interest that might occur because of this. With all factors taken into consideration, the decision was made to retain the format of two interviews, each of approximately 45–60 minutes. This time-frame was seen as giving the researcher and families sufficient time to reach a natural conclusion to each interview.

4.3.2 The Two Series Interview in practice

Johnson (2002) sees a successful interview as one based on planning and preparation. Careful consideration was given to the structuring of the interviews to ensure the time was used effectively and appropriately, with all participants in the interview having time for ‘real listening’ (Stanfield, 2010, p. 10) to tell and hear what was being said about the important matters of their particular lived experience.

These interviews were designed to discuss two distinct times in the students’ life journeys: from birth through early childhood placements to enrolment in a regular school provider, with the second interview focussing on the transition from these regular school placements to those offered by special schools. This second interview was structured to conclude with a discussion of the students’ current educational situation and possible plans for future educational placements. This gave the families the opportunity to discuss any planning underway relating to the ongoing care for their family member once they reached the special school leaving age of 21. It also gave them a time to talk about their hopes for their family member.

Only four of the interviews with the families followed this two-step pattern. These four families participated in very intense, focussed discussions that ranged in time from 50 to 70 minutes. When the interview reached the time of transition to a special school placement, there was a mutual agreement between all participants that this was a natural time to bring the conversation to a close. It was also decided that the break would give everyone a time to reflect, to review and to plan for the second meeting.

At the time of the second meeting, the participants were ‘ready to go’. They had an understanding of the interview process; they had had time to reflect on the first discussion; and were focussed on the next stage of the interview process. Some participants returned to the earlier discussions and added new information. Other participants presented ‘physical’ examples such as letters and photos to support statements they had made at the first interview.

The remaining five family interviews became a ‘one series’ interview for a number of reasons. Although it was not planned, two of the interviews in cafes were over 2 hours in length. At the time of the first ‘cafe’ interview, after the introductory conversation, it was decided by both the participants and the researcher to combine the two planned interviews into ‘one long’ interview. This decision was because all participants in the interview were very involved with extended family commitments and the mutually agreed time and venue of the first interview had taken time to negotiate. When the interview reached the time of transition to a special school placement, a ‘drinks break’ gave all the participants ‘time out’.

The second of the café-based interviews was intended to be the first of two. However, the discussion ensuing from the guiding questions became very intense. The participants had come to the meeting with documentation relating to the student’s experiences within the education system. There was a story to tell and it was acknowledged and accepted by the interviewer that this was an appropriate time for the telling of the story.

It was difficult to meet with you and dredge up the past. However, it was quite cathartic and a necessary experience to enable me to move forward psychologically. (Lynne, 2011)

The decision made by the researcher to ‘go where the informant seems to want to go’ (Johnson. 2002. p. 113) resulted in a 2-hour interview that told the story of the student’s life journey from early childhood to current schooling placement. A ‘drinks break’ was not seen as appropriate during this time. However, all participants were rewarded with ‘refreshments’ at the conclusion of what had been a very intense, informative and focussed interaction between family members and the researcher.

As with the previous meetings, the three remaining ‘one meeting’ interviews were planned to be the first of the two meetings to discuss the students’ educational journey. However, in all three meetings, the information being given by the respondents told of a very different journey for the families because of the early diagnosis of their children’s’ special needs. The nature of the information meant that the interview time was shortened, and thus all three interviews became ‘one meeting’ interview.

In three interviews, the children who were enrolled in special schools participated in the discussions. In the remaining six interviews, the children were not included in the interviews as their communication was primarily non-verbal and, because of the severe nature of their particular disability, they were not able to participate in conversations at the level of understanding and interaction being used by other participants. One of these six children was within the vicinity of the interview conversation. However, the only interaction with the participants was to use a known ‘signed’ communication to ask for something to eat.

4.3.3 Additional family interviews

The invitation to participate in the interviews included everyone the family wished to invite to support them – extended family and friends. At the end of one interview with a family group, it was suggested by one of the participants, that it may be *‘interesting’* to meet with the student’s grandparents, *‘without us there’* because *‘their version would be interesting’* (Theodore).

A participant in another interview suggested that a meeting with her daughter might give an insight into how that person managed their educational journey. ‘*Kate would love to go out to the cafe with you. You could go when she gets home from school. Yes, that would be great.’* (Donna).

These invitations were accepted. Both interviews were ‘one meeting’ interviews, with the mutually agreed venue being the participants’ home and a cafe. As with the earlier interviews, the initial communication was by telephone. Both participants were aware of the interviews with their families, and had an understanding of the underlying nature of the proposed interview. As with the first family interviews, the information letters and consent forms were posted before the meetings and both meetings were recorded.

4.3.4 Recording the interviews

The use of a recording device introduces a ‘particular social context’ (Warren, 2002, p. 91) for an interviewed conversation. In the introductory letters to the family groups, all participants in the research were asked if an audio recording could be made of the interviews. A reminder of the use of a recording device was also included in the consent forms. All participants but one agreed to the use of this recording device. The one person who did not wish to have the interview recorded agreed to a ‘note taker’ being present throughout the interview. The person taking the notes did not participate in any part of the interview apart from initial introductions and greetings at the beginning and end of the interview. At the conclusion of this interview, the notes were given to me and the note taker had no further participation in the research procedures. The signing of the ‘Note taker’s confidentiality agreement’ (Appendix G) was completed before the interview commenced.

Warren (2002) discusses the 'on and off the record' (p. 92) interactions that participants in interviews may have with the introduction of recording devices in an interview setting. In the first of the series of interviews for this research, the interview had appeared to reach its natural conclusion and the recording device was turned off. In the ongoing conversation, one of the participants began to discuss an incident from the student's early childhood years that had had a significant impact on the decisions that were made in the student's later years. The use of a 'field journal' to record this discussion ensured this information was not forgotten. However, in all future interviews, the recording device was not turned off until the 'goodbyes' were completed, for 'unrecorded data of this kind' (Warren, 2002, p. 92) are as important as those transcribed from the structured interview.

4.3.5 Transcribing the interviews

The use of computer software was not considered as an option for the analysis of the interviews. Although considerable time was needed to complete the transcription (1 hour of taped interview taking 3–4 hours of transcribing), they 'captured how things were said' (Bailey, 2008, p. 129). All the details were transcribed in the language of the participants. With repeated careful listening of the tapes, features of the talk such as emphasis, speed, tone of words timing and pauses resulted in familiarity with the data. Having been part of this experience and therefore able to visualise the setting when transcribing, I had an intimate familiarity (Denzin & Lincoln. 2008) with both the field settings and those persons participating in the interviews.

Copies of the transcriptions were posted to the families with a covering letter (Appendix H1) advising them that should they wish any part of the transcription to be removed or changes to be made to the content, the script could be returned to me in the stamped addressed envelope included in the posting. The families who had participated in the two interviews received the transcript of the first interview before the second interview took place. This enabled the families to read the transcripts with any changes and additions being discussed before the start of the planned second interviews. The requests received were for changes to the spelling of siblings' names, and the spelling of educational providers and professional organisations providing support of the family. Once all transcriptions were corrected and final copies were sent to all participants, authorisation was requested for the release of the transcripts (Appendix H2) in order that the edited transcript and extracts might be used in reports, presentations, and publications arising from this research.

The transcription of the interview that was not recorded was also forwarded to the participants who returned an revised copy that included a more comprehensive record of the discussion. This amended copy was accepted as a record of the interview.

4.4 Coding the data

When all transcribing was completed, the transcriptions were reread to give a further familiarisation with the data. Corrections were also made when the transcriptions were received from the families and requests for alterations were noted. No coding was done at this time, although the rereading did help with what Bertrand, Brown and Ward (1992) refer to as ‘getting started on the arduous task of condensing literally hours of free flow conversation’ (p. 204). It was time to begin the ‘ambitious task of sorting through large amounts of data, reducing them to a few themes’ (Creswell, 2012, p. 17).

A set of key word codes that referred to words used in the original questions in the research questions, and the lead questions in the interviews, was established. These codes were one or two letters, e.g., TA representing teacher aide, OR representing information referring to ORS applications and funding. The transcripts were then read again, with coding being placed in relevant places in the margins of the transcripts. Identification of ‘quotable’ passages was made with an asterisk in the margin.

The use of hand analysis of the data meant the data were read, marked by hand, and divided into themes (Creswell, 2012). At this stage, the codes were based on ‘word descriptions’ using common words and phrases that enabled the organisation of large amounts of information into smaller parts for later retrieval and focused coding (Bailey, 2007). Once all the transcriptions from the family interviews and the two additional meetings with grandparents and a student were coded, the codes were reviewed and grouped together into larger categories that further reduced the data. By taking one topic at a time, and reading the coded items in the transcript, it was possible to read what different participants in the interviews said about the topic. With these comments ‘fresh in the mind’ (Bertrand et al., 1992, p. 205), a visual display was constructed with quotations to support the themes and sub-themes being developed

Given the challenges in managing a number of different codings and supporting documentation, the ‘cut and paste’ method of organisation was implemented. Once the transcripts were coded, and the larger categories established, the transcripts were cut into chunks of words and organised under the headings of the categories onto large sheets of paper. These categories originated from the codes used at the time of the first reading of the transcripts.

One unexpected problem was the coding of the names of the participants in each interview session. Initials relating to first names had been used in the transcripts and this meant that there was a crossover of initials when the transcripts were cut and pasted. A reprint of the transcripts onto colour coded paper resolved this problem with each family group identified by colour within the categories.

Figure 4.1 *Visual display of coded data*

A section of the visual display of the coded data

The next step in the analysis was to complete the visual display of the data showing the links between the themes, the sub-themes identified within the themes, the number of identifications, and examples and quotes from the transcripts to support the findings. As described by Creswell (2012), the use of hand analysis data, although a very labour-intensive activity, gave me the impression of being close to the data, of knowing the data, and of being able to ‘see into the data’ without the intrusion of a machine to distract the process of analysing what the families and young people had talked about.

Table 4.1:

A visual model of the coding of qualitative research

Initially read through the text data	Divide the text into segments of information	Label the segments of information with codes	Reduce overlap and redundancy of codes	Collapse codes into themes
Many pages of text	Many segments of text	25 codes	Codes reduced to 12	Codes reduced to 3 major, 8 sub-themes

Adapted from Creswell (2012)

The purpose of coding the data was initially to understand the data. The data were then divided into pieces of information that were labelled with codes. The codes were revised and reduced to 3 major and 8 sub- themes. Although the data not included in the data coding were not used directly in providing evidence for the selected themes, they were not discarded but 'put aside' should the need arise for further rereading of the transcripts.

A discussion of the findings emerging from the data gathering is presented in Chapter Six.

4.5 Journals

At the time of making first contact with the family participating in the research, a blank paged book was included in the information package. The information letter (Appendix E6) outlined the possible use of the book as a journal to support the family during the interviews. The letter emphasised the confidentiality of the journal to the family and the voluntary nature of its use.

Asking research participants to keep diaries or journals can provide both the researcher and participants with 'thick descriptions' (Glesne, 2006, p. 69) that support or challenge interview data. Getting something down on paper may provide the participants in research with the prompts useful for stimulating discussion (Blaxter, Hughes, & Tight, 2006). These descriptions of the experiences 'from the inside' (van Manen, 1990, p. 64) may be used by the family to give insight into the journey they had taken with their family member. The journal may enable the family to create a 'detailed catalogue of events' (Mason, 2002, p. 99) to support their reflections in an interview setting.

There was a possibility that the life experiences of some participants and their family might take place over more than a decade. Participation in an interview discussing a life history may require considerable reflection and research. To help the family prepare for the interview series, they were given the option of using this journal in a supporting role; it was a place where observations and events that have meaning could be noted, where memories were recorded, and where feelings, moods and emotions could be expressed. These journals were confidential to the participants and their families, and did not become part of the research data collection. In hindsight, the inclusion of a journal in the data collection may have resulted in further ‘rich data’ complementing the families’ statements.

Although the journals were on the table at the time of the nine family interviews, only one family had used it to record their thoughts. Reference was made to the journal at times when this family was discussing events that had happened a considerable time before the interview. This family also referred to their family’s photograph albums to give a visual description of events that had considerable impact on their family member’s early years.

In all the family interviews, the ‘raw telling’ of the story they had to tell was very much a part of their everyday living and they had their own collection of documents which were shared with the all the participants in the interview and were used to support their responses to questions and the information they were giving. These documents included letters and responses to communications with principals and Board of Trustees, MoE officials, and photographs. In one family meeting, uniforms worn at sporting occasions were included in the family memorabilia. The journal was not used or needed. The journey they had travelled with their family member was an ongoing living experience.

4.6 Field Notes

Bailey (2007) describes field notes as the ‘backbone of collecting and analysing field data’ (p. 122). They are seen by Heller et al. (2011) as the documenting of a journey while giving the researcher the opportunity to reflect on the field work process before, during and after the event. Both Bailey (2007) and Gray (2004) draw on the work of Lofland (1971) for the different sources of data that are generally found in field notes.

When first entering the field, the researcher must record as much detail as is possible when within the setting. This 'raw data' is recorded in detail and without explanation or attempt to interpret why a person acted in a particular manner. These 'jotted notes' (Gray, 2004, p. 244) recording such details as key words and changes in voice tones, will be used later in the written recording when things 'previously forgotten and now remembered' (Bailey, 2007, p. 117) are recalled when reviewing the 'raw data'.

The emerging themes and insights revealed at the time of the review will become a more analytical component of the notes. Gray (2004) warns against censoring when reviewing the data, with the 'good, the bad and those (ideas) about which you are not certain' (Bailey, 2007, p. 118) included in this analytical phase.

Participation in field research provides many opportunities for the emergence of personal feelings about people, conversations and information that have been divulged. The field journal is a collection of these memories, of feelings and impressions that can influence people's actions. The field journal is also a record of forward planning; of ideas that may need following up; of the need for clarification of information given earlier; or for planning the next step of the research process.

Bailey (2007) sees the final stages of the field journal entries as 'your reflective thoughts' (p. 118). This gives the writer the opportunity to better understand the experience, and address the learning and questioning that happen, not only at the time of the interviews but at a later time when the interviewer has time to understand the setting the context and the culture in which this interaction took place.

As a researcher, I found this aspect of the research process very challenging. Throughout the interviews I was very aware that the conversations were being taped. I did not have to take a written record of the discussions, and I was therefore able to focus on formatting the next question or comment, while listening to spoken words. Once the interviews were completed, I was usually preparing for the return journey to my home town. There was a discipline that had to be learned and practised. I drove for about 5 minutes, and then stopped in a suitable parking area to write brief notes that were stimulated by the mental notes that were rushing around my head.

During the transcribing of the recordings, the field journal was read and used to make anecdotal notes recording my personal feelings about the interview, the impact the interview had upon me, and my reactions to the actions of the participants. It was a time to record information that was underlying the spoken words on the tape the change of tone in a speaker's voice, laughter, and tears. This was also a time to record patterns and themes that would later become an integral part of the analysis of the transcriptions.

The recording of 'things to think about and do' (Bailey, 2007, p. 118) was spread between two places – my personal daily diary and the field book. This pattern of recording was implemented after experiencing extreme frustration when intending to work on the 'must do' list only to find the field book was in another place. The recording of the 'must do' list in my daily diary ensured that the action would be taken.

The field journal has been an essential component of the analysis of the raw data. It has given an added focus to the world outside the conversations, and put the data into the context and culture of the family to give a further insight into the spoken words.

One of the criteria used when selecting families to participate in this research was that their children had moved from regular to special schools. The second component of this study was an investigation as to whether this movement of students was occurring nationwide.

4.7 Survey of special schools

Newby (2010) describes a survey as a systematic collection of data through questionnaires, interviews and observations. In a survey, the investigator selects groups of respondents, collects information, and analyses the information to answer the research questions.

McMillan (2004) suggests that although the group of subjects is usually selected from a larger population through probability sampling, a survey of an entire population can be seen as acceptable. Surveys are also a means of maximising the accuracy of the results, with what Walker (1985) describes as a form of achieving the same results as face-to-face interviews. The wording in the survey needs to be sufficiently precise to ensure they mean the same to all respondents (Bell, 1996). The wording must also ensure the respondent is capable of giving an accurate answer from information that is readily available and easily accessed.

4.7.1 Informal survey of special schools 2007

In 2006, I was working in the senior department of a special school. We were often visited by family groups seeking information about the school, as they were planning to move their ORS funded family member from their current placement in a regular school. These visits were often at a time when their family member was not able to continue attending their current provider because of times of transition at the end of Year 6 or Year 8.

Knowing that these families had made the decision to enrol their family member in a regular school placement at the time of entering primary school education, I was interested in the reasons underlying this decision to approach a special school. I was also interested whether other special schools were welcoming similar family groups to their school, or whether it was happening only in our area.

In 2007, I had conducted an informal survey of all twenty-seven day special schools in Aotearoa New Zealand who were providing learning programmes for students identified as having intellectual and physical disabilities. One school was not included in the survey because of its specialised role working with students with a specific learning need.

The results of this survey from fourteen special schools indicated that over the period 2005–2007, 127 students in Years 7 to 13+ had transferred from regular schools to the special schools who responded to the survey. These findings were similar to those of Pickering and Wilton (1996), whose report showed that 22% of the students who had enrolled in special schools in 1995 had previous experience in regular schools. These results reassured me that the number of students transitioning from regular schools to the special school where I was working was not exclusive to one school. The trend was nationwide except for the results from one special school. The comment '*(name of area) does not really reflect what happens (in other areas) as (name of area) is very pro mainstream so students and families are not encouraged to seek special schooling at this stage'* (Principal of a special school, 2007), suggested that although the students were not transferring in this particular geographic area, the move from regular to special schools was acknowledged by the special school principals in the other special schools.

A comment from a principal of a special school that '*I think it takes about two years in the mainstream for everything to fall apart'* (Principal of a special school, 2007) was the challenge that resulted in my decision to ask the question 'Why are these families moving their students?' 'Why are things falling apart?'

4.7.2 Survey of special schools 2010

As one component of the data gathering for this research, a survey of the twenty-seven special schools was implemented to obtain 2010 figures relating to the number of ORS students who, in 2010, had transferred to a special school, after at least 2 years enrolment in a regular school. This survey was designed to produce quantitative data to complement the findings from the family interviews.

The survey was constructed and trialled in a special school. Changes were made to the trial document, and the covering letter and survey (Appendices J1 and J2) were emailed to the remaining twenty-six special schools in Aotearoa New Zealand. Although completed surveys were received from ten of the twenty-seven special schools, a number of responses from schools indicated that the information requested was not able to be accessed readily from the schools' data bases. Email and personal contact with the schools identified that the schools' computer programmes used to store pupil records did not give pre-entry information. Because the survey asked that the students included in the data had attended a regular school for at least 2 years, the completion of the survey was seen by the school ancillary staff as being very challenging to complete. In schools with small pupil numbers, a staff member was able to complete the form from knowledge of the individual students' pre-enrolment history. In the larger schools, however, the personal educational history of every student was not known to one member of staff. To request that the survey be completed by individual classroom teachers would not be a practical solution to gain this information. It must be acknowledged that the pilot survey was conducted in a special school with a smaller student roll than the majority of the special schools in Aotearoa New Zealand, and this may have masked the problems of access to data experienced by the larger schools.

4.7.3 Data from Ministry of Education sources

Approaches were made to the MoE and GSE to obtain the data indicating the number of students who had transferred from regular to special schools, from within the statistics relating to special education. Although statistics are available giving numbers of students enrolled in special schools, together with their gender and ethnicity, no statistics were readily available to identify the number of students who had transferred from regular school to special school in any given period of time.

> *Please note we (MoE) do not hold the information regarding the number of students who transferred from regular schools to special schools*. (B. McPherson, personal communication, 3 June 2011)

A manual search of the individual student records was seen by GSE as the only means by which this information could be obtained. I was not able to make this search because of privacy and ethical restrictions allowing access to the Enrol programme. Enrol is the programme used by all state and integrated schools to store student information. However, after discussions with a GSE staff member, an approach was made to a GSE Area Manager to ascertain if the figures could be obtained. This GSE manager did obtain the numbers of students who had, in 2010, enrolled in the special schools in the region. However, it was not possible to identify whether these students had transferred from another special school or regular school placement, or whether this enrolment was the student's first placement in primary school education, i.e. the student was enrolling from an early childhood placement and had not been enrolled in a regular school placement.

The decision was made to analyse the survey returns received from the ten schools, and look for trends within the data. The analysis would ascertain the percentage of pupils in schools who had transferred to the school during 2010. A comparison was also made with the data received in the 2007 informal survey. These data are presented in Chapter Six. A report of the findings of the Survey of Special Schools 2010 is presented as a resource in the literature review section 2.12.

4.8 Summary

This chapter outlines the methodology of this study, describing procedures for sample collection, the data-gathering tools, and the analysis of the data. The qualitative data were gathered from a series of family interviews. Margin coding was used to establish themes emerging from the transcriptions of the interviews. A survey of all special schools in Aotearoa New Zealand was implemented to obtain quantitative data used to further support the findings from the margin coding. The findings from this data will be discussed in Chapter Six.

Chapter Five introduces the families and presents their stories within a framework that discusses the gaining of a diagnosis for the children, their experiences at early childhood, at primary school, the families' experiences that lead to the children transitioning to special schools, and their experiences of the special schools. The chapter concludes with a discussion introducing the themes emerging from the families' stories.

CHAPTER FIVE

Meet the families

Mum. She's the one I unload on. I am sure she's got hearing aids and turns them off. But I don't care, I've got to speak otherwise I'd go bonkers.

(Lynda, mother of Joshua and Katrina, 2011)

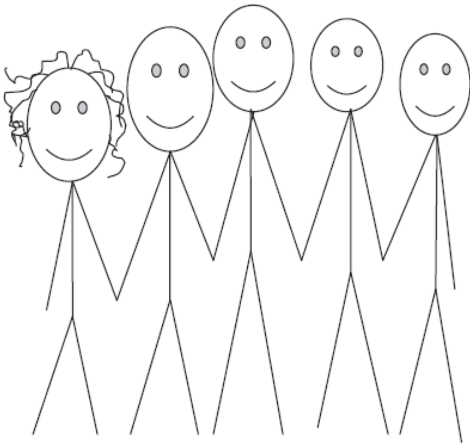
5.1 Introduction

This chapter introduces the nine families who participated in the series of interviews giving an insight into the experiences they had of educational placements in regular schools for their children. Each family story tells of the journey they have travelled, from the birth of their child, through their time in a regular school placement, to the time of enrolment in a special school. These stories describe the world of 'inclusive' education as experienced by these families. It also tells of their reasons for choosing to leave regular school settings and move to the exclusive setting of a special school, and how this choice came to fruition.

Each family is introduced in turn. For ease of identification, an introductory portrait of the family groups is provided in a fold-out format in Appendix K1 at the back of the thesis. Extracts from the interviews are written in italics. Where two or more family members were interviewed at the same time, the extracts are identified by the name of the family member.

This presentation of the chapter is under the following headings: diagnosis, experiences at school, experiences leading to transition to special school, and a description of the student's and their family's experiences when attending their chosen special schools. The chapter concludes with a discussion of the key issues identified by the families as influencing their decisions to move their children to special schools.

5.2 The Brown family



Axel lives with his mother, Kathy, and his three brothers in a suburb of a coastal resort city in Aotearoa New Zealand. Their home is a Housing New Zealand bungalow, with a front garden planted with vegetables and flowers. The trampoline in the back garden is secured in such a manner that Axel is able to be active in the area with limited supervision. The section is fenced and 'Axel proofed'. At the front entrance to their home, there is a 'pool style' gate to enable the house to be secure, a second gate at the hall way as it exits the lounge, and a third gate at the kitchen entrance. These gates ensure that Axel is safe in his home and the family is also safe from him entering their spaces when he is unsupervised.

Axel is the third of four boys aged between 9 and 20 years of age. He was 11 years old at the time of the interviews. His eldest brother works full time in a retail position. His second brother was enrolled in the local intermediate school, and his younger brother attended their neighbourhood school. Axel's mother Kathy is a registered nurse, but at the time of the interview was a full-time mother for Axel and *for my other children. They need a mum who has got time for them.*

Kathy has her own room, Axel has his own room, and his three brothers share the third bedroom. Kathy's eldest son has found the sharing of a bedroom with his two younger brothers challenging. He had, in the past, set up a bedroom space in the garage attached to the house. However because the owner of the property, Housing New Zealand, does not permit the garage to be used as a room, the furniture was moved back into their home. At the time of the interviews, there had been some discussion between Kathy and her eldest son about the finding of alternative accommodation.

The family area, the lounge and dining room are open-plan. There were no pictures or distracting visual displays on the walls as this form of decoration causes Axel stress. In the bookcase in the lounge there was a selection of books that were suited to Axel's interest level. There was a small video player on the dining table and this was used when Axel indicated he would like to watch a video.

5.2.1 Diagnosis

At the age of 1 year, Axel was not speaking although he *appeared reasonably normal in gross motor movements.* His mother Kathy approached the Well Child nurse at the neighbourhood primary school attended by her older sons but it was not until Axel was about 20 months old that she *finally got someone to come.* At this time Axel was still not speaking and had developed monotonous routines. He would run aimlessly around the open area at the home in which they were then living. He would also run his finger and thumb along objects such as the table edge, and watch these movements by squinting out of the corner of his eye. These actions were concerning Kathy. With two other young boys in the home there were plenty of toys available, other children to play with, and very able role models who would have enjoyed having their brother join in their games. *I read books to them and things like that.*

The Well Child nurse acknowledged that Axel was developmentally delayed and a referral was made to GSE. But because of a *massive backlog* he was not seen by GSE until he was over 2 years old. Following the interview with GSE, Axel was referred to and seen by a visiting neurodevelopment therapist and a play therapy programme was started, with a focus on teaching Axel to play with toys. It was at this time that the basic checks of hearing and vision were completed, together with blood tests to investigate the possibility of Axel being diagnosed Fragile X. The tests proved negative and a diagnosis of autism was made.

Another component of the ongoing support Axel received from GSE was an interview with a specialist working in the area of child and adolescent mental health. He was also enrolled in an Early Bird programme being established in the area. It was while Axel was attending this programme of activities designed to raise the developmental levels of the children, that Kathy met another family who was promoting the programme ABA. *It seemed a most positive thing to do***.** Funding of 1 hour a week from GSE and another hour from the neurodevelopment services, enabled the hiring of a therapist trained to implement the ABA programme. Every 4–6 months a leader for the programme would visit and review and revise the learning programme. This activity-based programme was held in the family home with Axel's room set up as a classroom. At this time a Speech Language Therapist was also working with Axel to encourage his acquisition of language. *He didn't have speech as such*, although Kathy noted that he had a noun vocabulary of approximately 100 words such as *apple, bikky*. However, Axel would only use these known words when prompted with visuals such as pictures, or the actual article.

5.2.2 Experiences at school

Axel attended kindergarten, as had his older brothers. The underlying reason for his attending kindergarten was that he would have something different in his programme and have the opportunity to interact with other children of his own age. He received funding accessed through the GSE Early Intervention Services that allowed the support of a teacher aide while he was at Kindergarten. His ABA therapist was employed to take the role of teacher aide when Axel was at kindergarten and this ensured the *very close supervision* that he needed was consistent with that implemented in his home based programme.

Dawn: *And how did he get on with the other kids at Kindy?*

Kathy: *Ignored them...the (fire) alarm went off one day and he didn't even twitch. He just kept doing what he was doing*

By the time he reached his 5th birthday, Axel was receiving funding through GSE that allowed him to participate in 25 hours of ABA and kindergarten each week. At the time of a review of Axel's early childhood learning programme, a GSE support person asked '*Why can't he go to school? He'll get a teacher aide and why shouldn't he be around normal children. He's more likely to learn off them and there's more of him that is normal than not normal'.*

In response to this meeting, Kathy visited her neighbourhood school where her two older sons were enrolled and said, *I'd like to enrol my child who is severely autistic and could you please work out how to do that.*

With the help of GSE, an application was made for ORS funding, which was granted with Axel being resourced at the very high needs level. *Of course they thought they were terribly clever getting very high needs. I thought what else would he have been. I wasn't impressed that it equated to only 15 hours and he needed 1 on 1. He was still in nappies.*

With the documentation completed, Axel was enrolled in his neighbourhood school. As the school was within walking distance of his home, Kathy walked him to school every day. At Kathy's suggestion, the school employed his ABA therapist as his teacher aide because she knew Axel and had established a very good rapport with him. Because it was not possible for Axel to be at school for the whole lunch time, he would walk home with his teacher aide, and after he had eaten his lunch, he would play in the back yard while she had her lunch. *It worked really great and it didn't matter if I wasn't at home. She knew how to come into the house.*

In order for Axel to have 1-to-1 TA support for all the time he was at school, *the school and GSE sorted it out* to enable him to have 25 hours teacher aide hours. As *they (GSE) have a policy of not paying for 30 hours*, Kathy paid for the lunch hour support from a Care and Support grant. *You read every book and you talk to every person and you belong to every group. You really do all your damndest. I really felt I am not here for anyone else. I am only here for Axel. I said that. Once the hurdle was reached and he started school, it was a really wonderful thing. It was a special thing.*

In consultation with GSE support workers and the school, it was decided that Axel's transition to primary school would be gradual, starting with a morning only. By the end of the first term he was attending school on a full-time basis:

> *It was a lovely time and the children in the class were magnificent. The teacher was fantastic. He was never going to do academically what they were doing so he worked alongside them and some of the things he could join in and some he couldn't. He had time on the computer; he joined in with the singing and storytelling. He had his own programme and when the children, quite a lot of them, would finish their work early, they would go and work with (TA) and Axel.   They handled it beautifully.*

For a time Axel worked with support therapists who visited the school. But Kathy found the programmes that were implemented did not meet her expectations. *To be honest they seemed to have very unreasonable expectations of both me and the school.*

Kathy described 'sensory based' therapy exercises that were introduced into Axel's school programme with the understanding that the exercises would be integrated into his home activities. The exercises had to be repeated every 2 hours. *My God! No! I can't do that every 2 hours. I might do it once or twice a week. This is ridiculous.* Kathy talked about having to work with Axel on these specific exercises and how the time required encroached on her time with the other family members. *I had three other kids that needed their mother.* She then recalled the specialist working in the area of child and adolescent mental health commenting that ‘We *need to look after this mum. If she falls over, the whole family falls over.’ It started to make me think what I needed for me.*

5.2.3 Transition to special school

He only lasted a full term at school and the second term he only went occasionally. Axel’s behaviour began to deteriorate. He started to cry. *He would become distressed by noises.* He started to develop ‘phobic’ behaviours. *He would baulk at doorways.*

In order to ascertain that there were no physical problems causing this distress, Axel’s hearing, sight, teeth, and general medical welfare were ‘checked out’; the results showed there were no obvious health reasons for his distress. The specialist team working in the child and adolescent mental health programme introduced *several different treatments*, which included changes to Axel’s medications.

> *Axel’s demeanour was obviously still pretty bad and that’s when we decided. It was like it all just got lost, so lost he was losing his speech. He was doing less and less and less.*

Kathy then related the story of how she had seen a stall outside The Warehouse – it was a fundraising cake stall and she picked up a brochure introducing the special school in the area.

> *I had never heard of them. I took the brochure home and was really fearful of it. Even though they were lovely it was like, ‘What am I doing? This is the bottom of the bottom’.*

She approached the social worker from the health provider that funded the therapists working with Axel and asked her to arrange an interview at the special school. *I just couldn’t do those sorts of things. It was too hard. Everything was too hard.*

Kathy and Axel’s TA visited the special school. *They were very welcoming, very positive. We spent half a day there.*

At this time, Axel was not attending school on a regular basis. *He was barely there.* As a result of visiting the special school, a meeting was held and was attended by the teacher and TA working with Axel at the primary school, the principals of the special school and the primary school, Kathy and representatives from GSE.

> *It was highly emotional. The people from the school were very disappointed that it hadn't worked as well as they had hoped. I think they were gutted they hadn't been able to do more. There were glimmers of wonderful stuff happening earlier on. I thought they had done a wonderful job, a good job, and it was entirely because of where Axel had reduced to.*

The decision was made for Axel to enrol in the special school at the start of the next school term.

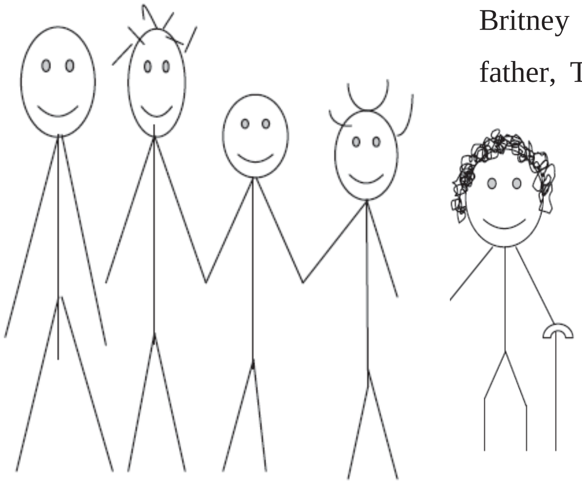
> *We put him in the van and off he went with a big bag full of spare clothes*

5.2.4 Experiences at special school

Axel is now attending a special school. *I am glad we had it (the time at regular school) but it's great (special school) because no matter how he is at home, they have him at school.* At the time of the interviews with Kathy Axel was preparing to move to a class where he would be the youngest student in the group. *He's been transitioning and doing half a day there.* Kathy talked about the role of the TAs. *They have a whole different insight to what he is like and they can work one on one with him.* Kathy now has time during the day for her own interests. *It's good to know he is there and firmly in the system and that no one can take it away hopefully. I feel they have taken a lot of the burdens off me. They listen to me. I don't have to fight. I don't have to make big education decisions for him til he is 21. That's wonderful.*

Kathy is enjoying caring for her family and being a grandmother.

5.3 The Serville family



Britney lives with her mother Eleanor, her father, Theodore, and her older brother in a seaside suburb of a North Island city. Their home is a two-storey, open-plan house in a quiet cul-de-sac one block back from the beach. The house section is fenced with a gate that can be operated from inside the home. There are no indications that this is the home of a young teenage girl with special learning needs, although her father did say that the chocolate was kept on the top of the pantry unit in the kitchen and sometimes Britney does try to climb up when she feels hungry.

Britney, aged 14, is the youngest of three children in the Serville family. Her brother attends a coeducational secondary school in a suburb some distance from the family home. Her sister does not live in Aotearoa New Zealand, and has a young child. Eleanor is a primary school teacher and Theodore is a self-employed contractor working in the horticulture industry.

During the interviews Britney was watching a DVD in a lounge area, but also had access to another room where another DVD was playing. Britney moved around the ground floor area of her home, with ease. Her brother was upstairs and I was told that Britney knew that she was not to go upstairs as that was her brother's place. She had downstairs, he had upstairs.

Britney's grandparents live in the same suburb as her family. Her grandparents are retired farmers. I met with Britney's grandmother in her home.

5.3.1 Diagnosis

Eleanor: *I knew things were not quite what they should be when she was about 3 months old.* She *didn't have muscle tone. She wasn't holding things the same.* As Britney was the Serville's third child, Eleanor was able to make a comparison with the milestones her two older children had reached in their earliest months after birth. She did not walk until she was about 22 months old. She held her hands and placed her feet in a way that was *markedly different* (Eleanor) from the other children. *Although she did eventually reach infant milestones, the gap was growing wider at that stage* (Eleanor).

Britney was not born in this country, although her parents were both citizens of Aotearoa New Zealand. Her first contact with providers of specialist services was with the (State) Special Services in her country of residence. *You have a really hard time convincing the doctors of anything because she didn't appear different to other babies, just slower* (Eleanor). As Britney was not walking at 22 months her parents were referred to the (State) Special Services for assistance. *I know this is not the way it is supposed to go* (Eleanor).

At this time, Britney's mother was in full-time work and her father was her primary care giver. She received support from occupational therapists and physiotherapists with her father taking her to appointments. She was in day care *and they would look after her so she was fine* (Eleanor). But as Britney gained her mobility it became necessary to restrict her access because *she would bolt and go places* (Eleanor).

5.3.2 Experiences at school

At the age of 4, Britney was enrolled with an early childhood provider that was linked to a special school. The decision to make this enrolment was two- fold. Britney had been diagnosed as being within the Autistic Spectrum and the early childhood centre had the resources to meet her special needs. However, a delay in gaining funding to support Britney in a regular early childhood setting meant that the needed resources were not available when she started school. *When we applied they told us we would have to wait for 6 to 8 months. We just never got any of the help that we were seeking...and we needed it* (Theodore).

At this time in Britney's life, the family visited Aotearoa New Zealand to attend a wedding. As the wedding was late in the year, the family decided to remain in the country to celebrate Christmas with their family. Because there were still 3 weeks remaining in the school term the family decided to enrol their two younger children in school. With her brother enrolled in the neighbourhood school, the decision was made to enrol Britney in the neighbourhood kindergarten. *They suggested we check out this (special school) place and we did. I took her along* (Theodore).

I had heard of (special school) through a friend whose daughter and son-in-law does respite care and they told me about (special school) (Grandmother).

Eleanor had returned to her work placement in the country in which they were residing and Theodore and the two children were living with their grandparents. Although contact had been made with the special school, *We (grandmother and grandfather) both went and had a look at it. That could be a good solution for Britney* (Grandmother).

Britney was not able to be enrolled because at this time she was only 4 years old. In Aotearoa New Zealand, children must be 5 years old before they can enrol in primary schools. Britney would be celebrating her 5th birthday in April. Theodore and the two children returned to their country of residence in January and returned to Aotearoa New Zealand in March in time for Britney to enter the special school when she was 5.

The reasoning behind the family's decision to relocate to Aotearoa New Zealand was twofold. There had been a change of government in their country of residence and the family was concerned that there appeared to be funding cuts to special education services. *When you came to apply for them (special needs funding) you would see a new person and they would say 'Sorry, that service does not exist anymore, that service is not available'* (Theodore). There was funding available in Aotearoa New Zealand for supplies such as nappies that was not available in their country of residence. *It was a big expense* (Theodore).

Because all the applications for ORS funding and enrolment in the special school had been completed before the family had returned to their home in January, the principal of the special school had *managed to get it all together for us. It was all done* (Theodore).

Dawn: *So you didn't think of going to a primary school?*

Theodore: *It was the best opportunity that we were going to get for Britney at that time. There was nothing else offering as many services as (special school) was offering at that time.*

They were living with me at that time. They had a mobility van and they dropped her off and picked her up. We felt she made good strides there. She was very happy there (Grandmother).

When Britney's mother had completed her teaching contract she returned to Aotearoa New Zealand and worked as a relief teacher.

At this time, the family noticed that Britney was exhibiting behaviours that were not part of her usual demeanour. *All of a sudden she was screaming and hitting her head... I felt she was picking up some bad habits* (Eleanor).

Towards the end of the first year we saw Britney developing mannerisms she didn't have before. I think she was copycatting (Grandmother). Meanwhile, Eleanor had accepted a long-term relieving position in a primary school in their locality. This gave her the opportunity to approach the school and discuss Britney's possible enrolment. *That was what I was looking for Britney to be once again mixing with neurotypical children so that she would be picking up on their habits. That was the whole idea behind it* (Eleanor).

You probably wonder why they decided to take her from (special school). Theodore didn't want to take her from (special school). (Grandmother)

In the second interview, Theodore commented that he did not want Britney to leave the special school and enrol with a regular school provider:

> *No, in this (meaning the family) democracy we decided that Britney would go to the mainstream because of the reasons Eleanor has outlined. I agreed to send her but I wasn't happy. They (Eleanor and Britney's grandmother) felt that they had justification so I just said all right, hoping it would work out.*

When Theodore informed the principal of the special school that Britney was being transferred to a regular school placement, the principal's response was *We'll see how it goes.* Theodore did stay in regular contact with the special school during the time his daughter was enrolled in a regular primary school.

At the age of 6, after 1 year in a special school, Britney transferred to the regular school where her mother was teaching. She entered a Year 2 class.

The transporting of Britney to school and the organisation of her therapy programmes was now the responsibility of GSE. The Special Education Itinerant Teacher (SEIT) supporting the ORS funded students in the school trained the TAs to make them more aware of the special learning needs of students identified with ASD. Although Eleanor acknowledged that the school *probably didn't have the services (the special school) had, such as horse riding and regular therapy times* and *the teacher aides needed a lot more training*, there were positive aspects to Britney's regular school experiences. *There was no way she could keep up with what they were doing, but she started to interact with the kids. She thrived in classes where the teachers had absolutely strong routine. That was the sort of thing I was looking for, for Britney to actually interact with children* (Eleanor).

Britney's parents talked about their daughter in the community, where she was known and acknowledged by other children who attended the same school and their parents. To Eleanor and Theodore being a part of the community was a very positive outcome of their decision to enrol their daughter in a regular school. *They are known in the community* (Eleanor).

Britney attended the regular school for 4 years. She moved through the school with her peer group and her TAs moved with her where possible. However, the number of changes in the TAs was a concern.

> *They (TAs) don't get paid a lot of money. For them it is a job and we found with Britney that she would go through two or three different TAs every year. A kid like Britney, she needs continuity. That probably did more harm than good over those years in (the regular school).* (Theodore).

She was in the regular class for some of the school day and was withdrawn for additional support teaching by the SEIT teacher or the teacher aide. The principal also ran a separate programme based on PMP (Perceptual Motor Programme) designed by the GSE psychologist for a block of time.

The school Britney attended was a full primary school, i.e. from Year 1 to Year 8. However, in the town there was an intermediate school offering Year 7 and 8 classes. For some students the option to attend the intermediate school meant they transferred schools at the end of their Year 6 studies. Britney reached the end of her Year 6 learning programme at this regular primary school. It was time for a change.

5.3.3 Transition to special school

Year 7 and 8 students are introduced to the Technology Curriculum when attending technology classes taught by specialist teachers. The students usually attend these classes at a secondary or intermediate school if their full primary school does not have the specialist teachers or classrooms.

Eleanor and Theodore acknowledged that the school was not able to meet Britney's ongoing special learning needs. *It would be just too much and not much advantage* (Eleanor). At the discussions with the SEIT teacher and the GSE advisor, Eleanor and Theodore stated *this is like the crossroads* (Theodore). Eleanor and Theodore then asked the SEIT teacher and GSE advisor *What's your idea about what's available in the area, the best place for Britney? Knowing what you know about her?* (Eleanor). One of the options was between the intermediate school and the school Britney was attending, but her parents and their support advisors could see no advantage being gained with a move to the intermediate school. *She might just have stayed at (the regular school)* (Eleanor). However, the special school did offer options to the family. The school had established a satellite class at the intermediate school**,** giving the family the option of enrolling in the base school or the satellite class at the intermediate. *It was really the bottom line choice between those two* (Eleanor).

Eleanor and Theodore visited both the special school's base school and the satellite class at the intermediate school. Eleanor was still very aware of her desire to have her daughter *surrounded by kids who could still interact.* She was also aware that, although there were some students who could communicate verbally, the majority of the students attending the base school were non-verbal or using alternative forms of communication such as DynaVox. It was an acceptable route for students from the regular school to move from their primary school to intermediate school. This was also an acceptable route for Britney to travel, with her destination being the satellite class at the intermediate school.

Eleanor: *The decision. We talked long and passionately (laughter) over deciding what to do.*

Theodore: *I never agreed to send her to (the regular school). It wasn't something I wanted to do. I wanted her to stay at (the special school).*

Grandmother: *When everything was sorted (for the transfer to special school), they (the regular school) said 'She could have stayed here'. Theodore said 'Not blooming likely'.*

Britney's grandmother spoke very passionately about the time her granddaughter had attended a regular school.

> *In hindsight it was a bad mistake. A very bad mistake, because all she has was a procession of babysitters. They really didn't know what they were doing. I went to every IEP meeting at (regular school), and we'd get all this information that would come out. I've still got it in there (indicating the office area of the home) of what their goals were, and what they were doing and it is going to be great. But there was no change. She had a procession of people that first year. About every term there was somebody different looking after her. They really didn't know what they were doing. It was basically a pointless exercise. I feel we have deprived Britney for 5 years, where she could perhaps have progress – more than she has.*

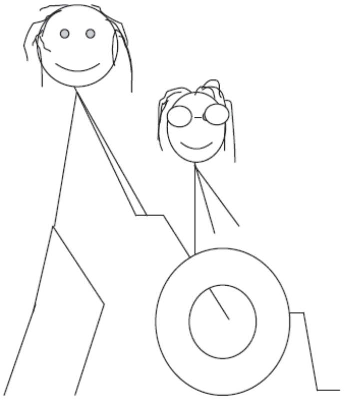
On the first day of the school year, Theodore took Britney to her new school, the satellite class at the local intermediate school. Her grandparents went with her. They met her new teacher at the door of the unit. She said to Britney 'Now Britney, here is the hook for your bag. Put your bag on it'. *Blow me down, she went and put her bag on it. She just walked in* (Grandmother).

5.3.3 Experiences at special school

Britney is in her final year at the satellite class where there are *other children she can model some positive behaviours with (*Eleanor) and where *they've got the same TAs, the same teacher and the same kids in the class, and that's what these kids need, consistency* (Theodore). *She is definitely better than she was. She is more settled* (Eleanor). Britney's grandmother identified an area that had concerned the family. *It's the difference between someone who knows what they are doing, what they are looking at and knows what to expect and see, and someone who is all at sea really and is just a baby sitter.*

There is a possibility that the special school will open a satellite class in a local secondary school and Britney is hoping to continue her schooling there.

5.4 The Smith family



Kate lives with her mother Donna in a small town servicing a rural farming area of Aotearoa New Zealand. Their Housing New Zealand home has been modified to enable wheelchair access. Their home is arranged to meet the use of a wheelchair in the house. Donna's partner has relocated to another town because of work commitments. Donna is enrolled in an Early Childhood teacher education course at the university, about 1 hour's journey from her home. Kate's grandmother, who lives in the same town, checks on Kate after school when her mother is at university. Kate is the only child of her parents' relationship. She sees her father, who lives in another town, every 2 or 3 weeks and is very accepting and comfortable with this arrangement.

I had met Kate and found her to be a very capable 15-year-old who enjoyed meeting people and was very verbally able. With the permission of her mother, Kate and I met in a cafe in the town where she lives. She was very excited at being out in the town without her mother, and really enjoyed selecting her afternoon tea and drink. Kate's comments are included in the family interview.

5.4.1 Diagnosis

In the last weeks of her pregnancy, Donna was told that the baby she was carrying had been identified as being having a birth defect with the backbone and spinal canal not completely closed. Donna and her partner spent these last weeks learning all they could about spina bifida. Kate was born in the hospital in the city servicing the area in which her mother lived. While still in hospital Donna met with other families who had children with spina bifida, and was made aware of the services that were available to her, and her baby. From her earliest days Kate received support for her medical condition.

From the age of 6 months she attended a centre that specialised in working with young children from birth or diagnosis to the age of 6, who have delays in their development or are at risk of developing delays. Working with physiotherapists and occupational therapists, the first focus for Donna was to have Kate sitting up, looking around, making eye contact with other people and *doing all the things that kids her age should be doing.* One of the underlying advantages of attending this clinic was that Donna met *a lot of other special needs parents there* and this gave her further support in meeting the needs of her own daughter. Kate remained *under the umbrella* of the clinic to the age of 6. Occupational therapists have worked with the family in assisting with equipment to be used in the home and *we have had a lot of doctors for all the different things that could go wrong.*

5.4.2 Experiences at school

Kate's family moved to another small town in the area and it was here that she enrolled in Kindergarten with the support of a full-time TA funded by GSE. *She (the teacher aide) was lovely. Kate loved kindergarten. She loved being involved with the children... She was there until she was just before 5.*

The transition to school went well. Before Kate started her primary school learning programme, Donna met with GSE, the TA and kindergarten and school personnel to ensure the school was ready for her arrival. *The school had to physically cope with a wheelchair.* A purpose-built bathroom area was a necessity, as were ramps to provide access to classroom areas. The kindergarten teacher aide transitioned to primary school with Kate.

Kate was ORS funded. *I found especially with ORS funding, it was easy to get because she is in a wheelchair and there is a physical condition.* She was supported in both the classroom and in maintaining of her health requirements. *She loved it. She thought the other people were unlucky because they had to walk everywhere so she felt lucky. She didn't feel sorry for herself because of the things she couldn't do.*

After 2 years in this town the family moved to a town in a semi-rural area *due to her dad's work. He changed jobs.* This move of residence meant that Kate's health and GSE needs were sourced from another regional provider. Kate had also had a time of illness related to her spina bifida and had spent several months in hospital and recovering at home.

Kate took a time to settle in to her new school. She had a new TA and her TA hours had been reduced from 5 to 3 hours a day.

Dawn: *And why was that?*

Donna: They decided she didn't need it.

Dawn: *Who are they?*

Donna: GSE.

Despite the reduction in TA support hours, Kate *coped very well* with the TA and the school using her hours to meet both her classroom and toileting and physical needs. *She loved (the regular school). She travelled on the bus to school until they decided she was too big to travel on the bus.* 'The bus did not have a wheel chair hoist. *Mum lifted me onto the bus and one of the TAs took me off the bus when I got to school* (Kate). After a time, it was decided by the school that they were no longer willing to assist Kate off and onto the bus. For Kate to remain at this school the only solution available to the family was for Donna to drive Kate to and from school. By this time Donna was working in a city about 30 minutes beyond the school Kate was attending. Kate was enrolled in an 'after school' care programme and her mother collected her on the way home from work. This proved very tiring for both mother and daughter and the decision was made to move to a primary school in the city where Donna worked. At this time, Donna's partner had left the family home and she was finding that she *didn't get to see Kate, so it was just not good. I'd get home, make the dinner and get her to bed.*

Kate was now 10 years old and although *she was slightly behind, she was keeping up with them, doing the work and socialising.* However, by the time Kate had completed her primary schooling to Year 6, her TA hours had been reduced to 1 hour a day, *which didn't cover much other than bathrooming. I didn't get much attention from the TAs. I didn't get much help from the TAs like I do now (at special school)* (Kate).

At the end of Year 6, Kate moved with her peer group to the intermediate school in the city. *The age group gap seemed to widen and because of the lack of teacher aide hours she was basically left to her own devices* (Donna).

5.4.3 Transition to special school

It was when Kate was at intermediate school that her mother saw evidence of bullying. *She would come home from school with dirt in her lunch box where the kids would take her lunch box and throw it around. The school's attitude with that was to make other children be her friends. They had a roster system of who had to be with Kate, which* *didn't go down well. I think the children resented the imposition and I could see their point.*

In her interview, Kate also spoke of being bullied. *They teased me because I was in the chair.*

Dawn: *What did you do?*

Kate: I just told the teacher. And she told the kids to stop.

Dawn: *What's it like when you are bullied?*

Kate: Not too nice. Really unhappy.

Donna noticed that the *gap had widened.* Kate was not up to the other students' academic and comprehension levels. Donna *spoke to GSE about extending her teacher aide hours but they felt she didn't need it.* With the 1 hour a day teacher aide hours being used for toileting, there was no support for Kate in the classroom. *She was left sitting in the corner. She was never expected to finish anything so she wouldn't even start things. She knew she wasn't going to finish these things so why bother. The teacher couldn't do any more. She said Kate needed more TA time but it just didn't happen.*

Kate: *I didn't get much help at all.*

Dawn: *How did that make you feel?*

Kate: *Really upset because everyone else got help but me and there were about 30 kids. Well, 29 and 30 counting me and one teacher.*

Kate's health then became a concern. Her shunt became blocked and she was hospitalised in the children's hospital in another city for a time. Her absences from school were of concern to the teaching staff and the outcome of an IEP meeting was a recommendation that Kate repeat her second year and remain at the intermediate school for a third year of schooling.

Donna was become more concerned about Kate's future schooling. She *did not want her held back because she would have no friends with her. I could not see her going to high school and coping with high school. She had enough problems at intermediate.*

There was just this huge gap that seemed to be widening more and more. Donna was finding her work load and caring for Kate was not giving her time to be with her daughter. Although there was a special school in the city where Kate was living, *SES and the teachers did not consider it necessary* (Donna) to further investigate this option for Kate's ongoing learning programme'.

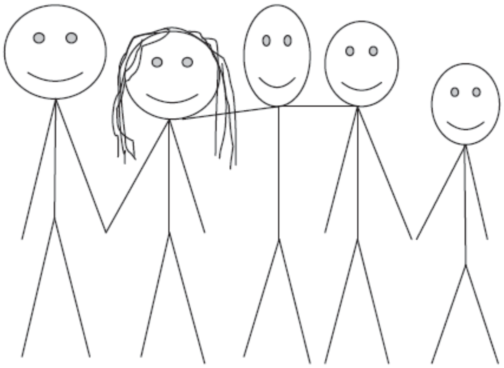
There was a special school in the town where Donna was raised and had attended primary and secondary school. Her parents were still living in this town and Donna knew *how the town works. I know this town. I don't know which was the main focus of the move. I think the main focus to attend (the special school) was her. The main focus for moving back to (her home town) was me.*

5.2.4 Experiences at special school

Kate is attending a special school enjoying the company of the other students. *I've got friends. A lot. It was easy for me to make friends at (special school) because they introduced each other to me. I feel yipeeee because I enjoy school. Yeah!!!* Donna commented on the change in Kate's academic work. *I can't imagine where she would be if she had stayed in the mainstream... I wouldn't go back to mainstream. She needs support when she wants the support and mainstream didn't allow for that. She is now allowed to finish things. She has improved no end. She's more confident in herself. She doesn't see herself as different any more.* Kate had talked about the bullying she had experienced in a regular school and made comparisons with the special school. *I don't get bullied at all whereas at my old school I did.* Kate had the final word about her experiences of regular and special schools. *I wouldn't go back to (regular school).*

Kate will remain at the special school until the year she turns 21. Her mother is completing her university study and when she has graduated, will seek employment in the locality where they live.

5.5 The Laurie family



Margaret and two of her four sons live in a town close to a city in the North Island of New Zealand. Margaret is employed in a full-time administrative position in a larger town about 10 kilometres from her home. Her son Hamish, aged 15, is the youngest of the boys. Because of work travel, and time restrictions I met with Margaret during the weekend, in a cafe in the town where she works. The boys were at home enjoying time on their bikes and with their friends.

5.5.1 Diagnosis

Margaret and her family were unaware of Hamish not meeting the expected early developmental mile stones until he was about 4 years of age. *He was not saying a lot but then he just had to make a noise or point and one of his brothers or I would go and get him a drink or something for him. He was very independent.* Because his mother was very involved in the play centre organisation, Hamish had been at *play centre since birth.* Being the youngest of four children, with *one at school and three at home,* he followed his brothers and went to play group when his mother went with his older brothers. A friend from within the playgroup organisation contacted Margaret and said, *'You'll probably want to kill me but we've got this free day at the speech clinic at (school in the area). Do you want an appointment? You said you were worried about Hamish not talking very much'. So I grabbed the opportunity with both hands*. At the clinic Margaret and Hamish met the Speech Language Therapist (SLT) and an Early Intervention Teacher who was known to Margaret through the play centre organisation. After working with Hamish in the clinic, both therapists worked with Hamish in his home environment. Their findings were that *this is not just a speech therapy problem* and it just *snowballed from there. I can't even remember how we decided he was autistic.*

5.5.2 Experiences at school

Hamish remained at play centre and received TA support through funding from GSE. Because of his late diagnosis, neither Hamish nor his parents had the opportunity to participate in the Early Bird programme designed to support families whose child has been diagnosed as being on the ASD spectrum. His ORS transitional application was completed with help from the Early Intervention Teacher who warned Margaret that it was *quite a dark process and they had to say things that were on the lower end of possibilities, to be quite negative.*

When discussing transition to school, Margaret decided that the special school satellite class at a regular school in their town would be an option. She knew of the unit through local knowledge and when discussing Hamish's education options with the therapists and GSE. During the first year of Hamish's time in the satellite class, Margaret *wasn't entirely happy*. Hamish had been very quick to discover that if he indicated he was tired, he would be allowed to have *a wee sleep on a bed* thus only doing half days in class. While Margaret was considering alternative educational placements for Hamish, her eldest son was transitioning to secondary school. Margaret decided to move her other two boys back to their neighbourhood school. There had been a change of principal and he was a *totally different kettle of fish.* She visited the school to ask if Hamish could be enrolled with his brothers. *There was a totally different attitude towards special needs* and *at 6½ years of age Hamish was mainstreamed into (neighbourhood regular school.*

With the transitioning of Hamish to the regular school, an approach was made to one of the TAs working in the satellite class, and an agreement was reached for her to move to the school with him. Because of study commitments this TA was unable to continue working, and after 6 weeks a new TA was appointed. *She was brilliant. She was a real advocate for the kids. She was really, really fabulous.*

I think I pretty much made the decision to move Hamish to a regular school. *My husband at the time pretty much left it to me. I was heavily involved in play centre so education was my thing.*

Hamish completed his primary school at his neighbourhood school. He moved classes with his peer group. He participated in the activities including the Year 8 school social where he was voted King of the Social because of his attitude and participation in the dance classes. *The girls all wanted to dance with him because he knew all the steps.*

5.5.3 Transition to special school

Hamish completed his Year 8 programme of learning at this regular primary school. It was now time for him to transition to a secondary school placement. Margaret *was pressed for a decision for transitioning (him) to kind of secondary school facility.* Margaret had just separated from her husband and the transitioning of Hamish was *a decision I really didn't want to make.* At this time the GSE support person was a person who had worked in schools for autistic students in England. Margaret met with this person, the TA and several of the teaching staff. Margaret had knowledge of the Learner Support programme in the local high school and stated very firmly that Hamish would only go to that school over her *cold dead maggoty body.* When attending his technology classes at another primary school in the town, Hamish had been bullied and to attend the local high school would mean he would be attending the same school as these bullies. Margaret, the TA and the GSE support person visited all the schools in the area that offered programmes for children with special learning needs. Their choice was a special school out of their area that offered access to NCEA programmes to their students.

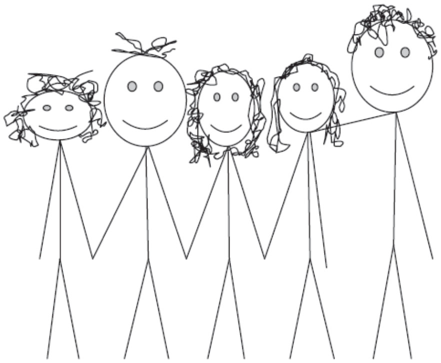
At the IEP transition meeting, the principal of the preferred special school was asked if the school would accept Hamish. The response was '*Yes we want to have him'. So that was very good.* The school completed all the paper work and *I just signed them. So on the first day (of the school year) I just put him on a taxi.*

5.5.4 Experiences at special school

Margaret described the decision to transition Hamish to a special school as *the right decision. They know what they are doing because they do it for all the kids. They are prepared to think outside the square. Each child is considered on their own merits.* Hamish is attending some Level One NCEA classes at the local secondary school Margaret acknowledged that *Hamish wouldn't have had the success he has at high school because they are not set up as specialists, not special education specialists and he wouldn't have had the TA support. He is ORS funded but he gets a whole lot more than that from his teacher and TAs at the special school. He enjoys going to school. He's fine.*

Hamish continues to enjoy participating in selected courses at the local high school.

5.6 Meet the Lawton family



The Lawtons live in a home in a city in the North Island of Aotearoa New Zealand. Stella, aged 15, is the oldest of the three Lawton children. She has a younger sister and brother. Isobella, her mother is a researcher and works from home. She is also completing university papers through a distance learning provider. Stella father works in a professional position in the city. At the time of our meeting, Stella was at the movies with her respite carer, a young woman in the second year of her teacher education.

5.6.1 Diagnosis

Gosh! Birth was quite traumatic for Stella. Stella was born in the 28th week of gestation, and during the birth process, had a stroke. At the time of her birth her parents were living in a city in the central North Island. Mother and baby were airlifted to the Base Hospital in another city where Stella was admitted to the Neonatal Intensive Care Unit. It was 3 months after her birth before Stella was able to live in her own home.

Once at home, the neonatal nurses visited the home and *taught you about all sorts of things.* Stella was not medically fragile, but was not reaching her milestones and *cognitively you could see that she wasn't where other babies were.* In their home town, there was a child development unit that *catered for a whole raft of children with special needs, not only medically, but educationally and emotionally and support for the families. It was a good hub for families.*

But politics comes into play. While Stella was attending the unit, it was closed by the District Health Board as it was seen as *isolating the children from the community. There was nothing that could fill the gap.* Therapists continued to support Stella and her family in home-based visits. A child care organisation undertook to manage the unit and Stella continued to receive support from speech language, occupational and physiotherapists.

5.6.2 Experiences at school

With the help of the Speech Language Therapist, Stella was transitioned to kindergarten, supported by a full-time TA from the child care unit. While Stella was attending kindergarten her family moved to the city where they now live. At this time her family were investigating Conductive Education programmes as a possible option for Stella. In the city they were now living a preschool with a conductive education programme was available. Stella was enrolled in the programme at the age of 4½ and remained in the unit to the age of 6.

An application for ORS funding supported by GSE was made at this time. *I could have signed a million forms and I was oblivious to it (the application).* Stella transitioned to the primary school section of the conductive education programme. The unit was based in a regular primary school. The students attended classes in the primary school for part of the school day, and worked in the unit for the rest of the day. *She was doing really well.* Stella remained in the local primary school and the conductive education programme until the age of 12 and was at a Year 8 level. *We knew she needed to stay in the conductive ed. for therapy but she was too old to be in the classes (in the primary school) so we looked to transition her out.*

5.6.3 Transition to special school

At the time of Stella's transition to secondary school, the parents of students in the specialist unit were *pushing for a high school unit.* However, this did not eventuate and *we knew it wouldn't be easy.*

We went to all the special units. We did the rounds. We did all the schools that could accommodate special needs kids. The family looked at a range of secondary schools that offered programmes of learning within a learning support structure.

> *It became increasingly obvious that Stella's physical needs in terms of her personal care were extremely important to us and some of the schools just couldn't do it. To be honest, what was driving where she was going to go was her care. We came to a point where it was either (two of the special schools in the city). It just had to be. Everything she needed was in one spot.*

At this time of decision making, the Lawton family investigated the programmes offered by a private school in their city. Their intention was to transition their three children to this school if Stella was accepted for enrolment. At the meeting with the senior management of the school, the principal refused entry to Stella, the reason given was '*We already have one child like that here. We don't need another'*.

The family, supported by GSE, visited the special schools and made a decision as to which school Stella would attend.

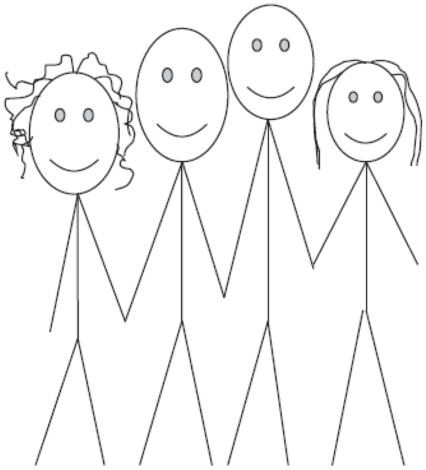
We went to (special school) and we got it! And we still continue to feel like that. Isobella laughed and clapped her hands as she spoke about Stella's acceptance into special school. She leaned back in her chair and continued smiling as she sat quietly. The relief in finding a school that had the willingness to accept her daughter into their special community was apparent.

5.6.4 Experiences at special school

In her first term at the special school, Isobella was disappointed how *poorly the teachers transitioned to Stella. They really struggled with Stella's high learning and care needs* But Isobella acknowledged that both the teacher and Stella were new to the school and by the second term *they had a reshuffle and she was away again.* Isobella discussed the role of the TA in the classroom. *She has had the same TA for two years. She knows Stella really really well and now works around a whole lot of stuff.* Stella has graduated to a power chair that she operates herself and this has given her the ability to make choices about her mobility. She has also become adept in using DynaVox and she and her family were preparing for a training camp that would assist her parents and siblings in using this communication aid. When talking about the special school, Isobella voiced her concerns about the ongoing support for Stella once she turns 21 and leaves the special school. *It's sad that we have a government that thinks that life changes when you turn 21. Stella will always be how she is. Things aren't going to change for her but there is nothing out there for her. They took it away and have replaced it with the notion that the community will support her. No, it is not going to happen. Every kid is different. Some families are facing having to give up work because there is nowhere for their children to go and they are not children. They are young adults.*

Stella is enjoying her classes at the special school although she would like to transition to a satellite class attached to a high school. She is working really hard to make this dream happen.

5.7 The Berry family



The Berry family live on the outskirts of a town close to a North Island city. Lynda is a registered nurse but is currently a full-time carer for her two younger children, Joshua and Katrina. Their elder sister has completed her tertiary qualifications and works and lives away from her family home. Lynda's husband is a shift worker working in an industry in a town close to the family home.

The family dog joined Lynda and me in the dining area talking about the experiences of her family living with two members with special learning needs.

Both Joshua, aged 19, and Katrina, aged 17, are ORS funded and enrolled in a special school close to their home. At the interviews, the story of their journey from birth through to special school was told as two separate events. In the retelling of their story I have told Joshua's story and supported it with excerpts from Katrina's story. Statements about Joshua are identified as 'J' and those for Katrina as 'K'.

5.7.1 Diagnosis

In her 6th month of pregnancy Lynda was told that the baby's (J) umbilical cord was crushed and the baby *might not have enough oxygen.* At the time of his birth Joshua was quickly taken from his mother for a possible hernia operation. *He was fine but he never looked at me. Then he screamed nonstop, and I mean nonstop. I told the Plunket Nurse. I told the doctors. They didn't listen. They kept thinking I was neurotic.*

Joshua was *in and out of hospital continuously.* The stress of having a very ill child was affecting the family. Lynda was offered medication. *I didn't need it. I needed sleep.* Her husband was at risk of losing his work placement because of falling asleep 'on the job'. It was at this time that Lynda and her husband decided on a strategy to maintain their family life. *The children are mine, work is yours and that's how we have had it the whole time.* A chance watching of a television programme alerted Lynda to a possible reason for her son's continual distress. A referral to a specialist confirmed her thoughts of *severe gastric reflux* and a remediation operation was completed when Joshua was 2 years old.

By this time Katrina had been born and she too was *screaming all the time.* As a new-born baby she *just rocked and when you walked with her everything flopped.* Katrina too was hospitalised regularly with ongoing health concerns and as with Joshua, a remediation operation to correct the gastric reflux was performed when she was 2.

> *I was in the bank one day and they (J and K) were screaming and rolling around on the floor. The bank teller asked me if they were tired. 'No, they aren't. They are always like this.' She said, 'OK I will tell you. There's a place called (name of a play group) and they've got children of all special needs. Would you like to go there? I will give you the phone number.' I was desperate. I took it and went there.*

The suggested centre was a play centre group run by a trust organisation. She enrolled both Joshua and Katrina in the centre. While the two children were attending this play group, the status of the venue changed to a preschool. Both children received funding from GSE to support the teacher aide at the play group.

At the centre Joshua received support from a speech language therapist who, when working with him, identified behaviours that were not appropriate to his age level. A referral was made for further specialist investigations. *They didn't say there was something wrong but they just kept doing tests. There's nothing wrong with your children.* I thought '*I am a parent and this is not acceptable'.*

When she was 3 months old, Katrina started a speech language therapy programme that focused on raising her muscle tone to assist her drinking and, at a later stage, her eating. Contact with the speech language therapists continued at the preschool.

At one interview, when Joshua was 5 and Katrina was 3, a junior doctor asked Lynda if she would like to see his senior. *I said 'Yes I would'. He was in the room two seconds and said 'It's autism', straight off. He said* '*Are you shocked?*' *I said* '*No. I don't care. Just give me the name and I can research it'.*

5.7.2 Joshua's experiences at school

When Joshua was 5 years old, Lynda approached their neighbourhood regular school to enrol her son. He was refused entry because of his inappropriate behaviours. The school stated that it would not enrol him as it *needed funding for this child.*

When approached for funding support for Joshua, the GSE support worker suggested because he had attended a early childhood placement that catered, in the main, for children with special learning needs, the behaviour he was exhibiting had been learned within that environment and he *obviously needed normal children around.* Joshua was then enrolled in a private kindergarten as suggested by GSE but *actually it (his behaviour) got worse.*

When Joshua was 6, his mother approached the neighbourhood school again, to request enrolment. The school refused him entry until ORS funding was available to support him in his learning programmes. The neighbourhood school's first application for ORS funding was refused. However, after a meeting with GSE, a second application was made and ORS funding was granted. Joshua then was accepted into the neighbourhood school, with TA support.

Joshua responded very well to a patterning-based form of instruction and was making progress in the classroom. However, once the teachers found this was a successful method of delivering his programme, the TA was moved to work in a different classroom, leaving Joshua unsupervised. He was found wandering in the very busy road outside the school gate, and incidents of bullying in the playground were recorded by Lynda. *I had meeting after meeting, but one of the teachers was determined that he was perfectly fine, and that he needed no help. It was his parenting.* The bullying continued and I was *banned from the school because he needed to be a normal boy.*

Lynda was contacted by a trainee psychologist who wanted to complete a field work project in the school, with Joshua as her focus. After the school's refusal, GSE intervened and the project was implemented. *She went to the classroom and watched him for about 3 hours. Then she came here (to the family home) and said, 'Honestly I would take him out of that school tomorrow'. He was gone!*

Lynda returned to her support network at the preschool and asked for advice as to alternative primary school placements for her son. One suggestion was a rural school in close proximity to the family home. Lynda visited the school and talked to the principal, who then contacted GSE. He was told by GSE it was '*only the parent and not the child'* who was of concern. The problems identified by Lynda were seen by GSE as '*nothing to do with the child'.* In his response to GSE the principal cited reports he had read from the paediatrician, who had known Joshua from a very early age, and his conversations with three psychologists. These interactions confirmed his belief that Joshua was a child with special needs and not, as suggested by GSE, that *'she (Lynda) doesn't need you.'*

5.7.3 Katrina's experiences at school

At the time of transition from preschool to primary school, Joshua's sister Katrina was visited by a GSE support worker to ascertain the level of support that would be needed at primary school. On being told that Katrina *was all right, she can go off to school,* Lynda referred to the Speech Language Therapist who supported her request that funding for teacher aide support be maintained. In order to determine the level of care that would be needed, Katrina visited the school for 1 day with the GSE support worker observing the interaction between the teacher and Katrina. The decision was that support was needed and an application was made for ORS funding. When approval was received, Katrina started her primary schooling in her neighbourhood school at the age of 5½ years. Her brother Joshua was also enrolled in the school.

Lynda moved all three children from their neighbourhood school. Her elder daughter transferred to the intermediate school in the town, and Joshua (7) and Katrina (5), moved to the rural-based school.

We worked as a team, the teachers and I worked as a team. One concern was the reduction in TA hours. *You don't need it as much as others* despite the psychologist's recommendation that Joshua's hours be increased. He was buddied with a group of students and was making progress in his reading and comprehension, but not at the same rate as his peers.

At the end of his Year 8 programme of learning, Joshua would need to transition to provider of secondary school programmes.

5.7.4 Transition to special school

In the penultimate year of his schooling at this primary school, the family received a letter from GSE stating that Joshua's funding would not be available when he transferred to high school. *Thanks for the warning.*

Lynda then decided to find another solution to her son's secondary schooling. With the help of the internet and talking to friends, the family considered relocating to a city that was offering secondary and tertiary education for their elder daughter and a special school for Joshua and Katrina. However, when travelling to visit the area, their elder daughter became very ill and it was decided that the move would not be possible.

On returning to their home, Lynda made contact with a person whose child attended the special school in the town close to their home. Although Lynda was aware of this school, she had been given information about the school that did not encourage her to make contact. But she thought *I'll go and have a look* and was very impressed with the school and the programmes that were offered.

At this time, Katrina was experiencing difficulties managing the routines of a busy classroom. *She was so far behind and that was so difficult.* She did not manage sudden changes in the class routines, and started to graffiti using faeces on the toilet walls. For some time she attended school on a 'morning' basis. At the time of Joshua's transition to special school, it was decided that Katrina would transfer at the same time. *The teachers all said to me 'It's the right decision'.*

Joshua transferred to the special school in the last term of his primary schooling at 13 years of age. Katrina transferred to a satellite class of the special school at the same time as her brother transferred to the Base School of the special school.

They accepted him straight away. He was included straight away.

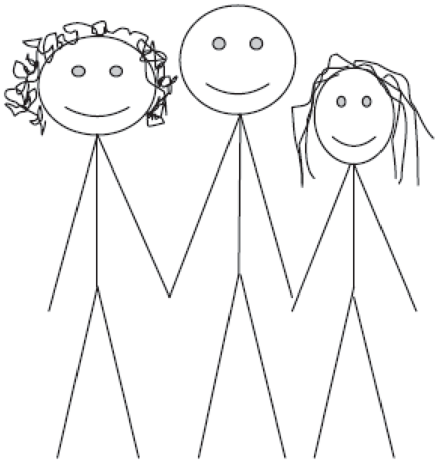
She toddled along and she really started excelling and started learning

5.7.5 Experiences at special school

Joshua and Katrina are both attending the special school. *I didn't realise how much stress it took off me. I was quite frequently having car accidents and I haven't had a car accident since I've been working with (special school).* However Lynda did acknowledge that there were some issues relating to Katrina's placement in a satellite class at an intermediate school. The students from the satellite class did not join the regular school students at interval and lunch times because of the behaviour of some of the regular school students. Lynda was concerned that this practice was isolating the students. *There was no mixing.* However having access to technology classes had very positive results. *She made one garment and then another and that was good.* After some time, Katrina moved to the Base School where s*he has done well.* Lynda acknowledged the role of the teachers and the TAs. *If I say to the teacher I need this done, she will always make sure it is done. In the mainstream it's parent parent, parent: your responsibility to do this, your responsibility to do that. In the special school its 'We'll take care and don't worry'.*

Joshua is enjoying the classes he attends at the local high school. He is looking forward to leaving school and hopeful of finding work in his local community. Katrina is making excellent progress in gaining the skills she will need to live independently when she leaves school.

5.8 The Wilson family



Lynne lives in a residential suburb of a North Island city with her son Mark and his younger sister. She has moved to this city from another city to access specialist support for her son. Lynne is a full-time carer for her two children but is studying at an undergraduate level with a distance learning provider. Because of travel and time restrictions I met with Lynne in a cafe in a cafe in a shopping mall on a day when Mark was at school.

5.8.1 Diagnosis

Mark is his parents' first born child. When Mark was 2 years old, Lynne approached the child specialists at the hospital in her city for support.

> *I didn't know what I was doing or how to cope with my child. He was throwing food, not talking, finger painting with his faeces and stimming. I was afraid of him because nothing about him was predictable. He would keep me awake all hours of the night, yelling and running around the house.*

The response from the health specialists was that Lynne should return when her son was 3 years old. *You are an only child. You are not a teacher, not a psychologist. You have no experience to draw on.*

Lynne found it very difficult to recall the sequence of event because *I was in such a state.* She described her situation as *driving a car I didn't know how to drive and no one was taking the wheel to give me directions and guidance.* She was very concerned about trying to find support for her son, her husband, and herself.

Contact was eventually made with GSE who sourced funding to enable Mark to attend kindergarten. It was at this time that a diagnosis of Autism Spectrum Disorder (ASD) was made.

5.8.2 Experiences at school

Lynne described an incident at the kindergarten when a teacher aide yelled at her son telling him not to touch an article in the room that interested him. *It took him years to get over it. He was afraid to pick up anything by himself, for example, a biscuit off a plate.* She also talked about the TA resigning following the incident.

At the age of 5 Mark made the transition to a regular school placement. When meeting with GSE at the time of making the decision to enrol Mark in the selected primary school, Lynne wanted to discuss the possibility of having Mark work at a programme that was developed specifically to assist children with ASD. Although no official diagnosis had been made, health specialists working with the family had suggested that Mark's behaviours were suggestive of a diagnosis of ASD. The response from GSE was that if Mark was enrolled in this specialist programme that was not within the MoE network and all funding sourced from GSE would be removed. Lynne was advised by the GSE support worker that the programme was *cruel* and asked Mark's parents not to pursue it. *I trusted GSE, but they gave me no alternatives to help us cope with Mark.* Lynne added a comment that she later discovered that no one from GSE had any understanding of this programme nor had anyone worked with it.

At his primary school Mark was *baby sat. The school didn't know how to deal with him.* The Wilson family paid for Mark's TA to be trained by the personnel from the specialist programme, but the classroom teacher would *not commit to the programme.* Mark's behaviour and general demeanour continued to deteriorate. The teacher's apparent resistance to assisting with Mark's development resulted in the situation becoming untenable. Lynne felt isolated from the other families and was concerned that Mark's behaviour was impacting negatively on the other students. *During his worst year in the mainstream primary school, he hit and spat at another student. I felt embarrassed, powerless and overwhelmed.*

After 6 months in primary school. Mark's inability to communicate and his rapidly deteriorating behaviour was causing concern for his parents. The decision was made for Lynne, Mark and Mark's younger sister to relocate to the city where the specialist programme was taught. Mark's father would remain in the family home as his specialist work would not transfer to this new locality. The family home was refinanced to cover the living costs of the family living in a motel and the costs of the specialist programme.

On learning of Mark's proposed enrolment in the specialist programme, GSE threatened to remove all ORS funding that would have been used to partially fund the programme's costs. The Wilson family made contact with their local Member of Parliament *who did a brilliant job* and the ORS funding was made available for the remainder of Mark's schooling. The specialist programme was acknowledged and accepted by GSE as an acceptable intervention programme for children with ASD.

As an alternative solution, Mark's grandparents were prepared to fund a trainer from the specialist programme to travel to their locality and train the teacher aide to continuation of the programme in his classroom, but this was refused by the classroom teacher who *was not prepared to have the programme in her classroom.* This refusal was supported by the principal of the school.

Mark worked for 6 months with the providers of the specialist programme in a city approximately 3 hours travelling from his home town. *He made huge gains in the first 6 months. He was learning in a formal environment and began to talk. There was a glimmer of hope after 5½ years. Coming to (the city) saved my life.*

While on the programme, Lynne heard Mark speak for the first time. When trying to tie his shoe laces to get ready to go to his programme, he said *Help me.*

At the end of the 6 months of intensive work with the specialists, Mark enrolled in a regular school close to where he was living in with his mother and sister. A marriage breakdown had meant that Lynne was no longer travelling to her family home every weekend, and had moved from the motel unit to a home in the vicinity of the specialist programme.

All went well for the first 2 years of Mark's learning but the success of his learning was *constrained by not being able to employ a TA who could cope with Mark's needs.* A change of classroom teacher after these 2 years proved *very damaging*, with Mark regressing from reading books in a group situation to *being an isolated child who spat and ripped books.* One day when visiting the school, Lynne found her son restrained on the floor, with him spitting and with wet pants. There had been no intervention from

GSE, and the Speech Language Therapist made two visits a year. Lynne's described the support received from GSE and therapists as *Token gestures and piecemeal rubbish.*

In his regular school placement Mark was *failing every day* and Lynne could see no other option but to look for alternative placements.

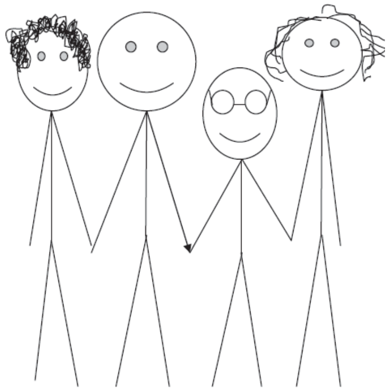
5.8.3 Transition to special school

There were no other options offered to the family by support personnel so Lynne *went looking.* Although she had heard that the local special school had a large number of low functioning students on its roll, Lynne had *no other alternative.'* She visited the school, and met the principal. *We were on the same page. Had I seen it earlier I would have moved him then.*

5.8.4 Experiences at special school

Mark is very settled in the special school. *They know who the child is. He is understood there and I don't get phone calls to go and pick him up.* Lynne has also seen a change in the family's home life. Mark is not as agitated as before and the family have a *better quality of night life as he is taking medication to be less active.* She has also seen a positive change in Mark's attitudes. *In the regular school he knew enough to know he was different. In the special school being different is the 'norm'.* Lynne acknowledged that for over 5 years she had been driving blind but now she is *happy*. Her younger daughter walks to her school. Mark catches the school transport to his school and his mother is continuing with her postgraduate studies knowing that she will not be called to the school and be asked to take her son home because of his behaviour.

5.9 The Anderson family



Susan, Iain and their son Andrew live on a life style block close to a city in the North Island of Aotearoa New Zealand. Their daughter lives and works in a city about 4 hours away from her family. Iain is a school bus driver and works as a teacher aide in the school his son attends. Susan is a full-time carer but does work on a temporary part-time basis in retail positions.

The house overlooks the paddocks and there is a large shed at the back of the house. Andrew's keyboard is in one end of the open-plan living areas.

5.9.1 Diagnosis

Andrew was born in his mother's birth country and was hospitalised for the first 2 months after birth. When he was 3 months old he was started on a physiotherapy programme to assist his movement. *Medical professionals and therapists in (his country of birth) took the attitude; we are not going to wait until he is 2 to find out whether or not he has cerebral palsy. We are going to assume he has. That was a bitter pill to swallow* (Susan). The family had a very strong support system that told them where to go for help when it was needed.

At the age of 3 Andrew moved to Aotearoa New Zealand with his family. They had chosen to settle in the area where they now live because Iain had grown up there and there was a very well-resourced hospital in the city near to their home. The first thing Susan did, on arrival was contact a early childhood centre specialising in working with young children who have delays in their development or are at risk of developing delays, from birth or diagnosis, to the age of 6.

It was amazing how much I heard from the other parents (Susan). *It's often the best way of finding stuff through the bush telegraph* (Iain). *And they tell you the barriers* (Susan).

At the centre Andrew and his family worked with the physiotherapist, occupational and speech therapists. An application was made for ORS funding and was approved before he entered primary school. Funding for his kindergarten placement ensured him TA support.

5.9.2 Experiences at school

The transition from the centre to kindergarten was *as smooth as anything* (Susan). *They just wanted to do the best they could* (Iain). The IEP's at kindergarten were *excellent. I came out buoyed up and thought 'Oh, this is great and we are making progress'. I felt really good* (Susan). Andrew remained at kindergarten to the age of 6, a decision made at an IEP meeting.

The Anderson family home is across the road from a primary school. It was this school that influenced the purchase of the property and home in which the now family live. The property was what they wanted but they knew there would be times when Andrew would need assistance at school, and if they lived close to the school, it would be more convenient for everyone.

At the time of enrolling Andrew at his neighbourhood school, Iain and Susan thought this school was the only option available to them. *We thought he had to be mainstreamed and that was it. We weren't made aware of anything else* (Susan). Andrew's older sister was attending the school and the family were impressed with the then principal of the school. A TA was employed. *She wasn't trained or anything but she was really caring* (Susan). Both Susan and Iain expressed concerns that the funding grant to the school was the underlying motive for the acceptance of Andrew's enrolment. *It appeared that programmes were structured around the funding and they might benefit Andrew* (Iain).

Although Andrew's parents were pleased with the standard of teaching, there were issues arising in the day-to-day management of the school. *I hated having IEPs because I would come home in tears. They made it feel to me that they were wording it (IEP) to get more funding. They were wording it to make it appear that Andrew was going backwards* (Susan). At times when there were absences in the office staff, the TA was taken from Andrew's class to cover the position. In the playground after a school outing, Andrew fell from a high wire in the playground. When his mother went across the road to collect him at the end of the school day, she found him very shaken. There were no teachers on duty although it was still within the time frame of the school day.

The response from the school management was that *Andrew needs to take responsibility for his own actions* (Susan).

But it was the attitudes of the teachers and the TAs that were seen as the key to Andrew's successes at the school. His TA followed him through the school as he moved classes with his peer group. *Of all the people, (the TA) has probably influenced him the most because she spent so much time with him* (Iain).

But the straw that broke the camel's back was the swimming sports (Susan). Although Andrew was required to attend the school swimming sports, he was not able to participate because there were no events suited to his water-based abilities. When the Principal was questioned by Susan as to the possibility of a 'novel' race being included in the programme the response was *No, we can't do that.* Susan reminded the principal that part of the swimming sports programme was a novelty race for parents. The response from the principal was *'That's a race'*. Susan was concerned that *They could have a novelty race for parents but not for the kids who weren't involved in the races. I said to Iain 'I don't want him here for Years 7 and 8'.*

5.9.3 Transition to special school

Andrew's parents had decided that they no longer wanted their son to attend his neighbourhood school. Although the school was a full primary school and catered for students through to Year 8, there was always a group of students who left the school at the end of Year 6 to enrol in an intermediate school in the city. At a meeting with the principal of the intermediate school, the family were informed there was a special school on the adjoining site to the school. Iain and Susan did not understand the terminology 'special school' and after a brief explanation, a call was made to the special school and the family walked across the field to meet the special school principal.

When questioned in the interview setting, both Susan and Iain were very certain that the option of Andrew attending a special school had never been made to them by GSE or the neighbourhood school. *I wish I had known about this school. I would have put Andrew there right from the beginning* (Susan).

Susan and Iain informed the primary school that Andrew was moving to the special school and requested a transition IEP. He enrolled in the special school at the beginning of Year 7. *He was happy to go. He'd had a couple of days visiting at the end of the school year and he thought it was great* (Susan).

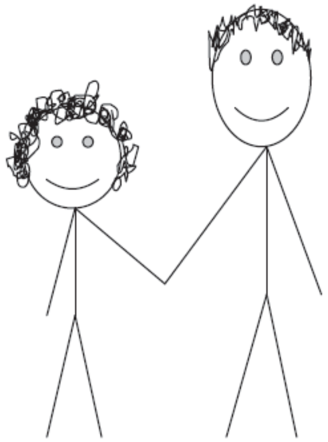
Yes they pulled me out (Andrew).

5.9.4 Experiences at special school

Andrew completed his high schooling at the special school. Susan described her special school experience as *night and da*y. *Can't! Won't! Not possible! These words do not fit in this school's mission statement anywhere. I have never seen a staff or school that can think outside the box like they do. Everything they do is amazing.* Susan's experiences of IEPs in the regular school were distressing. At the special school *I nearly fell off the chair with shock. They talked about Andrew and they listened.* Iain commented on the atmosphere within the school. *It's a school but a very caring school. It just seems to be really good.* Andrew was pleased to be working *on the big stuff* and that he was taking part in a transition programme to prepare him for the world beyond the school gate.

He left this school in the year he turned 21. He enrolled in a course designed to enhance his life skills and prepare him for employment in the community.

5.10 The Lucas family



Beth and her son Robbie, aged 19, live in a town house in a cul-de-sac road in a suburb of a city in the North Island of Aotearoa New Zealand. Beth works in a full-time position in an organisation providing disability support for families of children with special needs. Robbie attends a special school in the neighbourhood. Robbie is the youngest child of the family. His sister is working and living in another city and his brother lives with his father and is working in the city where his mother and father live.

Robbie's father Dick joined the family group for the first of the interviews. As all three members of the family participated in the interview, their comments are identified by their first names.

5.10.1 Diagnosis

Hideous for me (Beth). When Robbie was young he had very challenging health issues. He spent most of his first year in hospital, with whooping cough and encephalitis together with respiratory problems. It was very hard to pinpoint his milestones because of his illnesses and hospitalisation. He was fitted with grommets at 8 months and was identified as having major food allergies. He started walking around 9 months and was talking very early. He had a very good vocabulary but would start a sentence, and not be able to finish it and then would have to start again. *All of these issues plus his very wild behaviour made it very, very difficult* (Beth).

I kept saying 'There's something there, there's something going on' (Beth). He was attending a Child Development Clinic and at 4 years of age was diagnosed as ADHD (Attention Deficit Hyperactivity Disorder). *But I kept saying there's something else* (Beth). Robbie was self-stimming. In an effort to stop this stimming, his mother would have to physically hold him. The term Autism was discussed, but because of Robbie's high verbal skills was not seen as an appropriate diagnosis.

5.10.2 Experiences at school

Robbie attended the same early childhood provider as his brother. He was supported by a full time TA *because they could not do anything with him* (Beth). The transition to the regular primary school was hampered by the lack of information being transferred from the early childhood placement to the primary school. The school in which he enrolled followed an open plan format with sixty to eighty students in the junior school area. Because of ongoing behavioural concerns, a request was made by the school for a further assessment of Robbie's behaviours. A diagnosis of ASD was made and this was confirmed by the child development personnel. *He could read. He was left to read. He could hyper-concentrate and he would read for a long time* (Dick).

One of the recommendations from GSE was that Robbie be moved to a single cell classroom school format where the number of students in direct contact with Robbie would be reduced. This suggestion was carried out, but the behaviour patterns did not decrease. There were concerns about Robbie's security in this school. He absented himself from school to visit family friends who lived nearby. He would walk out of class and his absence not be noticed. He was also threatening suicide and was starting to self-mutilate.

While attending this school Robbie was selected to participate in a new initiative, the Serious Behavioural Initiative supported from within SE 2000. *He absolutely ran rings around them* (Dick). It was at this time that an application was made to the MoE and ORS funding was granted. Incidents of bullying by students and staff, seen by his elder brother and family friends, led to the family making a complaint to the school but it was *swept under the carpet because there was a change of Board of Trustees* (Dick). Robbie was withdrawn from the school and was home schooled by his father for one term. During this time, the family investigated the possibility of Robbie being enrolled in a satellite class that was being established by a special school in the city. The focus for the class would be catering for the learning needs of children with ASD.

Robbie attended the satellite class for one year. *It was good for Robbie* (Beth). *It was a completely different atmosphere because you are working with trained people who have a vocation for dealing with that sort of child, rather than people who weren't trained and found it a burden* (Dick).

At the time of Robbie's enrolment in the satellite class, his father moved to the city where they now live because of work commitments. Robbie, his mother, and his siblings remained in the city where they were living, *to give him the opportunity to maintain the work he was doing to remain on task in the classroom* (Beth). At the end of this year the family moved to join their father. The family had approached the special school in the area but were denied an enrolment because Robbie was considered too academically able for the classes at the school. The school did not offer a programme of learning designed specifically for students with ASD.

Robbie was enrolled in a regular school close to the family home. He was supported by a full time TA. Because the regular primary school catered for children from Year 1 to Year 6, Robbie had to move schools at the end of Year 6. Beth visited the school within walking distance of their home to request an enrolment for Robbie. She was told by the principal that *we don't have ORS funded students here*. An approach to an intermediate school met the same response. After further investigation Beth approached a school that offered ORS funded students a programme of learning. The learner support unit was on the site of the primary school. Robbie was accepted into the learner support unit, which was established by an intermediate school and funded and staffed from within this school.

Robbie's behaviour was still causing concern. The unit was not secure and he would leave the area. *I got really angry and attacked the janitor with a pin...got him in the neck with it* (Robbie). He caused damage in the principal's office, and was suspended from the unit for a time. Robbie remained at the unit until the end of Year 8, the time to leave primary education and enter secondary school.

5.10.3 Transition to special school

At time for Robbie to leave primary education and enter secondary school, the family visited schools in the area. The family did not want to enrol Robbie in the school his brother attended. In an earlier decision about Robbie's primary school placements, the decision to move his school placement was to *give (older brother) a break from being the sibling of the weird brother* (Beth). Two high schools offered Robbie a place at the school, on the condition that he study in the regular classes and receive support from the learner support teachers. I *was not prepared to put him in a situation where he was going to be in an abusive situation again* (Beth).

Beth visited the special school that in the area in which the family lived. There had been a change of principal and as a result of roll growth, programmes designed to meet the specific learning needs of students with ASD had been established. *They had a class specifically for ASD* (Dick).

5.10.4 Experiences at special school

When talking about transferring Robbie to a special school Beth's commented *it was the best thing we ever did. He is actually achieving. He is doing ASDAN and NCEA Level One. Fantastic for him. Robbie doesn't celebrate achievements. When he was in the mainstream he used to rip his certificates and stuff up. He doesn't do it here* at *(the special school) which is interesting.* Robbie joined the conversation. *They value me for me*. His mother continued with *they like him. He is understood there.* His father added *they celebrate each child for what they bring.* He also suggested that *mainstreaming is far too much a matter of luck for parents, far too much*. With Robbie at special school he travels to school in a taxi bus. This stability in transport and not being called to the school to collect her son had allowed Beth to work full time. Dick's remark that *parents have the prior right to choose the type of education for their children* were the thoughts of Robbie's parents who had experienced many barriers when selecting a provider of learning programmes for their son.

Robbie is completing the last year of his schooling at the special school. He is still planning his next adventure.

5.11 Discussion.

Although these families' experiences took place in different places and at different times, there is a commonality in their stories: anger and tension at the mismatch between their experiences and the policies, practices and procedures within education in Aotearoa New Zealand. The families questioned the effectiveness of the practice of inclusive education in meeting their children's special learning needs. These tensions culminated in their turning their backs on inclusive education as practiced by the regular schools their children attended, and the schools they approached when seeking ongoing education placements for these family members.

For three families whose children's needs for ongoing support was identified before or within the first weeks after their birth, accessing health and educational professionals and receiving ongoing support was relatively straightforward. This was recalled by these families as a positive and productive time because support was forthcoming and ongoing.

I was told 2 weeks before she was born. I had time to think about options and time to read (Donna).

I can't thank that system enough (Susan).

However, for the other six families, these early years were times when they continually had to justify their requests for assistance from health and educational personnel. *We had a really, really hard time convincing doctors of anything because she (Britney) didn't appear any different to other babies* (Eleanor). For Lynne contact with health professionals was a time consuming and debilitating: *It was a bleak time. I was becoming more and more exhausted and desperate.*

All the children in these families began their education journey in an early childhood centre. Seven children received additional support from GSE, while two families paid for additional support for their children because no 'official' diagnosis of their children's need for assistance had been received. One of these families, whose child received only partial support for his early childhood placement, was required to 'top up' the teacher aide hours themselves because the GSE funding did not support the entire time the child was at preschool. One child's family funded the early childhood placement he attended with his siblings. It was here that therapists approached his mother and suggested that interventions may be required.

For the children who had been supported by teacher aides funded by GSE in their early childhood placement, transition to primary school should have been a seamless procedure. However, for one family, the failure of GSE to complete the necessary procedures at the time of the child's transition to primary school resulted in him starting school with no additional support. When it was time for another child who was not funded by GSE to transition to his neighbourhood primary school, his family were informed that *the school wouldn't accept him because he couldn't behave* (Lynda). It took his family over 12 months to be granted the funding required enabling their child to be supported by a teacher aide and specialist teachers in their neighbourhood regular school. This family had an expectation that their child, having reached the age of 5, which is when the majority of children in Aotearoa New Zealand enter primary school, would follow the pattern of his sibling and be accepted into school. This child was not accepted into this school until he had turned 6.

All the families had a belief that, once their children were granted ORS funding, they would receive support throughout their primary and secondary school years. There was an obligation on behalf of the MoE that they would be supported by teacher aides, specialist therapists and teachers, and above all, classroom teachers who would have the skills to prepare and present programmes of learning that would be appropriate to their children's special learning needs. However, there was a gap between the families' expectations and the MoE guidelines, which state that 'Educators have the skills and confidence to assist young children and students who have a broad range of needs and abilities' (MoE, 2012, p. 2).

The experiences of these families showed that there were schools that were unable or unwilling to 'assist' their children in their learning. Kathy and Lynne withdrew their children from their regular school placement before the time of transition to intermediate or secondary school. In both cases, the schools acknowledged they were unable to meet the special learning needs of these young students. Although Kathy inferred that the transition was prompted because of '*where Axel was reduced to'*, it is the role of the school to ensure that the staff has the skills and the confidence to meet both the learning and the social needs of children such as Axel. When discussing

Mark's transition from primary school, Lynne voiced disappointment that the school was unable to place her son with a teacher who was prepared to accept him into a classroom. Neither the school nor GSE offered the family alternate options of classroom placement within the school or within the community.

When the Serville family transitioned Britney at the end of Year 6, the school had acknowledged that they were unable and unwilling to meet Britney's needs. *They (the regular school) weren't keen on her being there in Year 7 and 8 because they have tech and this and that* (Eleanor). For the Anderson family, the transition was seen by the family as a statement to the host school that the family was not accepting of school policies that were perceived as practising 'exclusion' within a school promoting inclusive practices.

The transition to high school is, for all families, a time of discussion and decision making. For the five families who transitioned their children to special school instead of secondary school, the reasons underpinning this decision had a common theme: the failure of schools and GSE to meet the expectations of the families. Within this theme were family concerns about the lack of information from GSE, reduced TA hours, bullying, and perceptions that possible host schools were or unable or unwilling both to meet the personal care of students and to present programmes of learning that were achievable by the students. For one family, statements from principals that their child would not be accepted into their schools or into programmes within the schools were seen as *So the attitude was we're not welcome. The point is the Ministry of Education had this philosophy of inclusion. If you've got bloody principals of a school saying that, how does inclusion work?* (Beth).

5.12: Summary

The source of tensions experienced by these families was that their expectations of both health and educational professionals were not met. These families expected to access health practitioners in a time frame that would enable the receiving of information and possible diagnosis that would ensure their children receive appropriate support prior to and when they enrolled at their early childhood centres and regular schools.

All of the families had an expectation that their right to enrol their children in regular schools of their choice would be met. These families also expected to access support from GSE personnel who would value, listen, and respect their wishes, and be transparent in their interactions. Once additional funding such as ORS was granted, the families expected their children would receive the additional support outlined in the ORS documentation.

All nine families had expectations that they were enrolling their children in safe, physical and emotional school environments where the staff working with their children would be educated and experienced in working with children with special needs

The key issues underpinning these tensions arising from the family interviews will be further discussed in Chapter Six.

CHAPTER SIX

HOW DOES THIS STUDY FIT WITHIN THE IDEOLOGY OF INCLUSIVE EDUCATION?

‘Parents have the right to choose the type of education they want for their child. They have the right to education like anyone else’.

(Beth, 2011)

6.1: Introduction

The families’ stories have revealed a number of key areas that are sources of tensions between the rights and expectations of the families and the policies and practices of the key stakeholders in this study: health and educational professionals, government departments, schools and the children and their families. How these issues fit within the education ideology of inclusion is examined and critiqued in this chapter.

Underpinning this analysis are the research questions:

- What were the experiences of selected families when supporting their children with special needs in regular schools?
- Why did these families decide to move their children from regular schools to special schools?
- How does this study ‘fit’ within the educational ideology of inclusion?

6.2 Families identify difficulties within inclusive education

Three major themes and eight sub themes emerged from within the coding of the family interviews:

- Families interactions with health practitioners because of:
    -the inability to access health professionals
- Mismatches between the families’ expectations and government legislation, policies and practices were identified as issues with:
    the philosophy of inclusion
    GSE

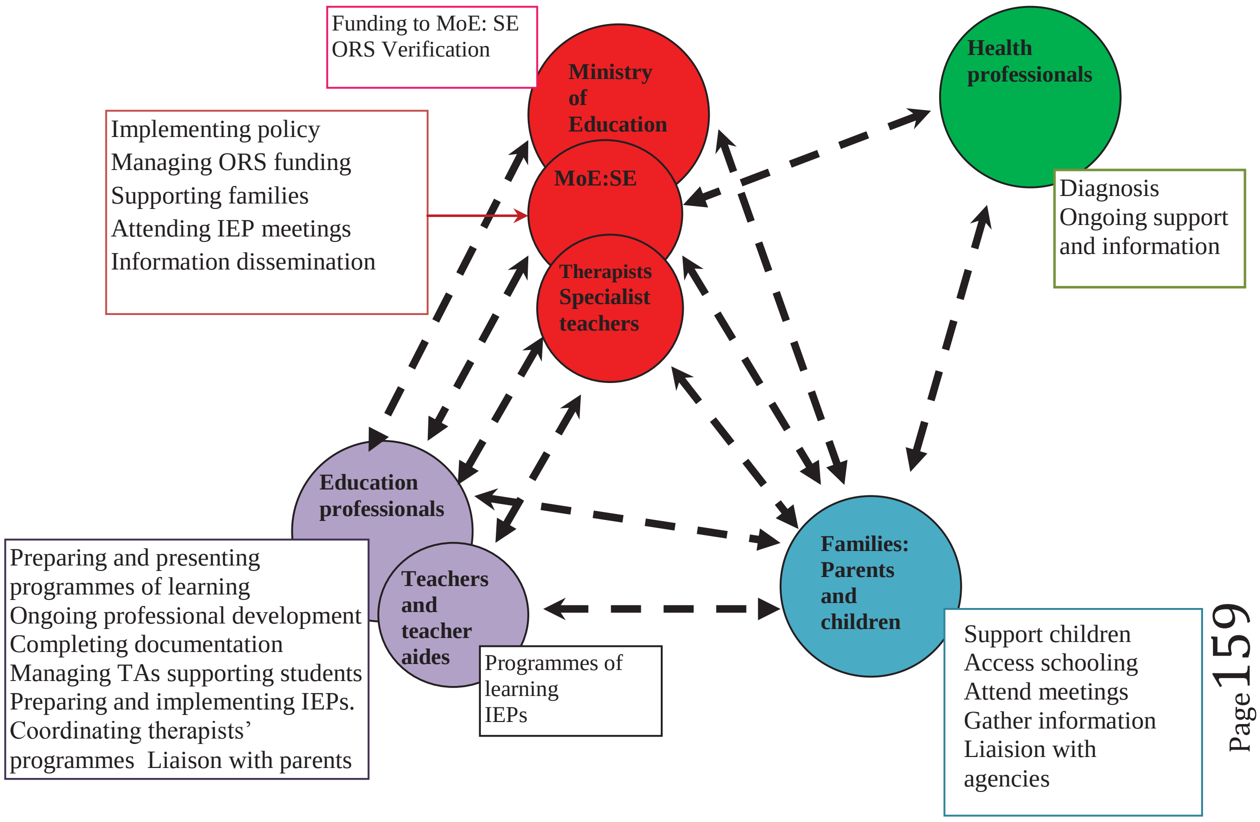
the implementation and outcomes of IEPs,
accessing and retaining government funded resources

- Issues with families' expectations of education policies were with:
  the skills of teacher
  TAs skills and the retention of TAs in schools
  school environments.

Interactions between the families and each of these stakeholders will be examined and sources of tensions identified and discussed in the following section.

Figure 6.1 presents a visual overview of the roles of families and key stakeholders in inclusive education. The text boxes outline the role of the key stakeholders within the provision of programmes of learning for children with special learning needs. It is the perceptions the families have of these stakeholders that have defined their roles in this model. The broken lines indicate that communication has been made between the families and stakeholders but it has not resulted in a complete or successful transfer of information or services.

Figure 6.1 *The families' perceptions of the roles of key stake holders within inclusive education*



6.3: Issues arising from interactions between families and health professionals

The diagnosis of the disorder seen as affecting the child's interactions with the environment in which he or she lives and learns is important if the family and child is to access resources that will enhance the management of their child. In most instances health professionals have the responsibility for this diagnosis. For children born with obvious disabilities such as cerebral palsy and Down syndrome, diagnosis is usually made at a time before or at birth or in the early months of the child's life. Three of the children in this study were diagnosed as requiring additional health and educational support from a very early age, although Stella's mother noted that although her daughter had a stroke at the time of her birth and spent the first 14 weeks of her life in the care of the neonatal intensive care unit *no one wanted to be responsible for saying the word (cerebral palsy)* (Isobella).

For these parents their expectations of the health professionals were met. Their children's health needs were supported by appropriate health personnel. The diagnosis given to their children supported the families' requests for additional educational resources to be accessible to their children before and when they entered their early childhood placement.

However, for five of the six remaining families, the diagnosis of the condition that was impacting on their children's behaviour was not forthcoming from health personnel, despite evidence from early intervention studies that emphasised the benefits of the early diagnosis of children with special needs (Nygren, Sandberg, & Gillstedt, 2012). Five families had expectations of positive and productive support from health professionals. The reality, however, was of a very different nature. Lynne's experiences are one example of a mismatch between the expectations of families when seeking support from health personnel. When her son was 2 years old Lynne approached health personnel at the Base Hospital in her city for assistance in managing her son's extreme behaviours. She was told to *Go away and come back when he is 3 years old.*

Delays in obtaining a diagnosis may result in a family being unable to access medical and educational support e.g. additional resources such as therapist and behavioural management programmes, which will enable their children and their families to experience a better quality of life.

The issues for the families are that health professionals must be aware that by delaying or giving an incorrect or vague diagnosis, there are likely to be flow on effects into the education system. The implication of a late diagnosis for inclusive education is that children may enter a school without the necessary information and support that would enable educators to provide personalised programmes of learning to meet their special learning needs.

6.4 Mismatches between families' expectations and government legislation, policies and practices

The families identified three key areas where MoE policies and practices did not support their expectations of an inclusive education system: the legislation underpinning the management of schools; the implementation of the policies within the legislation; and the practices used to implement the legislation and the policies.

6.4.1 Philosophies, policies and promises within inclusive education

Choosing a school and managing transitions between schools have been well documented as times of substantial stress for parents of children with special learning needs (Parsons, Lewis, & Ellins, 2009). In Aotearoa New Zealand times of transition for children enrolled in government funded schools are when students move from

- an early childhood placement to primary school
- primary school to intermediate school at the end of Year 6
- primary school or intermediate school to secondary school at the end of Year 8
- from secondary school to 'life beyond the school gate' at a time chosen by the students and their families

In Area Schools these transitions will be within the one school if the students choose to remain in that school to continue their education.

As legislated in the Education Act 1989 'people who have special education needs have the same rights to enrol and receive education at state schools as people who do not' (New Zealand Government, 1989). This right of access to state school was reinforced in the aim of SE2000 that students with special needs would be welcomed at their local school. The staff at these schools should have participated in school based professional education programmes to ensure the learning needs of all students are met.

These statements were not exclusive to one education sector. All schools were aware that children with special needs would be enrolling at their schools. Parsons, Lewis & Ellins (2009) suggest that there is ‘clearly room for improvement’ (p. 53) in the support and information families receive when choosing a school at a time of transition. The authors identified families of children with ASD seeking detailed confirmation that those working in a school have an understanding of the specific needs of their children and have access to appropriate recourses to support both the children and the curriculum they are using in classrooms.

All the families in this research had a belief and expectation that their children would enrol in a regular state primary when they reached 5 years of age and transition to a regular state secondary school when they had completed their Year 8 course.

Seven of the ten children began their primary school education in the regular school selected by their families. Two of the children were enrolled in special schools but transferred to regular schools after 1 year. One student was refused entry to a regular school until he was granted additional ORS funding. *They said flatly, No, we will not accept him without help* (Lynda).

For all nine families, transition to alternative education placements was necessary at a later time in their children’s schooling. Five families transitioned their children out of their regular primary school placement because of the families’ perceptions that these schools were unwilling or unable to meet their ongoing learning needs. For the remaining five children, the change of school was at a time of transition from Year 8 at primary school to Year 9 at secondary school. None of the five students enrolled in regular secondary school placements. The issues influencing the transition to special schools were linked to the families’ perception that possible host secondary schools were unable or unwilling to provide staff and/or services that would meet the learning and care needs of their children, despite the additional resources available to them. For one family, the refusal of at least two secondary schools to provide additional support for their child in his classes was to influence their decision to approach a school outside the regular school system.

Table 6.1

*The time of transition from regular school**

At a time of need	On the completion of Year 6	On the completion of Year 8
3 students	2 students	5 students

*Two students are members of one family participating in the research

If the policies underpinning inclusive education are to provide an education system where all children belong and are accepted in a school community where their education needs are met (Davies & Pragnell, 1999), there is a mismatch between these policies and the practices experienced by the families interviewed in this research. The expectations of these families were that the learning needs of their children would be met by teachers and support staff who were trained and experienced in preparing and presenting appropriate programmes of learning. The experiences of the families show that the practices of some schools did not meet their expectations.

6.4.2 Issues with GSE (MoE: SE) practices

GSE's role within the MoE is to 'deliver services and support for children with special education needs' (MoE, 2012, p. 1). GSE is often the fund-holder for the resources that support the students in their learning environments. Contact and communication with GSE is necessary if families are to receive support and have an active role in the management of their family member's education.

MacArthur, Kelly, and Higgins (2005), when comparing experiences of students and their families in regular and special schools, wrote that some parents and caregivers 'encountered adversarial relationships with GSE when they attempted to gain further resources for their children in regular education' (p. 53). These findings echo those of Repetto and Correa (1996) that many families find transition from one programme to the next traumatising, and may feel a sense of abandonment by professionals at these times. For six families participating in this research, the manner and outcome of their interactions when meeting with GSE personnel did have a significant influence on their decision making. When discussing the role of GSE in supporting the family and the student in the regular school, these families inferred that because of previous unsatisfactory interactions, they did not refer to GSE for information and did not ask for support in any decision-making process. GSE did not offer support to the families, despite the statement by the MoE that parents can 'be confident that GSE are well informed about the services and support that are available' (MoE, 2012, p. 1). *GSE were nowhere in sight. We hadn't seen them for two years* (Lynda).

Lynne's experiences of GSE summarise the experiences and expectations of six of the families: *I was driving a car I didn't know how to drive and no one was taking the wheel to give me directions and guidance (Lynne).*

6.4.2.1 Families experience issues with IEPs

The MoE 2012 guidelines outlining the IEP process state that it is vital to the success of the meeting that 'team members leave feeling they and their contributions have been valued and included' (p. 3). But for four families participating in this research, their experiences of IEP meetings *seemed to be one battle after another* (Susan).

The IEP guidelines suggest that the parents should be consulted on the venue and the time of the meeting. Eleanor voiced concerns that most IEP meetings were held during the school day when many parents were unable to attend because of work commitments. Field-Smith (2009) describes such 'logistic barriers' as meetings being scheduled by the education providers at times when parents are unable to attend, and lack of transport and access to child care that prohibit attendance, as major influences in how parents perceive the programme and their participation in it. The findings of this study support these claims.

Family members also expressed concerns that the development of the IEP did not meet their expectations: input from the family members was not acknowledged or accepted, the IEP meeting was at a time when the family were not able to attend, and the content of the IEP was not agreeable to the families. For four families, a 'positive parent-educator partnership' (van Haren & Fielder, 2008, p. 243) was not in place to ensure the decisions made were in the best interests of their children's needs.

For six of the families, their expectations of the services offered by GSE were not met. The expectation that GSE will 'make it easy for you to work with us' (MoE, 2012, p. 2) was not experienced by some families. GSE was unwilling or unable to provide information at times of need, to attend important information gathering times such as IEP meetings, or to have the stability of staffing to ensure families were able to contact case managers when they were in need of support.

6.4.3 Issues with accessing government funded resources

For all nine families, resources funded through ORS played a pivotal role in the selection of education provider for their children.

6.4.3.1 Issues with applying for resources

The experiences of the families when making the applications for resources were very different. The granting of funding and the level of resourcing appeared to depend on the strength and content of the application. The application form can be viewed at Appendix B3.

The accessing of funding is seen by Bartlett (2007) as having 'constantly shifting goalposts' (p. 124) as to if and when the funding will be granted. The tensions that arose at the time of application for funding to support three students were the result of mismatches between the expectations of the families and the practice of making an application for funding. This 'new funding method' (Brown & Moore, 2011, p. 187) was promoted to families of children with special learning needs as an individual resourcing scheme (MoE, 2000a, p. 2) that delivered 'appropriate education support' (ERO, 2005, p. 3) for children with high and very high learning needs. Families making application for this additional support for their children had expectations of receiving verification of their ORS application. Significant delays in receiving this funding resulted in the raising of unexpected and unacceptable barriers for three children beginning their education journey in regular schools.

Table 6.2

Families experiences when applying for funding (0RS)

Number of families	Response	Further information responses
3	Positive	The children were under the care of health and education specialists from a very early age
3	Positive	The application was completed by GSE case workers and therapists before the children transitioned from early childhood providers to primary schools
3	Negative	Verifications were delayed because of inadequate information or delays in making the applications

6.4.3.2 Issues with TA hours

The 'single largest special education resource provided by the MoE is ORS' (Ward et al., 2009, p. 150), with TA hours the most commonly reported resource provided by this funding. In regular schools, the hours a teacher aide works with a student is not set at a predetermined level. Each student receives an allocation of teacher aide time according to their needs. The allocation is set by the fund manager who responds to each student's needs as identified in their IEP (MoE, 2012). Using 'overs' and 'unders', fund managers allocate resources while working within an overall budget. This means students may receive different levels of resources during their time enrolled in learning programmes at primary and secondary school depending on their interactions with the learning environment. The allocation of TA hours for each student may also depend on the total pool of ORS funding available to all children being funded by that particular fund holder. This model of funding underpins the concerns experienced by two families participating in this research.

For many families, a TA supporting their child is a very visible 'solution to inclusion' (Rutherford, 2012, p. 4) and the loss or threatened loss of allocated hours becomes an issue that is seen to affect the quality of learning programmes accessed by their family member. *Kate's teacher said Kate needed more TA time but it just didn't happen (*Donna). For two families, the reduction of TA hours and the manner in which the information about these cuts was disseminated by GSE had considerable impact on their decisions when discussing a possible review of their children's educational placements.

6.4.3.3 Issues with therapist support

Before entering their regular school, all ten students had received specialist support from such disciplines as speech language, occupational therapy, and physiotherapy when attending their early childhood placements. One component of ORS resourcing is access to specialist expertise to develop and implement programmes to meet students' needs identified through the IEP process. In the regular school setting, specialist therapists visit schools usually once a term to discuss programmes of intervention that should be included in students' learning programmes. The implementation of these specialist programmes is usually the responsibility of GSE, the classroom teacher, support teacher or TA.

For the families, specialist support was *very, very limited* (Beth). *SLT involvement waned due to the lack of people really* (Margaret). Kate's comment that *I didn't do physio at the other schools* summarises the experiences of these children whose funding was based on identified needs: speech language therapy, physiotherapy, and occupation therapy, which were to be supported by specialist expertise. These findings echoes those of MacArthur, Kelly, and Higgins (2005), who, in their discussion comparing students' learning in regular and special schools, identified students experiencing 'poorer access to specialist professionals' (p. 53) in regular schools than that available to their peers in special schools

The families had expectations that their children would receive support from therapists who would prepare programmes of intervention that would become part of the children's daily routines. For the majority of the families this expectation was not met and the children did not receive the support of therapists that were available to them through funding managed by GSE.

6.5 Issues with families' expectations of education professionals

The MoE document *SE 2000-Getting it right, together* (1998) stated that professional development, education and information would be available for 'principals, teachers and parents of children with special needs' (p. 4) as it was necessary that schools and families decide together how the needs of these children be met. Issues arose when families expected that those working in the schools would have the knowledge and skills to ensure the learning needs of their children would be met. Their frustrations centred on several aspects of parent school interactions, in particular when families requested the enrolment of their children in regular schools.

6.5.1 Issues with teachers' skills

All the families identified the lack of experience and education of teachers as a barrier to their children accessing appropriate learning programmes in their regular schools or at times of transition to intermediate or secondary schools. Educators working with five of the students in their regular school settings acknowledged that the students' individual learning needs had exceeded the experience and education of those working with them in the classroom and in the school environment. *The ones from the school were very disappointed that it hadn't worked out as well as they had hoped. I think they were gutted they hadn't been able to do more* (Kathy).

Families were also confronted with ‘access’ barriers when transitioning their children from primary to secondary schools. *They don’t have the right attitude, so they are not welcoming. There’s a lack of willingness there for them to learn how to do it (meet the learning needs of students with special learning needs* (Beth).

The MoE statement that teachers will have the confidence to assist students who have a broad range of needs and abilities (2012b) gives families the expectation that the teachers working with their children in regular schools are trained and/or experienced in meeting the learning needs of their children. For all the families participating in this research, this MoE principle did not meet their expectations, be it in the classroom, as experienced by Axel and Mark, or as a perception that the needs of the students were not able to be met by the ‘whole school’, as experienced by such students as Robbie and Stella.

6.5.2 Issues with TA’s skills

For four families the support their children received from a TA had a positive outcome for their children, as described by Susan and Iain: *Andrew had the same aide from start to finish* (Iain). *They had a fantastic bond* (Susan). The families stated that these TAs had an understanding of the learning needs specific to their students and maintained this support as the students moved from one year level to the next. These interactions are consistent with those of Rutherford (2012) and Howard and Ford (2007) as being a positive observation that stability was an important component of the role TAs have when supporting students.

However, for five families, the support expected from the TAs for their children was not forthcoming. These families identified three issues that did not meet their expectations of the individual funded resourcing: the lack of trained TAs, the lack of continuity of TA staffing, and the relocation of the TA to other roles in the school. The Serville family voiced their frustration about issues relating to the use of TAs as a ‘solution to inclusion’ (Rutherford, 2012, p. 4) where the lack of pre-entry education and stability of staffing have a negative effect on the support available to students: *It was just a circus with TAs coming and going. There was no consistency. They just couldn’t get it right. That probably did more harm than good over those initial years* (Theodore).

The day-to-day management of the TA is the responsibility of the classroom teacher and the school management. It is therefore essential that the teachers and school management have an understanding of the role each TA has within the school and have that the TA has the necessary skills to meet the students learning needs. As identified by Blatchford, Russell, and Webster (2012), there is a need to prepare TAs for the role they have in the classroom and ensure those persons managing the TAs respect the role they have in the school. Lynne’s experiences mirrored those of these five families:

> *They were not able to employ a TA who could cope with Mark’s needs. It is important to get a good TA. You get a good one but he or she leaves because of the poor wage. In the regular school, the teacher is not trained to work with students with ASD, or to work with TAs in the classroom. The children are given an untrained TA.* (Lynne)

The families had expectations of the role of the TA in supporting their children in the classroom. The challenge for the schools was to meet these expectations by employing TAs with the education and skills to support the children in their classroom activities. For five families this challenge was not met by the TAs working with their children and therefore not met by the schools or the policies of the MoE.

As suggested by Giangreco, Broer, and Suter (2011), the use of TAs had emerged as a ‘mechanism that schools increasingly rely on’ (p. 1) to support students with special learning needs in regular school classrooms. However, the findings of Leger Rodriguez (2010) imply that TAs may have a high level of responsibility but a low level of education and support to help them do the work. The education of TAs is most necessary if the interaction between the students and their TAs is to elicit the most favourable outcomes for both participants. It is also important that the teachers working with TAs have received education to understand the role of the TA, and what ‘both parties may expect from their working relationship’ (Blatchford, Russell, & Webster, 2012, p. 59).

6.5.3 Issues with school environments

Bullying is a critical concern for all children with and without disabilities (Massachusetts Advocates for Children, 2009). The ‘right to be safe at school (both physically and emotionally) is a fundamental right’ (Kearney, 2008, p. 221). The National Administration Guidelines of the MoE require schools to provide a safe physical and emotional environment for all students (NAG 5(i)) (MoE, 2012b). It must be accepted that all parents have the expectation that the schools their children attend will be a ‘safe place’ where they can enjoy interactions with other children and adults during the school day. In this study bullying was identified by five families as one issue that influenced their decision to seek an alternative provider of learning programmes.

Donna referred to incidents of unacceptable behaviours towards Kate: *She was bullied although Kate didn’t realise she was bullied* (Donna). Donna’s experiences of Kate not understanding the nature of bullying are reinforced by MacArthur, Kelly, and Higgins (2005), who write that students with special learning needs ‘do not always understand the context in which the bullying has occurred’ (p. 60). In her study investigating the barriers experienced by disabled students when seeking inclusion in school, Kearney (2007) identified bullying as one of the factors parents of disabled students reported as excluding their children from regular school placements.

The bullying of their family members by both children and staff was one further factor illustrating the tensions created by the mismatches between the ideal and the reality of the experiences of these ten children and their families within a regular school in Aotearoa New Zealand. It also questions the procedures and practices schools have implemented in meeting the MoE guidelines for a safe learning environment for all students.

Table 6.3:

Summary of the themes emerging from the family interviews

Key finding	**Positive response**	**Negative response**	Information relevant to the findings
Interactions with health professionals	4	6*	Three students disabilities were diagnosed prior/at or in first months of the child' life.
Inclusion education	0	10	All children were withdrawn from regular school placements
Issues with GSE	4	4	One family recalled both positive and negative interactions
Issues with IEP meetings	0	4	Only four family groups commented on IEPs
Issues with government funded resources	0	10*	Three students were under the care of health providers while attending regular school. Their specialist support was sourced from these providers
Issues with teacher skills	0	10*	
Issues with TA skills	4	6*	Three students had no change of TA while attending regular school
Issues with school environments	0	4	Only 4 family groups commented on incidents of bullying.

*Two students are members of one family participating in the research

Table 6.3 presents a visual overview of the subthemes identified by the families as influencing their decision making

6.6 The families seek solutions to these issues and tensions

The families' solution to the issues and tensions experienced when their children were enrolled in inclusive schools was to move their children to 'more specialised knowledge, teaching and educational settings' (Parsons, Lewis, & Ellins, 2009, p. 53). All the reasons identified by the families for not selecting regular school placements were based on their experiences of practices within an education system that raised barriers that prevented their children from participating in learning programmes that accommodated their special learning needs.

Galotti (2007) suggests that when making decisions, people do not consider all available options but set goals and gather information to meet them. When making these decisions the families did adopt techniques and shortcuts by

- talking to personnel within support organisations and agencies such as GSE, Strengthening Families
- visiting possible providers of learning programmes
- participating in family and extended family discussions
- searching the internet
- making ‘accidental finds’, such as picking up a flier at a cake stall
- using knowledge from a previous education placement
- having knowledge of the education services within a particular town or city
- talking to other families supporting children with special learning needs
- talking ‘over the garden gate’ with members of the community

For families who were possibly ‘working to the lengths of their mental processing abilities’ (Drummond, 2001, p. 9), assistance from agencies was not seen as influencing or undermining the judgements that were made, but was seen as supportive and knowledgeable: *I did it through (child development support services)...they had a social worker there who was very much on our case and she arranged the interview* (Kathy).

No families reached the de facto decision described by Segrin and Flora (2005), where the decision was determined by factors beyond the control of the family, e.g. no students had been excluded from school. Six families adopted a decision-making style of consensus where all family members agreed to a decision before the decision was implemented. It must be acknowledged that three families making the decisions were single persons with other family members having given agreement to the decision being made on their behalf.

All the families participating in this research understood the concept of inclusion and inclusive education and supported it as an ideal by electing to enrol their children in their regular neighbourhood school when they were ready to transition from their early childhood placement. These families ‘exercised a degree of choice over school selection’ (Gasson, 2008, p. 118) when selecting a regular school as the first choice of provider of programmes of learning for their children. Although Grenot-Scheyer, Staub, Peck, and Schwartz (1998) suggest this support of inclusive education is often partly motivated by a willingness to provide their children with opportunities to develop friendships and interactions with peers with differing abilities, only one family identified the ‘role model’ of children attending regular schools as a motivation to seek a placement in a regular school for their children: *I felt that when going to a normal school she would be playing with normal kids and she would pick up normal kids ways* (Britney’s grandmother). Although these families understood the MoE’s policy that ‘all children and young people with special education needs receive their education in regular classrooms’ (McMenamin, 2009, p. 183), the decision to transfer their children to special schools was their solution to resolving issues that had arisen when the children were enrolled in regular schools.

But why did the families select a special school as their choice of placement for their children with ORS funding?

The families identified a variety of reasons that influenced their decision to transfer their children to special schools. However, for all nine families, the knowledge that special schools were able to offer the children programmes of study designed to meet their special learning needs was a major influence on their decision making.

The intended outcome of SE2000 was that additional resources would enable children and young people with high and very high needs to participate in learning environments in regular schools. This was not achieved by the ten students participating in this research. The classroom support was not effective in meeting the expectations of the families caring for these students. Specialist support funded through GSE and implemented by therapists was not seen by the families as being part of their family members’ daily routines.

The findings from this research emphasised the need to listen to families and give them the opportunity to discuss and voice their concerns for their education of their children. The findings have highlighted the issues and barriers confronting families when supporting their family member in a regular school setting. These finding also highlighted how, for these families, regular schools, charged with practising inclusive policies and receiving additional support, were unable to deliver appropriate educational programmes and support to students with high and very high learning needs.

6.7 Summary

As this discussion has shown, the tensions experienced by the families involved all the key stakeholders resulted in the families no longer supporting the policies and practices of inclusive education. The tensions and issues experienced were wide ranging, but fundamental to all the issues, was the mismatch between the expectations of the families and the promises of policies of inclusion.

Chapter Seven offers conclusions and recommendations that may assist people working in education and in government departments to develop policies and practices that will ensure all learning environments are supportive of all children, especially children with special needs.

CHAPTER SEVEN

CONCLUSIONS AND RECOMMENDATIONS

They're pushing for inclusive education but it's talk the talk. They are all saying this stuff but they need to get out and do it

(Isobella, mother of Stella, 2011)

7.1 Introduction

This thesis identifies tensions, issues, and challenges within education in Aotearoa New Zealand as seen through the experiences of nine families supporting their children with special learning needs in regular schools. My interpretation of these conversations revealed incongruities between the everyday experiences of the families and their children and the vision of inclusive education as promised in the policies and practices of the Education Act 1989 and SE2000: that all children will have access to high quality education that allows them to participate and achieve at school. The argument central to this thesis is that these issues impact adversely on the children and their families.

The findings of this study emerged from the stories told by the families. They recalled the experiences that underpinned their decisions to move their children from inclusive, regular school placements to special schools. They talked of their expectations regarding the practice of those people supporting them outside and of the experiences of the children in the classrooms.

In this chapter I return to my research questions as the foundation on which to integrate and interpret the overall findings of the study:

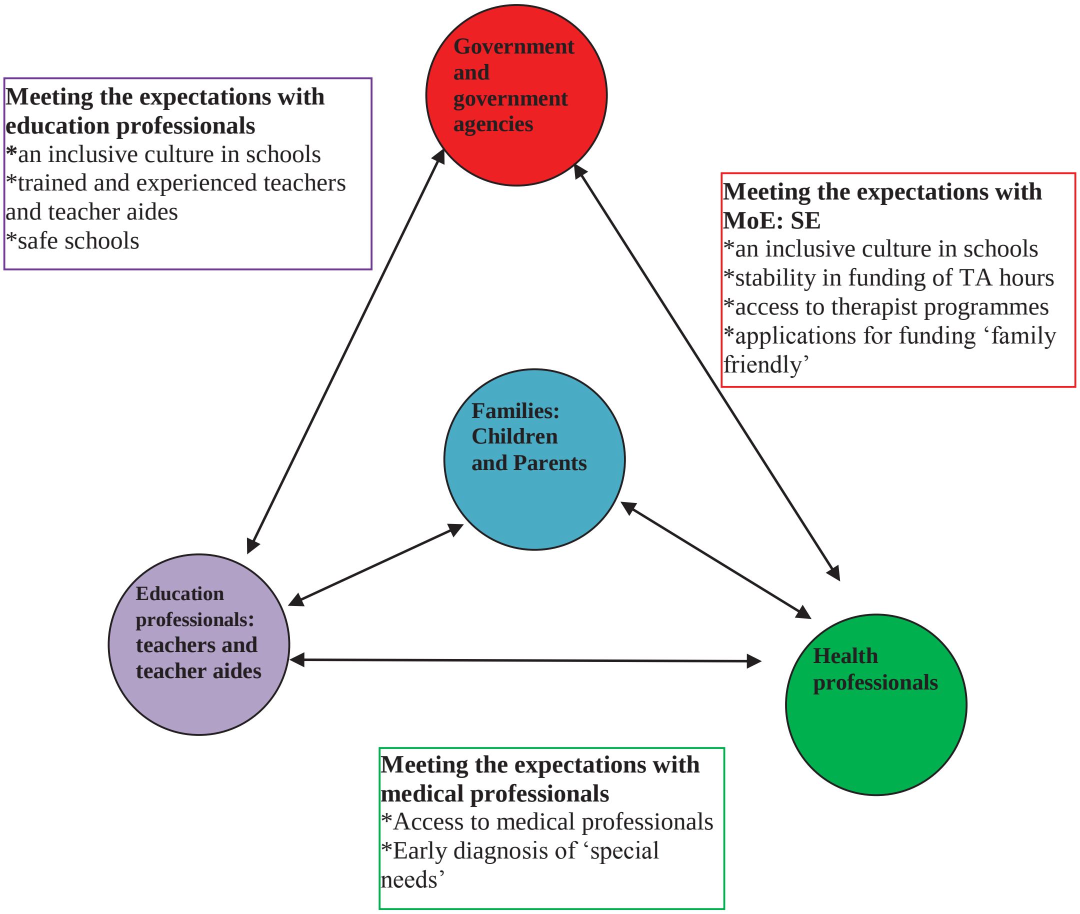
- What were the experiences of selected families when supporting their children with special needs in regular schools?
- Why did these families decide to move their children from regular schools to special schools?
- How does this study 'fit' within the educational ideology of inclusion?

These research questions have been addressed in previous chapters. The purpose of this chapter is to succinctly highlight again the key findings and to make a series of recommendations.

7.2 Meeting expectations in relationships between the key stake holders in the education of children with special needs

As shown in Figure 7.1 the families identified a number of expectations they had of the relationships between themselves and educational professionals.

Figure 7.1 *Meeting expectations in relationships between the key stakeholders in the education of children with special needs*



Meeting the expectations with education professionals
*an inclusive culture in schools
*trained and experienced teachers and teacher aides
*safe schools

Meeting the expectations with MoE: SE
*an inclusive culture in schools
*stability in funding of TA hours
*access to therapist programmes
*applications for funding ‘family friendly’

Meeting the expectations with medical professionals
*Access to medical professionals
*Early diagnosis of ‘special needs’

These expectations underpinned the families’ perceptions that the regular schools were unwilling or unable to become more accepting of their children in their practice of the philosophy of inclusion in their school community. There were also problems of communication with professionals employed in government agencies.

These concerns echoed the findings of Wylie (2000) who, in her review of the policies introduced in SE2000, concluded that it would be challenging for the MoE and GSE, as the government agency responsible for children with special needs, to offer students, parents, and schools the ‘seamless, integrated service which works best for students with special needs’ (p. 8). Expectations of communication between families and health professionals were identified as an issue that was to result in some children entering their early childhood placements without the support that would have enhanced their interactions with the learning programmes.

Each of the problems that arose in relationships between the families and the stakeholders is discussed in the following sections.

7.3 How can families’ expectations of health professional be met?

In New Zealand there are developmental child health programmes available to families who have concerns for their child’s development. The Ministry of Health (2012) makes the statement that if your child ‘isn’t achieving developmental milestones’ (p. 1) access to early intervention and specialist assessment services is available. However, such experiences as delays of over a year in gaining access to specialist support were highlighted by families as causing tension and, more important, delays in accessing support programmes.

To meet the expectations of families who have requested specialist support must be priority access to health professionals. Referrals from health and education based organisations such as Early Intervention, Well Child Tamariki Ora and general practitioners must be ‘fast tracked’ for, as stated by Nygren, Sandberg, and Gillstedt (2012), early diagnosis of such disabilities as autism is crucial to enable programmes of early intervention to be initiated.

Access to funding to support preschool children with special learning needs is provided by Early Intervention teams funded by the MoE. However, before students who require additional support enter their chosen primary schools, applications for ORS funding must be completed. Diagnosis of any health based disabilities, signed off by medical specialists, is required to further support the application for ORS funding. It is therefore important that the family has access to health professionals to ensure their children's funding support is secured before they transition to primary school.

7.4 How can families' expectations of educational professionals be met?

The experiences of the families indicate there is a mismatch between the families' rights and expectations of schools and the education and information being given to those working in the schools that these children with special needs have a right to enrol in regular schools and participate in programmes of learning appropriate to their needs.

7.4.1 Inclusivity in schools

As stated in the Education Act 1989, all state and integrated schools in Aoteroa New Zealand must prepare and maintain a school charter that establishes the missions, aims, direction and targets of the Board of Trustees and therefore of the schools. This document gives an overview of the guiding principles of the school and its staff students and school community. However, not all schools identify students with disabilities and students with special learning needs within their charter. Schools are organisations that have shared beliefs and values that dignify particular practices and behaviours (Paliokosta and Blandford, 2010). A culture of respect, tolerance, and acceptance is seen by Swearer, Wang, Maag, Seibecker, and Frerichs (2012) as a necessary component of a school that is promoted to its community as having a philosophy of inclusion. By increasing the awareness, understanding, and acceptance of all those working and studying within a school and its wider community to the shared values and behaviours that knit a community together, there will be a greater acceptance of students with special needs. In turn, it is only when schools are accepting of students with special learning needs into their student community that the these values and behaviours can be acknowledged and practised. As suggested by Booth and Ainscow (2002), successful schools are those that have 'restructured their cultures to increase the presence, participation and achievement of all students' (p. 3). It is these ethical standards and leadership that build the culture of an inclusive school (Education Review Office, 2010).

In an investigation of the education of children with high learning needs, ERO (2010) found that in Aotearoa New Zealand 'approximately half of the 229 state schools reviewed' (p.1) demonstrated inclusive practices. However this information is followed by a statement that this judgement was made on how the schools were meeting the needs of students enrolled in the schools at the time of the review. The statement from ERO that ‘schools may be less inclusive’ (p.32) should they enrol students whose behaviours or medical needs are not understood by the staff, indicates that the ERO reviewers were aware of the gaps in the professional development programmes that were targeted at making classrooms more inclusive. ERO was also aware that more comprehensive professional programmes would benefit not only the students with special learning needs but all students in the schools and their educators.

7.4.2 A safe learning environment

Children and their families also need to know that their school is a safe physical and emotional ‘bully-free’ learning environment (MoE, 2012). It is essential that all schools promote a school culture where all forms of bullying are not accepted and where students are encouraged to develop skills of mediation that will replace bullying behaviours. Not all students, especially those with special needs, have the necessary communication skills to report bullying. Therefore schools must ensure that procedures are in place to ensure all incidents of bullying are identified and recorded, and that families are included in this process.

Paliokosta and Blandford (2010) state that is it only through practice, exposure, and knowledge, that practitioners can develop an understanding of the philosophy of social justice that underpins inclusive education.

7.4.3 Educated and experienced teachers and teacher aides

The challenge from the families participating in this research is for all schools to ‘address the needs of diverse learners in order to raise overall achievement levels and reduce disparity’ (MoE, 2012b, p. 3). It is only by gaining ownership of changes in their role in the classroom that teachers and TAs will acquire the skills and confidence to plan and implement programmes of learning that will meet the special learning needs of these children. If the gate keepers in schools refuse entry to children with special needs, the classroom practitioners will not be able to acquire and practise these skills and meet the challenge of including children with special needs in their programmes of learning.

For people entering the teaching profession, preparation for meeting the needs of the diverse learning in schools begins at the pre-service teacher education programmes. Effective courses designed to prepare students for teaching in regular schools must be compulsory and include opportunities to observe and possibly interact in classrooms where effective programmes of learning to meet the learning needs of all students are implemented. These observations may be made in both regular and special schools.

For those already working in the schools, it is the role of the managers within the schools to ensure all people working in the school community have the necessary skills to meet the individual learning, social and care needs of all the students enrolled in their school. The funding to meet this professional development has been made available to schools. The MoE document *SE 2000-Getting it right, together (*1998) stated that professional development, training, and information would be available for 'principals, teachers and parents of children with special needs' (p. 4) as it was deemed essential and necessary that schools and families decide together how the needs of these children be met. Professional education programmes that are intended to ensure staff members would have the necessary skills to identify students requiring adaptations to the programmes of learning offered in the class, and ensure suitable resources were available to support the students' learning. However, although the funding is available for such essential professional learning, there is no apparent compulsory plan, programme or obligation in place for schools to participate in education that would enhance the interactions all those working in the school had with students with special needs.

An overview of topics that I think should be included in education programmes preparing teachers for working with children with special learning needs in regular classrooms is presented in Appendix C.

7.4.4 Transition to another school

As discussed in 6.4.1, in Aotearoa New Zealand children with special learning needs have the right to access programmes of learning in all state schools. However for all ten children participating in this research the 'seamless' integrated service promised and legislated by the MoE (2011a) was not available to them. The schools selected by their families as possible providers of their ongoing education needs were unwilling or unable to meet these children's special learning or care needs. These enrolment experiences made some families and their children aware that their children were not welcome in regular neighbourhood schools. It placed them ‘between a rock and a hard place’ (Runswick-Cole, 2008, p. 1).

Parents’ decisions are often influenced by their experiences. The research findings of Runswick-Cole (2008) suggest that when families are within an education system that constructs barriers to their children attending their neighbourhood regular school, they look for a ‘welcoming environment’ (p. 178) and for the nine families in this research, this welcome was found in a special school. For children with special learning needs to gain access to regular schools, especially at times of transition, there must be an acceptance by all schools that these students do have the ‘right’ to access appropriate programmes of learning in the school of their family’s choice. It is the responsibility of the school to ensure these programmes are readily available and all children have ‘barrier free’ access to them.

If a school’s response to the learning needs of the children is to encourage families to seek alternate placements, the MoE (2012) document ‘*Supporting future orientated learning & teaching-a New Zealand perspective*’ will become yet another document that only *talks the talk* and does not *get out and do it* (Isobella, mother of Stella).

7.5 How can families’ expectations of government agencies be met?

The role of the MoE: SE is to support, guide, and lead the education sector that delivers services and support for children with special education needs, and their schools, teachers, parents, and families (MoE, 2012). For the majority of families supporting children with special needs in regular schools, contact with MoE: SE is necessary because they are the fund holders managing the provision of such services as teacher aide hours and therapy support for their children. Issues relating to MoE: SE communications with families and their apparent inability to disseminate information were identified by four families as barriers to their children receiving the support that was expected. These findings are echoed in the Office of the Children’s Commissioner’s 2012 submission to the MoE, which states that ‘currently there is no guarantee that a student will be able to access the level of support required to succeed at his or her local school’ (p. 6).

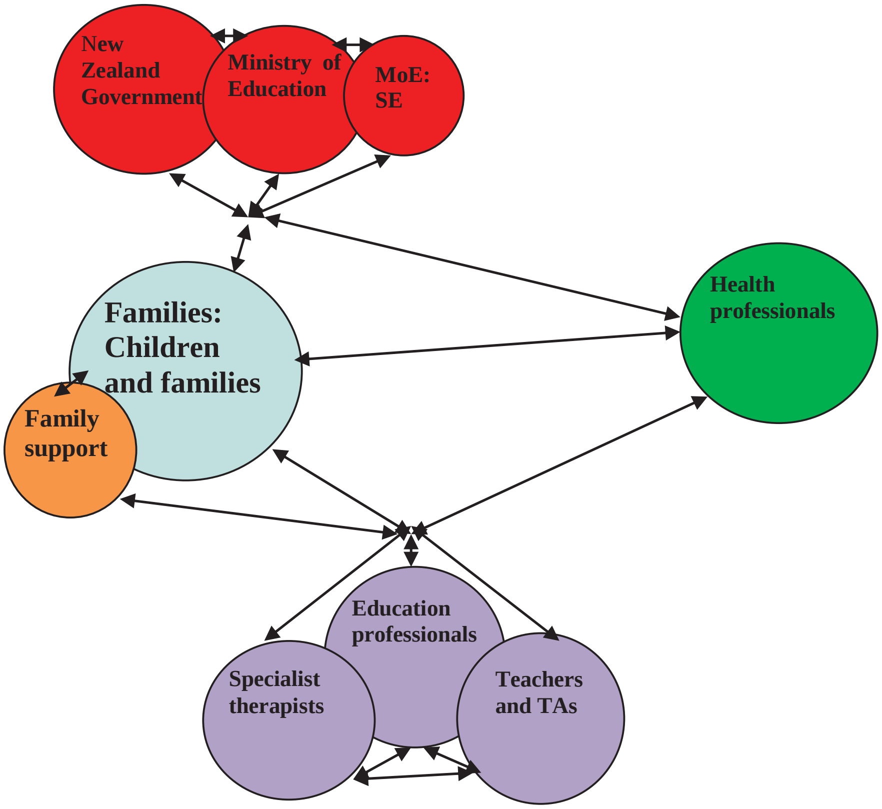
In granting children ORS funding there is an inherent promise of support for them: support that will enhance their interactions with their learning programmes. Four families participating in this research described the ‘in school’ support for their children as erratic, inconsistent and constantly under threat of being removed. The families’ expectations that decisions for individual resource needs were based on valid, fair and culturally appropriate assessment practices (MoE: SE, 2011a) were not met and barriers to communication with GSE remained an issue throughout their children’s education in regular schools.

Some families also voiced their frustrations at the absence of GSE at IEP meetings where a team of people closely involved with the students gather to develop learning programmes that met the students’ needs. As fund holders responsible for provision of resources, it was expected that GSE personnel would be part of the IEP team. The overview of MoE: SE’s policies and practices (2011) states that advisory services are available to families to support them and their children. The failure of GSE to support families in the IEP process was seen as a breach of contract. The support and dissemination of information from GSE was also expected by the families at times of transition.

The MoE: SE (2011a) overview presents the principle that all children and their families will have access to a seamless education from the time their needs are identified through to post school options (p. 3), with all students moving successfully from one education setting to another. For all ten of the students participating in this research the move was not seamless. The families met barriers within regular schools and regular school system. Only one family was supported by GSE personnel when alternative education providers were being sought by the families. For the remaining eight families, information was either not provided by MoE: SE or their personnel were unwilling to assist the families. Parents have the right to have access to a comprehensive overview of placements available to their children and not rely on fliers from a cake stall in a shopping mall.

The following figure presents a barrier free education system

Figure 7.2 *The communications between key stakeholders are barrier free*



The model introduced in Figure 1.1 presented the four key stakeholders in this study: children and their families, health professionals, educational professionals, and legislators, and government agencies working in education. Figure 6.1 identified barriers and issues between these key stakeholders. Figure 7.1 highlights recommendations that would lead to the removal of the barriers the families perceived as preventing their children remaining within the inclusive education programmes offered by regular schools. Figure 7.2 offers a model of education where families, the children and their parents are central to the inclusiveness of education. The support network is barrier free. All key stakeholders are interacting with the people for whom the philosophy of inclusive education has been legislated and promoted: children and families in Aotearoa New Zealand. The lines of communication are open and accessible to all those people who have a role in ensuring children and families experience positive and productive support from all stakeholders. In this model, all children are welcomed into safe, barrier-free school communities where the support services are focussed on ensuring the children participate in programmes of learning presented by education professionals who have the knowledge and skills to integrate appropriate practices into their classroom programmes.

7.6 Limitations

It is important to accept the limitations of this research study.

It must be acknowledged that the families invited to participate in the study were chosen because they had demonstrated dissatisfaction with their children's enrolments in regular schools, and transitioned them to special schools. This sample of nine families may not represent the views of other families whose children with special needs are enrolled in regular schools.

There was a limitation of dialogue when the families were talking about their children's after they had transferred to their special school. The focus of the conversations had been upon the families' experiences to the time of making the decision to move to a special school. A follow up interview would give further insight into the families' experiences of special education.

It is also acknowledged that there was an over representation of children with ASD in the sample. A revision of the criteria for children participating in the research resulted in three children not identified as being on the Autism Spectrum being invited to join the research group. A more balanced overview of children moving from regular to special school may be been achieved if more information about the students was gathered before making a decision as to which families were invited to participate in the research.

Although participating families were given the opportunity to invite members of their extended family to join them in the interviews, only immediate family members participated. However I met with Britney's grandmother in a separate location to hear her 'voice' when talking about the experiences she has shared with her granddaughter and her family. The input from family members not directly responsible for the daily care of the children may have added a different 'voice' to the conversations.

While it is difficult to see how bias can be completely avoided, I was aware that my teaching experience and partnership with families may have influenced my interactions with the families. I understood this possibility of bias and practised 'constant self control' (Gavron, 1966, p. 159) to ensure the interviews were as bias free as was possible. By referring to and reflecting on the questions adapted from Fine (2003) in 3.3.1 before visiting the families, 'self control' was very dominant in my preparations for the interviews.

7.7 Recommendations

Given that the educational ideology of inclusion is an evolving and complex concept grounded on 'key principles of social justice and human rights' (Higgins, MacArthur, & Rietveld, 2006, p. 4), the experiences of the nine families who participated in this study show there are problems within the practices of this ideology. For these families, 'inclusion' was a concept they understood as their being able to enrol their children in regular schools and to expect that the programmes of learning offered in these schools would be in keeping with their children's special learning needs. For all ten children the schools and the services and personnel working with them did not meet their families' expectations of regular schooling, despite the 'clear message from national documents that children with special needs are entitled to an education that supports their fullest possible social integration and development' (Office of the Children's Commissioner, 2012, p. 2).

The following recommendations, based on the findings from this study, are designed to improve the support families and their children with special needs who have made the decision to enrol their children in their neighbourhood regular schools. The recommendations are also intended to give better support to the people working in these schools that they in turn are able to give appropriate support to all the students in their school communities, especially those with special learning needs.

- That access to health specialists is 'fast tracked' to ensure early diagnosis of children with special learning needs.
- That the charters of all schools acknowledge the right of children with special needs to attend their neighbourhood regular school and participate in appropriate programmes of learning.
- That the charters of all schools address the school's commitment to a school culture that focuses on the quality of the experiences of all those within the school community.

- That there is a compulsory requirement for all students in pre-service teacher education courses and all teachers in schools to participate in programmes to gain an understanding of the rights of students with special education needs to have access to appropriate programmes of learning at all class levels, and the right to work with teachers who have the skills to develop these programmes to meet their unique learning needs.
- That 'whole school' professional development programmes for all those working in regular schools becomes a compulsory component of the professional development of all schools. At this time, all participants are introduced to and practice procedures that will enhance their interactions with all students in the school community, especially those students who respond to strategies developed to assist their interaction with other people.
- That professional development programmes for teachers and teacher aides include: specialised programmes to inform classroom staff of learning, health, and physical needs unique to individual students; and times of interaction with other classroom personnel to observe and discuss teaching practices to enhance the learning outcomes of these students with special learning needs.
- That all teacher aides working with students with special needs complete pre-service education programmes that promote the concept of inclusive education and provide a knowledge base on which to further develop their skills to support students with special learning needs.
- That the Ministry of Education: Special Education personnel complete a compulsory education programme that addresses the role they have within the Ministry of Education, and ensures they have the knowledge and skills to communicate effectively with the families of children with special needs and provide approved appropriate resources for their children.
- That Ministry of Education: Special Education personnel have knowledge of all the services that are available to families of children with special learning needs and offer this information to the families as and when it is needed.
- That the allocation of teacher aide support hours is discussed and set at the last IEP meeting of the school year and that these hours remain constant for the next year. This would enable the families, the students, the teachers, and the teacher aides to plan the students' programmes knowing there is continuity in the support available for a definite period.

- That all schools implement and practice a policy outlining procedures to ensure all persons within the school community enjoy a ‘bully free’ environment.
- That a new role of ‘neutral’ mentor be available to support families who are experiencing difficulties interacting with educational and health professionals and government agencies.

7.8 Further research

One of the key components underpinning the introduction of SE2000 was the formalisation of a partnership between families and those working in and with the schools their children attended. But very little consideration was given as to how this partnership was to be implemented (Brown & Wills, 2000). For the families interviewed, partnership with the host schools and the fund holders of the resources was a very problematic concept. Families of children and young people with special education needs ‘frequently need the specialist support and input that can only come from a professional or service provider’ (Wills, 2006, p. 197). Families also need to know that the education of their child is a joint enterprise involving both home and school. This joint partnership extends to the support and consultation received from government agencies such as MoE: SE and health professionals.

One solution to a successful partnership between the key stakeholders in inclusive education could be the use of a ‘neutral’ mentor whose role would be to support families experiencing difficulties in interactions with education and health personnel. The mentor would have knowledge of education in the community in which he or she was working. The neutrality of the mentor would be necessary to ensure the families would not have a sense of bias in any communication. Families could be made aware of such a service at points of contact at such settings as health centres, early childhood centres, Citizens Advice Bureau. This ‘mentoring’ role was identified by some families participating in this research as being most supportive when they were experiencing issues with agencies and schools, and were unable to *see the woods for the trees* (Kathy).

It has become apparent when discussing the role of the teachers and TAs in meeting the expectations of the families’ interviews that many of the teachers were inadequately prepared to work with or supervise the TAs working in their classrooms. When discussing findings arising from a study conducted by examining the experiences of disabled students and TAs, Rutherford (2008) advocates that teacher education, at both the pre-service and in-school levels, has a responsibility to ensure all teachers have a commitment to developing respectful relationships that underpin their interactions with all those working with the students in the school. Giangreco (2010) writes that 75% of teachers in regular education in USA had not had any education (pre-service or in service) to work with TAs. The onus for ensuring all students receive competent instruction is the responsibility of school's leaders and teachers. Research focussing on the education of teachers in the management of the resources available to them, particularly TAs, should clarify the role of the teacher in meeting the expectations of both TAs and the children they support in classrooms. As Griangreco (2010) discovered, it is not until this need for classroom management education is given to all teachers that the additional support resources will be fully effective in meeting the needs of all the students, particularly those with special needs who are reliant on these additional resources to access their programmes of learning.

Coleman (2011) states there is a 'dearth of research into the practical outcomes' (p. 11) for children supported by resources introduced in SE2000. One link between government-funded support such as TAs and specialist teachers and therapists and student outcomes is the IEP. In this document the intended learning outcomes of a student's programme are supported by statements describing how and with whom these goals will be achieved. Research investigating the translation of specialist support identified in an IEP into curriculum based outcomes would indicate the education added value for which the resources were indirectly responsible. Such research would also enable evidence to be gathered showing a distinction between the curriculum-based resource outcomes and those focussing on health and therapeutic outcomes for personal care purposes.

Research, based on IEP learning outcomes and resource support, could also be used as evidence to justify the need for ongoing provision of resources and therefore avoid the raising of barriers between education professionals, families and fund holders when discussing of student resourcing. Comparisons of IEP intended and achieved learning outcomes would also give families the confidence that the practice of inclusive education was meeting their children's learning needs.

7.9 Closing thoughts

The philosophy of inclusive education underpins current practices of the Ministry of Education, with the funding of resources designed to support children with special needs in regular schools. But one of the 'subtle and unplanned consequences' (Coleman, 2011, p. 20) of the pupil-bound funding (Sigaffoos et al., 2010) has been the roll growth of special schools, which, as fund holders for a number of students, are able to offer students and families access to learning programmes that are perceived as appropriate to the children's special needs.

The challenge for all those working in education is to establish an education service that is inclusive of all students. However, this ideal education provider of inclusiveness may have different interpretations for different students. Some students with special needs may be supported in classes attended by their peers; other students may be working in adjacent classrooms where all the students who have very high needs are supported by a larger staff of specialist teachers, TAs, and therapists. Nevertheless, in this 'inclusive school' all teachers members are presenting their students with programmes of learning needs adapted to meet their individual needs. This school is also a place where all those within the school's environment are practising their 'inclusive' skills to ensure the needs of every person are being met. It is then that students such those in this study will have the experience of completing all their schooling in a productive, positive, inclusive setting where they achieve their potential with their neighbourhood peers.

REFERENCES

AbilityPath.org (2012). Walk a mile in their shoes: Bullying and the child with special needs. Retrieved from http://www.abilitypath.org/areas-of development/learning-schools/bullying/articles/walk-a-mile-in-their-shoes.pdf

Adelman, C., Jenkins, D., & Kemmis, S. (1977). Rethinking case study: notes from the second Cambridge conference. *Cambridge Journal of Education 6*, 139–50.

Ainscow, M. (2008). Teaching for diversity: The next big challenge. In F. M. Connelly (Ed.), *The Sage handbook of curriculum and instruction* (pp. 240–260). Los Angeles, CA: Sage.

Allen, A. B. (1980). *They hear with the eye: A centennial history of the Sumner School for deaf children, Christchurch, New Zealand, 1880–1980.* Wellington, New Zealand: School Publications Branch, Department of Education.

Anderson, G. (1995). *Fundamentals of educational research.* Basingstoke, England: Falmer Press.

Appendices to the Journals of the House of Representatives (1881) I, E-6A. Wellington, New Zealand: Author.

Ashman, A., & Elkins, J. (2005). Opportunities, rights, and the individual. In A. Ashman & J. Elkins (Eds.), *Educating children with diverse abilities* (2nd ed., pp. 65–96). Sydney, Australia: Pearson Education.

Bailey, C. A. (2007). *A guide to qualitative field research* (2nd ed.). Thousand Oaks, CA: Pine Forge Press.

Bailey, J. (2008). First steps in qualitative data analysis: Transcribing. *Family Practice 25*(2), 127–131.

Ballard, K. (1996). Inclusive education in New Zealand: Culture, context and ideology. *Cambridge Journal of Education 26*(1), 33–45.

Bartlett, R. (2009). The Ongoing and Reviewable Resourcing Scheme: Policy and outcomes mismatch? *New Zealand Journal of Teacher's Work 6*(2), 123–128.

Beagle, J. M. (1974). *Children of the state: A study of the New Zealand industrial school system, 1880–1925* (Unpublished master's dissertation). University of Auckland, New Zealand.

Bell, J. (1996). *Doing your research project: A guide for first time researchers in education and social sciences.* (4th ed.). Berkshire, England: Open University Press.

Bertrand, J. T., Brown, J. E., & Ward, V. M. (1992). Techniques for applying focus group data. *Evaluation Review 16, 198–209.*

Blaikie, N. (2009). *Designing social research: The logic of anticipation* (2nd ed.). Malden, MA: Polity Press.

Blatchford, P., Russell, A., & Webster, R. (2012). *Reassessing the impact of teaching assistants: How research challenges practice and policy.* Abingdon, England: Routledge.

Blaxter, L, Hughes, C., & Tight, M. (2006). *How to research* (3rd ed.). Buckingham, England: Open University Press.

Bogdan, R.C., & Biklen, S. K. (2007*). Qualitative research for education: An introduction to theories and methods* (5th ed.). Boston, MA: Pearson.

Booth, T. (1996). Stories of exclusion: Natural and unnatural selection. In E. Blyth & J. Milner (Eds.), *Exclusion from school: Inter-professional issues for policy and practice* (pp. 21–36). London, England: Routledge.

Borbasi, S., & Jackson, D. (2012). *Navigating the maze of research: Enhancing nursing and midwifery practice* (3rd ed.). Chatswood, Australia: Elsevier.

Bourke, R. (1999, February). *Ongoing monitoring and evaluation: Where to from here?* Paper presented at the Special Education 2000 Research Conference, Wellington, New Zealand.

Boyden, J. (1994). *Families: Celebration of hope in a world of change.* London, England: Doubleday.

Brouillette, R. (1992). Theories to explain the development of special education. In P. Mittler, R. Brouillette, & D. Harris (Eds.), *World year book of education: Special needs education* (pp. 29-37). London, England: Kogan Page.

Brown, C. (1994). Special education policies of the Fourth Labour Government, 1984-1990: An interpretive analysis. (Unpublished master's dissertation), Massey University, Palmerston North, New Zealand.

Brown, C., & Wills, R. (2000). *Special education 2000: Getting it right together?* Paper presented at the International Special Education Conference 2000: Including the excluded, Manchester, England.

Brown, D., & Thomson, C. (2005). Special education policy. Meeting the challenges of diversity. In J. Codd & K. Sullivan (Eds.), *Education policy directions in Aotearoa New Zealand* (pp. 161–175). Southbank, Australia: Dunmore Press.

Brown, D., & Moore, D. (2011). Reconceptualizing special education. In C. M. Rubie-Davies (Ed.), *Educational psychology: Concepts, research and challenges.* (pp. 184–199). Abingdon, England: Routledge.

Burgess, R. G. (1984). The whole truth? Some ethical problems of research in a comprehensive school. In R. G. Burgess (Ed.), *Field methods in the study of education.* (pp. 139–163). Lewes, England: Falmer Press.

Burnett, N. (2009). *Foreword to policy guidelines on inclusion in education.* Paris, France: UNESCO.

Burns, R. B., (1998). *Introduction to research methods* (3rd ed.). Melbourne, Australia: Longman.

Butterworth, G., & Butterworth, S (1998). *Reforming education: The New Zealand experience 1984–1996.* Palmerston North, New Zealand: The Dunmore Press.

Callendar, D. (1972). Intellectually handicapped children. In S. J. Havill & D. R. Mitchell (Eds.), *Issues in Special Education.* (pp. 143–152). Auckland, New Zealand: Hodder and Stoughton

Carrol-Lind, J., & Rees, K. (2009, September). *Schools for all: Children's rights to an inclusive education in New Zealand.* Paper presented at the Making Inclusive Education Happen: Ideas for sustainable change Conference, Wellington, New Zealand.

Carson, T. (2008). *Understanding the family court.* Papakura, New Zealand: Alibi Press.

Chapman, J. (1988). Special Education in the least restrictive environment: Mainstreaming or Maindumping? *Australia and New Zealand Journal of Developmental Disabilities 14*(2), 123–134.

Christians, C. (2005). Ethics and politics in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.) *The landscape of qualitative research. Theories and issues* (3rd ed., pp. 139–164). Thousand Oaks, CA: Sage Publications.

Clark, J. (1997). *Educational research: Philosophy, politics, ethics.* Palmerston North, New Zealand: ERDC Press.

Clough, P. & Nutbrown, C., (2002). *A student's guide to methodology*. London, England: Sage.

Codd, J., & Openshaw, R. (2005). The education system in Aotearoa New Zealand. In P. Adams, R Openshaw & J. Hamer (Eds.) *Education and society in Aotearoa New Zealand* (2nd ed., pp. 155-186). Melbourne, Australia: Thomson Dunmore Press.

Coleman, P. (2011). Special Education 2000 policy: Our leaky home? *Kairaranga, 12*(1) 10–22.

Creswell, J. W. (2009). *Research design: Qualitative, qualitative and mixed methods approaches* (3rd ed.). Thousand Oaks, CA: Sage.

Creswell, J. W. (2012). *Educational research: Planning conducting and evaluating quantitative and qualitative research* (4th ed.). Boston, USA: Pearson.

Creswell, J. W. & Plano Clark, V. I. (2011). *Designing and conducting mixed methods research* (2nd ed.). Thousand Oaks, CA: Sage.

Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process.* Crow's Nest, Australia: Allen & Unwin.

Cumming, I., & Cumming, A. (1978). *History of state education in New Zealand 1840–1975.* Wellington, New Zealand: Pitman.

Cunningham, C., Stevenson, B., & Tassell, N. (2005). *Analysis of the characteristics of whānau in Aotearoa.* Palmerston North, New Zealand: Massey University.

Davies, B., & Logan, J. (2012). *Reading research: A user-friendly guide for health professionals.* Toronto, Canada: Elsevier.

Davies, T., & Prangnell, A. (2000, July). *Special Education 2000 – A national framework in special education.* Paper presented at the International Special Education Conference 2000: Including the excluded, Manchester, England.

Denzin, N. K. (2010). *The Qualitative Manifesto.* Walnut Creek, CA: Left Coast Press.

Denzin, N. K. & Lincoln, Y. S. (2008). Introduction: The discipline and practice of qualitative research. In *The SAGE handbook of qualitative research* (3rd ed. pp. 1–43). Thousand Oaks, CA: Sage.

Department of Education, (1987). *The draft review of special education.* Wellington, New Zealand: Government Printer.

Department of Health (1969). *Mental Health Act, 1969.* Retrieved www.moh.govt.nz/notebooks.nsf/0/23EODEF68DF843CE4C2565070018AA3F

Diener, E. & Crandall, R. (1978). *Ethics in social and behavioural research.* Chicago: University of Chicago Press.

Drummond, H. (2001). *The art of decision making: Mirrors of imagination, masks of fate.* Chichester, England: Wiley.

Durie, M., (1994, June). *Whānau, whānaungatanga and healthy development.* Paper presented to the Public Health Conference. Massey University Department of Māori Studies, Massey University, Palmerston North, New Zealand.

Education Counts (2012). School roll summaries. Retrieved from http://www.educationcounts.govt.nz/publications/schools/2259School_roll_summary_reports/july_school_roll_returns/

school_roll_summary-report_july_2006>

school_roll_summary-report_july_2007

school_roll_summary-report_july_2008

school_roll_summary-report_july_2009

school_roll_summary-report_july_2010

Education Gazette (2011). *A fully inclusive education.* Retrieved from mhtml:file//E:\Education Gazette.mht

Education Review Office (ERO). (2005). *An evaluation of the Ongoing and Reviewable Resources Schemes.* Wellington, New Zealand: ERO.

Education Review Office (ERO) (2010). *Including students with high needs.* Wellington, New Zealand: ERO.

Ervin, D. (2011). *Bullying children with disabilities: A global epic.* Retrieved http://www.eric.ed.gov.ezproxy.massey.ac.nz/PDFS/ED518488.pdf

Fancy, H. (1999). *Opening address.* Paper presented at the Special Education Research Conference, Wellington, New Zealand.

Fazel, Z (2011). *The development of a training program for secondary level educators on co-teaching* (Unpublished doctoral dissertation). San Diego, CA: Alliant International University.

Field-Smith, C. (2009). Families as decision makers: When researchers and advocates work together. *Childhood Education 85*(4), 237–242.

Fine, M., Weis, L., Weseen, S. & Wong, L. (2003). For whom? Qualitative research, representation, and social responsibilities. In N. K. Denzin & Y. S. Lincoln (Eds.), *The landscape of qualitative research: Theories and Issues (*2nd ed., pp. 167–207). Thousand Oaks, CA: Sage.

Fitzgerald, S. P. (2002). *Decision making.* Oxford, England: Capstone.

Flewitt, R., & Nind, M. (2007). Parents choosing to combine special and inclusive early year settings: The best of both worlds. *European Journal of Special Needs Education*, *24*(4), 425–441.

Forness, S. R., & Kavale, K. A. (2001). ADHD and a return to the medical model of special education. *Education and treatment of children, 24*(3), 224-227.

Foucault, M. (1991). *The Foucault Reader* (P. Rabinow Ed.). London, England: Penguin Books.

Franklin, A. D. C. (2008). *The Alli way of life. Living well with cerebral palsy*. Christchurch, New Zealand: Allison Franklin.

Frost, M. (2009). Plenary session, '*Making it happen'* Conference. Wellington, New Zealand.

Fulcher, G. (1989). *Disabling policies? A comparative approach to education policy and disability*. London, England: Falmer Press.

Galotti, K. M. (2007). Decision structuring in important real life choices. *Psychological Science 18*(4), 320–324.

Galotti, K. M., & Tinkelenberg, C. E. (2009). Real-life decision making: Parents choosing a first-grade placement. *The American Journal of Psychology 22*(4), 455–468.

Gasson, N. R. (2008). High fences and locked gates: Extreme special needs in the era of inclusion. *New Zealand Journal of Education Studies 43*(1), 107–126.

Gavron, H. (1966). *The captive wife.* London, England: Routledge & Keagan-Paul.

Gestwicki, C. (2007). *Home, school and community relations* (6th ed.). Clifton Park, NY: Thompson Delamar Learning.

Giangreco, M. F. (2010). One-to-one paraprofessionals for students with disabilities in inclusive classrooms: Is conventional wisdom wrong? *Intellectual & Developmental Disabilities 48*(1), 1-13.

Giangreco, M. L., Broer, S. M., & Suter, J. C. (2011). Guidelines for selecting alternatives to overreliance on paraprofessionals: Field testing in inclusive orientated schools. *Remedial and Special Education 32(*1), 22–38.

Gill, M. & da Costa, J. (2010). Students with disabilities in mainstream schools: District level perspectives in anti-bullying policy and practice within schools in Alberta. *International Journal of Special Education 25*(2), 148–161.

Glaser, B. G. (1992). *Basis of grounded theory analysis.* Mill Hill, CA: The Sociology Press.

Glesne, C., (2006). *Becoming qualitative researchers: An introduction.* Boston, MA: Pearson.

Graham, J., (1981). Settler society. In W. H. Oliver (Ed.), *The Oxford History of New Zealand*, (pp. 112–139). Wellington, New Zealand: Clarendon Press.

Gray, D. E., (2004). *Doing research in the real world.* London, England: Sage.

Greaves, A. (2003). *Special Education 2000: Rhetoric or reform*? *ACE papers* (2), 58–74.

Grenot-Scheyer, M., Staub, D., Peck, C. A., & Schwartz I. S., (1998). Reciprocity and friendships. In L. H. Meyer, H. Park, I. S. Grenot-Scheyer & Harry, B. (Eds.), *Making friends: The influences of culture and development* (pp. 149–167). Baltimore, MA: Paul H Brookes.

Group Special Education, (GSE), (2011). Reply from GSEdataRequests@minedu.govt.nz Received 03.06.2011

Gubrium, J. F., & Holstein, J. A. (2001). From the individual interview to the interview society. In J. F. Gubrium & J. A. Holstein (Eds.), *Handbook in interview research: Context and method* (pp. 3–32). Thousand Oaks, CA: Sage.

Gunn, A. C. (2008). *Heteronormativity and early childhood education: Social justice and some puzzling queries.* (Unpublished doctoral dissertation). University of Waikato, Hamilton New Zealand

Hanson, M. J., Horn, E., Sandall, S., Beckham, P., Morgan, M., Marquart, J., Barnsell, D., & Chow, H. (2001). After pre-school inclusion: Children's educational pathways over early school years. *Exceptional Children 68*(1), 65–83.

Heller, E., Christensen, J., Long, L., Mackenzie, C. A., Osano, P. M., Ricker, B., Kagan, E., & Turner, S., (2011). Dear Diary: Early career geographers collectively reflect on their qualitative field research experiences. *Journal of Geography in Higher Education 35*(1), 67–83.

Herr, S. S. (1993). Special education as a human and legal right. In P. Mittler, R. Brouillette & D. Harris (Eds.), *World Year Book of Education: Special Needs Education* (pp. 39–50). London, England: Kogan Page.

Hess, R. S., Molina, A. M., & Kozleski, E. B. (2006). Until someone hears me: parent voice and advocacy in special educational decision making. *British Journal of Special Education 3*(3) 148-157.

Higgins, N., Nairn, K., & Sligo, J. (2007). Peer research with youth. Negotiating (sub)cultural capital, place and participation in Aotearoa New Zealand. In S. Kindon, R. Pain, & M. Kesby (Eds.), *Participatory action research approaches and methods. Connecting people, participation and place* (pp. 104–111). London, England: Routledge.

Higgins, N., MacArthur, J., & Rietveld, C. (2006). Higgledy-piggledy policy: Confusion about inclusion. *Childrenz Issues 10*(1), 30–36.

Higgins, N., MacArthur, J., & Morton M. (2008). Winding back the clock: The retreat of New Zealand inclusive education policy. *New Zealand Annual Review of Education 17*, 145–167.

Hocutt, A., & Fowler, K. M. (2009). Case study research: An overview. In J. Paul, J. Kleinhammer-Tramill & K. Fowler (Eds.), *Qualitative research methods in special education* (pp. 53–94). Denver, CA: Love Publishing.

Howard, R., & Ford, J. (2007). The roles and responsibilities of teacher aides supporting students with special needs in secondary school settings. *Australasian Journal of Special Education 31*(1), 25–43.

Hulston, S. (2000). “Blurring the edges”: An in-depth qualitative study of inclusion and the curriculum in a New Zealand secondary school. (Unpublished doctoral dissertation) University of Canterbury, Christchurch, New Zealand.

Human Rights Act (1993). Retrieved from http//www.legislation.govt.nz/act/public/1993/0082/latest/whole.html

Human Rights Commission (1986). *The treatment of disabled persons in socialsecurity and taxation law*. Occasional paper No. 11, Canberra, Australia: Australian Government Publishing Service.

Jarvis, J., (2007). Jigsawing it together: reflections on deaf pupils and inclusion. In R. Cigman (Ed.), *Included or excluded. The challenge of the mainstream for some SEN children* (pp. 42–50). Abingdon, England: Routledge.

Jenkinson, J. C. (2001). *Special education: A matter of choice?* Victoria, Australia: ACER Press.

Johnson, J. (2002). In-depth interviewing. In J. F. Gubrium & J. A. Holstein (Eds.), *Handbook in interview research: Context and method* (pp. 103–119). Thousand Oaks, CA: Sage.

Kalyanpur, M., Harry, B., & Skrtic, T. (2000). Equity and advocacy expectation of culturally diverse families’ participation in special education. *International Journal of Disability, Development and Education 47*(2), 119–136.

Kauffman, J. (2007). Conceptual models and the future of special education. *Education and the treatment of children* 30(4), 241-258.

Kearney, A. C. (2007). *Barriers to school inclusion: An investigation into the exclusion of disabled students from and within New Zealand schools* (Unpublished doctoral dissertation). Massey University, Palmerston North, New Zealand.

Kearney, A. C. (2008). Exclusion at school: What is happening for students who are disabled? *International Journal of Diversity in Organisation, Communities and Nations 7*(7), 219–227.

Kearney, A. C. & Kane, R. (2006). Inclusive education policy in New Zealand: Reality or ruse? *International Journal of Inclusive Education 10*(2–3), 210–219.

Kershner, R. (2007). What do teachers need to know about meeting special education needs? In L. Florian (Ed.), *The Sage handbook of special education* (pp. 486–498). London, England: Sage.

Kirk, S., Gallagher, J., Coleman, M. R., & Anastasiow, N. (2012). *Educating exceptional children.* Belmont, CA: Wadsworth CENGAGE learning.

Kuhn, T. S. (1962). *The structure of scientific revolutions.* Chicago, IL: University of Chicago Press.

Lange, D. (1988). *Tomorrow's schools: The reform of education administration in New Zealand schools.* Wellington: New Zealand Government Printer.

Leger Rodriguez, T. N. (2010). *Paraprofessional preparation and supervision in special education* (Unpublished doctoral dissertation), University of California USA.

Li, F., & Sass, T. (2010). *What makes special education teachers special? Teacher training and achievement of students with disabilities. Working paper 49.* Retrieved from www.caldercentre.org/publications/calder-working-paper-49.cfm

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry.* Beverly Hills, CA: Sage.

Lofland, J. (1971). *Analysing social settings.* Belmont, CA: Wadsworth.

MacArthur, J (2009). *Learning better together: Working towards inclusive education in New Zealand schools.* Wellington, New Zealand: IHC.

MacArthur, J., Kelly, B., & Higgins, N. (2005). Supporting the learning and social experiences of students with disabilities: What does the research say? In D. Frazer, R Moltzen, & K. Ryba (Eds.), *Learners with special needs in Aotearoa New Zealand* (pp. 49–73). Southbank, Australia: Thomson Dunmore Press.

MacArthur, J., Sharp, S., Kelly, B. & Gaffney, M. (2007). Disabled children negotiating school life: Agency, difference and teaching practice. *International Journal of Children's Rights 15*, 99–120.

Macartney, B. C. (2011). *Disabled by discourse: Two families' narratives of inclusion, exclusion and resistance in education* (Unpublished doctoral dissertation). University of Canterbury, Christchurch, New Zealand.

Mackey, J. (1967). *The making of a state education system: The passing of the New Zealand Education Act 1877*. London: Geoffrey Chapman.

Mason, J., (2002). *Qualitative researching* (2nd ed.). London: Sage.

Massey University (2010). *Massey University code of ethical conduct for research involving human participants.* Retrieved from massey.ac.nz/massey/research/research-ethics/human-ethics.approval.cfm

Massachusetts advocates for children (2009). Targeted, taunted, tormented: The bullying of children with Autism Spectrum Disorder. Retrieved from http://www.massedovates.org/documents/Bullyong-Report_000.pdf

McKay, P. (2010). *A fully inclusive education*. Retrieved from mhtml:file://E:\Education Gazette.mhl

McKay, S. (2010). *Future of special schools reviewed.* Retrieved from http://www.stuff.co.nz/southland-times.news/3356755/Future-of-special-schools-reviewed

McMenamin, T. (2009). New Zealand Day Special Schools: Changes and challenges under Special Education 2000. *New Zealand Annual Review of Education 18*, 183–200.

McMenamin, T. (2011). The tenacity of special schools in an inclusive policy environment: The New Zealand situation 1996-2010. *Support for learning. British Journal of Learning Support 26*(3), 97–102.

McMillan, J. H. (2004). *Educational research: Fundamentals for the researcher* (4th ed.). Boston, MA: Pearson.

Merriam, S. B. (1998). *Case study research in education: A qualitative approach*. San Francisco, CA: Jossey-Bass.

Meyen, E. L. (1995). A commentary on special education. In E. L. Meyen & T. M. Skrtic (Eds.), *Special Education and student disability: Traditional, emerging and alternative perspectives* (4th ed., pp. 5–32). Denver CO: Love Publishing.

Meyen, E. L. (1995). Legislative and programmatic foundations of special education. In E. L. Meyen & T. M. Skrtic *Special Education and student disability: Traditional, emerging and alternative perspectives.* Denver, CO: Love Publishing.

Miles, M., & Huberman A. (1994). *Qualitative data analysis.* Thousand Oaks, CA: Sage.

Ministry of Disability Issues (2001). *The New Zealand Disability Strategy: Making a world of difference. Whakanui Oranga.* Wellington, New Zealand: Ministry of Health. Retrieved from: http://www.nzds.govt.nz

Ministry of Education (1991a). *Education provision for learners with special needs: A review of policy*. Wellington, New Zealand: Author.

Ministry of Education (1991b). *Special education in New Zealand: Statement of intent.* Wellington, New Zealand: Author.

Ministry of Education (1996). *Special education 2000.* Wellington New Zealand: Author.

Ministry of Education (1998). *Special Education 2000-Getting it right, together*. Wellington New Zealand: Author.

Ministry of Education (2000). *Ongoing and Reviewable Resourcing Scheme: Guidelines and application forms for school students.* Wellington, New Zealand: Author.

Ministry of Education (2002). *Kai Tutangata Ai – Supported learning.* Wellington, New Zealand: Author.

Ministry of Education (2003). *Education priorities for New Zealand*. Wellington, New Zealand: Author.

Ministry of Education (2005). *Local service profiling national report.* Wellington, New Zealand: Author.

Ministry of Education (2010a). *Review of special education: Discussion document.* Wellington, New Zealand: Author.

Ministry of Education (2010b). *Review of special education: Public response.* Wellington, New Zealand: Author.

Ministry of Education (2010c). *Fact sheet. Success for all. Every school. Every child*. Wellington, New Zealand: Author.

Ministry of Education (2011a). *Special Education: Policy guidelines* Retrieved from www.minedu.govt,nz/NZEducation/EducationPolicies/ SpecialEducation /PolicyAndStrategy/SpecialEducationPolicy.aspx

Ministry of Education (2011b). *Success for all – Every school, every child*. Wellington, New Zealand: Author.

Ministry of Education (2011c). *The Ongoing Resourcing Scheme: Information for Educators.* Wellington, New Zealand: Author.

Ministry of Education (2012a). *ORS guidelines.* Retrieved from www.minedu.govt.nz/NZEducation/EducationPolicies/SpecialEducation/FormsAndGuidelines/IPEGuidelines/The_IEP_Process.aspx

Ministry of Education, (2012b). *Supporting future-orientated learning & teaching – a New Zealand perspective.* Wellington New Zealand: Author.

Ministry of Health, (2012), *Child development*. Retrieved from www.health.govt.nz/yourhealth-topics/disability-services/childdevelopmental services

Mitchell, D. R., (1999). Special education in New Zealand: A decade of change. In M. Thrupp (Ed.), *A decade of reform in New Zealand. Where to now?* (pp. 199–210). Hamilton, New Zealand: School of Education, Waikato University.

Mitchell, D. R. (2000). Policies and systems for students with special education needs. In M. Thrupp (Ed.), *A decade of reform in New Zealand. Where to now? (pp. 199-210).* Hamilton, New Zealand: School of Education, Waikato University.

Mitchell, D. R. (2010). *Education that fits: Review of international trends in the education of students with special education needs.* Retrieved from www.educationcounts.govt.nz/publications/special_education/education-education-that-fits

Mitchell, D. R. & Havill, S. J. (1972). Introduction. In S. J. Havill & D. R. Mitchell (Eds.), *Issues in New Zealand special education* (pp. 9–13). Auckland, New Zealand: Hodder and Stoughton.

Mitchell, D. R., & Mitchell, J. W. (1985). *Out of the shadows: A chronology of significant events in the development of services for exceptional children and young persons in New Zealand 1850–1983.* Hamilton, New Zealand: University of Waikato, Department of Education.

Mittler, P. (2000). *Working towards inclusive education: Social contexts.* London: David Fulton.

Mock, D. R., & Kauffman, J. M. (2005). The delusion of full inclusion. In J. M. Kauffman & D. P. Hallahan (Eds.), *The illusion of full inclusion: A comprehensive critique of a current special education bandwagon* (2nd ed., pp. 295–316). Austin, TX: pro-ed.

Moore, D., Anderson, A., Timperley, H., Glynn, T., Macfarlane, A., Brown, D., & Thompson, C. (1999). *Caught between stories: Special education in New Zealand.* Wellington, New Zealand: New Zealand Council for Educational Research**.**

Mortlock, S. G. (1985). Education legislation. In N. N. Singh & K. M. Wilton (Eds.), *Mental retardation in New Zealand: Provisions, services and research* (pp. 19–29). Christchurch, New Zealand: Whitcoulls.

Morton, M., & Gorton, L. (2006). *Inclusive education in Aotearoa: What are we doing in initial teacher education, professional learning and development?* Christchurch, New Zealand: Christchurch College of Education.

Munford, R., & Sanders, J. (2001). Interviewing children and their parents. In M. Tolich (Ed.), *Research ethics in Aotearoa New Zealand* (pp. 99–111). Auckland, New Zealand: Pearson Education**.**

Murray, M. M., Christensen, K. A., Umbarger, G. T., Rade K. C., Aldridge, K., & Niemeyer, J. N. (2007). Supporting family choice. *Early Childhood Education 35*, 111–117.

Neilson, W. (2005). Disabilities, attitudes and discourses. In D. Fraser, R Motzen, & K. Ryba (Eds,), *Learners with special needs in Aotearoa New Zealand,* (3rd ed., pp. 9–21). Southbank, Australia: Thomson, Dunmore Press.

Newby, P. (2010). *Research methods for education*. Harlow, England: Pearson.

New Zealand Government (1877). *Education Act.* Wellington, New Zealand: Government Printer.

New Zealand Government, (1901). *School Attendance Act.* Retrieved from www.paperspast.natlib.govt.nz/cgi-bn/paperspast?

New Zealand Government, (1914). *The Education Act 1914.* Retrieved from www.teara.govt.nz/en/1966/education=evolution-of-present-system/4

New Zealand Government, (1951). *New Zealand Consultative Committee on Intellectually Handicapped Children.* Wellington, New Zealand: Department of Education.

New Zealand Government, (1964). *Education Act*. Retrieved from www.legislation.govt.nz/act/public/1964/0135/DLM356732.html

New Zealand Government, (1989). *Education Act.* Wellington: New Zealand Government Printer.

New Zealand Government, (1993). *Human Rights Act*. Retrieved from http://www.legislation.govt.nz/act/public/1993/0082/latest/whole.html

Nind, M., Flewitt. R., & Johnson, B. (2005). *Parents choosing to combine special and inclusive early year settings: the best of both worlds.* Southampton, England: University of Southampton.

Nirge, B. (1985). The basis and logic of the normalization principle. *Journal of Intellectual & Developmental Disability 11*(2), 65–68.

Norwich, B. (2008). What future for special schools and inclusion? Conceptual and professional perspectives. *British Journal of Special Education 35*(3), 136–142.

Nygren, G., Sandberg, E., & Gillstedt, F. (2012). A new screening programme for autism in a general population of Swedish toddlers. In *Research in Developmental Disabilities: A Multidisciplinary Journal 33*(4), 1200–1210.

O'Brien, P., & Ryba, K. (2005). Policies and systems in special education. In D. Fraser, R. Moltzen, & K. Ryba (Eds.), *Learners with Special Needs in Aotearoa New Zealand*. (3rd ed., pp. 22–48). Victoria, Australia: Thomson Dunmore Press.

Office of the Children's Commissioner (2012). *Development of a new intensive wrap-around special education service and consultation on the future role of residential special schools.* Wellington, New Zealand: Author.

Oliver, M. (1996). *Understanding disability*. Basingstoke, England: MacMillan.

Oliver, P. (2003). *The students' guide to research ethics.* Maidenhead, England: Open University Press.

Olssen M. & Matthews, K. M. (1997). Introduction. In M. Olssen and K. M. Matthews (Eds.), *Education policy in New Zealand: the 1990s and beyond* (pp. 7–40). Palmerston North, New Zealand: The Dunmore Press.

Osgood, R. L. (2005). *The history of inclusion in the United States.* Washington DC: Gallaudet University Press.

Paliokosta, P., & Blandford, S. (2010). Inclusion in school: A policy, ideology or lived experience: Similar findings in diverse school cultures. *The British Journal of Learning Support 25*(4), 179–186.

Pankhurst, K., Pankhurst, J., & Elkins, L. (1987). *Special education in New Zealand – Report of a 1982 Survey*. Wellington, New Zealand: New Zealand Council for Educational Research.

Parsons, S., Lewis, A., & Ellins, J. (2009) The views and experiences of parents of children with autistic spectrum disorder about educational provision: comparisons with parents of children with other disabilities from an online survey. *European Journal of Special Needs Education 24*(1), 37–58.

Patton, M. Q. (1990). *Qualitative evolution and research methods.* California, CA: SAGE Publications.

Paul, J., Kleinhammer-Tramill, J., & Fowler, K. (2009). Qualitative research in special education. In J. Paul, J. Kleinhammer-Tramill & K. Fowler (Eds.), *Qualitative research methods in special education* (pp. 1–14). Denver, CO: Love Publishing.

Payne, V. (2010). *Gone but not forgotten: Memories of Mangere Hospital and Training School.* Auckland, New Zealand: Copy and Print Document Centre.

Pickering, D., & Wilton, K. (1996). *New Zealand special schools. Students, parents, teachers.* Melbourne, Australia: School of Studies in Disability, Deakin University, Victoria, Australia.

Pihama, L. (1997). Policy constructions: In whose interest? A critical analysis of parents as first teachers in relation to Māori education. In M. Olssen and K. M. Matthews (Eds.), *Education policy in New Zealand: the 1990s and beyond.* Palmerston North, New Zealand: Dunmore Press.

Post Primary Teachers' Association (PPTA), (2010). *Submission to the Special Education Review*. Wellington, New Zealand: PPTA.

Reppeto, J. B., & Correa, V. I. (1996). Expanding views on transition. *Exceptional children 62*(6), 551-563.

Riddell, S., & Brown, S. (1994). *Special education needs policy in the 1990s*. London, England: Routledge.

Robertson, J., Gunn, T. R., Lanumata. T., & Pryor, J. (2007). *Parental decision making in relation to the use of Early Childhood Education services.* Wellington, New Zealand: Ministry of Education.

Ross, D. H. (1972). Special education: Retrospect and prospect. In S. J. Havill & D. R. Mitchell (Eds.), *Issues in New Zealand Special Education* (pp. 17–32). Auckland, New Zealand: Hodder and Stoughton.

Runswick-Cole, K. (2008). Between a rock and a hard place: Parent's attitudes to the inclusion of children with special educational needs in mainstream and special schools. *British Journal of Special Education 35*(3), 173–180.

Rutherford, G. (2012). In, out or somewhere in between? Disabled students' and teacher aides' experiences of school. *International Journal of Inclusive Education.* Retrieved from http://dx.doi.org/10.1080/13603116.2010.509818

Rutherford, G. (2008). *Different ways of knowing? Understanding disabled students' and teacher aides' school experiences within a context of relational social justice* (Unpublished doctoral dissertation). University of Otago, Dunedin, New Zealand.

Ryan E. J. (2004) Failing the System? Enforcing the right to education in New Zealand. Victoria University of Wellington Law Review Retrieved from http://austlii.edu.au/nz/jourmals/VUWLRev/2004/29.html

Ryba, K. & Annan, J. (2005). Students with intellectual difficulties. In D. Fraser, R. Moltzen & K. Ryba (Eds.), *Learners with Special Needs in Aotearoa New Zealand*. (3rd ed., pp. 271–293). Victoria, Australia: Thomson Dunmore Press.

Sainsbury, C. (2002) *Martian in the playground. Understanding the school child with Asperger's Syndrome.* Sydney, Australia: Software Publications.

Sandow, S., Stafford, D., & Stafford, P. (1987). *An agreed understanding: Parent-professional communication and the 1981 Education Act.* Windsor, England: NFER-Nelson Publishing.

Schwandt, T. A. (2003). Three epistemological stances of qualitative inquiry: Interpretivism, hermeneutics, and social construction. In N. K. Denzin & Y. S. Lincoln (Eds.), *The landscape of qualitative research: Theories and Issues* (3rd ed., pp. 292–331). Thousand Oaks, USA: Sage.

Segrin, C. & Flora, J. (2005). *Family communication.* New York, NY: Lawrence.

Seidman, I (2006). *Interviewing as qualitative research. A guide for researchers in education and social sciences* (3rd ed.). New York, NY: Teachers' College, Columbia University.

Shaddock, A. J., MacDonald, N., Hook, J., Giorcelli, L., & Arthur-Kelly, M. (2009). *Disability, diversity and tides that lift boats: Review of special education in ACT*. Chiswick, NSW, Australia: Services Initiative.

Sheehey, P. H. (2006). *Parent involvement in education decision making –a Hawaiian perspective*. Retrieved from www.highbeam.com/doc.1P3-1333787371.html

Shuker, R., 1987. *The one best system? A revisionist history of state schooling in New Zealand.* Palmerston North, New Zealand: Dunmore Press.

Sigafoos, J., Moore, D., Brown, D., Green, V. A., O'Reilly, M. F., & Lancioni, G. E. (2010). Special Education funding reform: A review of impact studies. In *Australasian Journal of Special Education 34*(1), 17–35.

Sigmon, S. B. (1987). *Radical analysis of Special Education: Focus on historical development and learning disabilities*. London, England: Falmer Press.

Slee, R. (2001). Social justice and the changing directions in educational research: The case of inclusive education. *International Journal of Inclusive Education 5*(2–3), 167–177.

Sleek, D., & Howie, D. (1987). Legislation, rights and advocacy. In D. R. Mitchell & N. Singh (Eds.), *Exceptional children in New Zealand* (pp. 57–69). Palmerston North, New Zealand: Dunmore Press.

Snook, I. (2003). *The ethical teacher*. Palmerston North, New Zealand: Dunmore Press.

Soltis, J. F. (1989). The ethics of qualitative research. *Qualitative Studies in Education 2*(2), 123–130.

Stanfield, B. (2009). *The art of focussed conversation.* Retrieved from http://www. ica-assocciates.ca/Resources/AFC.cfm

Stephens, D. &Villano, M. (2011). The targets: Why children with special needs are frequent targets: bulling, learning and teaching styles. *Ability Path.* Retrieved from http://www.abilitypath.org/areas-of-development/learning-school bullying/articles/bullying-special-needs-children-targets.html

Stuart-Cassel, V., Bell, A., & Springer, J. F. (2011). *Analysis of state bullying laws and policies.* Retrieved from http://www2.ed.gov/about/offices/list/opepd/index.html

Swearer, S. M., Wang, C., Maag, J., Siebecker, A. & Frerichs, L. (2012). Understanding the bullying dynamics among students in special and general education. *Journal of School Psychology 50*(4), 503–520.

Swick, K. J., & Hooks, L. (2005). Parental experiences and beliefs regarding inclusive placements of their special needs children. *Early Childhood Education Journal 32*(6), 397–402.

Symes, W., & Humphrey, N, (2011). School factors that facilitate or hinder the ability of teaching assistants to effectively support pupils with autism spectrum disorders (ASD's) in mainstream secondary schools. *Journal of Research in Special Education Needs 11*(3), 153–161.

Taylor, G. R. (2000). Qualitative research methods. In G. R. Taylor (Ed.), *Integrating quantitative and qualitative methods in research.* Lanham, MD: University Press of America.

Tuhiwai Smith, L. (2005). On tricky ground: Researching the native in the age of uncertainty. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed. pp. 85–108*)*. Thousand Oaks, CA: Sage.

Tuli, F. (2010). The basis of distinction between qualitative and quantitative research in social science: Reflections on ontological, epistemological and methodological perspectives. *Ethiopian Journal of Education and Sciences 6*(1), 97-108

Turnbull, A. P., & Turnbull, H. R. (2001). *Families, professionals and exceptionality (*4th ed.). Ohio, U.S.A: Merrill/Prentice Hall.

Turnbull H. R., & Turnbull, A. P. (1988). *Free appropriate public education: The law and children with disabilities* (5th ed.). Denver, CO: Love Publishing.

Turner, R. H. (1970). *Family interaction.* New York, NY: John Wiley & Sons.

United Nations (1948). *The Universal Declaration of Human Rights.* Retrieved from http://www.un.org/en/documents/udhr/index/shtml

United Nations (1971). *Declaration on the rights of mentally retarded persons.* New York, NY: Author.

United Nations (2008). *The United Nations convention on the rights of children.* New York, NY: Author.

United Nations Educational, Social and Cultural Organisation (2009). Policy guidelines on inclusion in education. Paris, France: Author.

van Haren, B., & Fiedler, C. (2008). Support and empower families of children with disabilities. *Intervention in School and Clinic 43*(4), 231–325.

van Manen, M. (1990). *Researching lived experience. Human science for an action sensitive pedagogy*. London, Ontario, Canada: Althouse Press.

Vincent, C. (1985). *Special education as social control: the historical development of industrial schools and special classes* (Unpublished master's dissertation). Massey University, Palmerston North, New Zealand.

Wadsworth, Y, (2011). *Do it yourself social research. The best-selling practical guide to doing social research projects* (3rd ed.) Crows Nest, Australia: Allen & Unwin.

Walker, R., (1985). *Doing research: A handbook for teachers.* London, England: Routledge.

Ward, L., Purdie, N., Irving, E., Weston, B., Armstrong, C., King, M., & Henderson, A. (2009). *Survey of special education resourcing.* Wellington, New Zealand: Ministry of Education.

Warren, C. A. B., (2002). Qualitative interviewing. In J. F. Gubrium & J. A. Holstein (Eds.), *Handbook in interview research: Context and method* (pp. 83–102). Thousand Oaks, CA: Sage Publications.

Weick, K. E. (1979). *The social psychology of organizing*. Reading, MA: Addison-Wesley.

Wills, R. (2006). Special Education 2000: A New Zealand experiment. *International Journal of Inclusive Education 10(2–3)*, 189–199.

Winterbourn, R. (1944). *Educating backward children in New Zealand.* Christchurch, New Zealand: Whitcombe & Tombs.

World Health Organisation. (1980). *The international classification of impairments, disabilities and handicaps.* (ICIDH) Geneva: World Health Organisation.

Wylie, C. (2000). *Picking up the pieces: Review of Special Education 2000.* Wellington, New Zealand: Ministry of Education.

Yin, R. K, (2009). *Case study research. Design and methods* (4th ed.). Thousand Oaks, CA: Sage.

Yin, R. K. (2011). *Qualitative research from start to finish*. New York NY: The Guilford Press.

Yin, R. K. (2012). *Applications of case study research* (3rd ed.). Thousand Oaks, CA, USA: Sage.

Young, J., Ne'eman, A., & Gelser, S. (2012). *Bullying and students with disabilities: A briefing paper from the National Council on Disability*. Retrieved from http://www.eric.ed.gov.esproxy.massey.ac.nz/PDFS/ED528255.pdf

Zeichnerm K. M. (1994). Research on teacher thinking and different views of reflective practice in teaching and teacher education. In I. Carlgren, G Handal, & S. Vaage (Eds.), *Teachers' minds and Actions: Research on teachers' thinking and practice* (pp. 9–27). London, England: Falmer Press.

GLOSSARY

ABA: Applied Behaviour Analysis: the use of behavioural learning theory to modify overt behaviours. The focus is usually on observable relationship of behaviour to the environment. ABA is usually linked with the education of individuals with autism. (http//rsaffran.tripod.com/consultants.htm).

Asperger's syndrome (AS): A form of autism at the higher functioning end of the autism spectrum. People with Asperger's syndrome are of average (or higher) intelligence and generally have fewer problems with language, often speaking fluently, though their words can sometimes sound formal; and ideas that are abstract, metaphorical or idiomatic may cause confusion and be taken literally (www.autism.org,nz)

Attention Deficit, hyperactivity Disorder (ADHD): a condition characterised by excessive hyperactivity, inattention and impulsivity. (ADHD.org.nz)

Autism (ASD): Also known as Autism Spectrum Disorder. ASD is a life-long developmental disability affecting social and communication skills. People with the disability can also have accompanying learning disabilities (www.autism.org.nz).

Cerebral palsy: Cerebral Palsy is a term used to describe a group of disabling conditions that affect movement and posture. It is caused by a defect or lesion to one or more specific areas of the brain, usually occurring during foetal development before, during or shortly following birth or during infancy (www.cpsoc.org.nz).

Decile rating: the indicator used to measure the extent to which schools draw pupils from their socio economic communities. The decile ratings range from a 1–10 rating, with 1 being the lowest and 10 the highest rating. The rating is based on the census data for the householders with school-aged children living in the school catchment area. The decile ratings are relocated following each census every five years. (www.minedu.govt.nz).

Down's syndrome: A chromosomal condition caused by the presence of or part of, an extra 21st chromosome. This extra genetic material causes delays in the way the child develops both physically and mentally. (http://kidshealth.org/Parents/MedicalProblems

Early bird programme: A 3-month programme designed and funded by Autism NZ to support parents of children with a diagnosis or probable diagnosis of autism spectrum: www.autismnz.org,.nz

Early intervention teams (EIT): work collaboratively with families, educators and specialists from other agencies to strengthen and extend young children's educational learning. The teams have an in-depth understanding of early childhood development and knowledge of special education in early childhood (www.minedu.govt.nz).

ENROL: The electronic management system for state schools in Aotearoa New Zealand first introduced to pilot schools in 2007. Enrol has six flags that are used to identify students with special learning needs including: enrolment in a special school, specialist support from GSE, counted as a regular student until the year in which the student turns 21 (www.minedu.govt.nz).

Family: 'the whānau: a diverse unit where people not necessarily sharing common ancestors form a cohesive group within which certain responsibilities and obligations are maintained'

Fragile X: A genetic condition involving changes in part of the X chromosome. http://www.ncbi.nlm.nih.gov

FTTE: Full time teacher equivalent: for students verified as having High Needs ORS funding, students receive the equivalent of 0.1 FTTE support and students verified as having Very High ORS needs receive 0.2% FTTE support.

Fund holders (Accredited Special Education Service Provider ASESP): Fund holders are responsible for the money provided to schools each term to pay for the support the students receives. The Ministry of Education: Special Education is the fund holder for many schools. Some schools are accredited fund holders for groups of schools. Special schools are fund holders for the students enrolled in each school. (www.minedu.govt.nz).

Group Special Education (GSE): A section of the Ministry of Education that provided services to children and young people with special education learning needs and their families and whānau, schools and early childhood centres (Ministry of Education, 2010). GSE was renamed Ministry of Education: Special Education in 2011. In this report GSE is used to identify the department within the Ministry of Education responsible for the management of students with special learning needs.

Individual Education Programme (IEP): A programme developed for school students with special education needs. It outlines the student's goals and the resources, support monitoring, and evaluation required to enable the child to meet those goals over a defined period (www.minedu.govt.nz).

Inclusion: A process of increasing the participation of pupils in, and reducing their exclusion from, the cultures, curricula, and communities of their local schools (Ainscow, 1999, p. 218 cited in MacArthur & Kelly, 2004, p. 44).

Mainstreaming: The selective placing of special education students within a regular classroom. The students would have demonstrated their ability to meet the social and educational expectations of the regular classroom teacher in their host school (Hulston, 2007).

Māori: The *tangata whenua*: the people of the land. The indigenous people of Aotearoa New Zealand.

Ministry of Education: Special Education (MoE: SE): Provides funding, services and support for children with special education needs. MoE: SE was previously named Group Special Education (GSE) and Special Education Services (SES).

NCEA (National Certificate of Educational Achievement): The NCEA achievement standards assess learning goals derived from the New Zealand Curriculum, while unit standards provide a link with technical and vocational training. www.nzqa.govt.nz/qualifications-standards/qualifications/ncea/understanding-ncea/the-facts/factsheet-2

Neighbourhood School: A school attended by students who live in the neighbourhood.

Neurotypical (NT): A term used in the autistic community as a label for people who are not on the autism spectrum.

PECS: Picture Exchange Communication System (PECS) is a communication system that allows a child to use a picture (or series of pictures) to express his or her needs and desires without a prompt or cue from another person.

Perceptual Motor Programme (PMP): A movement-based programme designed for young children. It concentrates on development of perceptions and language through a series of carefully planned activities (www.movingsmart.co.nz/home/school/pmp).

Ongoing Resourcing Scheme (ORS): Funding granted to students who have been identified as having the highest need for special education. See Appendices A1 and A2 for further information. www.minedu.govt.nz/NZEducation/EducationPolicies/Special Education/ServicesAndFunding/ORSOngoingResourcingScheme/Guide/aspx)

Regular school: The state school is not a special school, and includes Māori medium settings such as Kura Kaupapa Māori, Kura Iwi and Kōhanga Reo providers (Ministry of Education 2010).

Satellite class: A class where the students and staff 'belong' to a special school but the school is located on the site of a regular school.

Specialist Education Itinerant Teacher (SEIT): Teachers employed by a special school that supports students funded by ORS and their teachers in regular school placements. The students' host schools agree to transfer the additional ORS teacher staffing component, 0.1 or 0.2, to the special school who provides the SEIT service.

Serious Behaviour Initiative: Specialist support and guidance for pupils displaying severe and challenging behaviour through MOE: SE.

Special education: The provision of additional assistance to enable children and young people to access the curriculum in a range of education settings (www.minedu.govt.nz).

Special Education Grant (SEG): The Special Education Grant is a component of Special Education 2000. It is a grant paid directly to schools to be used to meet the needs of students with special education needs. The grant is linked with the decile rating and roll of the individual school (www.minedu.govt.nz)

Special Education Services (SES): The section of the Ministry of Education that provided services to young people with special education learning needs before the establishment of GSE. In this report, GSE is used to identify the department within the Ministry of Education responsible for the management of students granted ORS funding.

Special school: Schools funded by the Ministry of Education to provide support student with high learning needs in Aotearoa New Zealand. There are 26 day special schools. There are eight residential schools supporting students who are hearing or vision impaired, or who have severe behavioural needs, or educational, social and emotional needs, together with a low rate of learning (http:/minded.govt.nz/NZEducation/Education Policies/SpecialEducation/).

Spina Bifida (Myelonemingocele): A birth defect in which the backbone and spinal canal do not close before birth. Hydrocephalus may affect as many as 90% of children with spina bifida. Children with spina bifida may have partial or complete lack of sensation below the gap in the spinal canal, paralysis of the legs, loss of bladder and/or bowel control and weakness of the hips, legs and feet (http://www.ncbi.lm.nih.govt/publichealth/pmh0002525).

Stimmimg: Repetitive body movement that self-stimulates one or more senses in a regulated manner. Common forms among people with autism include hand flapping, body spinning or rocking, lining up or spinning toys or other object (http://autism.wikia.com/wiki/Stimming).

Teacher Aide (TAs): Also known as teaching assistant, para-educator, paraprofessional, classroom assistant, and learner support assistant. In the context of special education, TAs are school employees who work under the direct guidance of a teacher to assist with the implementation of IEP strategies to support students' learning. (www.minedu.govt.nz).

Well Child Tamariki Ora: a service offered free to all children between birth and 5 years of age in Aotearoa New Zealand. Well Child aims to provide families with the knowledge and skills to respond to their children's needs at different stages of their development. Well Child providers include Plunket, Māori Health, public health nurses and social workers. www.wellchild.org.nz

Whānāu: A diverse unit based on common whakapapa, descent from a shared ancestor or ancestors and within which certain responsibilities and obligations are maintained (Durie, cited in Cunningham, Stevenson & Tassell, 2005, p. 13).

Widgit: A bank of approximately 11,000 symbols used to represent over 40,000 words and phrases to communicate ideas and information to people who find the printed word hard to access. Widgit is a communication language used for students not yet able to read and but who have an understanding of conventional print formats. (www.widgit.com)

Appendix A: Education in government-funded schools in Aotearoa New Zealand (as at 2012)

In Aotearoa New Zealand all children between the age of 3 and 19 years, who have right of residence in Aotearoa New Zealand, are legally entitled to attend government funded early childhood centres and schools of their choice. Students enrolled in special schools have the right to attend school until January 1st of the next year after they have celebrated their 21st birthday (New Zealand Government, 1989).

Early childhood centres offer a wide range of learning programmes catering for the different needs and requirements of the family and whānau. Early childhood centres called kindergartens are government funded and staffed. Children from the age of 2½ years may enrol in kindergarten but most children do not start until they are 3 years of age. Primary schooling is compulsory for all students aged 6 to 16, although most children begin school at age 5. Exemptions may also be implemented by the Secretary for Education for students who wish to leave school aged 15 years.

Primary schooling compromises the first 8 years of school (Years 1–8); in Years 9–13 pupils attend secondary schools. In larger towns and cities, intermediate schools, also known as Middle Schools, offer programmes of learning for children in Years 7 and 8. In more rural areas with lower populations of young people, all students in the locality attend the one school, an area school for students enrolled in Years 1–13, although in some Area Schools the last year offered is Year 12. While the majority of schools in the primary school sector include the term primary school in their title, secondary schools may be titled high school, college or grammar school; all three titles, however, signify an educational locality that offers programmes of learning to students enrolled in Years 9–13. However, in more rural areas some secondary schools offer classes for Year 7 and 8 students.

Within the state education system of Aotearoa New Zealand are schools with a special philosophy of education. These schools are known as ‘integrated’ schools and have a special character, maybe of a religious nature, or a special education philosophy such as Steiner Education. Schools whose education philosophy is founded on Māori language and culture are also integrated into the state education system and follow the established enrolment criteria.

There are very few separate early childhood centres for children with special learning needs (Macartney, 2011). Most pre-schoolers who have been identified as requiring specialist assistance in their learning are supported by a special education early childhood intervention service (EIS). EIS work with the children and their families, and with the personnel working in the early childhood education service the child attends.

Special schools are also an education option for students with special learning needs, aged between 5 and 21. Although the majority of the students enrolled in special schools are supported by Ongoing Resourcing Scheme (ORS) funding, some special schools do enrol students who have not been accepted into the ORS scheme.

Appendix B1: Special education 2000

SPECIAL EDUCATION 2000 (SE2000)

The special education policy framework called Special Education 2000 was first announced in the 1996 Budget to enhance resourcing for children and young people with special education needs.

With its aim to 'achieve a world class inclusive education system that provides learning opportunities of equal quality to all children and school students' (Ministry of Education, 1996, p. 5) the key objective underpinning SE2000 were to:

Improve educational opportunities and outcomes for children with special education needs in the early childhood and school sectors.
Ensure there is a clear consistent and predictable resourcing framework for special education.
Provide equitable resourcing for those with similar needs irrespective of school setting or geographic location.
Assist in enabling schools to take ownership in meeting the full range of students' needs.
(Ministry of Education, 2003)

The seven components of SE2000 were designed to support the learning of children from early childhood until they completed secondary school. These components are the:

Serious behaviour initiative providing specialist support and guidance to students displaying severe and challenging behaviour through Group Special Education (GSE): now known as Ministry of Education: Special Education
Speech Language Initiative providing specialist support and guidance to students with severe communication needs through GSE
Ongoing Resourcing Scheme (ORS) providing support for students with high and very high learning needs through GSE (A more comprehensive overview of ORS is available at Appendix B2)
Resource Teachers Learning and Behaviour (RTLB) providing services for students with moderate learning and/or behavioural difficulties

Special Education Grant (SEG) to schools, based on the decile rating, to support students with moderate learning needs

Early intervention support at early childhood providers for children with special learning needs through GSE

Support for children with hearing and visual impairments and those in need of additional technological support through GSE

Since its introduction in 1996, there have been a number of changes to the original framework of SE2000 to respond to the demands from the schools, families and support agencies to meet the learning needs of students with special learning needs. Examples of new initiatives were:

The introduction of a Schools High Health Needs Fund to provide support for students with high health needs so they may attend schools safely,

the Supplementary Learning Support for students who were receiving support from one or more or the SE2000 initiatives and 'just missed out' on ORS funding.

An extension of ORS funding to an additional 1100 school age students in 2010 as part of the Success for all-Every school, every child response to the 2010 Review of SE2000

An extension of ORS funding for three years to an additional 1000 students in 2010 as part of the Success for all-Every school, every child response to the 2010 Review of SE2000

Increases in ORS funding to rural schools

Removal, in 2011, of the Reviewable Resourcing scheme and the ORRS acronym shortened to become ORS

Two other aspects of SE2000 covered the eligibility requirements and terms for transport and equipment, and the provision for research, monitoring and evaluation of the policy.

Appendix B2: The Ongoing Resourcing Scheme (ORS)

Introduced to the people of Aotearoa New Zealand in the 1996 budget, Special Education 2000 (SE2000) was promoted as the reforms needed to enable a ‘world class inclusive education system that proved learning opportunities of equal quality to all students’ (Ministry of Education, 1996, p. 5). One major component of the SE2000 initiative was an ‘individual resourcing scheme,’ (Ministry of Education, 2000a, p. 2) the Ongoing and Transitional Resourcing scheme that would deliver ‘sound education and appropriate educational support’ (Education Review Office, 2005, p. 3) to students with high and very high educational needs wherever they attended school. This individual portable funding scheme was to support students with the greatest needs who were enrolled in primary, secondary and special schools. Initially introduced as the Ongoing and Transitional Resourcing Scheme (OTRS), the initiative was, in 2000, renamed as the Ongoing and Reviewable Resourcing Scheme (ORRS). In 2011 the reviewable component of the scheme was withdrawn and the scheme became ORS.

Students with ongoing high levels of need due, for example, to a severe or profound intellectual or a serious physical or sensory disability, may be directly resourced through ORS. When ‘verified’ as eligible for ORS funding, the students receive support from ORS resourcing until they leave secondary school. To meet the criteria for verification, students must have extreme or severe difficulties in one or more of learning, hearing vision, mobility, or language use and social communication. Students with moderate or high learning difficulties from any two of hearing, vision, mobility and language use or communication may also apply for ORS funding. Some student applications for ORS may be based on the need for intervention from specialists and specialist teachers to adapt the content of the New Zealand Curriculum because of the student’s rate or style of learning. Students requiring specialist equipment or technology, an adapted curriculum or special teaching strategies to access the curriculum content may also apply for ORS funding.

Applications for ORS are appropriate for students with high special education needs who are

- Transitioning to school from an early intervention programme
- 5–6 years old and have had little or no involvement in early childhood education
- Identified as having a significant increase in their needs

- Recent or intending migrants to New Zealand.
- Students are eligible to apply if they meet at least one of nine criteria:
- Need total adaptation of all curriculum content
- Need special assistance to engage in face-to-face communication (e.g. rely on signing, Braille)
- Need specialist 1:1 intervention at least weekly and/or specialist monitoring at least once a month to assist with mobility, positioning or personal care
- Need specialist 1:1 intervention at least weekly and specialist monitoring at least once a month.
- Need support for needs arising from a severe disorder of both language use and appropriate social communication
- Need significant adaptation of all curriculum content
- Need specialist teacher contact time at least ½ day a week (e.g. deaf education teacher) to access the curriculum
- Need specialist 1:1 intervention at least once a month and specialist monitoring at least once a term to assist with mobility, positioning or personal care
- Need specialist 1:1 intervention at least once a month and specialist monitoring at least once a term to assist with language use and appropriate social communication
- Students with combined moderate needs within one or more criteria identified in the previous criteria

The application form is usually completed by a teacher who has worked with the student. The information should be drawn from assessments of the child's or student's responses to special interventions over time. These assessments will be the work of professionals involved in an ongoing way with the child or student. Information supporting the application may be sought from the student's family, support persons within the school, and MoE: SE case managers. The declaration must be signed by the all those participating in the preparation of the application including the student's parents or legal caregivers.

- Students granted ORS funding are verified as having 'high' or 'very high' needs.
- Students granted very high needs receive 0.2 (two tenths) Full Time Equivalent (FTE) teacher support.
- Students granted high needs receive 0.1 (one tenth) FTE teacher support.

ORS resource funding is used to purchase:

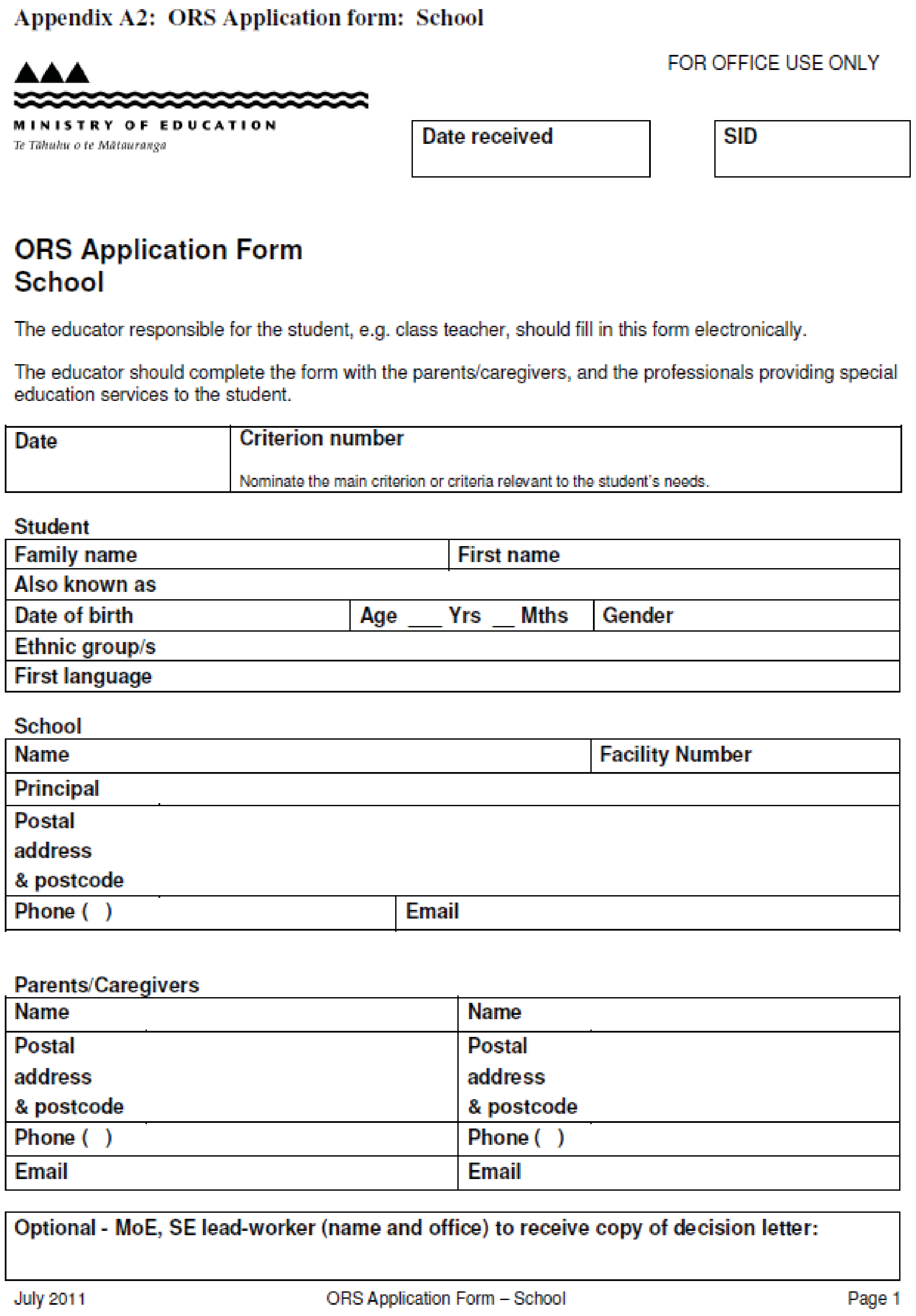
- Specialist and therapist expertise
- Additional teaching support
- Teacher aide support
- Consumable items

The total pool of resources is managed by MoE: SE (formerly GSE and SES). The management of ORS may be delegated to approved schools with the title Accredited Special Education Service Providers (ASESPS) formerly known as Fund Holder schools. Special schools manage the ORS funding received to support their ORS funded students.

Since the trialling of ORS in 1997 a number of changes have been made to the scheme:

- 1997: The ORS is trialled
- 1998: ORS is implemented nationally. Transitional resourcing is introduced for children aged 5–7 years whose long tern educational needs were still unclear
- 1999: The combined moderate needs criteria is added, chiefly to accommodate pupils with Asperger’s Syndrome
- 2000: Transition resourcing is replaced by Reviewable Resourcing Scheme. The ORS guidelines are published
- 2004: ORS guidelines and application forms are revised.
- 2006: ORS guidelines are revised and printed but the criteria for application are not changed.
- 2010: An ORS extension was created to assist students who had not gained verification. This extension was introduced at a time when the government was carrying out the review of Special Education. Students granted ‘extension’ ORS funding receive funding until they leave school or the year they turn 18.
- 2011: Reviewable resourcing is removed and the ORRS acronym became ORS
- 2011: A further extension of ORS funding for both school age students and for students in their first three years of schooling.

Appendix B3: ORS application form for school



Appendix A2: ORS Application form: School

MINISTRY OF EDUCATION
Te Tāhuhu o te Mātauranga

FOR OFFICE USE ONLY

Date received	**SID**

ORS Application Form
School

The educator responsible for the student, e.g. class teacher, should fill in this form electronically.

The educator should complete the form with the parents/caregivers, and the professionals providing special education services to the student.

Date	**Criterion number** Nominate the main criterion or criteria relevant to the student's needs.

Student

Family name	**First name**	
Also known as		
Date of birth	**Age ___ Yrs __ Mths**	**Gender**
Ethnic group/s		
First language		

School

Name	**Facility Number**
Principal	
Postal address & postcode	
Phone ( )	**Email**

Parents/Caregivers

Name	**Name**
Postal address & postcode	**Postal address & postcode**
Phone ( )	**Phone ( )**
Email	**Email**

Optional - MoE, SE lead-worker (name and office) to receive copy of decision letter:

July 2011 ORS Application Form – School Page 1

Describe the student's competencies when they are relevant to the nominated criterion. Include information about adaptations to the student's learning contexts and teaching strategies. Refer to the NZ Curriculum learning areas and key competencies.

Thinking	understanding rules; generalising; identifying problems; solving problems; absorbing knowledge; retaining what's learned;	using knowledge functionally; making choices; thinking flexibly; using imagination; showing curiosity;	asking and responding to questions; understanding risks and consequences of actions.
Text box expands.			

Using language, symbols and texts	listening; understanding and use of expressive language; generating and using ideas for writing;	understanding and using text including concepts about print and reading accuracy, and comprehension; understanding and using mathematical concepts including functional maths skills;	understanding and using NZSL, Braille, augmentative communication systems; use information from bi-lingual assessments where appropriate.
Text box expands.			

Managing self	managing personal care and belongings; gross and fine motor skills; transferring and positioning; using specialised equipment e.g. seating, walkers, computers; functional living skills e.g. using public transport;	following rules, routines and social conventions; behaving responsibly; acting positively; using common sense; seeking help; attending to task; engaging in learning; persevering when it is hard; expressing angry/upset feelings safely; making a mistake and feeling OK about it.
Text box expands.		

Relating to others	attending; responding to and initiating communication; considering the needs of others; sharing; taking turns;	interacting socially; co-operating in games and activities; accepting others' differences; showing awareness of others; engaging with others.
Text box expands.		

Participating and contributing	participating in group, class, home, and community activities; sharing ideas; commenting; answering questions; initiating conversation; offering opinions;	understanding another person's point of view; making suggestions; taking on responsibility; showing enjoyment; taking an interest; working on a task with others.
Text box expands.		

Interventions	
Summarise the specific programmes or interventions the student has received, from whom and give their job title.	Length of intervention e.g. hours per week, number of weeks.
Text box expands.	

Further information	**Include where relevant:** ▪ for Year 1 and Year 2 students, information about their early childhood and/or early intervention history ▪ specialised equipment and technology currently used ▪ immigrant students - length of time in NZ and history of education prior to arrival in NZ ▪ current audiogram showing both unaided and aided hearing, and audiologist's report ▪ current ophthalmologist's or optometrist's report showing best corrected vision ▪ diagnosis, date made and specialist designation.
Text box expands.	

Complete the Declaration (next page).

Send the completed form by

1. **Email**
   Scan the completed form including the signed Declaration page and send to manager.eligibility@minedu.govt.nz . Do **not** post a duplicate print copy.

   If no scanner is available, email the form as an attachment. Post the signed Declaration page (**only**) to the address below.

   Or

2. **Post**
   Assurance and Eligibility Unit
   Ministry of Education, Special Education
   P O Box 2522
   Addington
   Christchurch 8140.

   Receipt of your application will be acknowledged by email.

Declaration

Student's name

By the educator completing this application

I have read the completed application and confirm that it truly represents the student.

Name of educator	**Job title**
Place of employment	
Postal address and postcode	
Phone( )	**Email**
Educator's signature	
Educator's manager **Name**	**Job title** **Signature**

By the people providing information used in this application

I have read the completed application and agree that the information I have provided is used appropriately.

Name	Job title	Signature	Date

By the parents/caregivers

I have read the information in this Application Form and agree that it is an accurate description of my child. I allow it to be given to, and used by, the Ministry of Education to decide on the eligibility of my child for entry into the Ongoing Resourcing Scheme (ORS). If my child is eligible for the ORS, I give consent for this information to be given to others involved in the allocation of special education resources and to professionals providing special education services for my child.

____
Signature of parent/caregiver

____
Date

Appendix C: Teacher education programmes

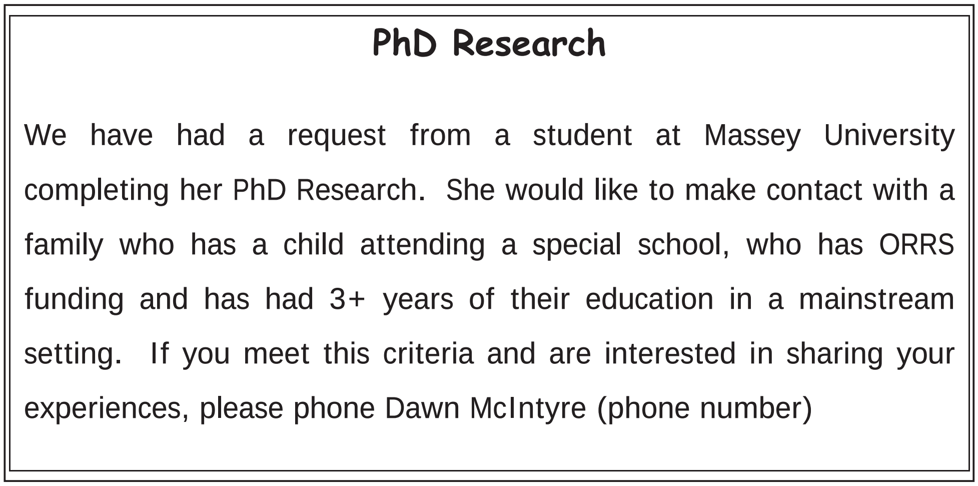
Teacher education programmes preparing students for working with children with special learning needs must include:

- An understanding of ‘people issues’ that influence the interactions of children with special needs in the classroom and the school:
    - Everyone working with children sees the child first and then the disability.
    - -There are many differences within each spectrum. Every child is different.
    - -The cultures that teachers, students and their families bring to the classroom and the school must be acknowledged.
    - -Effective interaction with families supporting all children, especially those with special learning needs is acknowledged and practised.
- Knowledge of education and support agencies that support students with disabilities, their families, their schools and their communities.
- Knowledge and understanding of ‘classroom and school issues’ that impact on students’ achievements.
    - -Adaptation of programmes of learning to meet the learning needs and abilities of all the children in a classroom is planned and implemented.
    - -Knowledge of policies and practices that underpin the education of children with special needs-ORS, right to attend regular schools.
    - -A broad overview of the differing forms of disability within the sensory, physical and intellectual spectrums.
    - -Class room management of classroom support staff and therapists.
    - -Knowledge of communication aids used by non verbal students and those with emerging language skills.

Compulsory practicum for all students

- Observation and possible participation of good teaching practises in classrooms where students with special learning needs are actively engaged in the class activities.

Appendix D: Advertisement in a special school newsletter



PhD Research

We have had a request from a student at Massey University completing her PhD Research. She would like to make contact with a family who has a child attending a special school, who has ORRS funding and has had 3+ years of their education in a mainstream setting. If you meet this criteria and are interested in sharing your experiences, please phone Dawn McIntyre (phone number)

Advertisement in a special school's weekly newsletter *Community News*

Appendix E1: Information for principals

MASSEY UNIVERSITY
COLLEGE OF EDUCATION
TE KUPENGA O TE MĀTAURANGA

The route is different every time

The journey families travel when making decisions about the educational placements for their ORRS funded family member

Principal's Information Sheet

Dear (Principal's name)

You may remember that I contacted you in late 2007 about a doctoral research study I was contemplating. Now I am in the process of implementing the research component of the study having being accepted into the Massey University PhD programme.

My study is looking at the decisions that parents of students with ORRS funding have made when deciding on the most appropriate education provider for their child. The families that I would like to include in my research are those whose child has started their schooling in a regular school and then moved to a special school. I am hoping to look this journey from the time the student have entered a learning programme such as kindergarten or play group through to their move to your school.

I would like to make contact with one or two families from your school whose students have recently transferred to you from a regular educational setting having been at least two years in regular education. I would be very happy to meet with the families at your school, to talk about the research before they made a decision as to whether they wished to participate.

A brief outline of the proposed research plan is for two interviews each about 45-60 minutes in length in a venue of the family's choice. The first interview will be a time to talk about the journey the family took for their child to be first enrolled in an inclusive educational setting. This may have been at playgroup, kindergarten or primary school.

The second interview will be a time to discuss how the family made the decision to move their child from a regular setting to one offered by a special education provider. There will also be a time to reflect on the decisions the family have made throughout their child's life. It will be a time to talk about what it means for their child to be now educated in a special education provider and to reflect on the experience of the series of interviews and talk about the findings that have emerged from the discussion.

The outcome of the research will, I hope, be findings that identify why families are moving their children into special education providers having initially decided to follow a regular education pathway. These findings may assist both regular and special schools to work together to make the education of these very special young people less stressful for both themselves and their families.

If you would like more information about my research or the selection process of possible families who would be able to assist me in the research, please contact me at dawnmc@xtra.co.nz or 07 868 2217 (home). I would be very happy to travel to your school and meet with you to talk about my research and the interview process I hope to have underway this term.

Regards

Dawn McIntyre

Researcher
Dawn McIntyre
RD5 Thames 3575
dawnmc@xtra.co.nz

Supervisor
Dr marg gilling
Senior lecturer
School of Educational Studies
Massey University
Ph: 06 356 9099 extn 8851
m.gilling@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 09/52. If you have any concerns about the conduct of this research, please phone Dr Karl Pajo, Chair, Massey University Human Ethics Committee: Southern B, telephone 04 801 5799 x 6929, email humanethicsouthb@massey.ac.nz

Appendix E2: Information for parents

MASSEY UNIVERSITY
COLLEGE OF EDUCATION
TE KUPENGA O TE MĀTAURANGA

The route is different every time

The journey families travel when making decisions about the education placements for their ORRS funded family member.

Parent Information Sheet

Dear (family's contact name)

Thank you for giving me the opportunity to introduce myself and the reason I am contacting you. I am a Massey University PhD student doing research about students moving from an inclusive school placement to a special school or special unit.

I am a trained special education teacher. My interest is the journey the students, their parents and their family members have taken from the earliest involvement with learning in an educational setting. I would like to meet with your family to talk about the decisions you have made regarding (student's name) education, and how this has impacted on your decision to move him to a special school. You may wish to ask members of your family to support you and they are most welcome to participate in the discussions if it is your wish. You may choose to have (student's name) present and participating in all or part of the interview time.

The research plan is for two interviews each about 45-60 minutes in length in a venue of your choice. The first interview will be a time to talk about the journey you and your family took for (student's name) to be enrolled firstly in a special school setting and then in a regular educational setting.

The second interview will be a time to discuss how you and your family made the decision to move (student's name) from a regular setting to one offered by a special education provider. There will be time to reflect on the decisions you and your family have made throughout (students name) life. It will be a time to talk about how (student's name) understands his present educational and personal life in the context of him and the family's life experiences. This will also be a time to reflect on the experience of the series of interviews and talk about the findings that have emerged from the discussion

This may seem rather a long period of conversation but I am sure you will find that the time will pass quickly. It would be helpful if the interviews could be arranged with a two week interval between the meetings. This would enable me to review the discussion tapes before moving onto the next phase of the decision making. However the timing of the interviews is at your convenience and can be discussed when I make contact to discuss your participation and answer any questions.

You have the right to withdraw from the interviews at any time. You also have the right to not answer any question or comment on any statement made during the interview.

The interviews will be taped. Only my two university supervisors, the person transcribing the tapes and I will have access to the tapes. The transcriber will have signed a confidentiality agreement before receiving the tapes for transcription. The information collected from the interviews will be used only for the purposes of my doctoral thesis and any related publications. Names of the children and family members will not be disclosed and stringent measures are in place to protect the confidentiality and anonymity of all participants. At the end of the research, all the audio tapes will be destroyed. All transcriptions will be removed from the researcher and transcriber's computers. It is your right to have the tape recorder turned off at any time throughout the interviews.

In order to help you to remember the events of the past, I will give you a journal in which you may wish to make notes, record milestones in student's name) journey, keep photos and other memorabilia that may jog your memory when we are talking about (student's name). This journal will be solely for your use and will not be looked at or retained by me or anyone else involved in this research.

I am sure there will be questions you may wish to ask. I can be contacted by email at dawnmc@xtra.co.nz

If you agree to participate in the research programme, you and your family members will need to complete consent forms before the first interview can begin. I will give them to you and they can be collected at the time of our first meeting.

I look forward to meeting you and your family and talking with you about the educational journey you have travelled with (student's name).

Dawn McIntyre

Researcher
Dawn McIntyre
RD5 Thames 3575
dawnmc@xtra.co.nz

Supervisor
Dr marg gilling
Senior lecturer
School of Education Studies
Massey University
m.gilling@massey.ac.nz

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MASSEY UNIVERSITY
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TE KUPENGA O TE MĀTAURANGA

Yes

I would be interested in hearing more about your research. Please send an information pack or contact me at:

Name: ______________________________ email: ______________

Address:

____

Phone: ____________________________Mobile: _______________

Appendix E3: Information for students

MASSEY UNIVERSITY
COLLEGE OF EDUCATION
TE KUPENGA O TE MĀTAURANGA

The route is different every time

The journey families travel when making decisions about education placements for their ORRS funded family member.

Student's Information Sheet

Dear (student's name)

I am writing to tell you about myself and some work that I am doing for my research study. I am a teacher who works with students with special learning needs in a special school.

I am studying at university and part of my study is how you and your family have chosen the schools you have attended.

I would like to meet with you and your family to talk about your story. You can choose to meet with me or if you do not want to meet with me, that is OK. It is your choice.

If you decide to join your family in the meetings, you must know that

- everything that is talked about will be saved on a recorder. This is to help me remember what was said when I am writing about the meetings.

- you may ask for the recorder to be turned off at any time.

- everything that is talked about is information for just me, you and your family, and the person who writes what is said on the tape. I will write a report at the end of the meetings.

- if I ask you a question that you do not what to answer, that is OK. You do not have to answer if you do not want to.

- there will be two meetings. You can bring anything to the meetings that you may like to share with your family and me. You may have some photos of you at school, or even some books you made when you were at school. They may help you when we talk about your school. You will take these things home with you at the end of the meetings. If you want to know more about these meetings, you can ask your family.

I have put another paper with this letter. It says that you are OK with talking to me about your school times. You will need to write your name on the paper and bring it with you when we meet for the first talk.

I hope your family will want to talk with me. I am really looking forward to meeting with you and talking about your school.

Dawn McIntyre

Researcher
Dawn McIntyre
RD5 Thames 3575
dawnmc@xtra.co.nz

Supervisor
Dr marg gilling
Senior lecturer
School of Educational Studies
Massey University
m.gilling@massey.ac.nz

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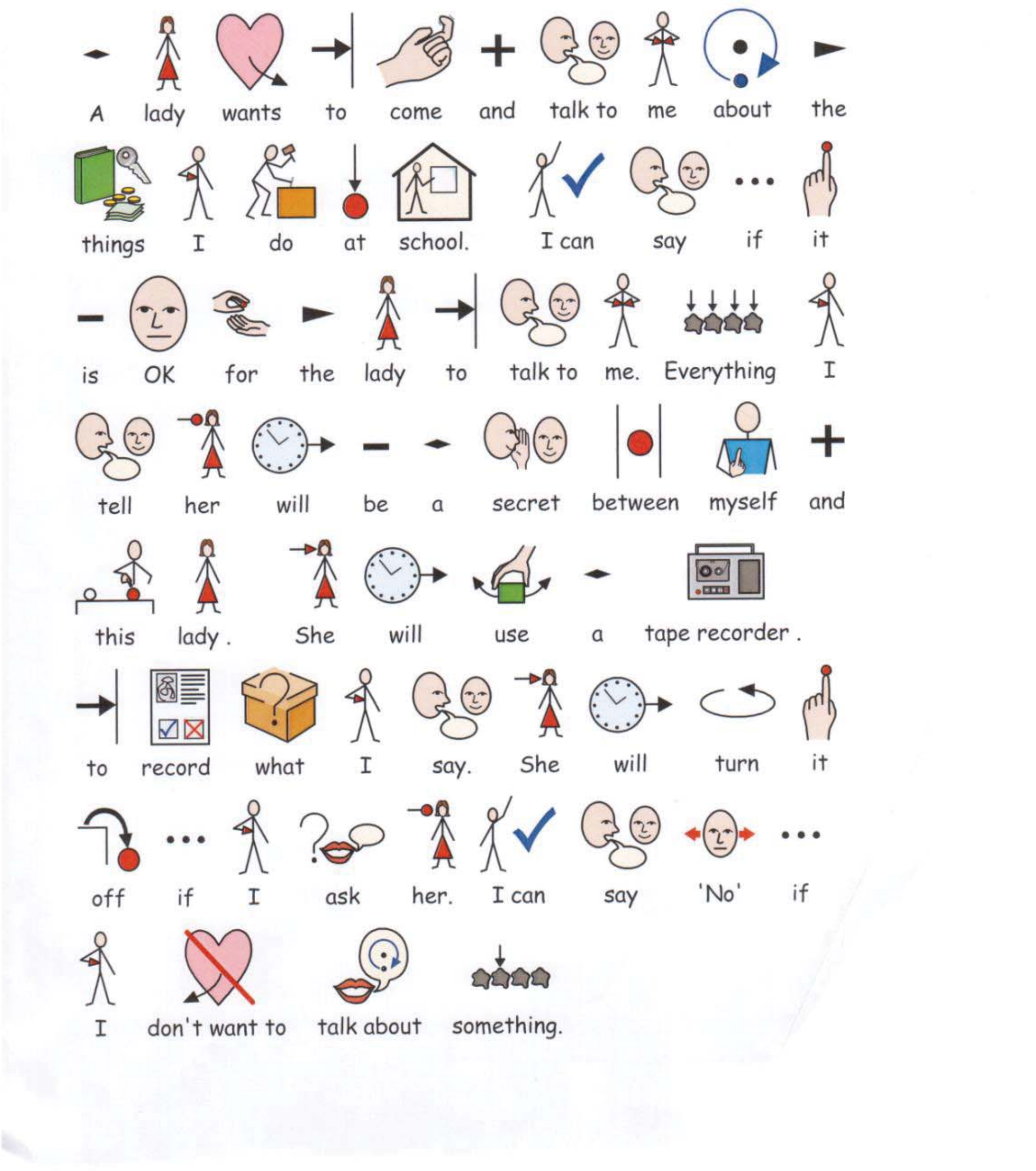
Appendix E4: Information for students using Widgit



A lady wants to come and talk to me about the
things I do at school. I can say if it
is OK for the lady to talk to me. Everything I
tell her will be a secret between myself and
this lady. She will use a tape recorder.
to record what I say. She will turn it
off if I ask her. I can say 'No' if
I don't want to talk about something.

Appendix E5: Information and support sheet for parents and their families

MASSEY UNIVERSITY
COLLEGE OF EDUCATION
TE KUPENGA O TE MĀTAURANGA

The route is different every time

The journey families travel when making decisions about the education placements for their ORRS funded family member.

Information and support available for parents and their family members

Perhaps as a result of talking about some of the experiences you or your child has had at a place of learning, you feel you need to seek professional help in resolving some of these matters. The following is a list of people and organisations that may be able to help you. There may be some cost involved in accessing these support services. Any costs incurred will be the responsibility of you and your family.

- The Office of the Commissioner for Children employs duty advocates who can be contacted at 0800 224453 (0800 ACHILD) or by post at PO Box 5610, Wellington.

- Parent legal life line for school issues (PLINFO) AT 0800 499488

- Child and Family Mental Health Services *(address to fit the area in which the participants live)*

- Child, Youth and Family at 0508 326 459 (0508 FAMILY)

- Your Doctor or Public Health Nurse (from the green pages in the phone book)

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Appendix E6: Letter to accompany journal

MASSEY UNIVERSITY
COLLEGE OF EDUCATION
TE KUPENGA O TE MĀTAURANGA

The route is different every time

The journey families travel when making decisions about education placements for their ORRS funded family member

Dear (participant's name)

I am very pleased that you are willing to participate in the research component of my university study. I look forward to meeting with you on (date of meeting).

I have enclosed a 'journal' that you and your family may wish to use to 'jog' your memory or to make notes about discussion points you may want to cover when we talk. The journal is for your use only and will not become part of the research.

I have also enclosed the consent form for you, and there is also a consent form for (child's name) should he/she wish to attend the meeting. I have also enclosed consent forms for other members of the family, or friends, that you may invite to participate in the interview.

Regards

Dawn McIntyre

Researcher
Dawn McIntyre
RD5 Thames 3575
dawnmc@xtra.co.nz

Supervisor
Dr marg gilling
Senior lecturer
School of Educational Studies
Massey University
m.gilling@massey.ac.nz

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Appendix F1: Parent’s consent form

MASSEY UNIVERSITY
COLLEGE OF EDUCATION
TE KUPENGA O TE MĀTAURANGA

The route is different every time

The journey families travel when making decisions about education placements for their ORRS funded family member.

Parent’s Consent Form

I have read the information sheet and have had the details of the study explained to me. My questions have been answered and I understand that I may ask questions at any time.

I understand that:

- I can withdraw from the study at any time and I can decline to answer any particular questions.
- I can be supported in the interviews by members of my family.
- my child, who has ORRS funding, may choose to attend the interviews.
- the interviews will be taped for further reference by the researcher. If I make the request, the tapes will be returned to me at the end of the research programme.
- I can ask for the tape recorder to be turned off at any time.
- my name will not be used in the thesis or any publication resulting from the research.
- any information given during the interviews will be confidential to the researcher, the university supervisors and publications arising from this research.
- Findings from the research will be given to me at the end of the study. This presentation may be in an oral or written format.
- The journal I may use to record personal data is my property and will not become part of the collected data.

Signed: ______________________________ Date: _____________

Name: ____(Please print)

Researcher
Dawn McIntyre
RD5 Thames 3575
dawnmc@xtra.co.nz

Supervisor
Dr marg gilling
Senior lecturer
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m.gilling@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 09/52. If you have any concerns about the conduct of this research, please phone Dr Karl Pajo, Chair, Massey University Human Ethics Committee: Southern B, telephone 04 801 5799 x 6929, email humanehticsouthb@massey.ac.nz

Appendix F2: Student's consent form

MASSEY UNIVERSITY
COLLEGE OF EDUCATION
TE KUPENGA O TE MĀTAURANGA

The route is different every time

The journey families travel when making decisions about education placements for their ORRS funded family member.

Student's Consent Form

I have read the information sheet and have had the details of the study explained to me. My questions have been answered and I understand that I may ask questions at any time.

I understand that:

- I can leave the study at any time and do not have to answer all the questions.
- I can ask members of my family to be with me during the interview.
- the interviews will be taped for further use by the researcher.
- I can ask for the tape recorder to be turned off at any time.
- my name will not be used in the written work about this study.
- any information given during the interviews will not be given to anybody except the researcher, the university teachers, the people who listen to the tapes to write the words, and any writing about the study.

Signed: ______________________________ Date: ________________

Name: ____(Please print)

Researcher
Dawn McIntyre
RD5 Thames 3575
dawnmc@xtra.co.nz

Supervisor
Dr marg gilling
Senior lecturer
School of Educational Studies
Massey University
m.gilling@massey.ac.nz

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Appendix F3: Family’s consent form

MASSEY UNIVERSITY
COLLEGE OF EDUCATION
TE KUPENGA O TE MĀTAURANGA

The route is different every time

The journey families travel when making decisions about education placements for their ORRS funded family member

Family’s Consent Form

I have read the information sheet and have had the details of the study explained to me. My questions have been answered and I understand that I may ask questions at any time.

I understand that:

- I can withdraw from the study at any time and that I can decline to answer any particular questions.
- my role in the interviews is one of support for the parents and their child.
- the interviews will be taped for further reference by the researcher.
- I can ask for the tape recorder to be turned off at any time.
- my name will not be used in the thesis of any publication resulting from the research.
- any information given during the interviews will be confidential to the researcher, the university supervisors and publications arising from this research.

Signed: ______________________________ Date: ______________

Name: ______________________________________(Please print)

Researcher
Dawn McIntyre
RD5 Thames 3575
dawnmc@xtra.co.nz

Supervisor
Dr marg gilling
Senior lecturer
School of Educational Studies
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Appendix F4: Parent giving consent on behalf of their family member

MASSEY UNIVERSITY
COLLEGE OF EDUCATION
TE KUPENGA O TE MĀTAURANGA

The route is different every time

The journey families travel when making decisions about education placements for their ORRS funded family member.

Parent giving consent on behalf of their family member

I have read the information sheet and have had the details of the study explained to me. My questions have been answered and I understand that I may ask questions at any time.

I agree to my child taking part in the interviews under the conditions that were explained to me in the information sheet.

Signed: ____________________________ Date: _____________________

Name: ____(Please print)

Full name of child (please print): ___________________________________

Researcher
Dawn McIntyre
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dawnmc@xtra.co.nz

Supervisor
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Senior Lecturer
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m.gilling@massey.ac.nz

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Appendix G: Note taker's confidentiality agreement

MASSEY UNIVERSITY
COLLEGE OF EDUCATION
TE KUPENGA O TE MĀTAURANGA

The route is different every time

The journey families travel when making decisions about education placements for their ORRS funded family member

Note taker's Confidentiality Agreement.

I agree:

- to keep all information about this study confidential.
- to return all notes taken at the time of the interview, to the researcher.

Signed: ______________________ Date: ______________

Name: ____

(Please print)

Researcher
Dawn McIntyre
RD5 Thames 3575
dawnmc@xtra.co.nz

Supervisor
Dr marg gilling
Senior lecturer
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m.gilling@massey.ac.nz

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Appendix H1: Letter to accompany return of transcripts

MASSEY UNIVERSITY
COLLEGE OF EDUCATION
TE KUPENGA O TE MĀTAURANGA

The route is different every time

The journey families travel when making decisions about education placements for their ORRS funded family member

Dear (family name)

Earlier this month we met and talked about the decisions you had taken when choosing an educational placement for (student's name). The transcribing of the interview is now completed and I have enclosed a copy of the interview. This is to allow you to read the transcript if you wish, or to just have a record of what was talked about when we met. After reading the transcript and talking about it, you may wish to have some parts of the interview deleted. I have enclosed a stamped addressed envelope to enable you to return the transcript to me with the changes marked. I will make any requested changes and return the amended transcript to you.

The next step is for me to read through the transcripts again to identify the important points. These points will become part of the report I will write when I have finished coding all the interviews. No people who participated in the interviews will be identified. No names of parents, children, family members or schools will be used in the report.

Thank you again for your time. If you have any questions or require further information, please do not hesitate to contact me.

Kind regards

Dawn McIntyre

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Supervisor
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Senior Lecturer
School of Educational Studies
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Appendix H2: Authority for the release of transcripts

MASSEY UNIVERSITY
COLLEGE OF EDUCATION
TE KUPENGA O TE MĀTAURANGA

The route is different every time

The journey families travel when making decisions about education placements for their ORRS funded family member.

Authority for the release of transcripts

I confirm that I have had the opportunity to read and amend the transcripts of the interviews conducted with me and my family.

I agree that the edited transcript and extracts may be used in reports and publications arising from this research.

Signed: ________________________ Date: ________________________

Name: ____(Please print)

Researcher
Dawn McIntyre
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dawnmc@xtra.co.nz

Supervisor
Dr marg gilling
Senior lecturer
School of Educational Studies
Massey University
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Appendix J1: Letter to Principals: Survey of special schools 2010

MASSEY UNIVERSITY
COLLEGE OF EDUCATION
TE KUPENGA O TE MĀTAURANGA

(Date)

The Principal

(School name, address and email address)

Dear (name of principal)

In late 2007, I contacted your school to request the completion of a questionnaire to ascertain the number of ORRS funded students who had transferred to your school from a regular school setting over the last three years. The information from this survey was to give me base line information and preliminary data for my PhD research which will investigate the reasons underlying the decisions families make when moving their ORRS funded family member from a regular school placement to a special school.

I am now doing a survey as one phase of the research process in order to gather factual current information relating to the numbers of ORRS funded students who have transferred from a regular school to a special school placement (i.e. to include students who had been enrolled for at least two years in a regular school placement, either a combination of early childhood and regular school placements, or regular school placements only) to establish whether there are any patterns evident.

I invite you to participate in this phase of the research by completing the questionnaire: completion of the questionnaire implies consent. The results of this nationwide survey of special schools will be aggregated and included in the final report. There will be no identification of individual schools. The naming of your school on the questionnaire form is solely to enable a follow up forms of that are still outstanding.

Thank you very much for your time, effort and information

Yours sincerely

Dawn McIntyre

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This project has been evaluated by peer review and judged to be of low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researchers named above are responsible for the ethical conduct of this research.

If you have any concerns about the conduct of this research that you wish to raise with someone other than the researchers, please contact Professor John O'Neill, Director (Research Ethics), telephone 06 350 5249, e-mail humanethics@massey.ac.nz

Appendix J2: Survey of special schools 2010

MASSEY UNIVERSITY
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TE KUPENGA O TE MĀTAURANGA

Special School Survey (Name of school)

ORRS funded students transferring from a regular school placement to a special school.

*	Year 2		Year 3		Year 4		Year 5		Year 6		Year 7		Year 8		Year 9		Year 10		Year11		Year 12	
	M	F	M	F	M	F	M	F	M	F	M	F	M	F	M	F	M	F	M	F	M	F
2007																						
2008																						
2009																						
2010																						
2011																						

*Please use appropriate age/'school year' placement for this survey.

Please include <u>only</u> ORRS students who have attended a regular early childhood and/or regular school placement for <u>at least two years</u>.

Any comments?

Any questions?

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Appendix K: The families

The Samuel family:

Jane, Fred, their son and daughter Olivia

The Brown family:

The Serville family:

Theodore, Eleanor, their son and daughter Britney

The Smith family:

Donna with her daughter Kate

The Laurie family:

Margaret and her two younger sons. Hamish is her youngest son.

The Lawton family:

Isobella and her husband live with their three children. Stella is their first born child.

The Berry family:

Lynda, her husband, their only son Joshua and younger daughter Katrina.

The Wilson family:

Lynne, her son Mark and his younger sister.

The Anderson family:

Susan and Iain and their son Andrew. Their daughter lives in another town.

The Lucas family:

Beth and her son Robbie. Dick, Robbie's dad lives at another location