

Disabled by the Discourse:
Two families' narratives of inclusion,
exclusion and resistance in education

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*A good head and a good heart are always a formidable combination...
Wounds that can't be seen are more painful than those that can be seen and
cured by a doctor. I learned that to humiliate another person is to make him
suffer an unnecessarily cruel fate...Overcoming poverty is not a gesture of
charity. It is an act of justice. It is the protection of a fundamental human
right, the right to dignity and a decent life. If the experience of South Africa
means anything to the world at large, we hope that it is in having
demonstrated that where people of goodwill get together and transcend their
differences for the common good, peaceful and just solutions can be found
even for those problems which seem most intractable.*

Nelson Mandela, (2009, pp. 120-123)

I am the bird

I am the bird and the Rosella

I wonder with my imagination

I hear this singing

I see Flying Foxes

I want food and drink

I am flapping my wings

I pretend I am a Kea

I feel full of happiness

I touch pink roses

I worry about my twin sister

I cry for my mummy

I am flying to her

I understand I am flying really high

I say: "I'm going to be human again"

I dream of me being a bird

I try to sleep calmly

I hope I'll fly in the sky again

I am the bird and the Rosella

Maggie Rose Macartney Paine

Dedicated to the loving memory of
Great Aunty Maggie and Tom Cutbush, Sarah Walker,
Joseph Matthews and Andrew Nuttall - van Toor.

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He ihu waka, he ihu whenua, this is where our canoe touches the land.

Arohanui, Bernadette Macartney

Abstract

This qualitative study is based on the narratives of two families who each parent a young disabled child. It focuses on the children's and families' experiences of inclusion and exclusion within educational settings and the implications of these experiences for pedagogical change. New Zealand's policy and curriculum contexts are considered in relation to education, disability and inclusion. I examine how the families' perspectives and experiences interact with dominant, deficit discourses of disability. In my interpretation of the family narratives I identify particular disciplinary mechanisms that operate as tools and tactics of disabling power-knowledge production (Foucault, 1977, 1980). I argue that the policing of disabled children and families' participation are primary processes and outcomes of these disciplinary mechanisms.

The study uses a Disability Studies in Education (DSE) framework to understand and approach disability as socially, politically and culturally constructed. The assumptions underlying traditional Western educational knowledge and norms are critiqued from a counter-narrative based on experiences of disability. I use DSE research and literature to challenge knowledge regimes that interpret disability as an individual deficit requiring 'special' intervention and treatment. I argue that a 'disability critique' makes an important contribution to understanding the workings and effects of Western, Eurocentric knowledge traditions on children and families. This research further argues that exclusion is experienced by those *within* and *outside* of the dominant culture.

I envisage the main research audience of this thesis to be early childhood and primary school teachers, teacher educators, early

intervention and special education personnel, therapists and medical professionals. The stories and experiences of the families in this research may support teachers and other professionals to critically reflect on, and make changes to their thinking and practices. I hope to contribute to the growing body of research that can be used to support parents and families of disabled children in their efforts to promote educational change and to support the full inclusion of their children as valued people and learners within their educational contexts.

I develop two main arguments in this research. The first is that in order to transform education, deficit discourses and their effects must be named and understood. The second is that New Zealand educationalists can build on existing, local frameworks to develop critical, narrative and relational pedagogies to transform exclusionary power relations and support inclusive experiences for all children and their families. I argue that approaches to disability and education based on a belief that exclusion is 'inevitable' and that creating a fully inclusive education system and society is an impossible dream, should be challenged and rejected. A lack of optimism and vision reproduces exclusion, and leads to weak reforms at best. Disabled children and their families deserve and have a right to an inclusive life and education and this requires people at all levels of society to take responsibility.

Chapter One: Introduction

Since our daughter Maggie was diagnosed thirteen years ago by a paediatrician as being disabled, my partner Tony and I have needed to communicate and negotiate with a lot of people. We have become advocates for Maggie in an effort to secure meaningful and inclusive learning experiences in her early childhood centre and at school. We have worked hard to encourage respect for our values and views as a family (Ogonowska-Coates, 2003). Through these experiences I have learnt a lot about being an advocate for my child and for inclusion. Tony and I would describe many of our experiences with professionals, early interventionists and Maggie's first six years at school in terms of a struggle for our contributions and perspectives to be acknowledged and valued. My motivation for choosing this research topic is my desire for a more inclusive education and world for both of my children.

I have worked for thirty years in early childhood education in a variety of roles - as a teacher, tertiary lecturer, writer, researcher, and parent. Early in my teaching career I taught in an early childhood centre for children labelled as 'intellectually disabled'. During that period I also worked in a large residential facility for children and adults labelled as intellectually disabled. This included working alongside adult residents in a 'sheltered workshop' where they were engaged in menial work for little remuneration. Those experiences challenged me to begin questioning the 'truth' and value of deficit labels and assumptions. Through developing relationships with that group of disabled people and their families I began learning to respect and value people for who they are, not what others say they are or should be. I am still learning this lesson through my relationships and journey as Maggie's mum. This research has allowed me

to use my knowledge and experiences to view disability from multiple perspectives. I have strong views and feelings about the issues raised in this research. The implications of my roles as a participant-researcher are considered in Chapter Three.

1.1 The focus of this thesis

The voices and narratives of disabled people, and their families, must be central to disability scholarship (Allan, 1999; Ballard, 1994a; Bray & Mirfin-Veitch, 2003; P. Ferguson, 2009; P. Ferguson & Ferguson, 1995; Goodley, 2001; Linton, 1998; Oliver, 1990, 1996; Raymond, 2002; Slee, 2003; Van Hove, et al., 2009). The privileging of the voices and perspectives of marginalised groups who are the focus of research is relevant to any social or cultural group. Listening to people and being open to learning from their experiences resists traditional tendencies to reify, simplify and over-generalise knowledge and meanings associated with particular identities or subject positions (Erevelles, 2006; Ferri, 2006; Lather, 2003; Linton, 1998; Maynes, Pierce, & Laslett, 2008; Van Hove, et al., 2009; Ware, 2006). Listening to and reflecting on the autobiographical accounts of disabled people and their families is used as a strategy in teacher education for complicating and challenging able-bodied student and qualified teachers' views and assumptions about what disability means (Ferri, 2006; Van Hove, et al., 2009; Ware, 2006).

This research involved interviews with members of two families about their experiences and perspectives as parents of disabled children. Using each family's narratives, and also drawing from texts, images and documents related to one of the families, I examine and critique Western knowledge frameworks, New Zealand educational policy and curriculum documents, early childhood centre's, school's and special education knowledge and practices. The research aims to be of particular interest and use to early childhood educators, primary school teachers, early

intervention personnel, therapists and other professionals working with disabled children and their families. I hope that the stories and experiences of the families in this research will help to provide some insights and motivation for teachers and other professionals to critically reflect on and make changes to their pedagogies. I am also hopeful that my research might empower some parents and families of children with disabilities to advocate for their children, support educational change and the full inclusion of their children as people and learners in early childhood and school settings.

1.2 Setting the context

This introductory chapter sets out the broad academic, legal, policy, pedagogical and curriculum contexts for the thesis. I begin by situating the study within the academic and political field of Disability Studies in Education (DSE). I support the DSE premise that disability is a social-political-cultural issue and construct, and challenge approaches that view disability as a biological, individual and private ‘problem’.

I then present local and international literature and research that explores the experiences and positioning of families of disabled children in New Zealand and other Western societies. In particular, I consider the ways in which families are marginalised through professional and deficit knowledge and practices.

I then explore New Zealand’s legislative and policy environment as it relates to disability and education. What was happening in legal and policy environments around the time that the participants’ were involved in their child’s education is an important indication of some of the problems they faced when trying to negotiate early childhood education and schooling.

With a view to further understanding and locating the experiences of the participants and their children, I turn my attention to the implications of dominant knowledge in education for teaching, learning and inclusive education. I critique educational and developmental psychology in regards to its deficit, normalising, and exclusionary underpinnings. In particular, I consider how normalising, deficit knowledge positions and affects children who do not fit 'normal' expectations for learning, development and behaviour. I begin to make a case for educational transformation based on social-political-cultural approaches to diversity, inclusion, curriculum and pedagogy.

In the next section, I provide a brief description of early childhood and compulsory school education provision in New Zealand as it relates to all children and to children labelled as having 'special educational needs'. I then focus on New Zealand's curriculum context and documents. The curriculum documents are central to an analysis of the participants' and their children's experiences. They are the official guide for teachers to the theories, practices and approaches relevant to their settings. Before closely examining the structure and contents of each curriculum document I examine the political influences on their development.

Finally, I consider the implications of New Zealand's legal, policy, and curriculum contexts for disabled children and their families. I conclude that the voices, perspectives and aspirations of disabled children and their families, are lost within a context characterised by unclear, contradictory and confused messages about disability, difference and 'inclusive' education. I argue that the voices of families and children must be sought and acknowledged as integral to any meaningful attempts to address and remove barriers to disabled children's learning, contributions and participation. At the conclusion of this chapter, I briefly outline the contents of the thesis.

1.3 Disability Studies in Education (DSE)

This research is situated within the political and academic field of Disability Studies (DS) and Disability Studies in Education (DSE). Within this study the narratives of the two families are central to developing a critique of, and response to dominant and exclusionary discourses (P. Ferguson, Ferguson, & Taylor, 1992c; Maynes, et al., 2008). Disability Studies in Education scholars privilege disabled peoples' knowledge, expertise, accounts of their lives and perspectives in understanding the meanings, experiences and lived effects of being viewed and labelled as 'disabled' or 'impaired' (Connor, Gabel, Gallagher, & Morton, 2008; Goodley, 2001; Linton, 1998). Through exposure to multiple and diverse insider accounts from disabled people, students of DSE often become aware of and attuned to the diversity and differences that exist between disabled people (Goodley, 2001). The realisation that disabled peoples' experiences and biographies are just as diverse in regards to their aspirations and desires, as other groups in society, is an important insight for developing a critique of and resistance to universalist, expert-based systems of knowledge and intervention in response to disability and difference (Bogdan & Taylor, 1992; Ferri, 2006; Linton, 1998; Slee, 2001; Ware, 2005, 2006).

DSE is comprised of an international network and community of scholars, teachers, disabled people, family members and activists who are committed to including, listening and responding to the voices of disabled people, challenging inequalities and advocating for the full and meaningful participation of disabled people in education and society (Connor, et al., 2008; Gabel, 2005; Linton, 1998; Smith, Gallagher, Owen, & Skrtic, 2009). As such, DSE positions itself morally and ethically as a social and political movement as well as an academic discipline (Connor, et al., 2008; Linton, 1998; Slee, 1997, 2001; Smith, et al., 2009). Roger Slee (1997)

describes DSE as, "... a project in cultural politics" (p. 407). Gabel (2005, p. 9) suggests that DSE:

research is concerned with a Freirian form of praxis, or a conscious effort at social change that brings about equity, social justice, and full participation in society where the work toward social change is led by those who are themselves, oppressed.

This indicates a responsibility on the part of DSE researchers to share the stories and aspirations of disabled people and their family members with a view to supporting social action and change.

Disability Studies has entered the international disability rights movement and field of education relatively recently (Connor, et al., 2008). DSE became formalised as "what has become a growing movement in educational research, theory and practice" through the establishment of a DSE special interest group of the American Educational Research Association (AERA) in 1999 (Gabel, 2005, p. 1). The DSE movement is underpinned by an emancipatory conceptual framework traditionally emerging from the 'social model of disability' (Abberley, 1987; Barnes, Mercer, & Shakespeare, 1999; Gabel, 2005; Oliver, 1990, 1996). The 'social model' was developed in the 1970s and 1980s by UK disability activists and sociologists as a reaction against traditional medical, biological, and individualistic understandings of disability (Connor, et al., 2008). The 'social model' has been critiqued, expanded and reinterpreted over recent years, but the basic argument that disability is a social construction, and that disabled people are discriminated against on the basis of medical, deficit constructions of disability, remains central to disability activism and studies (Connor, et al., 2008; Gabel, 2005; Goodley, 2001).

In the United States, the disability movement was influenced by the civil rights movement with a focus on disabled people as a discriminated against, minority group in society. This minority group perspective is based on disabled peoples' collective experiences of discrimination on the grounds of their perceived negative deviation from 'the norm' (Connor, et al., 2008; Gabel, 2005). In the late 1970s, American disability activists and researchers Bogdan & Biklen (1977, p. 14) developed the term "handicapism" to describe "...a set of assumptions and practices that promote the differential and unequal treatment of people because of apparent or assumed... differences". Sensitising concepts in Disability Studies such as 'handicapism', 'ableism' and 'disablement' move the focus regarding disability from the 'damaged individual' to the 'disabling society'. Simi Linton (1998, p. 132), a disabled scholar and activist describes disability studies "...as a socio-political-cultural examination of disability" and contrasts this with deficit and "...interventionist approaches that characterize the dominant traditions in the study of disability". Disability Studies is well positioned to critique dominant and traditional 'knowledge regimes' such as developmental psychology, behaviourism, psychiatry and special education and their conceptual and practical divisions of disabled people from the rest of society (Goodley, 2001; Linton, 1998; Skrtic, 1991, 1995; Slee, 1997, 2001).

Disability Studies: 'Disability' and/or 'impairment'?

An important and fruitful area of debate within Disability Studies is related to the concepts of 'disability' and 'impairment' (Erevelles, 2005; Gabel, 2005; C. Thomas, 2002). Although there is much agreement within DSE about deficit constructions of disability resulting in disablement, there is on-going debate about the separation of 'impairment' and 'disability' within the traditional social model (Goodley, 2001; Linton, 1998; C.

Thomas, 2002). Debates about whether ‘disability’ and/or ‘impairment’ are emphasised in a consideration of disabled people’s experiences, have been influenced by what is believed to be the most likely to produce positive material outcomes for disabled people in areas such as access, employment, appropriate housing, and inclusive education (Gabel, 2005; Gabel & Peters, 2004; Oliver, 1990). Researchers and disabled activists aligned with the ‘traditional social model’, initially argued for a clear separation between ‘disability’ and ‘impairment’ (Barnes, et al., 1999; Oliver, 1996). From a traditional social model perspective, ‘disability’ was framed as oppression, which was caused by society’s negative responses to people who have physiological ‘impairments’ (C. Thomas, 2002). Oliver (1996) argued that this separation between ‘disability’ and ‘impairment’ was necessary to emphasise the social, economic, and political oppression of disabled people. He argued that a focus on disabled individuals’ experiences of ‘impairment’ would contribute little to transforming or improving disabled peoples’ material circumstances and might even support deficit views and discourses (Oliver, 1996).

A criticism of ignoring the social construction of ‘impairment’ within the social model, is that this supports the false assumption that disabled peoples’ embodied experiences and ways of being are separate from and not relevant to social-political-cultural constructions of disability and impairment (Goodley, 2001; Linton, 1998). Gabel (2005) and others (Ballard, 1994c; Ballard & Macdonald, 1998; Linton, 1998; L. Lyons, 2005; MacArthur, Kelly, & Higgins, 2005; Slee, 2001; G. Thomas & Loxley, 2001) suggest that the embodiment of disability through living with an ‘impairment’ and the interaction between people with ‘impairments’ and their social, cultural, historical and political contexts must be acknowledged as a rich source of knowledge and understanding about disability, impairment and social justice. Rather than ignoring or de-

emphasising the embodied experiences of disabled people, Linton (1998) and others (P. Ferguson & Ferguson, 1995; Goodley, 2001; Goodley & Lawthorn, 2008; B Macartney, 2007b; Rapley, 2004) emphasise the *interactions* between individuals and their contexts in the production of meanings and experiences of disability. Linton (1998) highlights the social construction of meanings around ‘disability’ *and* ‘impairment’ and suggests that we must look much more closely at how these meanings are produced and maintained within specific, localised contexts. She suggests that, although disability studies and the disability movement have “demonstrated that disability is socially constructed to serve certain ends, ... it behoves us to demonstrate *how* knowledge about disability is socially produced to uphold existing practices” (p. 4) (emphasis added).

According to Linton (1998), and others (Goodley, 2001; G. Thomas & Loxley, 2001) what is needed and currently under-theorised in disability studies is an interest in the meaning making of disabled people through their embodied experiences of ‘having’ an impairment *and* living within particular socio-political-cultural contexts. In this regard, and from her perspective as a disabled woman and scholar, Linton states:

Given that my experience or the experience of someone who is blind or deaf, or someone who has mental retardation has been underrepresented across the disciplines, we are missing the constructs and theoretical material needed to articulate the ways impairment shapes disabled people’s version of the world. The fact that impairment has almost always been studied from a deficit model means that we are deficient in language to describe it in any other way than as a “problem” (p. 140).

A problem with splitting ‘disability’ off from ‘impairment’, through essentialising impairment as biologically determined, is that the medically derived dichotomy between ‘disability’ and ‘impairment’ is maintained (Goodley, 2001). The socio-political-cultural construction, or “discursively

embodied nature of impairment” (Goodley, 2001, p. 208) is not recognised and a significant aspect of disabled peoples’ lives and experiences is left unexamined, and therefore absent in developing more realistic and accurate understandings of the social construction of disability and its lived effects. As Linton (1998) suggests, “deterministic and essentialist perspectives flourish in the absence of contradictory information” (p. 25).

An understanding of experiences of disability and impairment can only emerge when disabled people and their families are listened to. This should include on-going consideration of the lived implications of the language that is used around disability and how we might replace and/or re-conceptualise concepts such as ‘disability’, ‘impairment’ and ‘inclusion’ (Gabel, 2005; Goodley, 2001; Linton, 1998; Slee, 2001).

Rather than conceptualising ‘disability’ and ‘impairment’ as separate and discrete objects of experience, my approach in this thesis has been to remain open to the interactions between individual experiences of ‘disability’ and ‘impairment’, and the social-political-cultural norms, structures, arrangements and contexts in which they are produced (Goodley, 2001; Rapley, 2004). In particular, I am interested in looking at the relationships between dominant discourses about disability and impairment and *how* those meanings are used to (re)-produce and maintain exclusionary practices through ‘special’ and ‘regular’ education (Linton, 1998).

Shared constructs in DSE

DSE scholars and researchers share a common concern with exposing, challenging, and problematising taken for granted culturally and historically based understandings of disability as individual deviation from

an idealised set norms and as an indication of deficiency (Ferri, 2006; Gabel, 2005; Ware, 2005, 2006).

There is a commitment within DSE to working from and across a range of disciplines (Connor, et al., 2008; Ware, 2006). For example, Ware (2006) talks about her experiences of teaching DSE to prospective ‘general’ and ‘special education’ teachers. She describes teaching using a DSE approach as:

...an effort to integrate humanities scholarship; educational and curriculum theorists who extend and integrate disability studies content; and those who author insider accounts; fiction and film... and other media. In addition, classroom based research that has the dual focus of informing awareness of disability studies scholarship and developing curriculum that draws on this content is also included (p. 272).

DSE opens up spaces for conversations amongst and between individuals and groups representing and using very different tools and perspectives in their analysis of disability and difference (Ferri, 2006; Millar & Morton, 2007; Valenzuela, Connery, & Musanti, 2000; Ware, 2005, 2006). Interdisciplinary conversations, coupled with the representation of multiple perspectives on disability and inclusion, retain the complexity and diversity of the experiences of disabled people (Allan, 2008; Ware, 2006).

Critical Inquiry

There is a strong critical component within DSE involving an interrogative interest in the workings of power and knowledge and its inclusionary and exclusionary effects (Ferri, 2006; Graham, 2005; Graham & Slee, 2008; Smith, et al., 2009; G. Thomas & Loxley, 2001). DSE is concerned with exposing and interrogating the dominant culture and society, in particular the construction and effects of beliefs, assumptions, and knowledge based on a fictional but powerful notion of ‘the norm’ (Davis, 1997; Macartney,

2007b, 2010a). This critical focus extends beyond traditional critical theories in education in regards to how ‘categories of difference’ such as disability, ethnicity, gender, class and sexuality are conceptualised (Ferri, 2006; Ware, 2005). Ferri (2006) questions approaches to understanding and explaining difference that focus on one marker of identity such as class, race, gender, sexuality, or disability, to the exclusion of others. She (2006, p. 291) suggests that, rather than isolating any category of identity as a singular and fixed phenomenon: “Scholars in disability studies in education... (work) ...to critically examine disability as a constructed category, inter-connected to all aspects of identity and culture.” Ferri (2006) and others (P. Ferguson & Ferguson, 1995; B Macartney, 2008b; Slee, 1997; Ware, 2005) contrast DSE’s critical and complex theorising with traditional ‘special education’ understandings and explanations of disability and difference. She (2006, p. 293) criticises methods in special education for restricting their focus to singular aspects of identity and experience in ways that “highlight and exaggerate differences between groups of students and fail to question the constructedness of the normative centre.”

An area of intersection between ethnic and disabled identities in education is the significant over-representation of students from minority, non-white and non-English speaking cultures who are categorised as having ‘special educational needs’ and subsequently referred to special education (Connor, 2008; Danforth, Taff, & Ferguson, 2006; Erevelles, 2006; Erevelles, Kanga, & Middleton, 2006; Goodley, 2001; Slee, 1997). The over-representation of minority cultures in special education challenges special education’s claims to the objectivity and neutrality of its knowledge. Over-representation indicates that special education is inextricably linked with relations of power and social inequality. Ferri (2006, pp. 294-295) points out that “rarely is the white, heterosexual,

middle-class, able-bodied exemplar... included as a category of analysis, reproducing an unstated and unexamined norm by which all others deviate.” In contrast, DSE works to investigate “how various systems of oppression *interdepend*” (p. 295) (emphasis added), and analyses social phenomena with the intention of making, “the normative strange” (p. 299).

DSE: Disabled peoples’ voices and experiences

‘Disability’ and/or ‘impairment’ are often conceptualised as a “different kind of difference” outside of Disability Studies, if they are considered at all (Ferri, 2006, p. 301). Disability Studies scholars are critical of the lived and embodied experiences of disability being ignored and trivialized by critical scholars and researchers outside of the Disability Studies field, particularly in disciplines such as sociology and education that do pay attention to other experiences of marginalisation based on gender, class, ethnicity, and sexuality (Erevelles, 2005; Gabel, 2005; Linton, 1998). Ferri (2006) suggests that the non-recognition of disability as an experience of oppression is due to many non-DSE scholars sharing the dominant essentialist assumption that disability is a purely biological condition. Linton (1998, pp. 36-37) argues that in research outside of Disability Studies:

Disabled people have existed predominantly as marginal figures, their contributions and perspectives are not generally noted... The most fundamental problem...is that disabled people’s voices are almost completely absent from this picture, and so the understanding of disabled people’s place in these situations is filtered through the experience of people who have never been in that place.

As part of their interrogation of dominant discourses and culture, DSE scholars challenge traditional ideas about who has the authority and expertise to represent, understand and respond to disability within education and society (P. Ferguson & Ferguson, 1995; Ferri, 2006; Linton,

1998; B Macartney, 2009b; G. Thomas & Loxley, 2001; Van Hove, et al., 2009; Ware, 2006). Ferri (2006, p. 304) suggests that “Disability Studies troubles existing theories at the same time it offers alternative counternarratives that complicate any easy conceptions of difference and normativity.”

1.4 Families of disabled children within a ‘disabling society’

The contexts in which disabled people and their families live are extremely complex. Disabled people and their families exist, create, resist, are shaped by and negotiate meanings within a web of competing discourses about disability and difference (Arkwright, 2005; B Macartney, 2008b). They are positioned within a context of unequal power relations with people and structures such as educational, social service and medical professionals and institutions (Barrkman, 2002; Bogdan & Taylor, 1998; P. Ferguson, 2009; P. Ferguson & Ferguson, 2006; Linton, 1998; Raymond, 2002; Seymour, 2001). Attitudes, fears, assumptions, and values embedded within discourses of disability and difference influence professional practice, relationships, and interactions with people with disabilities and their family members (Fine & Asch, 1988; Fulcher, 1989; MacArthur & Dight, 2000; MacArthur, Purdue, & Ballard, 2003; Purdue, 1996; Van Hove, et al., 2009; Wills, 1994).

Family relationships with professionals

Families and caregivers of children with disabilities often describe their dealings and relationships with professionals who are working with them and/or their child/ren in negative terms (Barrkman, 2002; Bevan-Brown, 1994; Bogdan & Taylor, 1998; Brett, 2002; Brown, 1994; P. Ferguson, 2001; Fine, 1993; Lynn, 2004; MacArthur & Dight, 2000; B Macartney, 2002; Raymond, 2002; Seymour, 2001; Van Hove, et al., 2009; Wills, 1994). Many of these authors argue that the relationships between families

with disabled children and professionals are problematic because the attitudes, talk and actions of many professionals conflict with the way families view and feel about their children, and what they need and might benefit from (Ballard, 1994c; Bogdan & Taylor, 1992; P. Ferguson, 2009; Van Hove, et al., 2009). In New Zealand, professional intervention is generally a requirement of the child and/or family receiving funding for services and additional ‘support’ (Millar & Morton, 2007). The links between access to funding and professional involvement make the participation of professionals in the child and family’s life compulsory and leaves families with little flexibility in making choices about who and what they think would be useful to them and their child (B Macartney, 2002; Wills, 1994).

The nature and content of relationships with professionals usually adheres to pre-determined roles, expectations, processes, modes of delivery and rules. From the perspective of specialist professionals and services, it is assumed and expected that families will welcome a range of additional people and services into their lives, be grateful for their input and co-operate with them (P. Ferguson, 2009; P. Ferguson & Ferguson, 2006; G. Thomas & Loxley, 2001). However, the compulsory nature and level of professional involvement coupled with a focus on deficit, lack of flexibility, and perhaps fairness in what is provided contributes to parents and caregivers’ feelings of ambivalence and/or antagonism towards at least some of the professionals and service providers they encounter (MacArthur & Dight, 2000; B Macartney, 2002; Van Hove, et al., 2009; Wills, 1994).

Professional constructions of knowledge and interpretation of families

Family knowledge, outlook and experience are generally not valued or recognised by ‘special education’ and medical professionals or ‘experts’, in their approaches to and understandings of disability (Bevan-Brown, 2004;

Biklen, 1992; Bray & Mirfin-Veitch, 2003; P. Ferguson, 2001; Fine, 1993; MacArthur & Dight, 2000; B Macartney, 2002; Raymond, 2002; Seymour, 2001; Slee, 2001; Wills, 1994). Singer (1992, 1998) suggests that most professionals trained in or influenced by the discipline of psychology do not question the expert and objective status given to their theories, knowledge and approaches. The knowledge and perspectives of disabled people and their families are often discounted as inexpert and 'subjective' and as having little meaning or relevance to professional knowledge and interventions (G. Thomas & Loxley, 2001). This privileging of 'expert' knowledge influences relationships and pedagogy within early childhood centres and schools (Dunn, 2004; MacArthur & Dight, 2000; B Macartney, 2009b; Purdue, 2004; Slee, 2001). Teachers, most of whom have been immersed in a Western psychology-based knowledge paradigm in their teacher education programmes (Bishop, Mazawi, & Sheilds, 2005; Fler, 2005; Nuttall, 2003a; Skrtic, 1991, 1995; Slee, 2003), often defer to 'special education' personnel as the 'experts' about disabled children and will seek their 'specialised' input and uncritically follow such 'expert' advice in their approaches to disabled children and their families (Brantlinger, 2006; B Macartney, 2009b; Purdue, 2004; Slee, 1997).

Singer (1998) suggests that researchers using psychological theories to frame their studies about children's experiences in early childhood settings have usually ignored and/or misjudged parent's values, perspectives and cultural backgrounds (P. Ferguson & Ferguson, 1995, 2006; Slee, 2003). As a consequence, family knowledge and perspectives have had little or no role to play in informing researchers thinking, construction and dissemination of knowledge about 'disability' and about children's learning, development and behaviour (Singer, 1998). If researchers based in psychology were to acknowledge and address this issue, Singer (p. 70) suggests that they "...would have to distance

themselves from their claim of being more expert than parents, and to acknowledge that their theories can yield no neutral advice.” She suggests that an acknowledgement of the subjective nature of knowledge within the field of developmental psychology “...is rare” (Singer, 1998, p. 70). It is much more usual for professionals to assume and impose their interpretations and understanding of reality in families’ ‘best interests’ (Ballard, 1994a, 1994b, 1994c; P. Ferguson, 2001; P. Ferguson & Ferguson, 2006; Singer, 1998; Van Hove, et al., 2009).

Ballard (1994a) suggests that the most significant difficulties families of disabled children face in their dealings with professionals are due to professionals using a medical discourse that primarily views people with disability (and their families): “... in terms of their ‘problems’ or ‘deficits’” (p. 18). In Chapter Two, I examine the content and effects of ‘disabling discourses’ and the cultural assumptions and beliefs that underpin them (Allan, 1999; Arkwright, 2005; P. Ferguson & O’Brien, 2005; Fine & Asch, 1988; Fulcher, 1989; Hughes, 2002; MacArthur, et al., 2003; G. Mercer, 2002; Oliver, 1990, 1996; C. Thomas, 2002). Family members are much better positioned than professionals to view and relate to their children as ‘people first’ (MacArthur & Dight, 2000; B Macartney, 2002; Van Hove, et al., 2009). They live with and are usually well aware of their child’s individual attributes, strengths, weaknesses, and ways of communicating and expressing their desires and needs (Bogdan & Taylor, 1992). Because of this, families are much less likely to view their child solely or even primarily in terms of their ‘disabilities’ and/or ‘impairments’ (Barrkman, 2002; Biklen, 1992; Brett, 2002; P. Ferguson & Ferguson, 1995; B Macartney, 2002; Raymond, 2002). Thus, family accounts are much more likely than professional accounts to retain and communicate the complexities, richness and diversity of ‘disabled identities’ and experience.

Professional knowledge: who benefits?

Through their induction into the theoretical and applied knowledge of their profession, teachers and therapists internalise: ‘...the value system, norms, and established behaviour patterns of the group he or she is entering’ (Skrtic, 1991, p. 93). In a discussion of the politics of theorizing disability, Slee (1997, p. 408) suggests we must consider who is producing theory, for what purposes and, “to what ends are theories manufactured and deployed?” Raymond (2002, p. 163), in her narrative inquiry into the experiences of parents trying to secure an inclusive education for their disabled children, poses the questions: “*what* knowledge counts?” and “*whose* knowledge counts?” within the “professional knowledge landscape”. In a discussion of the social-political-cultural construction of disability knowledge and its implications, Slee (2001, p. 171) argues that: “At the heart of our survey about disability knowledge must be the question of meaning and interest. In whose interests do particular forms of knowledge operate?”

Slee (2001) and others (Danforth, et al., 2006; Raymond, 2002; Skrtic, 1995; G. Thomas & Loxley, 2001) argue that it is the ‘helping’ professions, policy makers, administrators and bureaucracies that have developed and grown around deficit notions of disability “...that derive greater benefit from the expanding practice of special education” (Slee, 2001, p. 171). Tom Skrtic (1991), and others (Brantlinger, 1997; Slee, 1997, 2001; Smith, et al., 2009) argue that special education and the medical profession act to maintain a disabled clientele and to protect their professional self interests from the consequences of a theoretical framework and human rights movement that seeks to expose, critique and undermine their role and existence. Smith et al., (2009, pp. 236-237) challenge the neutrality and benefits of special education knowledge. They argue that special education has “demonstrably worked against the goals of

educational and social equality by objectifying and stigmatizing people labelled as having disabilities,... impoverishing the instructional approaches used to educate them, and institutionalizing educational segregation.”

It is also argued that both special education *and* the regular school system are major benefactors of the conceptual and physical separation of children with and without ‘special educational needs’ is (Danforth, et al., 2006; Slee, 2001; G. Thomas & Loxley, 2001). The development of the ‘helping’ professions has meant that regular schooling systems have historically been ‘let off the hook’ through the expansion of special education personnel and responses to difference. ‘Regular’ schools and the ‘regular’ teaching profession have been ‘saved’ from fully addressing their responsibilities to meet the educational needs and aspirations of *all* children and their families (Danforth, et al., 2006; Slee, 2001, 2003; Stromstad, 2003; G. Thomas & Loxley, 2001). Special education can be perceived as a conservative reaction to the increasing heterogeneity of school populations (Danforth, et al., 2006). The relegation of groups of children and their families to special education provision and knowledge re-produces and maintains the hegemonic social order of regular schooling. The knowledge, techniques and provision of special education have been used to control, sideline and diminish any potential influences diversity might have on the social order and status quo (Danforth, et al., 2006). Roger Slee (1997, p. 407) has described the movement of ‘problematic’ students and populations out of the regular school system into special education as one of, “theoretical, and political deflection...”. Special education, coupled with resistance to inclusion and diversity within general education, have created space for the continuation of an “unreconstructed school system” (Slee, 1997, p. 407).

Ferguson & Ferguson (1995, p. 107) suggest that telling and interpreting people's stories can impact positively on power relations because "it gives voice to those not usually asked to describe anything. Complete description challenges power, because an important part of being powerful is the ability to limit description, to define terms, to set the agenda." Raymond's (2002) narrative research showed how classroom teachers, and special education professionals, can interact with families in ways that negate, marginalise and reject the knowledge and insights they have to offer. Educators and other professionals can benefit from research that locates disability in personal, family, social, political and cultural contexts (Bray & Mirfin-Veitch, 2003; G. Thomas & Loxley, 2001; Valenzuela, et al., 2000). This thesis offers professionals an opportunity to learn from parents' voices and experiences.

1.5 New Zealand's legislative and policy context

Formalised expectations for education are communicated through professional networks, curriculum documents, regulations, policies, and laws governing educational practice. The development and interpretation of policy and curriculum is a process of meaning making, negotiation, competition and occasionally compromise between differing priorities and worldviews. As Thomas and Loxley (2001, p. 99) argue: "Policy is not...the virtuous outcome of some consensual democratic process. Rather it is the outcome of struggle and contestation, of a continually shifting political process, which not only decides *what* ideas are permissible, but *who* should articulate them." Even when key documents, policies and laws are supportive of inclusion, teachers routinely defer to deficit 'special education' explanations and approaches within their contexts (MacArthur & Dight, 2000; MacArthur, et al., 2003; B Macartney, 2002, 2009b; Rutherford, 2009).

New Zealand educational policy: Confusion about ‘inclusion’

Over the past 20 years or so, a policy and legislative environment has developed in Aotearoa-New Zealand that can be viewed as supportive and encouraging of inclusive attitudes and practices with regard to the human rights and participation of disabled people in education and society (Gordon & Morton, 2008; IHC, 2008; O'Brien & Ryba, 2005; Rutherford, 2009). Some argue that the existence of policy and legislative support for inclusion means that disabled people and their families are in a better position to assert their rights and have more opportunities for redress when treated in ways that undermine or exclude them (O'Brien & Ryba, 2005). However, as U.K. disability scholars and advocates Thomas and Loxley (2001, p. 99) warn, “there can never be a single, objective reading (of any text), only a struggle between sets of readings...all encased within the usual political jostlings...we can also argue that the ‘victorious’ reading cannot be treated as absolute, but more of a temporary settlement.”

New Zealand disability researchers and advocates for inclusive education Higgins, MacArthur and Rietveld (2006) and Rutherford (2009) strongly criticise New Zealand educational policies for providing unclear, inconsistent and mixed messages to families, schools and teachers about what educational inclusion for disabled students requires and means. Of particular concern is the absence of any “leading, overriding, coordinating or national policy about inclusion from which schools and teachers can develop their inclusive programmes and practice... (and) that such a ‘higgledy-piggledy’ approach to inclusion creates confusion and pedagogical inconsistencies in schools” (Higgins, et al., 2006, p. 30).

New Zealand’s Ministry of Education policies and documents have been criticised for regularly making statements of policy that align and equate ‘inclusion’ with the language and practices of ‘special

education' (Higgins, MacArthur, & Morton, 2008; Higgins, et al., 2006; Ministry of Education, 2010). For example, Ministry of Education policies and official documents combine references to 'inclusion' with statements that support the retention of 'special' schools, and special classrooms or units within 'regular' schools (Higgins, et al., 2008). The Ministry of Education uses neo-liberal arguments and rhetoric to justify State support and funding for separate schooling 'options' for disabled students (Higgins, et al., 2008; Higgins, et al., 2006). Underpinning neoliberalism are beliefs that education is a private good, that individuals do and should act as 'rational' and 'autonomous' agents, and that parents/consumers have equal educational opportunities and 'choices' (Ballard, 2004; Gilbert, 2010; Gordon & Morton, 2008; Higgins, et al., 2008; Millar & Morton, 2007; Slee, 2010; G. Thomas & Loxley, 2001).

Within New Zealand's confused policy context, early childhood centre and school management, families and teachers are left without a clear direction about what is expected of them in developing inclusive educational environments for all children, and disabled learners in particular (Higgins, et al., 2008; IHC, 2008). Government legislation and policies supporting the rights of disabled students to full and equal participation in the education system can and are being used to challenge existing structures and practices and to argue for significant and systemic changes within the system (IHC, 2008; Ministry of Education, 1996a; Ministry of Health, 2001).

Neo-liberalism in New Zealand education

Consistent with the rise of neo-liberal ideology, practices and structures in New Zealand and other 'developed' countries over the past two or three decades, financial and administrative responsibilities for New Zealand schools were devolved to local communities in 1989 (Gordon & Morton,

2008; Taskforce to Review Education Administration, 1988). A major aspect of this Government initiative was the establishment of individual school Boards of Trustees (BOTs) primarily made up of school parents and staff.

Initially a national Parent Advocacy Council (PAC) was established as part of these changes. The PAC was described in the new policy as "...a mechanism...required for consumers to have their views promoted or to seek redress when they feel they have been unfairly or unjustly treated" (Taskforce to Review Education Administration, 1988, p. 57). The PAC was disestablished by the incoming conservative Government one year later, closing a potential line of influence for families.

The establishment of school Boards of Trustees effectively narrowed the government's role, responsibilities and direct relationship with schools (Gordon & Morton, 2008; Higgins, et al., 2006). Since this policy was enacted, New Zealand schools have been treated and referred to as 'self governing units' who compete with each other within an education 'marketplace' (Gordon & Morton, 2008). The delegation of school management to families and teachers has distanced government and Crown agencies from the decisions schools make and their practices in areas such as responding to disabled children and their families and implementing 'inclusion' (Gordon & Morton, 2008; IHC, 2008; Slee, 2003).

Fourteen years ago, the Ministry of Education (1996a, p. 1) stated its intention to create "...a world class inclusive education system." This sentiment has been repeated recently in the government's '*Success for All – Every School, Every Child*' document (Ministry of Education, 2010). Higgins, MacArthur and Morton (2008, p. 146) suggest that, rather than New Zealand education moving towards inclusion, there is:

...a growing body of evidence that New Zealand's neoliberal paradigms (with their emphasis on the individual and on education as a private commodity), and mixed messages about education for disabled children, have limited the country's progression towards an inclusive education approach, where the focus is on quality for all children.

Higgins, MacArthur and Morton (2008) describe this situation as evidence of the State, "winding back the clock" and mounting a political retreat from inclusive education. At the very least, it appears that the Ministry's working definition of 'inclusion' is directed at learners who are labelled as having special education needs, rather than transforming the system in ways that will enhance the inclusion of all learners (Ministry of Education, 2010).

A legal challenge to the exclusion of disabled students

In 2008, the IHC, a New Zealand organisation that advocates for the rights and inclusion of more than 11,000 people with intellectual disabilities and their families in New Zealand, lodged a formal complaint with the Human Rights Commission against the New Zealand Government (IHC, 2008). The complaint was "aimed at government policy that impacts negatively on access to education for students with disabilities after parents have exercised or have attempted to exercise the right to enrol their sons or daughters at schools that operate within a mainstream setting" (p. 4).

The IHC provided evidence in the form of 148 affidavits, seventy percent of these were from families that have experienced discrimination and exclusion within the state education system (O'Donovan, personal communication, April 17, 2010). Schools also contributed to the complaint. Many of the school affidavits spoke of their frustrations about inadequate provision of resources and professional support for responding to and meeting the needs of disabled children within their settings. Affidavits

were also provided by New Zealand academics using research evidence to support the IHC's claims against the Government. IHC argued that, although many of the Government's laws and policies and their commitment to international agreements that protect and uphold the rights of disabled people to an inclusive education, are supportive of inclusion, the State has not ensured these commitments are appropriately resourced, widely understood and enacted throughout the education system. They also argued that many schools feel unwilling and/or unable to support the full and equal participation of disabled students alongside their non-disabled peers (IHC, 2008). The New Zealand Human Rights Commission agreed that IHC's complaint had substance and merit and is currently facilitating a process of mediation between the IHC, the Crown Law Office and the Ministry of Education. The focus of the mediation is on the systemic problems of discrimination against disabled students and their families at all levels of the education system (O'Donovan, personal communication, April 26, 2010).

'Partnership' with families

Fine (1993) discusses the problems families experience in being able to influence meaningful, structural change and involvement in Western education systems. Her criticism is that, although parents in some US states have been invited to participate in management structures similar to New Zealand school Boards of Trustees, parental participation is underpinned by the incorrect assumption that partnerships between school staff and parents are "power neutral" (p. 682). Fine suggests that models of partnership that do not address unequal power relations between parents, teachers and administrators will not succeed in producing the systemic, material changes that parents might advocate for.

The rights and choices that parents of disabled children typically advocate for are the same opportunities and experiences that parents of non-disabled children take for granted (Brown, 1999; IHC, 2008). One of the costs to families of being advocates for their disabled children at schools that are now managed locally, is that parents often find themselves battling against their own neighbours and community members to ensure that their child's entitlements are acknowledged and upheld (Brown, 1999). That these rights and entitlements are enshrined in laws and policies does not mean they are understood and enacted on a school by school basis. Slee (2010), commenting on the New Zealand Ministry of Education's continued support for 'special education' structures, thinking and approaches challenged the Government's notion of parental 'choice'. He argued that:

Parent 'choice' is a false notion. If schools had the capacity to teach all children in their local area; children received the support they need there; teachers had the skills and knowledge to teach all children; and the physical environment accommodated all, then there would be a real choice for parents. But at the moment, conditions make it very difficult for children and parents, and often the only alternative is segregation. This situation is dressed up as 'choice', but it is not really choice at all. Neither 'option' is a good one. What we need to do is concentrate on building an education system which can meet the needs of all children in local, regular schools (p. 3).

In addition to government support for educational exclusion through special schooling 'options', there is much evidence demonstrating the exclusion of disabled children attending 'regular' schools and early childhood settings (Higgins, et al., 2006; IHC, 2008; MacArthur, Kelly, & Higgins, 2005; MacArthur, Kelly, Higgins, et al., 2005; Purdue, 2004; Rietveld, 2005). Increasing numbers of families with disabled children in New Zealand are 'choosing' to use special schools and classrooms in preference to 'regular' schooling options (Higgins, et al., 2008). The

espoused view of the New Zealand Government is that ‘special education’ options are part of a continuum of provision for disabled children and their families, and that families are ‘free’ to choose the ‘best’ option for their child (Higgins, et al., 2006; Ministry of Education, 2010). However parental ‘demand’ for ‘special schooling’ can be interpreted in less favourable terms. Families may ‘opt’ for special schools because they don’t trust and/or have experienced exclusion within the ‘regular’ settings they have attended. Many families may be opting to enrol their children at ‘special’ schools by default (Armstrong & Armstrong, 2006; Higgins, et al., 2008).

‘Inclusive’ education as a human right

Higgins, MacArthur and Rietveld (2006) lament the lack of accountability and professional mentoring and support for regular schools in developing and maintaining inclusive academic and social environments focussing on school culture, leadership and inclusive pedagogy. The existence of inclusive policies and legislation, even without the Ministry of Education’s loyalty to ‘special education’ responses to disability, does not guarantee wide ranging changes in attitudes and practices within education (Higgins, et al., 2006; Rice, 1993).

The legal right of disabled children to attend their local school was legislated for in 1989 in an amendment to the Education Act (New Zealand Education Act, 1989). This amendment recognised the rights of children with ‘special education needs’ to attend their local school on the same basis as children who do not have ‘special education needs’. Twenty years later, disabled children are still turned away from their local school without families seeking legal redress (Grant, 2008; IHC, 2008). Neither does being legally required to enrol disabled children ensure that those children will be provided with an inclusive education and that every school

will work in partnership with families to that end (MacArthur, Kelly, & Higgins, 2005; B Macartney & Morton, 2009).

Millar and Morton (2007) suggest that a structural factor inhibiting moves towards an inclusive education system in New Zealand and internationally are the, “apparently separate worlds of special education and curriculum policy (and the) persistent silence” (about disabled learners) “in the broader discourses of education” (p. 163/164). They suggest that “if the deep structures of special education – those issues that underlie relations of power, control, dominance and subordination – are not identified and transformed, exclusion and marginalization will be reproduced even under the most well intentioned and well-supported of programmes” (p. 168). Much work needs to be carried out within education contexts to challenge ‘special’, deficit thinking and practices and to support and make space for inclusive pedagogies (Alton-Lee, et al., 2000; MacArthur, et al., 2003; B Macartney, 2002, 2009b, 2010; B Macartney & Morton, 2009; Millar & Morton, 2007; Purdue, 2004). The Ministry of Education continues to communicate contradictory messages about inclusive education. These messages do little to prioritise or support the development of inclusive approaches in education. They help to maintain confusion about what inclusion means and inhibit moves towards more inclusive education (Higgins, et al., 2008).

The Human Rights Act

Disability is included in the Human Rights Act (New Zealand Human Rights Act, 1993) as one of the grounds on which discrimination in New Zealand is prohibited. Within such areas as education, the media, housing, access to public places, services and health care, people who have experienced discrimination because of their disability can seek redress under the Act through the Human Rights Commission. Although the

practice of turning disabled children away from enrolling at schools has been illegal in New Zealand since 1989 (New Zealand Education Act, 1989), it is common knowledge that many New Zealand families are regularly denied enrolment by schools when the school finds out that a child has 'special needs' (Grant, 2008; IHC, 2008). This practice generally goes unreported and therefore under the 'official' radar of the Human Rights Commission and the Ministry of Education. Families are often of a mind that they don't want to place their child in a school that is unwelcoming and resistant to including them. This is likely to be a factor in many families 'choosing' to move on rather than complaining through official channels about being discriminated against.

The New Zealand Disability Strategy: Making a world of difference

At the same time as the New Zealand Government retreats from inclusive education, cross-government policy originating in the health sector advocates partnership with disabled people to advance their calls for recognition, participation and access within education and society (Ministry of Health, 2000, 2001). Some New Zealand policy and initiatives show that there are pockets of official support for and commitment to social-political-cultural understandings of disability in New Zealand (IHC & Centre, 2010). Challenges to a construction of disability as an individual and private misfortune are embedded in the *New Zealand Disability Strategy (NZDS)* (Ministry of Health, 2001). The *NZDS* was developed in close consultation with disabled people and the disability sector and the final document received wide support from within the sector. The focus in defining 'disability' in the *NZDS* is on the role of society in creating and maintaining barriers to the full inclusion and participation of disabled people. The *New Zealand Disability Strategy* clearly aligns itself with the social model in stating that:

Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have. Our society is built in a way that assumes that we can all move quickly from one side of the road to the other; that we can all see signs, read directions, hear announcements, reach buttons, have the strength to open heavy doors and have stable moods and perceptions (p. 3).

Ruth Dyson, New Zealand Minister for Disability Issues at the time the *NZDS* was published, suggested in the document that a common experience of disabled people in New Zealand is in facing “many lifelong barriers to their full participation in New Zealand society” (Ministry of Health, 2000, p. 1). The *NZDS* communicates its aim as helping to transform “New Zealand from a disabling to an inclusive society” (Ministry of Health, 2001, p. 1). The *NZDS* (p.1) states that: “New Zealand will be inclusive when people with impairments can say they live in a society that highly values our lives and continually enhances our full participation.” The key education objective in the Strategy is a commitment to: “Improve education so that all children, youth and adult learners will have equal opportunities to learn and develop in their local, regular educational centres” (p. 11). A reading of the *NZDS* indicates that New Zealand governments support inclusive, accessible educational opportunities for disabled people and their families in their local communities. The existence of the *NZDS* alongside governmental support for special education provision and segregation in New Zealand schooling indicates that Crown agencies such as the Ministries of Health, Social Development and Education have very different views of and approaches to ‘disability’ and ‘inclusion’ (Higgins, et al., 2006; IHC & Centre, 2010; Ministry of Education, 2010).

New Zealand governments have produced many stated and legal commitments to the full acceptance, inclusion and participation of children

with ‘special education needs’ within regular educational settings (Ministry of Education, 1996b, 1998, 2000, 2002, 2007; Ministry of Health, 2000, 2001; New Zealand Education Act, 1989). However, there is a substantial gap between official rhetoric about the full participation and inclusion of disabled students, and the existence of appropriate educational structures, provision and practice (Ballard, 2004; Brown, 1999; Higgins, et al., 2006; IHC, 2008; MacArthur & Dight, 2000; MacArthur, Kelly, Higgins, et al., 2005; B Macartney, 2009b; Purdue, 1996, 2004; Wylie, 2000). All government agencies are required to report annually on their progress towards meeting the goals of the *NZDS*. This involves an expectation that every government agency will contribute to transforming New Zealand from a disabling to an inclusive society. Unfortunately, over the decade of its existence, the *NZDS* and its potential significance for education structures, policy and pedagogy has not been taken very seriously or far by successive governments and the Ministry of Education (Grant, 2008; Higgins, et al., 2008; Higgins, et al., 2006).

1.6 Approaches to teaching, learning and ‘diversity’

This section sets the context for New Zealand educational pedagogy (Ministry of Education, 1993a, 1996b, 2007b). New Zealand’s early childhood and English-language-medium compulsory school curriculum documents draw from traditional Western knowledge paradigms, and from potentially transformative approaches to education such as indigenous and socio-cultural perspectives. Before introducing the curriculum documents, this section considers traditional and transformative understandings of teaching and learning and how these might impact on inclusive education in New Zealand.

Education: ‘special’, ‘regular’ or ‘inclusive’?

Deficit views of disability and difference remain prevalent and dominant within New Zealand education and society despite government policies, legislation and documents that support inclusive conceptualisations of education (Bishop & Glynn, 1999; Bishop, et al., 2005; IHC, 2008; Ministry of Health, 2001). English-language-medium New Zealand education continues to privilege and emphasise a view of disabled children as different to non-labelled children with the conclusion that this means disabled children need ‘special’ approaches to their education (Ballard, 2004; Higgins, et al., 2008; Higgins, et al., 2006; MacArthur, Dight, & Purdue, 2000; Ministry of Education, 1996b, 2007b). MacArthur, Kelly and Higgins (2005; MacArthur, Kelly, Higgins, et al., 2005) carried out an extensive review of New Zealand and international research literature on supporting the learning and participation of disabled students in education. Their review found that separate education, compared with regular education for disabled students, limits disabled students’ access to a range and depth of learning opportunities, levels of educational achievement and successful transitions into employment, further education and community life after leaving school (MacArthur, Kelly, & Higgins, 2005; MacArthur, Kelly, Higgins, et al., 2005).

Many New Zealand disability researchers and commentators have also argued that disabled and non-disabled children in regular educational settings do not experience an inclusive education by virtue of sharing the same physical location (Cullen, 1999; L. Lyons, 2005; MacArthur, Kelly, & Higgins, 2005; MacArthur, et al., 2003; B Macartney, 2010; B Macartney & Morton, 2009; Purdue, 2004; Rietveld, 2005; Rutherford, 2009). Ballard (2004) suggests that special education and deficit thinking separates disabled children from others, sometimes physically, but also pedagogically. He (2004, p. 315; Ballard & Macdonald, 1998) argues “that

alternative understandings of disability and of education are necessary to transform schools and classrooms so that they meet the needs and aspirations of all children.” MacArthur et al (2005, p. 51) suggest that, rather than referring to all regular education settings as ‘inclusive’, some “...may be more accurately described as ‘less segregated’” than special education settings. Rutherford’s (2009, p. 94) research findings suggest that disabled children’s access to the *New Zealand Curriculum* in regular school settings can be categorised in terms of “(a) full and meaningful participation in the curriculum, (b) partial access and participation mediated by a teacher aide or (c) no access at all.”

Theories of teaching and learning: What and whose knowledge counts?

Critical education theorists and researchers argue that dominant Western knowledge traditions privilege white, male, able-bodied, heterosexual and middle class views of ‘human development’ and learning (Bishop & Glynn, 1999; Cannella, 1997; Dalhberg & Moss, 2005; Farquhar & Flear, 2007; Flear, 2005; Graham, 2005; Gunn, et al., 2004; Linton, 1998; MacNaughton, 2005; Rinaldi, 2006; Rogoff, 2003; Singer, 1992, 1998; Skrtic, 1991, 1995). Australian DSE researchers Linda Graham and Roger Slee (2008, p. 86) argue that within the related fields of medicine, special education and psychology “... normalization is a man-made grid of intelligibility that attributes value to culturally specific performances and in doing so, privileges particular ways of being.” A key criticism of Western developmental knowledge is its presumption that development and learning are solely or primarily internal individual processes (Carr, 2001; Rinaldi, 2006; Rogoff, 2003).

‘Child development’ knowledge is communicated as ‘the true’ explanation for how human beings do and should develop. In addition to

locating learning and development within the individual, the content, timing and trajectory of ‘normal’ human development is treated as universal, knowable and predictable (Singer, 1992). Child development knowledge is assumed to be unbiased and neutral because it is a ‘factual’ representation of reality (Cannella, 1997). However, Fler (2005) and others (Mayall, 2002; Rinaldi, 2006; Rogoff, 2003; Singer, 1992), suggest that human growth and development are much more complex, variable, social, cultural, historical, political and contextually situated than an adherence to developmental perspectives would lead us to believe.

Using a socio-cultural framework, Fler (2005, p. 7) argues that: “Development is not something that exists within the child, but rather takes place as the child interacts with his/her cultural community.” Rogoff draws from socio-cultural and cross-cultural research to argue that:

In the emerging sociocultural perspective, culture is not an entity that *influences* individuals. Instead, people contribute to the creation of cultural processes and cultural processes contribute to the creation of people. Thus, individual and cultural processes are *mutually constituting* rather than defined separately from each other (2003, p. 51). (emphasis in the original)

Rogoff suggests that separating individual and social-cultural factors produces a “false dichotomy” (p. 65). Rather than assuming that biological and environmental influences on learning and development work in isolation, Rogoff suggests that genetics, biology and culture interact in complex and unpredictable ways.

Developmentalism and diversity

Developmental approaches understand ‘diversity’ and difference as individual and collective deviations from ‘the norm’ (Bishop, et al., 2005; B Macartney, 2010). These ‘deviations’ are conceptualised either as

individual deficits or gifts, in relation to a stable centre/norm (Graham & Slee, 2008). In the case of ‘deficits’ and ‘delays’ in development, if these are not easily attributable to a ‘biological condition’, it is regularly assumed that development has been stymied because of ‘cultural deprivation’ within the individual’s home and/or community (Bishop & Glynn, 1999; Singer, 1998). Pathologising difference through using individualising and/or cultural deprivation explanations positions the ‘norm’ at the centre, with its truth claims remaining unquestioned and unchallenged. Western images of ‘the child’ and constructions of ‘child development’ colonise the diversity of experiences, beliefs, practices, ways of being, contributions and aspirations of many children and families engaged in education (Bishop & Glynn, 1999; Bishop, et al., 2005; Fler, 2005; FourArrows-Jacobs, 2008; Mayall, 2002; Rivalland & Nuttall, 2010; Rogoff, 2003; Singer, 1992, 1998; Veck, 2009). Knowledge and practices that claim to be universal tend to default to the dominant group’s belief system, norms and stereotypes. Because developmental approaches are monocultural, eurocentric and limiting to many children, Fler (2005, p. 6) suggests in relation to early childhood education that “...it is our professional responsibility to find possible directions to move the field forward” and away from our loyalty to, and reliance on, universalised developmental knowledge.

A ‘pedagogy of listening’ and ethics-based approaches to education

The negative workings of power and unequal outcomes for different groups within education and society strongly influence children’s learning, participation and inclusion (Bishop & Glynn, 1999; Bishop, et al., 2005; Dalhberg & Moss, 2005; Freire, 1997, 1998; Linton, 1998; B Macartney, 2008b, 2009b; B Macartney & Morton, 2009; MacNaughton, 2005; Rinaldi, 2006; Valenzuela, et al., 2000; Veck, 2009). Critical, ethics-based pedagogies open the way for the diversity and complexity that exists within

education and society to be recognised and responded to rather than marginalised and ignored (Bishop & Glynn, 1999; Dalhberg & Moss, 2005; Ministry of Education, 1996b; Rinaldi, 2006; Robinson & Jones Diaz, 1999).

Dahlberg and Moss (in Rinaldi, 2006, p. 15) describe a ‘pedagogy of listening’ as creating spaces where “politics and ethics come together in an approach to education which rejects the regulatory bonds of developmental classifications and education as transmission and normative outcomes, and which emphasises the importance of otherness and difference, connectedness and relationships.” Conceptualising ethics as being about our relationships and obligations towards others positions inclusion, justice and emancipation as central to education (Dalhberg & Moss, 2005; Rinaldi, 2006; Slee, 2001; Smith, et al., 2009).

A ‘pedagogy of listening’ (POL) is a social constructionist, democratic and ethical approach to early childhood education that originated from Reggio Emilia early childhood services in Italy (Rinaldi, 2006) and has also been taken up by early childhood educationalists from Denmark and the United Kingdom (Dahlberg, Moss, & Pence, 2007; Dalhberg & Moss, 2005; Moss & Petrie, 2002). It is based on an ‘ethic of care’ and obligation to the ‘other’ (Dalhberg & Moss, 2005; Rinaldi, 2006; Veck, 2009). A pedagogy of listening sees it as the teacher’s role to identify and remove barriers to learning and participation through attentive ‘listening’ to the other within relationship based contexts (Carr, et al., 2000; Dalhberg & Moss, 2005; Moss & Petrie, 2002; Veck, 2009). .

Within a pedagogy of listening approach, possibilities for co-constructing meaning and making sense of experience are expanded through listening, dialogue, interpretation and critique. Teaching becomes an ethical pursuit in which listening is used as a tool for understanding,

respecting and responding with openness to the 'other'. Veck (2009), in his discussion of listening as pedagogy, suggests that teachers work from an attentive and open orientation where:

What is attended to in listening is not, then, what we think we know about a speaker, but the possibilities for newness that dwell within their personhood whose mystery precludes full knowing. Attentive listening thus involves an existential leap, a transformation in being that moves the listener beyond the security of the known. It requires listeners to prepare for change and to allow themselves to be changed by the words they hear (p. 148).

Rinaldi's (2006) description of listening as pedagogy includes teachers being curious about the patterns (languages, symbols and codes) that connect us to others in the process of sharing and constructing knowledge and making sense of our experiences. A listening orientation includes:

Listening as welcoming and being open to differences, recognising the value of the other's point of view and interpretation... Listening that does not produce answers but formulates questions; listening which is not insecurity but, on the contrary, the security that every truth is such only if we are aware of its limits and its possible 'falsification' (Rinaldi, 2006, p. 65).

An implication of a view of knowledge and learning as situated and provisional is the liberation of teachers and children from the limits of pre-defined knowledge and outcomes (Veck, 2009). In this regard, a pedagogy of listening can be described as a framework for growing socially just communities of practice based on on-going recognition of and responsiveness to diversity and difference (Moss & Petrie, 2002; Rinaldi, 2006).

1.7 New Zealand's curriculum context

This section provides a background to the development, pedagogical influences, and contents of New Zealand's early childhood education and compulsory school curriculum documents (Ministry of Education, 1993a, 1996b, 2007b). I discuss the influences of competing discourses on teacher, early childhood centre and school practices, and child/student identity, learning, and participation. I begin with a brief description of the early childhood and compulsory education sectors in New Zealand.

Early childhood and compulsory education in New Zealand

In Aotearoa-New Zealand all children, disabled and non-disabled, are legally entitled to attend the early childhood centre/s and state school/s of their choice (New Zealand Education Act, 1989; New Zealand Human Rights Act, 1993). Early childhood services, and schools each have a mandated national curriculum document (Ministry of Education, 1996b, 2007b). Each document states that the curriculum is written and relevant for all children. Both emphasise teacher, early childhood service and school roles in recognising and valuing diversity and in empowering children and their families. New Zealand has a diverse range of early childhood education settings which include sessional and full-day centres, parent led, and teacher led services, not-for-profit and for-profit centres, home-based child care, and centres that are based on the language and cultural needs and aspirations of particular groups such as Maori (New Zealand's indigenous population), and Pacific Island communities.

There are very few separate early childhood centres for disabled children in New Zealand. Most if not all preschoolers who are labelled as having 'special educational needs' are linked to a special education early intervention service (EIS). EIS staff work with the child and family, and with any early childhood education service the child attends. The EIS

employs education support workers (ESWs) who work within the early childhood centre. The EIS also provides specialist intervention and advice to centres and families. If the child is not attending an early childhood centre, the EIS will work with the family and child at home and/or at the EIS.

Schooling is compulsory in Aotearoa-New Zealand from age six through to sixteen. Most children begin school at age five. Primary schooling comprises the first eight years (5/6-12/13 yrs), and secondary school comprises the next five years (12/13 – 17/18 yrs). Many disabled children in New Zealand attend regular schools. Each regular school receives general and targeted special education funding depending on the decile rating of the school, and the particular children attending. Special education funding is provided to individual schools to employ teacher aides and additional .1/.2 specialist support. Some schools also supplement teacher aide funding using ‘general’ funds and/or financial contributions from the parents of the disabled child (Grant, 2008; IHC, 2008). Special education services and personnel work in an itinerant manner with individual schools and children.

‘Special schools’ are an ‘option’ for disabled children in New Zealand with the proviso that they have been accepted into the Ministry of Education’s *On-going Reviewable Resources Scheme (ORRS)*. The *ORRS* scheme provides funding for individual disabled school aged children who have been assessed as having ‘high’ or ‘very high’ ‘special needs’ according to Ministry of Education criteria. *ORRS* funding is used to pay for additional part-time teacher hours to support the classroom teacher, teacher aide hours, additional resources or equipment and the involvement of a special education provider and therapists while the child is at school. Children who are *ORRS* funded can and do attend regular schools. *ORRS* funded students constitute a maximum of around 1% of the total school

population. There are many children labelled as having ‘special educational needs’ who do not receive *ORRS* funding. Some special schools specify particular impairments such as visual or hearing impairments that children must have to enrol. Other special schools work with a wide range of children who have been accepted into the *ORRS* scheme. Many regular secondary schools have what are often termed ‘satellite’ or ‘special’ units for labelled students. The practices of regular primary and secondary schools vary widely in regards to the types and levels of ‘segregation’ or ‘integration’ of labelled students within their regular classes and programmes.

The curriculum documents and their general support for inclusive education

Although not unproblematic in their alliance to socio-cultural approaches to teaching and learning both *Te Whaariki-The Early Childhood Curriculum* (Ministry of Education, 1996b) and *The New Zealand Curriculum (NZC)* (Ministry of Education, 2007b) draw significantly from ecological and socio-cultural theories of education. However, as with New Zealand’s policy context, tensions and potential mismatches are evident within each document. These tensions coalesce around individualistic, technicist, developmental conceptualisations of teaching and learning, and human rights-based, ecological, sociocultural pedagogies.

Because the *NZC* has only recently been introduced to New Zealand schools, there are few completed research commentaries about the effects that the new curriculum is having on educational thinking and practice. However, it seems clear that the development and introduction of *Te Whaariki*, and more recently the *NZC*, has provided an opportunity for New Zealand teachers, and educational settings to question and re-think much of their taken-for-granted and assumed knowledge about the aims of

education, how children learn, and the teacher's role in supporting this (Carr, 2001; Millar & Morton, 2007).

Curriculum development in New Zealand

Both *Te Whaariki* and the *NZC* are very different from the guiding documents and knowledge traditions they replaced (Carr & May, 2000; Mutch, 2003). Up until the introduction of the draft early childhood curriculum in 1993 (Ministry of Education, 1993b), there was no national curriculum document for the provision of early childhood education in New Zealand. A key motivation for developing a national early childhood curriculum in the early 1990s was a widespread concern within the early childhood sector about statements coming from the conservative, neo-liberal Government. These statements indicated a view of early childhood curriculum and pedagogy as a 'watered down' academic and subject-based version of the school curriculum (Carr & May, 1993; Middleton & May, 1997; Te One, 2003). This view met with strong opposition from within the early childhood sector. A traditional school based early childhood curriculum was seen as a threat to the previously un-formalised, but strongly held 'free-play', 'child and family centred' traditions within New Zealand early childhood education (Carr & May, 1993; Te One, 2003).

Carr and May, two of the key writers of *Te Whaariki*, are highly regarded members of the early childhood education sector. They were successful in leading a nationwide, consultative and inclusive process in developing what quickly became a widely accepted curriculum document (Te One, 2003). Over the six year trajectory of its development, and up to the release of the final document in 1996, *Te Whaariki* managed to retain its socio-cultural, bicultural, family-community centred and relational approach to early childhood theory and practice (Carr & May, 2000). The early childhood curriculum was very different from the more traditional,

individualised, subject and outcomes based *New Zealand Curriculum Framework (NZCF)* (Ministry of Education, 1993a) which was developed during the same period (Mutch, 2003). *Te Whaariki* largely succeeded in staying below the neo-liberal radar that influenced the development and contents of the compulsory school curriculum (Mutch, 2003). Partly because of its development during a political period that was hostile to collectivist and humanist conceptualisations of education and its bicultural/bilingual framework, *Te Whaariki* has been celebrated as:

...one of a range of subversive, collaborative initiatives from within the early childhood sector at a time when, along with other sectors, it was suffering badly in the 1990s... *Te Whaariki* created a point of solidarity in an unsympathetic and at times adverse political climate (Te One, 2003, p. 42).

Mutch (2003) and Middleton and May's (1997) analyses suggest that political and business leaders and organisations in New Zealand have historically shown a keen interest in the development and contents of compulsory schooling and curriculum documents in line with New Right and neo-liberal ideologies. In a comparison of *Te Whaariki* (Ministry of Education, 1996b) and *The New Zealand Curriculum Framework* (Ministry of Education, 1993a) Mutch (2003) concluded that:

An analysis of the layout and contents of the *New Zealand Curriculum Framework* clearly shows the tensions between the wishes of the neo-conservative and neo-liberal arms of the new right, and New Zealand's more liberal and humanist traditions. This tension led to some of the contradictory aims and wording in the document. The overall outcome, however, was a stratified and compartmentalised approach to curriculum and assessment (p. 126).

The *NZCF* was criticised for over emphasising academic skills, communicating a restricted view of children and of success, providing insufficient guidance on adapting the curriculum for diverse learners, being

fragmented into seven subject-based ‘essential learning’ documents, and framing most learning as linear, predictable and hierarchical (Millar & Morton, 2007; Mutch, 2003). The *NZCF* was the school curriculum in place during the time I was gathering data about Maggie and Clare’s school experiences. However, I have focused more closely on the *NZC* (Ministry of Education, 2007b) document in this research because it is the curriculum that school teachers are now working with and I am interested in advancing our current understandings of how the *NZC* might contribute to inclusive pedagogies.

Official support for inclusive education in New Zealand curriculum policy

Like the broader educational policy context, curriculum policy and documents are politically situated, highly contested and subject to multiple and competing interpretations in practice (Barton, 2004; Millar & Morton, 2007; Rutherford, 2009). Many Ministry of Education (1996b, 1999, 2000, 2002, 2007b) documents distributed to schools and/or early childhood services over the past decade have expressed an expectation that early childhood services and schools will develop ‘inclusive’ policies, procedures and practices. The Ministry’s rationale for inclusive education emphasises a ‘human rights’ discourse and an expectation that diversity amongst learners will be acknowledged, welcomed and valued. For example, within early childhood education, there are documents that position inclusion within a human rights framework:

‘Inclusion’... is intertwined with issues of human rights and equity. Inclusion means that diversity is expected and valued. Inclusion in an early childhood service means that every child is valued as a unique individual and supported to be fully involved in all aspects of curriculum (Ministry of Education, 2000, p. 10).

A human rights discourse is also supported through the *New Zealand Disability Strategy* and New Zealand's international commitments to upholding and ensuring the rights of children and disabled people through being a signatory to international conventions (U. N. General Assembly, 1990, 2007). Ministry of Education (2002, p. 6) support for educational inclusion as a human right is also reflected in the Ministry's recognition that: "Affirming the right of every student to learn requires organisational structures to change to meet the needs of diverse groups of learners. This right embraces values, beliefs and attitudes about justice, equality, freedom and human dignity." This statement acknowledges the need for structural change in order to ensure all students' rights to education.

Both *Te Whaariki* and the *NZC* can be considered to be 'inclusive' in that teachers are expected to take responsibility for the group and individual learning needs of *all* children attending their settings (Ministry of Education, 1996b, 2007b). The *Desirable Objectives and Practices (DOPS)* (Ministry of Education, 1998, p. 45) for New Zealand early childhood services require there to be "equitable opportunities for learning for each child, irrespective of gender, ability, age, ethnicity or background; children are affirmed as individuals; and children are encouraged to work with and alongside others."

Such statements and requirements could lead those reading them to assume that disabled children in New Zealand and their families generally experience welcoming, supportive and inclusive educational environments. However, we know that this is often not the case and that New Zealand politicians, policy makers, parents, teachers and children live and work within a cultural and political context in which deficit and 'special education' discourses dominate, and compete with inclusive, social-political-cultural conceptualisations of disability (Higgins, et al., 2006; Linton, 1998; Millar & Morton, 2007; Rutherford, 2009).

Te Whaariki

Te Whaariki – The Early Childhood Curriculum was written with the explicit intention of disrupting a Eurocentric, universal, static and singular image of ‘the child’ (Carr, Hatherly, Lee, & Ramsay, 2003; Carr & May, 2000). *Te Whaariki* uses a weaving metaphor for pedagogy in its title and structure. ‘*Te Whaariki*’ is translated from te reo Maori (the Maori language) into English as “the woven mat”. The weaving metaphor, and the document’s bicultural emphasis and bilingual framework “tried to set up a curriculum that was not dominated by one worldview of the child and childhood” (Carr & May, 2000, p. 61). The weaving metaphor is used to encourage teachers and other adults to approach the curriculum as a whaariki or mat *woven* by members of each learning community within their specific philosophical, historical, cultural and relational contexts (Carr & May, 2000). The weaving metaphor highlights and emphasises diversity, teacher and child agency, multiplicity and the importance of family and community contexts in early childhood education (Carr & May, 2000; Ministry of Education, 1996b). Pedagogical practices such as assessment, planning and reflection on practice involve communities, families, teachers, parents and children weaving diverse curriculum strands. These strands include the philosophical underpinnings within particular early childhood education services, the lived context, and the aspirations, cultures, interests and talents of children, families, teachers and the wider community (Carr, et al., 2000; Ministry of Education, 1996b).

Each early childhood setting is expected to weave its own unique curriculum through co-creating a pattern of learning and relationships that is inclusive, responsive to and empowering of teachers, families and wider communities (Carr & May, 1994; Ministry of Education, 1996b). This ‘situated’ approach to pedagogy involves recognising and negotiating culturally based values and beliefs as central to growing an early childhood

setting as a community of learners in Aotearoa-New Zealand (Carr & May, 1994; Carr, et al., 2000; Ministry of Education, 1996b; Reedy, 2003; Ritchie, 2003).

Rather than using a prescriptive framework for pedagogy, *Te Whaariki* is based on a set of guiding principles, strands, goals and learning outcomes. Teachers are required by the curriculum to interpret and negotiate how the principles, strands, goals and learning outcomes relate to their specific centre community. The curriculum is defined broadly in the document as “the sum total of the experiences, activities, and events, whether direct or indirect, which occur within an environment designed to foster children’s learning and development” (Ministry of Education, 1996b, p. 10). Although the non-prescriptive nature of the curriculum is viewed as being supportive of responsiveness to diversity, there have been criticisms of the challenges that this poses to teachers who are required to understand the socio-cultural, bicultural, critical and ecological theoretical underpinnings of the curriculum in order to fully realise its potential (Cullen, 2003; Fler, 2003; Meade, 2002; Ritchie, 2003).

Te Whaariki has also been critiqued in terms of the range and (in)-compatibility of the theories of learning and development that it draws from (Cullen, 2003; Fler, 2003, 2005). Carr and May (2000, p. 67) refer to Joy Cullen’s critique of *Te Whaariki* which “highlights the tensions between the developmental and socio-cultural perspectives inherent in *Te Whaariki*, and expresses concern that much of the professional development training in early childhood is being conducted by educators unfamiliar with the theoretical underpinnings of the latter” (socio-cultural theory).

Fleer suggests that:

...there are many theoretical voices in *Te Whaariki*. It is a strength because it moves away from having a single, “universal” perspective underpinning the document... However it is also a weakness, because the range of voices prompts us to ask: Are they in harmony? Are they discordant? Are some voices louder and therefore more privileged than others? Are some voices so soft that they are not heard? (2003, p. 254)

These are important questions that are explored in relation to the data, discussion and conclusions of this thesis.

The principles, strands, goals and learning outcomes of Te Whaariki

The principles and strands of *Te Whaariki* can be interpreted as outlining the ethical obligations of early childhood educators towards young children (0-6yrs) and their families within early childhood education settings. The curriculum is underpinned by four key ‘principles’ which require teachers to: recognize and foster the *empowerment* of young children as they learn and grow; practice in ways that reflect a *holistic* understanding of children and their learning; acknowledge the integral place of the wider world, *community and family* in children’s learning and participation; and view learning as an intersubjective process where children: “... learn through *responsive and reciprocal relationships* with people, places and things” (Ministry of Education, 1996b, p. 14) (emphasis added).

The curriculum ‘strands’ and goals focus on children: experiencing a sense of *belonging* and *well-being*; as being engaged in active *exploration*; as possessing and developing diverse ways to *communicate* and express themselves; and as having their *contributions* valued and developing a sense of *responsibility* towards others. Each goal has a series of associated learning outcomes. Rather than being tightly

worded and easily ‘measured’, the learning outcomes have a dispositional focus that describe learning as a combination of “knowledge, skills and attitudes” (Carr, 2001; Ministry of Education, 1996b, p. 44). For each goal and set of learning outcomes there are questions for adult critical reflection, and examples of practices, and experiences that could help to meet the learning outcomes for infants, toddlers, and young children.

Te Whaariki has stimulated a relational and ‘narrative turn’ in approaches to assessment and pedagogy in Aotearoa-New Zealand (Carr, 2001). Over the past 15 years, much work and qualitative research has been carried out to explore and realize the implications of a *Te Whaariki* based framework for assessing and planning for children’s learning, and teacher reflection on practice (Carr, 1998, 2001; Carr, et al., 2003; Carr, et al., 2000; Greerton Early Childhood Centre, 2010; Ministry of Education, 2005; Podmore, May, & with Mara, 1998; Ritchie, 2003; Te One, et al., 2010). An implication of this relational and narrative turn for assessment has been a focus on telling, documenting, discussing and interpreting stories of learning ‘in action’, within the relational context/s in which learning and teaching are happening (Carr, 1998, 2001). In Chapters Six and Seven, I will return to this research for its potential to provide insights into inclusive pedagogies.

The New Zealand Curriculum (NZC)

The New Zealand Curriculum (Ministry of Education, 2007b) applies to all English-medium primary and secondary schools. There is a separate curriculum document for total immersion Maori language primary and secondary schools (Ministry of Education, 2008). The *NZC* provides the foundation, framework and direction for teachers and schools in relation to what knowledge, skills and attitudes are important, how learning and

teaching are conceptualised, and the implications of this for curriculum content and teaching practices.

The Curriculum principles

The curriculum document draws from human rights discourses and socio-cultural theory in its descriptions and responses to student learning and participation. The espoused vision for New Zealand school students is that they will develop into "...confident, connected, actively involved, lifelong learners" (p. 7). An example of socio-cultural perspectives in the *NZC* are the inclusion of a set of principles which are described in the document as the "foundations of curriculum decision making" (p. 9). The principles are broad statements of philosophy, belief and intent and are organised around the following ideals for schools and teachers: setting high expectations for the learning and achievement of all students; recognising and upholding "the bicultural foundations of Aotearoa New Zealand" through acknowledging the principles of the Treaty of Waitangi; valuing and responding to cultural diversity; being inclusive of, "students' identities, languages, abilities and talents"; acting in non-discriminatory ways; emphasising the importance of students "learning to learn"; engaging communities in education; providing a coherent curriculum that makes links between learning areas; and encouraging students to "look to the future by exploring such significant future-focused issues as sustainability, citizenship, enterprise, and globalisation" (p. 9). Schools are instructed in the document to use the principles to "underpin all school decision making" and that "all curriculum should be consistent with these eight statements" (p. 9). Furthermore, "These principles put students at the centre of teaching and learning, asserting that they should experience a curriculum that engages and challenges them, is forward-looking and inclusive, and affirms New Zealand's unique identity (p. 9). The principle regarding 'high expectations' of every learner states that the "curriculum

supports and *empowers all students to learn and achieve personal excellence*, regardless of their individual circumstances” (p. 9) (emphasis added). The principles also include an expectation that “The curriculum has meaning for students, connects with their wider lives, and engages the support of their families, whaanau (extended family) and communities... (and that) ...students’ identities, languages, abilities, and talents are recognised and affirmed” (p. 9).

The Curriculum’s approach to pedagogy

The curriculum communicates the expectations that schools will create environments where students develop a shared sense of belonging, take responsibility for themselves and others, and develop an understanding of and respect for equity, diversity and human rights. Rather than drawing from a traditional ‘expert’, transmission model, the *NZC* emphasises teaching and learning as socio-cultural processes involving the co-construction of knowledge. The curriculum describes the orientation of the “effective teacher” as “cultivating the class as a learning community. In such a community, everyone, including the teacher, is a learner...” (p. 34). The positioning of teachers as learners and learners as teachers, challenges the idea of teachers being the only ‘experts’ when it comes to understanding and making decisions about the teaching, learning and participation of students. In this regard, the *NZC* states that:

Learning is inseparable from its social and cultural context. Students learn best when they feel accepted, when they enjoy positive relationships with their fellow students and teachers, and when they are able to be active, visible members of the learning community (p. 34).

These statements communicate a responsive and credit-based approach to learning and teaching where students are positioned at the centre of the

curriculum, diversity is valued and inclusion and excellence are actively encouraged.

'Levels of learning'

Within the curriculum document however, there are tensions between inclusive and exclusive ways of defining a successful learner and student. The second half of the curriculum document contains eight separate subject-based “learning areas” (p. 38). Each of the learning areas such as the arts, health and physical education, mathematics and statistics etc... is accompanied by a list of hierarchically arranged levels and descriptors of knowledge, skills and attitudes associated with that subject. The learning levels begin at level one and go through to level eight. A diagram before the learning levels section is described as showing “how the curriculum levels typically relate to years at school” (p. 45). In this part of the document successful learning, and therefore what is deemed to constitute a successful student, is defined through what is assumed to be “typical” or “normal” for particular ages and year groups of children. The retention of age-based learning levels, aligned to predetermined outcomes in the new curriculum raises questions about the positioning and images of disabled students and other minority groups at school.

How Te Whaariki and the NZC talk about ‘disabled learners’

Like *Te Whaariki*, the *NZC* contains statements that strongly support ‘inclusion’ and communicate the expectation and requirement that teachers will value and be responsive to diverse groups of learners, their families and wider communities. However, the wide acceptance of deficit assumptions about disability in education and society makes it particularly problematic that neither curriculum document explicitly addresses the role that education plays in reproducing social inequalities and exclusion

regarding disability. That is, each document is silent about disabled people and children as marginalized groups. Within the documents disabled children are generally subsumed within the groups, “students”, “children”, “infants”, “toddlers” and “young children”. This may have been intended as a way of not separating disabled children and their rights to access the curriculum from the rights of non-disabled children. However, the effect of not addressing the commonplace exclusion and marginalization of disabled children in education, is not to raise it as an important issue for teachers to consider and address in their relationships and work (Millar & Morton, 2007).

The few references that *are* made to disabled children in the curriculum documents draw from deficit language around disability. Disabled children are referred to in both documents as having ‘special educational *needs*’ whereas children (presumed not to be ‘disabled’) whose achievements are assessed as being above normal expectations, are referred to in the school curriculum as having “special *abilities*” (p. 39). This conveys the implicit assumption that, if you are ‘disabled’, your identity as a learner should be interpreted in terms of deficit, lack and need.

The absence of an explicit recognition, in both curriculum documents, of the teacher’s role to identify and remove barriers to disabled students’ learning, infers that a critical consideration of disabled children’s participation is not necessary, relevant or important. It is likely that many teachers, without being given information and direction about the exclusion of disabled children, will default to thinking and practices that maintain exclusion even when they have guiding curriculum documents that can and do support inclusive pedagogies (B Macartney, 2009b; G. Moore, Molloy, Morton, & Davis, 2008; Purdue, 2004; Slee, 2003).

1.8 Who gets heard in a landscape of competing discourses?

In this concluding section of the chapter I consider the positioning of disabled people and their families within the context of competing discourses about disability and difference presented in the chapter. I argue that the narratives and perspectives of disabled people and their families, coupled with rights-based, socio-cultural responses to disability and education can act as a counter-narrative to normalising discourses that silence and exclude 'other' ways of being in the world. I conclude the chapter by re-stating the contention that we need to find and create spaces in education and society for reducing the gap between inclusive rhetoric and social-political transformation.

Children's and families' voices

Families of disabled children, and of other marginalised groups, are generally much more aware than members of dominant groups that education is not a level playing field. In regards to disabled learners there is tension and conflict between 'special education' deficit knowledge and practices, and inclusive pedagogies. These tensions are played out in schools and early childhood centres (Alton-Lee, et al., 2000; Cullen & Carroll-Lind, 2005; Dunn, 2004; L. Lyons, 2005; MacArthur & Dight, 2000; MacArthur, et al., 2000; B Macartney, 2002; Purdue, 2004; Rutherford, 2009). Although there is a long history of support among New Zealand early childhood services for the attendance of disabled children in regular early childhood settings (Cullen & Carroll-Lind, 2005), disabled children and their families regularly experience exclusionary practices within early childhood centre and school environments (MacArthur, Kelly, & Higgins, 2005; MacArthur, et al., 2003; B Macartney, 2008c, 2009b; Purdue, 2004; Rietveld, 2005). Family members of disabled children often struggle to have their children's needs, ways of being and rights responded to in inclusive ways. Families often have to make hard financial and/or

emotional compromises in the interests of having their disabled child attend a school or early childhood centre alongside their siblings and familiar peers (Grant, 2008; IHC, 2008; MacArthur, Kelly, & Higgins, 2005; B Macartney, 2007b; B Macartney & Morton, 2009; Purdue, 2004).

The unique position of disabled people and their family members in education and society presents an opportunity to explore, deconstruct and understand disability from the 'inside' (Linton, 1998; B Macartney, 2007b; Raymond, 2002). Parents of disabled children often become politicised and develop advocacy skills and knowledge of inclusive education practices as a result of experiencing barriers to securing an inclusive education for their children (Brown, 1999; Van Hove, et al., 2009). Families are in a unique position to critique social and educational responses to disability, and their stories can provide others with insights into the lived effects of particular attitudes, assumptions and practices on disabled people (Ballard, 1994a; Barrkman, 2002; Raymond, 2002; Van Hove, et al., 2009).

The silencing and marginalisation of families with disabled children in education has been partially acknowledged in official government documents as an issue that needs addressing and remedying. An aspect of government's official discourse on 'disability' and 'inclusion' over the past decade has been an acknowledgement that, in the past, the possibilities for the involvement and contribution of families and whaanau of disabled students have not been adequately valued or recognised by classroom teachers or other (special education) professionals linked to schools. For example, Lianne Dalziel (Ministry of Education, 2002, p. 2), a former Associate Minister of Education, commented that during her time in that position:

...there is one fact that has come through loud and clear. Your knowledge as parents and caregivers and your experience and skill in communicating with your child form the fundamental basis for their learning. I would be the first to say that this has not always been recognised by education providers. I am determined to change this. The government expects teachers, principals and specialists to work in a close relationship with you, and listen to and include your points of view.

The Ministry of Education *Special Education 2000 Policy Guidelines* (Ministry of Education, 1999) and supporting documents for early childhood services and schools, explicitly include recognition of the centrality and importance of family and whaanau to children's education and learning. This includes a requirement that schools invite, encourage and value family contributions to assessment, planning, programming, evaluation and other decision making regarding their child (Ministry of Education, 1999).

In addition to *families* having their voices and perspectives heard in education, there is also a need to address the silencing and marginalisation of *children and young people's voices* and influence within their educational contexts (Allan, 2008; Carr, May, & Podmore, 2001; Freire, 1997, 1998; Mayall, 2002; Podmore, et al., 1998; Rutherford, 2009). Researchers and commentators from the disability sector suggest that the voices and perspectives of disabled children and adults, and their families are absent or marginalised in much of the research and debates around 'inclusive education' (Allan, 2008; Barrkman, 2002; Bennett, Lee, & Lueke, 1998; Brown, 1999; P. Ferguson & Ferguson, 1995; A. Lyons, 1993; MacArthur, Kelly, & Higgins, 2005; Raymond, 2002; Rice, 1993; Smith & Barr, 2008; Van Hove, et al., 2008). Allan (2008) argues that students' voices and perspectives have not traditionally been sought, heard, or valued within Western education and that, to the contrary, they have been marginalised, controlled and restricted. She (p. 103) argues that,

“rigidly hierarchical and bounded relationships between teachers and children” act as a barrier to students’ learning, contributions and participation in education. Allan suggests that schools need to create ways to remove barriers to students’ ability to contribute to and influence the school curriculum through, “addressing the power imbalances that exist within schools and shifting these in favour of students to enable them to participate fully and effectively” (p. 103).

Disability as a counter-narrative

Through its critique of Western, normalising knowledge, socio-cultural theory provides an opportunity for re-thinking pedagogy (Carr, 2001; Fler, 2005; MacNaughton, 2005; Rivalland & Nuttall, 2010; Valenzuela, et al., 2000). Fler (2005) has called for critical dialogue amongst early childhood professionals about Western knowledge traditions being assumed as the basis for understanding and responding to children’s learning and participation. She argues that a sustained critique of child development knowledge might provide a forum and momentum for moving early childhood education pedagogy in Australia and New Zealand to a less restricting and exclusionary set of assumptions and knowledge on which to base our images of children, pedagogy and environments.

I hope that my research contributes to such a debate through providing a critique of developmental and ‘special education’ knowledge as ‘regimes of truth’ with particular, exclusionary effects on disabled children and their families. This research develops a critique of the content, practices and underlying assumptions of traditional Western educational knowledge and norms from a marginalised position and counter-narrative based on the experience of disability. The participants in this study have been positioned as outsiders to dominant cultural norms, through developmental and ‘special education’ knowledge (Veck, 2009). Personal

accounts of experience can provide counter-narratives that represent a powerful challenge to educators' taken-for-granted acceptance of the grand theories, meta-narratives and 'historical truths' that circulate and are reproduced through dominant discourses within education and society (Clandinin & Connelly, 2000; P. Ferguson, 2009; P. Ferguson & Ferguson, 1995; Ferri, 2006; Linton, 1998; B Macartney, 2008b; Ware, 2006). Each of the two families within this study are of Pakeha (New Zealand European) descent, and so the participants are both 'outsiders' in terms of disability and 'insiders' in terms of belonging to the dominant culture. I hope that this 'insider' cultural positioning will highlight or affirm the need for critiques of Western and Pakeha knowledge as it negatively affects non-members *and* members and of that culture (Bishop & Glynn, 1999; Bishop, et al., 2005; Farquhar & Flear, 2007; Flear, 2005; Rogoff, 2003; Singer, 1992, 1998).

Chapter summary

In this chapter, I have set the context for this project through describing the landscape of dominant and competing discourses around disability and difference that were widely circulating when Fran, Tony, and I began our journeys as new parents. I have situated the study within the field of Disability Studies in Education to develop the argument that disability and inclusive education are fundamentally ethical, social, political and cultural issues. I have examined some of the key debates and understandings around teaching, learning and pedagogy that prevailed during the time the families in this study navigated early childhood education and the school system. I have argued that there is much confusion and competition within New Zealand educational policies, structures, curriculum and practices between individualised, deficit-based and socio-cultural, credit-based views of disability and difference. I have argued that the full and meaningful participation of disabled children and their families in

education and society is shaped and restricted by medicalised, deficit, ‘special’ and ‘regular’ responses to difference. I have outlined New Zealand’s curriculum documents, and introduced a ‘pedagogy of listening’. I will continue to consider the potential of these for supporting emancipatory approaches to diversity and difference in New Zealand pedagogy. Before moving onto the next chapter, I provide a brief overview of each of the thesis chapters.

1.9 Introduction to thesis chapters

In Chapter Two, I present the theoretical frameworks that I have drawn from in my interpretation and analysis of the research data. I examine the ways in which social constructionist and interpretivist epistemologies and theories regarding the ‘self’ and ‘other’, narrative inquiry, socio-cultural perspectives in education, critical theory and key aspects of Foucault’s theories related to discourse and power are relevant to a consideration of how disability is constructed and experienced. I justify and explain the use of multiple and related theoretical perspectives within this thesis. I provide a rationale for the selection of Foucault’s theories of discourse, ‘regimes of truth’, knowledge, and power as the main analytical framework and methodology underpinning the thesis.

In Chapter Three I discuss and justify the methodological approaches I have used in the research and the issues raised by these in terms of their relevance to the research questions and the theoretical perspectives outlined in Chapter Two. I discuss the implications of the chosen methodologies employed for the research methods and design. This part of the discussion focuses on reflexivity, representation and validity. I also discuss ethical issues related to the methods used in this project and the limitations of the research.

The findings chapters (Four, Five and Six) represent and interpret selected data from the two participating families in narrative forms. These narratives include excerpts from interview transcripts, family narratives and photographic images from Maggie's 'baby' and early childhood centre 'Learning Story' books, personal recollections, and documented assessment narratives from medical, and special education professionals. Socio-cultural, critical and emancipatory approaches to education are used as the basis of a critique of Clare and Maggie's experiences. One findings chapter is dedicated to each participating family.

The implications of socio-cultural and critical theories for the development of transformative, inclusive pedagogies are the major focus of Chapter Six, the final findings chapter. Chapter Six, presents and uses potentially emancipatory pedagogical frameworks based on *Te Whaariki* and a 'pedagogy of listening' (Dahlberg, et al., 2007; Dalhberg & Moss, 2005; Rinaldi, 2006; Veck, 2009) and the New Zealand *Learning and Teaching Story Framework* (Carr, 1998; Carr, et al., 2001; Carr, et al., 2000; Podmore, et al., 1998) to critique Clare and Maggie's experiences in their educational settings and to generate inclusive and critical interpretations of pedagogy.

In Chapter Seven the key research findings from this research are re-presented in summary form and discussed in relation to the thinking, research and literature used throughout the thesis. A 'pedagogy of listening' (POL) is developed further within this chapter and is used to inform the conclusions and recommendations of the thesis. The thesis concludes with recommendations for creating a more just and inclusive New Zealand education system and society.

Chapter 2: Theorising Disability

2.1 Introduction

In this chapter I explain how I have approached and used theories about knowledge, society, disability and education to develop an understanding of social constructions and experiences of disability. Firstly I set my theoretical approach within the parameters of social constructionist, interpretive, critical and emancipatory paradigms. I examine two key theoretical perspectives in particular detail. These are a Foucauldian approach to discourse, subjectivity and power, and social-political-cultural theorising from narrative inquiry, disability studies and critical race theory literature.

In the introductory chapter I began a critique of special education which is continued in this chapter in regards to the epistemological and theoretical approaches I discuss. As well using the term ‘special education’ to refer to a particular profession, body of knowledge and set of practices, I use the term in a much broader sense to refer to any instances of thinking and practice that are underpinned by deficit, individual, and pathologising conceptions of disability and impairment.

I develop an argument for theory to be used tentatively as a tool for interpretation, critical reflection, understanding and the generation of dialogue about ideas and possible actions. In keeping with a formative and reflexive approach to theory, I have drawn from a range of theoretical perspectives for the insights each offers to an examination of the social construction of disability and the lived experiences of disabled children and their families. Employing a methodology that combines and utilises multiple theories and approaches as ‘tools for thinking’ (Slee, 1997; G.

Thomas & Loxley, 2001) has encouraged me to think in more complex ways as different ideas and approaches have ‘rubbed up’ alongside each other in my discussion and interpretation of the participants’ narratives (Allan, 2006).

2.2 Approaches to theorising disability

Rather than using theory to provide a tidy and complete explanation of what disability means and how it is constructed and experienced, I have used theoretical frameworks and ideas as “tools for thinking” about the social construction of disability (Slee, 1997; G. Thomas & Loxley, 2001, p. 221). In my approach in this thesis, I have tried to avoid tidily fitting the participants’ experiences into pre-existing theoretical frameworks (Allan, 2006; Clandinin & Connelly, 2000; Lather, 2003). Instead, I have endeavoured to use theory critically, tentatively and reflexively in interpreting human experiences as they have been communicated through the narratives of the participants (Clandinin & Connelly, 1988, 2000; Freire, 1997, 1998; Lather, 2003; Lather & Smithies, 1997; Slee, 1997; G. Thomas & Loxley, 2001). In addition to considering how theory has informed my understanding and analysis of the participants’ narratives, I have aimed to consider how participants’ experiences and perspectives have informed my interpretations (G. Thomas & Loxley, 2001).

Critiquing grand narratives and special education

Thomas and Loxley (2001) suggest that academics, teachers and others can fall into a trap of investing a kind of super-faith in ‘scientific’ knowledge and theorising that it does not deserve. Special education knowledge and practice can be criticised for its unquestioning faith in the explanatory powers of scientific knowledge (Brantlinger, 1997, 2006; Linton, 1998; Skrtic, 1991; Slee, 1997). Roger Slee (1997) strongly criticises special education’s assumptions about the ‘scientific’ and ‘expert’ status of its

knowledge base and the ways that an empiricist, 'scientific' discourse is used to assume the questionable legitimacy and neutrality of that knowledge.

Brantlinger (2006) undertook an examination and critique of ten commonly used special education textbooks produced for teacher education. She argues convincingly that the ideology, knowledge, value base and techniques of special education theory are communicated as if individual, deficit, and biologically based views of disability are a straight forward presentation of scientific facts. Although these texts are embedded within and communicate a particular ideology and positivist worldview, they are written in an authoritative voice, and as if the contents of each text provides a comprehensive, objective, beneficent and adequate understanding of disability (Brantlinger, 2006). Brantlinger points out that these texts transform ideology, myths and interpretation into 'truths' and 'facts'. This transformation is achieved through crafting selective and choreographed accounts of disabled children's lives that sound authoritative and undisputed, but that actually represent a particular viewpoint and 'grand narrative' about disability. The 'grand narrative' implies that knowledge about disability and impairment is straightforward and technical and that there is a high degree of consensus about what disability means and the implications of this for practice. The implications of the Disability Studies and disability rights movement critiques for thinking, policy and practice in education are not referred to within these texts. Instead, special education authors and publishers ignore, and/or pay lip service to the vast body of literature, research and theorising of disability as a social construction, site of oppression and resistance, and as a fluid and embodied experience.

Not surprisingly, special education's typical response to critiques of the content and effects of its knowledge, is that the links made between

disability, deficit discourses and oppression are not valid because they are based on 'political ideology', not on 'scientific evidence' (Brantlinger, 1997). However, special education knowledge is just as value based, political and subjective as any other form of knowledge (Brantlinger, 1997, 2006; Linton, 1998; Skrtic, 1991; Slee, 1997, 2001). From a social constructionist perspective, the grand narratives of positivist science ignore and obscure relations of power while simultaneously exercising that power through restricting what can be 'known' and who can speak and act with authority on any given issue or identity (Burr, 1995). It can be argued that the major difference between DSE and special education knowledge is that DSE recognises and is open about its ethical, political and ideological stance whilst special education knowledge obscures and denies its subjective underpinnings and the political and lived effects of its theories and practices (Brantlinger, 1997, 2006; Skrtic, 1991; Slee, 2001).

In my approach to theorising, I have paid attention to critiques of scientific research and theorising that invest uncritical confidence in the explanatory capabilities of 'grand' narratives and theories (Clandinin & Connelly, 2000; Freire, 1997; Maynes, et al., 2008; Rinaldi, 2006; Slee, 2001; G. Thomas & Loxley, 2001). Any explanatory theory cannot be grounded in and cognisant of all the complexities, variability, and mysteries of lived experience. This is true whether those theoretical explanations are underpinned by positivist, humanist, or social constructionist views of reality (Clandinin & Connelly, 2000; Goodley, 2001; G. Thomas & Loxley, 2001; Valenzuela, et al., 2000).

2.3 Approaches to understanding human experience

The assumption that scientific inquiry should and can be used as the sole basis for understanding human experience, rests on a belief that there are stable and fixed realities and 'best' evidence 'out there' waiting to be discovered (Crotty, 1998; P Ferguson, et al., 1992c; Skrtic, 1991, 1995).

‘Scientific knowledge’ is assumed to be the best and only legitimate driving force behind human change and ‘progress’. The techniques of positivist science attempt to describe, predict, shape and control human behaviour and progress towards preconceived outcomes (Crotty, 1998). From this viewpoint, the pursuit and construction of knowledge is treated as a relatively straight forward and technical enterprise (Goodley, 2001; Neyland, 2005). From a positivist viewpoint, differential social outcomes are explained more in terms of individual or cultural pathology than as a consequence of unjust social and political arrangements (Bishop, et al., 2005). Assuming that all reality is knowable and open to manipulation leads to power relations not being noticed, and/or seen as inevitable consequences of biological, cultural and/or behavioural differences.

Social constructionism and interpretivism view knowledge as the outcome of cultural, relational, and subjective meaning making processes (Clandinin & Connelly, 2000; P. Ferguson & Ferguson, 1995; Slee, 1997). Knowledge is the (provisional) outcome of interpretation, negotiation and co-construction. The articulation of particular meanings, through human activity and society, are assumed to have differential outcomes for particular individuals and groups.

Narrative approaches to human experience

Clandinin and Connelly (2000, p. 30) describe universal explanations and descriptions of human experience, and dualisms such as theory and practice, as the “hallmark” of grand narrative approaches. They suggest that the use of universal explanations for human behaviour relies on distancing meaning making (‘theory’) from lived experience and context (‘practice’). A narrative viewpoint argues that understanding the social construction of meanings must include a keen interest in the experiences and stories of people in their temporal, spatial and relational contexts

(Clandinin & Connelly, 2000; Court, 2004; Maynes, et al., 2008; Stroobants, 2005; Watson, 2009). Because grand narratives dis-locate their explanations from lived experience, Clandinin and Connelly describe their story telling as constructing "...essentially people-free notions" about 'reality' (p. 30). Brantlinger's (2006) examination of special education text books is a good example of the exclusionary effects of narratives and stories that are distanced from the lived contexts and experiences of the individuals and groups they are purporting to represent (Clandinin & Connelly, 2000). As well as pathologising difference, the text book images and vignettes communicated a consensual, simplistic, 'rosy' and idealised view of classroom environments, family relationships with schools, and teacher responses to 'diversity' within the classroom (Brantlinger, 2006). Brantlinger's (2006) examination also demonstrates how portrayals of reality divorced from lived experience can be used as a rich source of insight into understanding exclusionary mechanisms in society.

The understandings derived from thinking narratively are situated in experience, tentative and provisional (Clandinin & Connelly, 2000; Court, 2004). Clandinin and Connelly (p. 31) suggest that: "In narrative thinking, interpretations can always be otherwise... Thus, the attitude in a narrative perspective is one of doing "one's best" under the circumstance, knowing all the while that other possibilities, other interpretations, other ways of explaining things, are possible." Throughout this study I have done 'my best' to be true to the stories and perspectives of the research participants through trying to represent their meaning making and interpretations accurately and with respect (Bogdan & Biklen, 1992). I have also endeavoured to be honest in presenting my interpretations of the participants' narratives as tentative and provisional. I have tried to avoid using an authoritative voice in ways that uncritically privilege my

interpretation over other ways of making meaning (Brantlinger, 1997, 2006; G. Thomas & Loxley, 2001).

Knowledge, power and subjectivity

Investing an unquestioned faith in science's ability to explain human action, means privileging theoretical knowledge over knowledge embedded in personal narrative and experience (Clandinin & Connelly, 1988, 2000; Freire, 1998; Maynes, et al., 2008; G. Thomas & Loxley, 2001). Empiricist research treats the stories and perspectives of families and disabled people as irrelevant, and of inferior status to the 'knowledge' gained from the direct observation and manipulation of predetermined variables and 'facts'. From a Foucauldian perspective, knowledge about disability is inextricably linked with identity, inter-subjectivity and power (Tremain, 2002, 2005). Foucault (1982) conceptualised grand theories and narratives: 'discourses' or 'regimes of truth'. He (1980, 1982) suggested that 'regimes of truth' discipline and control individuals through tying them to particular identities and subject positions. Through knowledge regimes such as medicine and psychology, disabled people and their families are both subjectified as disabled identities, and objectified as 'abnormal', 'impaired cases'. This process of subjectification involves individuals and groups internalising and/or resisting deficit constructions of who they are and can be.

Foucault (1972, 1976, 1977) studied the historical, political and social situations of individuals and groups to understand the relations and workings of power. He (1982, p. 208) argued that to understand Western power-knowledge and social inequalities, we need to consider *how* individuals and groups are shaped through knowledge and 'truths' "which transform human beings into subjects." Foucault suggested that "a technique, or form of power" can be exposed and subsequently

interrogated through examining lived experience (1982, p. 212). In regards to power-knowledge being the vehicle through which people are governed and govern themselves, Foucault stated:

This form of power applies itself to immediate everyday life which categorizes the individual, marks him (sic) by his own individuality, attaches him to his own identity, imposes a law of truth on him which he must recognize and which others have to recognize in him. It is a form of power which makes individuals subjects. There are two meanings of the word *subject*: subject to someone else by control and dependence, and ties to his own identity by a conscience or self-knowledge. Both meanings suggest a form of power which subjugates and makes subject to (1982, p. 212). (emphasis in original)

Power-knowledge can be understood through considering the interactions between grand narratives and structures, and personal narratives and lived experience (Foucault, 1977; Freire, 1998; Linton, 1998). Discourse and narrative theories are interested in subjectivity, and in the ways individuals and groups construct meaning from their worlds within socio-cultural contexts. Both discourse and narrative theories recognise the past, present and future as integral to understanding lived reality and how humans make sense of it (Clandinin & Connelly, 2000; Maynes, et al., 2008). Although Foucault (1972, 1976, 1977) studied macro structures and processes, his primary interest was in the ways in which power and knowledge interact to govern and produce individuals as subjects (Allan, 2008; Foucault, 1977, 1982; MacNaughton, 2005; Tremain, 2005). Foucault (1982, pp. 208-209) stated that he was trying to “create a history of the different modes by which, in our culture, human beings are made subjects... Thus it is not power, but the subject, which is the general theme of my research.” His reason for pursuing an interest in how power relations govern individuals and their bodies was that, although

social scientists were developing analytical frameworks for studying the history and relations of human signification and economic production:

...for power relations we had no tools of study. We had recourse only to ways of thinking about power based on legal models, that is: What legitimates power? Or we had recourse to ways of thinking about power based on institutional models, that is: What is the state? It was therefore necessary to expand the dimensions of a definition of power if one wanted to use this definition in studying the objectivizing of the subject (p. 209).

Using personal narratives and lived experience to examine and understand the social constructions of disability and their (power) effects might be viewed as a departure from Foucault's focus on the grand narrative. An interest in personal narrative *and* discourse however, is potentially useful for examining subjectivity and social constructions and experiences of disability (Court, 2004; Goodley, 2001; Goodley & Lawthorn, 2008; Linton, 1998; MacNaughton, 2005; Tremain, 2005). The possibilities - for interpreting and understanding social action - that are stimulated through recognising meaning making as nested in the relationship between individuals and our social-political-cultural contexts are explored throughout this thesis. From interpretivist, socio-cultural and emancipatory perspectives, narratives and lived experience are the central means for constructing and making sense of human reality and action (Ballard, 2003, 1994c; Clandinin & Connelly, 2000; P. Ferguson & Ferguson, 1995; Freire, 1997, 1998; Maynes, et al., 2008).

2.4 Social Constructionism

A social constructionist epistemology assumes that individuals can exercise agency through their participation in the social construction and interpretation of their world (Burr, 1995; Clandinin & Connelly, 2000; Crotty, 1998; P. Ferguson & Ferguson, 1995; Gergen, 1999; Maynes, et al.,

2008; Rinaldi, 2006; Rogoff, 2003). Crotty (1998, p. 42) explains that from a social constructionist perspective “all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context.” Social constructionism is interested in the contents and effects of particular knowledge(s) and how individuals and groups, as knowledge producers, assign meaning to their world (Crotty, 1998).

Social constructionism is interested in shared systems of meaning. It takes a critical stance towards ‘face value’, common sense or taken-for-granted knowledge (1995). It has provided insights into the construction of particular identities based on characteristics such as sex, race, ability, and sexual orientation that were once widely considered to be biological, stable and natural states of being (Brantlinger, 1997; Erevelles, 2006; Erevelles, et al., 2006; Slee, 1997).

Relationships between individuals and society

Social constructionist researchers have differing interests and varying degrees of emphasis in relation to individuals and society (Gergen, 1999; Maynes, et al., 2008). Rather than creating strict theoretical divisions between the personal/individual and the social/society, social constructionism focuses on the *inter-relationships* between the individual and socio-cultural contexts in producing meaning, knowledge and reality. Those whose interest is more focused on the individual more often describe their theories and methods as social ‘constructivist’. Social constructivism tends to focus more on individual-social psychology and the cognitive, ‘internal’ construction of social experience (Gergen, 1999). Social constructionism focuses more on social processes, structures and relationships than on individual meaning making. Gergen suggests that

rather than criticising a constructivist approach for focusing on the individual, "...we can locate openings to new forms of intelligibility and action that draw from both domains" (p. 272). Narrative sociologists Maynes et al. (2008) suggest that research and theorising alert to interactions between social-discursive structures and practices, and the embodied meaning making of individuals, allow for a more complex and nuanced consideration of the individual and society. In this research, I have drawn from narrative, socio-political-cultural and Foucauldian theoretical perspectives in an effort to remain open to nuanced views of subjectivity, social construction and action. Tensions and opportunities arising from crossing boundaries between discursive and narrative thinking are addressed in Chapter Three.

2.5 Emancipatory research

An issue related to the knowledge generated through social science research involves a consideration on the part of researchers of *why* we are interested in researching particular social phenomena, identities and experiences. That is, what are our motivations for developing and disseminating such knowledge? Lather (2003, p. 186) discusses research approaches based on "transformative agendas" that seek to engage in, "emancipatory theory building." Rather than beginning with the premise that researchers can, or should, be value neutral, Disability Studies and this research are underpinned by an explicit ideology that views disability as a social construct, expressed structurally and ideologically through a web of unequal, oppressive, and change resistant, power relationships (Bogdan & Taylor, 1998; Brantlinger, 1997; Fine, 1993; Skrtic, 1991, 1995; Slee, 2001). Fine & Weis (2002) stress that, within the fields of qualitative and ethnographic research:

Researchers can no longer afford to collect information on communities without that information benefiting those

communities in their struggles for equity, participation, and representation. Although such collaborations are by no means easy..., they are essential if social research is to serve the public good (pp. 293-294).

Within DSE a primary motivation for research and action is the recognition of discrimination, inequality and injustices based on deficit cultural understandings, structures and practices that restrict and exclude disabled people because of their differences (Linton, 1998; Smith, et al., 2009). People working in the DSE field feel a moral and practical desire to challenge this situation. It is important to keep this ethical and political aim and impetus to the fore in relation to the research process, content, and findings and their implications for contributing to change. Without emancipatory intent and approaches we risk being part of the problem (Allan, 2006; Barton, 1996; Oliver, 1996; Smith, et al., 2009).

The retention of hope, ‘utopian’ visions and optimism is critical within emancipatory projects such as Disability Studies in Education and the disability rights movement (Freire, 1997; Stromstad, 2003; G. Thomas & Loxley, 2001). Paulo Freire (1997), the Brazilian critical educationalist and social activist, whose work has made significant contributions to thinking and practices within fields of progressive education and critical pedagogy, suggested that, without recourse to hope, all that remains is fatalism. Fatalism leads to apathy, resignation and inaction. In regards to the relationship between hopes, dreams and social change, Freire (1997, p. 91) said: “There is no change without dream, as there is no dream without hope.” Furthermore, he argued that “Dreaming is not only a necessary political act, it is an integral part of the historico–social manner of being a person. It is part of human nature, which, within history, is in a permanent process of becoming” (1997, p. 90). Reverting to fatalism or hopelessness about our reality and circumstances, involves giving up, ‘accepting’ and contributing to inequality through doing nothing to dismantle it. By “daring

to think otherwise” (Allan, 2003, p. 179), we can work hard to understand, resist and thereby create new alternatives, possibilities and spaces for action (Allan, 2006; Bogdan & Taylor, 1992; Dalhberg & Moss, 2005; Freire, 1997, 1998; MacNaughton, 2005; Moss & Petrie, 2002).

Other ways of ‘knowing’

I have argued that knowledge and interpretation are provisional and contestable, and therefore constitute ‘works in progress’. Scientific inquiry is not and does not need to be imbued with a magic quality guaranteeing it a privileged status in its claims to truth. It is useful and potentially transformative to acknowledge that other forms of knowing can contribute significantly to our understanding and framing of human experience and action (Ballard, 2003; Clandinin & Connelly, 1988, 2000; FourArrows-Jacobs, 2008; Freire, 1997, 1998; Maynes, et al., 2008; G. Thomas & Loxley, 2001).

As an emancipatory field of inquiry, Disability Studies in Education has taken a critical, varied and open stance towards sources of knowledge and interpretation to develop a nuanced understanding of disability, identity, disablement and social change (Allan, 2006; Brantlinger, 2006; Connor, 2008; Ferri, 2006; Ware, 2006). This is particularly evident in DSE’s use of qualitative, multi-method and multi-disciplinary approaches. ‘Popular culture’ genres such as fiction, poetry, auto-biography, music, film, photography and performing arts, are used in DSE to help inform understandings about, and responses to, disability, difference, impairment and inclusive education (Connor, et al., 2008; Ferri, 2006; Gabel, 2005; Ware, 2006). The narratives, experiences and aspirations of disabled people and their families are of prime importance, in recognising and learning from multiple sources of knowledge (Connor, et al., 2008; Ferri, 2006; Gabel, 2005; Linton, 1998; Ware, 2006).

The “intelligence of experience”

There is a strong call from within Disability Studies and the wider disability rights movement to invite, acknowledge, listen to, and privilege the knowledge of disabled people in considering disablement and what to do about it (Allan, 2006, 2008; Barnes, Oliver, & Barton, 2002; Barton, 1996; Bevan-Brown, 1994; Connor, et al., 2008; Goodley, 2001; Linton, 1998; Oliver, 1990, 1996; Slee, 2003; G. Thomas & Loxley, 2001; Van Hove, et al., 2009; Veck, 2009). In an informal meeting with family members of disabled children, Tony Booth (personal communication, September 30, 2009), a UK disability researcher, educator and advocate for inclusive education talked about his belief in the importance of family knowledge and experience in contributing to emancipatory changes for disabled children in education. He suggested that disabled people and families’ “intelligence of experience” is central to understanding disablement in education and society.

‘Ingenuous’ and ‘epistemological’ curiosity

Freire (1997) argued that a view of education as a process and context for realising goals such as democracy, social justice and emancipation, must include a respect for and understanding of the contexts and lived experiences that students and teachers bring to the classroom. He suggested that teachers’ respect for lived experience is fundamental to an emancipatory pedagogy and project (1998). He urged progressive educators to recognise and value the experiences of students in their everyday worlds through engaging with popular culture. What I take from Freire’s (1997, 1998) writing, in regards to the social construction of disability, is that the development and negotiation of our theories and explanations must be closely tied to the experiences and realities of those

whose exclusion and marginalisation we are seeking to address (Goodley, 2001; Linton, 1998; Oliver, 1996; Rapley, 2004).

Freire (1997, 1998) suggested that theorising should start *but not stop* with taken-for-granted, common sensical understandings and explanations of our social, cultural, economic and political realities. He (1998, p. 38) believed that, once we view ourselves: “As men and woman inserted in and formed by a socio-historical context of relations, we become capable of comparing, evaluating, intervening, deciding, taking new directions, and thereby constituting ourselves as ethical beings.” Freire (1998, p. 37) argued that the ability to think critically and reflexively comes from using and developing a keen and creative intellectual curiosity that is “capable of self-criticism. In criticizing itself, ingenuous (‘common-sense’, ‘everyday’) curiosity becomes “epistemological curiosity”, as through greater methodological exactitude it appropriates the object of its knowing.” Freire argued that to understand and transform society we must be ‘ingenuously curious’ about how we and others construct meaning through our experiences of living and being situated within particular historical, economic, social, political and cultural contexts. In order to transform ourselves and our contexts, Freire suggests that we must take our ‘knowing’ one step further into the sphere of “epistemological curiosity” (1998, p. 37). Epistemological curiosity involves critical thinking and inquiry about what we know, how we came to know it and what effects these various ways of knowing the world have on our place, and the position of others in society. In regards to the relationship between theory and lived experience, Freire (1998) echoes Brantlinger when he says that:

...theoretical discourse itself, necessary as it is to critical reflection, must be concrete enough to be clearly identifiable with practice. It’s epistemological “distance” from practice as an object of analysis ought to be compensated for by an even

greater proximity to the object of analysis, in terms of lived experience (p. 44).

Rather than privileging and distancing theoretical discourse from knowledge that comes from practice, intuition and experience, I have attempted to develop knowledge through a critical and reflexive consideration of experience (Ellis, 2004; Freire, 1997, 1998; Lather & Smithies, 1997). In interpreting the participants' stories, I have combined a respect for the 'intelligence of experience' with a 'critical epistemological curiosity' that acknowledges the integral place of commonsense and taken-for-granted explanations in constructing reality and the implications of those constructions for how disabled children, and their parents, are positioned in education and beyond.

2.6 Discourse theory

Gee (1990) defines discourses as more than language, spoken or written. Discourses are both constitutive of, and embedded in social, political and cultural practices (Gee, 2004; Linton, 1998; MacLure, 2003; Rogers, 2004). Discourses are expressed through language, behaviour, institutional arrangements and social practices. They are:

...ways of behaving, interacting, valuing, thinking, believing, speaking, and often writing that are accepted as instantiations of particular roles by specific *groups of people*, whether families of a certain sort, lawyers of a certain sort... They are always and everywhere *social*. Language, as well as literacy, is always and everywhere integrated with and relative to *social practices* constituting particular Discourses (Gee, 1990, p. 5). (emphasis in the original)

'Discourse' is also described as "...a means of both producing and organizing meaning within a social context" (Edgar & Sedgwick, 2002, p. 117). Edgar and Sedgwick (p. 17) note that a key function of discourse is not only what it includes but also what it excludes: "Discursive

formulations provide rules of justification for what counts as knowledge within a particular context, and at the same time stipulate what does not count as knowledge in that context.” New Zealand Disability researchers and educationalists Ballard, et al. (2003, pp. 134-135) describe deficit discourses in education as:

...very powerful; they are accepted as “the truth”, and influence, reinforce, and control out thoughts, ideas, language, actions, and practices as teachers, and our reactions to people with disabilities. Other discourses, however, may be viewed as less important and are marginalised or rejected.

Critical and discourse theory and analysis can be used to expose and transform language and power relations.

Discourse, power and knowledge

Discourse theorists Phillips and Hardy (2002) suggest that, like other qualitative approaches, discourse analysis is interested in the meanings of social life. They further suggest that, rather than only seeking to understand the meaning of the social world for participants as it exists “discourse analysis endeavours to uncover *the way* in which it is produced...It examines *how* language constructs phenomena, not how it reflects and reveals it” (p. 6) (emphasis added). Foucault (1972, p. 49) described discourses as “practices that systematically form the objects of which they speak.” The processes and lived effects of assigning disability labels to individuals is a key example of the power of discursive practices to shape reality and experience.

According to Foucault (1980), there is an interdependent relationship between the production of systems of knowledge and ‘truth’ and how power is accrued and exercised (Yates, 2005). In regards to knowledge, ‘truth’ and power Foucault said that:

Truth is a thing of this world. It is produced only by virtue of multiple forms of constraint. And it induces regular effects of power. Each society has its regime of truth, its 'general politics' of truth: that is, the type of discourse which it accepts and makes function as true; the mechanisms and instances which enable one to distinguish true and false statements, the means by which each is sanctioned; the techniques and procedures accorded value in the acquisition of truth; the status of those who are charged with saying what counts as true (1980, p. 131).

He argued that, in the modern world, power is not only or even primarily exercised through externally imposed acts and systems of repression. Instead, Foucault suggested, individuals actively participate in their own subjugation through discursive activities and relations. He saw individuals as actively involved in discursive relations of power. In discussing the nature of power and the relationships between power, knowledge and truth production Foucault said:

If power were never anything but repressive, if it never did anything but to say no, do you really think one would be brought to obey it? What makes power hold good, what makes it accepted, is simply the fact that it doesn't only weigh on us as a force that says no, but that it traverses and produces things, it induces pleasure, forms knowledge, produces discourse. It needs to be considered as a productive network which runs through the whole social body, much more than as a negative instance whose function is repression (1980, p. 119).

Burr (1995) suggests that a key relationship between discourses and the exercise of power is that discourses function in ways that obscure the unequal power relations operating in society. The knowledge and 'common sense truths' that particular discourses privilege, and the power relations they maintain, are taken for granted and accepted as 'natural'; a representation of a stable and fixed reality rather than as contestable and

subjective versions of events and phenomena embedded in relations of power.

Bio-Power and the notion of 'the norm'

Foucault (1980) argued that individuals, as subjects, are subject to someone else's control at the same time as actively controlling or disciplining themselves:

Power is employed through a net-like organisation. And not only do individuals circulate between its threads; they are always in the position of simultaneously undergoing and exercising this power. They are not only its inert or consenting target; they are also the elements of its articulation (p. 98).

He suggested that the workings of power can best be studied and understood through looking at its circulating *effects*. The focus of analysis is on the "micro-mechanics of power" - the expression of power through the language and actions of individuals and groups (Foucault, 1980, p. 101). In his view of individual subjects and power-knowledge, Foucault said that the individual:

...is already one of the prime effects of power that certain bodies, certain gestures, certain discourses, certain desires, come to be identified and constituted as individuals. The individual, that is, is not the *vis-à-vis* of power, it is, I believe, one of its prime effects...at the same time...it is the element of its articulation (1980, p. 98). (emphasis in original)

According to Allan (1999, p. 18) Foucault's "main interest is in the ways in which individuals are constructed as social subjects, knowable through disciplines and discourses...". 'Bio-power' or 'bio-politics' were the terms Foucault (1977) used to refer to the power that began to emerge in the second half of the eighteenth century. Foucault (1977) saw the body as the prime site of the exercise of disciplinary power. 'Bio-politics' involved the

development of a statistically based science of knowledge, which was interested in the experience of human and non-human life, and which utilised and was dependent on the new construct of a human 'population' which could be measured, defined, classified, divided and controlled (Foucault, 1977; Reeve, 2009; Tremain, 2005). The rise and emergence of the institution of medicine was central to the development of bio-politics and has had a major influence on the construction and experience of 'disability' (Barnes, et al., 1999; Oliver, 1990; Tremain, 2005). Western medicine has created the 'bodily conditions' of impairment and disability, and a view of disability as a biological, pathological (not 'normal') condition contained within individuals that requires professional intervention and management. The division of 'disabled' and 'able' bodies is both a process and effect of bio-power (Tremain, 2002, 2005).

Foucault (1977) contended that the construction and use of statistical knowledge was a pre-condition for the development of the dominant mode of "bio-power" or "bio-politics" in the modern world (Tremain, 2005, p. 4). The central classification that underpins dominant discourses and practices related to disability, and education is the notion of the 'norm' (Davis, 1997; Dudley-Marling & Gurn, 2010; B Macartney, 2007b, 2010). The concept of a set of norms, which are subsequently positioned as the ideal, requires the existence of the 'abnormal' and deviant in society. The abnormal is defined as anything that deviates from established norms.

The development of the construct of statistically defined norms in relation to human attributes and behaviour and an acceptance that human traits and characteristics can and should be defined, measured and ranked in relation to established 'norms', is relatively recent in human history (Davis, 1997). For example, the word "normal", meaning conforming to standards accepted as regular and usual, has only been in common usage in

the English language since around 1840 (Davis, 1997). The development and advancement of medical science, behaviourism and developmental psychology have contributed to our understandings and practices around the powerful notion of 'the norm' (Fleer, 2005; Goodley & Lawthorn, 2008; Graham, 2005; B Macartney, 2007b). From a bio-medical standpoint, disabled people are contrasted with the classifications of 'healthy', 'normal', 'fully participating' members of society and are 'found' lacking.

Discourse and identity

Disability Studies scholar Shelley Tremain uses a Foucauldian analysis to argue that discourses create parameters around who people can be:

By a process of division either within themselves or from others, subjects are objectivized as (for instance) mad or sane, sick or healthy, criminal or good...through these objectifying procedures of division, classification and ordering, subjects become attached to a personal and social identity (2002, pp. 35-36).

Through discursive relations, individuals develop and become tied to particular socially ascribed or 'acceptable' identities (Drinkwater, 2005; Foucault, 1980; Gee, 1990; Goodley, 2001; Graham, 2005; Phillips & Hardy, 2002; Rapley, 2004; Yates, 2005). These identities prescribe the expected characteristics and behaviour of particular types or 'kinds' of people (Yates, 2005).

Oliver (1990) suggests that, through drawing from medicalised, deficit discourses of disability, popular media and culture re-presents images of disabled people as needy, pitiable, frightening, super human or less than human. He further suggests that significant and generalised 'others' in disabled people's lives, such as medical and educational professionals reinforce deficit stereotypes of disability and the view of

disability as an individual and private 'problem'. Many DSE scholars challenge the idea that disability, or any singular characteristic or social position, is adequate for defining a person's identity and experience (Clandinin & Connelly, 2000; Connor, et al., 2008; Erevelles, et al., 2006; Ferri, 2006; Fine & Asch, 1988; Goodley, 2001; Linton, 1998; Oliver, 1990; Rapley, 2004; Ware, 2006). These scholars argue that constructions and expressions of identity and experience are fluid, complex and contextualised processes.

Resistance and individual agency

Foucault's social theories have been criticised as being overly pessimistic and as leaving little or no room for individual agency, positive social change or the transformation of power relations (Allan, 1999; Clandinin & Connelly, 2000). Although it can be argued that there is little space made for agency in his analyses, Foucault did acknowledge possibilities for resistance as well as subjugation:

...discourse can be both an instrument and an effect of power, but also a hindrance, a stumbling block, a point of resistance and a starting point for an opposing strategy. Discourse transmits and produces power; it reinforces it, but it also undermines and exposes it, renders it fragile and makes it possible to thwart it (1976, p. 101).

Foucault (1976), Gergen (1999), and Arkwright (2005) address the possibilities for resistance that are inherent in the existence of multiple, contradictory discourses and constructions of meaning surrounding a social phenomenon. Gergen makes a:

...strong invitation ... for the emergence of new forms of language, ways of interpreting the world, patterns of representation. Invited are generative discourses, that is, ways of talking and writing (and otherwise representing) that

simultaneously challenge existing traditions of understanding, and offer new possibilities for action (p. 49).

Arkwright (2005), a New Zealand disability researcher and writer, suggests there are possibilities for resistance, transformation and change when disabled individuals view and position themselves as discourse users. Arkwright's contention is that there is potential for agency in being aware of the intersections between personal experience and social-political-cultural mechanisms such as discourse. From his perspective as a disabled person Arkwright (2005, p. 33) suggests that "producing oneself as a discourse user can... (be used as) ...a means for furthering our current understandings of disability, one that is both conceptually and practically useful for disabled people." Understanding ourselves as discourse users also holds potential for the critical reflection and practices of teachers (Alton-Lee, et al., 2000; Ballard & Macdonald, 1998; Gee, 2004; Rietveld, 2005). Developing an understanding and critique of how discourses work to limit or marginalise disabled people and their actions, creates possibilities for resistance and agency and the generation of different ways of framing experiences such as disability (Gabel & Peters, 2004).

Disciplinary mechanisms: The making of subjects

Foucault (1977) suggested that modern regimes of power rely on the social-cultural-political belief that individuals are autonomous and that their thoughts actions and circumstances are based on the exercise of individual free will. Rather than the external imposition of punitive discipline by more powerful, elite groups, modern Western bio-power is primarily exercised through a process of self regulation and discipline centred around what Foucault (1977, p. 138) described as a "mechanics of power" which acts on and through the "docile body". Tremain (2005, p. 4) suggests that one of the most original aspects of Foucault's analysis of the mechanics of bio-power "...is the idea that power functions best when it is

exercised through productive constraints, that is, when it enables subjects to act in order to constrain them.” Individuals ‘willingly’ scrutinise and conduct themselves through monitoring and regulating their own behaviour in relation to dominant classifications and constructs such as the existence of the ‘normal’, ideal individual in Western society.

Once named and classified, particular bodies/groups/populations can be controlled and disciplined through normalising strategies embedded in discursive practices. Because the knowledge produced through dominant discourses is largely accepted as the ‘truth’ the assumptions and ideas that underpin that knowledge and its practices are often seen as unproblematic and not in need of scrutiny or challenge. In this way, the relationship between coercive power, politics and discourse is obscured (Burr, 1995).

How this power/knowledge - that disciplines people’s lives and identities in ways that are generally accepted – operates on the level of lived experience is a key focus in this study. The particular disciplinary practices that I use as tools for interpreting the research participants’ narratives are: surveillance; hierarchical observation; normalising judgements; and the examination.

Surveillance

Foucault (1977) argued that the government of space and bodies were key elements of the disciplinary practices associated with bio-power. According to his analysis, disciplinary practices involving the self-regulation of individuals developed in institutions such as prisons, schools, asylums and hospitals. To demonstrate the relationship between architecture, the arrangement of people in space and the exercise of disciplinary power, Foucault used the example of Jeremy Bentham’s design of a ‘Panopticon’, in the ‘Strangeways’ prison built in England in

the nineteenth century. At Strangeways, single cells were arranged around a high, central viewing tower. Prison guards could constantly observe the inmates in their cells from the viewing tower, but the prisoners could not see the guards. The prisoners were aware that they could be under surveillance, and the 'disciplinary' or 'panoptic' gaze of the guards at any time. Knowing they could always be under observation, Foucault argued, led to the prisoners monitoring, regulating and modifying their own behaviour in line with the guards' expectations and rules. Foucault suggested that similar architectural and spatial arrangements, where the possibility of surveillance is constant, are reflected in school buildings, environments and classroom, factories and asylums. Architecture acts as a social control mechanism which has self-regulating effect on 'children', 'workers' 'prisoners' and 'patients'.

Hierarchical Observation

Allan (1999, p. 21) argues that the disciplinary gaze operating in schools constructs disabled children "as objects of power and knowledge." Although all children (and teachers) are the subjects of a disciplinary gaze in education settings, she suggests that labelled children within 'regular', and 'special' education settings, are subjected to greater scrutiny and surveillance than their non-disabled peers. She cites the more constant supervision that disabled children often experience, such as the close presence of a teacher aide during classroom and break times, as an example of this closer scrutiny. Social controls and mechanisms of surveillance within institutions such as schools and early childhood centres allow for children to be sorted into different types or kinds through recorded and informal observation, supervision, assessments and judgments by teachers, teacher aides, special educationalists and peers. Mandated requirements such as Individual Education Planning assessments and documentation for disabled children receiving *Ongoing and Renewable Resources Scheme*

(ORRS) funding can be viewed as examples of individualising and pathologising disciplinary mechanisms involving close observation and normalising judgements (Ministry of Education, 1996b; Morton & Gibson, 2003).

Normalising judgments

Disabled children and their families are frequently the objects of a normalising gaze, and judgements. Linda Graham (2005), used a Foucauldian analysis to examine how ‘behavioural disorders’ are constructed in the school system in Queensland, Australia. She argues that the binary division between normal and abnormal in developmental psychology paves the way for differential treatment of children defined as abnormal and is a site where disciplinary power can be exercised. Foucault (1977) suggested that the construction of ‘normal’ allows institutions, such as schools, to establish ‘the norm’ as a:

...principal of coercion in teaching with the introduction of a standardized education...Like surveillance and with it, normalization becomes one of the great instruments of power at the end of the classical age... It is easy to understand how the power of the norm functions within in a system of formal equality, since within a homogeneity that is the rule, the norm introduces, as a useful imperative and as a result of measurement, all the shading of individual differences (p. 184).

Hence, the construct of “the abnormal is extricated from the shadow of the normal and becomes subject to an uninterrupted play of calculated gazes” (Foucault, 1977, p. 177).

In relation to the norms of developmental psychology and behaviourism, Graham (2005) suggests that the articulation of ages and stages of development, and the production and use of normative standards and practices in education constructs and reifies a view of difference as

deficit. The acceptance of normalising judgements as a foundation for educational theory, practice and discourse has had the effect of emphasising individual differences and defining them as pathological. The pedagogical response to this perceived lack or deficit is the construction of ‘non-achievers’ who are assumed to need additional support, remediation and cure. According to Western traditional knowledge regimes, children whose behaviour or characteristics fall outside of the norm have ‘special educational needs’ (Ministry of Education, 1996b, 2007b). They are assumed to require a ‘special’ and, therefore, different education than their peers who are constructed as ‘normal’ (MacArthur, et al., 2000). In this regard, ‘treatment’ and ‘intervention’ are rationalised as necessary and benevolent responses to individual ‘needs’ (Graham, 2005; G. Thomas & Loxley, 2001).

The examination

Foucault’s (1977) description of disciplinary mechanisms included the production, collection and storage of written documentation about individual’s perceived differences and deviations from the norm. The ‘examination’ involves a set of professional practices and artefacts that are familiar to many disabled children and their families (Ballard, 1994a; Barrkman, 2002; Brown, 1994; P. Ferguson, 2001; P. Ferguson & Ferguson, 1995; MacArthur & Dight, 2000; B Macartney, 2002, 2008b, 2009b; Wills, 1994).

The ‘examination’ refers to productive processes of objectification. ‘Examinations’ construct or produce the subject in a particular way, using a body of knowledge that claims to be and believes it is, an objective view of reality (Brantlinger, 1997, 2006; Skrtic, 1995; Slee, 1997). Examinations can happen anywhere, be carried out by anyone and can be informal and other times more formalised. They involve

surveillance - in the form of written observations, verbal accounts, tests, measurements and assessments by 'experts' - to quantify how a child or adult deviates from the norm. Rather than being viewed holistically, individuals become defined, labelled and treated as a 'case' (Foucault, 1977). Foucault described this process as involving:

...the pinning down of each individual in his (sic) own particularity... (and) ...clearly indicates the appearance of a new modality of power in which each individual receives as his status, his own individuality, and in which he is linked by his status to the features, the measurements, the gaps, the 'marks' that characterize him and make him a case (1977, p. 192).

The effects of processes based on the examination, are the effects of disciplinary power. In education these effects include structures, decision making, pedagogies and interventions that result in exclusionary practices. The examination acts as a vehicle for producing normalising judgements. A primary focus on labelled students becomes limiting or eradicating their deviations from established norms (Hehir, 2002). Allan suggests that the examination, and the documentation that accompanies it, marks the disabled child out:

...for perpetual surveillance throughout the remainder of his or her school career and beyond. Parents and professionals also come under scrutiny as part of the continuous review of the recorded child's needs. All are caught by a gaze which is always alert to the deviant (1999, p. 22).

In conclusion, the use of Foucault's theorising about discourse, bio-power and micro-mechanisms of power-knowledge such as surveillance, hierarchical observation, normalising judgements and the examination, provide a useful theoretical lens for considering the positioning and experiences of disabled children and their families in education and society (Allan, 1999; Graham, 2005; B Macartney, 2008b; Tremain, 2002, 2005).

Disability discourses

A critique of ‘disability discourses’ is necessary in understanding the generation, privileging and effects of particular knowledges within education and society (Fulcher, 1989). Writers and researchers in Disability Studies and the disability rights movement have attempted to unpack and make visible the knowledge, assumptions, influences and effects surrounding discourses that are relevant to the construction and experience of disability (Allan, 1999; Ballard, 1994c; Fine & Asch, 1988; Fulcher, 1989; MacArthur, et al., 2003; Oliver, 1990; Purdue, 2004). Fulcher (1989) outlines five main disability discourses. These are medical, corporate-managerial, charity, lay and rights discourses. I have already discussed the basic tenets of medical discourses of disability. Here I will elaborate on disability discourses based on corporate-managerial, charity-lay, and human rights-resistance views of disability.

Corporate-managerial discourses

In a corporate discourse the focus is on ‘disability’ as a management issue. Fulcher (1989) noted the emergence of a corporate-managerial discourse in Western governments alongside neo-liberalism twenty years ago. Since the devolution of New Zealand’s education system, in line with neo-liberal philosophies, there has been a pre-occupation in government and Ministry of Education initiatives with mechanisms and systems for allocating and distributing resources (Lange, 1988; Millar & Morton, 2007; Ministry of Education, 1996a; New Zealand Government, 2010; Taskforce to Review Education Administration, 1988). A managerial discourse has taken precedence in New Zealand government reforms in education and ‘special education’ to the detriment of concerns about human rights and arguments and research evidence that support fully inclusive education (Ministry of

Education, 1996a; New Zealand Government, 2010; Taskforce to Review Education Administration, 1988).

A corporate-managerial discourse exercises power and influence through its “institutional base” in government policy and funding arrangements, special education professional networks and structures and support for private sector provision of ‘disability services’ (Fulcher, 1989, p. 26; Gordon & Morton, 2008). In line with a managerial discourse, New Zealand governments responses to the education of learners with ‘special needs’ in Aotearoa-New Zealand primarily focuses on allocating, distributing, monitoring and managing resources (Millar & Morton, 2007; Ministry of Education, 1996a, 2010; Wylie, 2000). A fragmented, professional workforce providing services to disabled people has thrived in New Zealand and throughout the Western world in a technicist-managerial climate (Fulcher, 1989; Slee, 1997; G. Thomas & Loxley, 2001; Wills, 2006). Through funding and contracting out a complex mixture of public, non-governmental and private sector disability and special education ‘services’, successive New Zealand governments have distanced themselves from taking central responsibility for ensuring that inclusive education happens. As outlined in Chapter One, an outcome of diminished state responsibility and a focus on resource management has been the growth and entrenchment of systems based on the “separate worlds” of ‘special’ and ‘regular’ education (Millar & Morton, 2007, p. 163).

Charity-lay discourses

Fulcher (1989) suggests that a charity discourse sits well with a medical discourse. The focus is on disability as a ‘problem’ experienced by unfortunate individuals. A charity discourse characterises disabled people as pitiable, helpless, childlike, dependent on others for care and as victims of a personal tragedy. The value, status and identities of disabled people

within a charity view of disability are limited and diminished. A charity discourse emphasises the differences between disabled and non-disabled people and reinforces the notion that separate ‘treatment’ and ‘help’ by ‘experts’ is necessary and appropriate (G. Thomas & Loxley, 2001). Disabled people and their families are assumed to benefit from and be grateful for the services (‘help’) they receive. In this regard “having a disability is synonymous with needing help and social support” (1988, p. 12). Disabled people are constructed as passive recipients rather than full citizens with rights, preferences and desires (P. Ferguson & O’Brien, 2005; Fulcher, 1989; G. Thomas & Loxley, 2001). An emphasis on ‘need’ and ‘dependence’ diverts attention from the human ‘rights’ of disabled people and the impacts of discrimination on their enjoyment of life and full participation in society.

Through everyday, taken-for-granted language and activities dominant meanings and knowledge about disability are perpetuated and maintained. Fulcher (p. 29) suggests that: “Lay perceptions of disability are informed by medical discourse, a charity ethic and fear, prejudice, pity, ignorance, misplaced patronage and even resentment... It is these themes which inform social practices which are blatantly discriminatory.” Her conception of a ‘lay discourse’ suggests, as do Foucault (1980) and Freire (1997, 1998), a complex, far reaching and insidious expression of coercive power through the everyday use, expression and reproduction of deficit language and discourses.

Human rights-resistance discourses

Over the past ten to twenty years Disability Studies research and theorising has grown to encompass a diverse and nuanced range of responses to ‘disability’ and ‘impairment’ as social, political, and cultural constructions alongside a growing interest in the lived experiences of disabled people

and their families (Ballard, 1994c; D. Ferguson & Ferguson, 2008; P. Ferguson, 2001, 2009; P. Ferguson & Ferguson, 2006; Gabel, 2005; Goodley, 2001; Goodley & Lawthorn, 2008; Linton, 1998; B Macartney, 2002, 2007b, 2008b; Valenzuela, et al., 2000; Van Hove, et al., 2009; Van Hove, et al., 2008).

Approaches to disability centred on a human rights discourse and 'resistance theories' have drawn from and expanded understandings of disablement based on the social model (Allan, 1999; Gabel, 2005; Gabel & Peters, 2004). Like the social model, rights-based discourses perceive disability as a social, political and cultural issue (Allan, 1999; Barnes, et al., 1999; Fulcher, 1989; Linton, 1998; Oliver, 1990, 1996; Slee, 2001). Fulcher (1989, p. 31) argued twenty years ago that, despite a rights discourse being increasingly articulated in government legislation, policy, curriculum and International Conventions, it "has had little effect in challenging the hegemony of a professionalized discourse on disability in the institutions of the British and Australian welfare states." The same can be said of the officially sanctioned and resourced dual systems of 'special' and 'regular' education in New Zealand.

Gabel and Peters (2004) suggest that, while the social model is indispensable as an explanatory framework for understanding and challenging deficit views of disability, its status as a grand narrative sets limits on its capabilities for providing insights and guidance around transformative social action and change. The social model's universal rejection of the medical/individual model, can deny the possibility that in some situations and contexts medical interventions can produce welcome and liberating changes in disabled peoples' lives (Gabel, 2005). While agreeing that macro social and political mechanisms are a significant barrier to disabled people, resistance-based approaches also recognise and accept more nuanced and contextually situated understandings of disability

(Alton-Lee, et al., 2000; Gabel, 2005). Gabel suggests that viewing social action and disability in terms of resistance between competing expressions of power, allows for the complexity and diversity of experiences of disability and creates space for multiple lines of representation, thinking and action.

A recognition of power and resistance as constantly circulating in multiple directions, ways and levels throughout society characterises resistance-based approaches (Foucault, 1980, 1982; Gabel & Peters, 2004).

2.7 Social-political-cultural perspectives

This section presents research and viewpoints that interpret disability from a social-political-cultural standpoint. I look at several key discursive assumptions underpinning the social construction of disability in education and society (Barton, 1996; Bogdan & Biklen, 1977; Bogdan & Taylor, 1982; Brantlinger, 2006; P. Ferguson, 2001; Fine & Asch, 1988; Goodley, 2001; Hehir, 2002; MacArthur, et al., 2000; Rauscher & McClintock, 1996; Reeve, 2009; Sleeter, 1995; Smith, et al., 2009; G. Thomas & Loxley, 2001). I conclude that superficial adjustments to the language and rhetoric of 'special' and 'regular' education stymie and sabotage efforts to challenge the exclusion of disabled people in education and society (Brantlinger, 2006; Goodley, 2001; Slee, 1997, 2001, 2003, 2010; Sleeter, 1995; Smith & Barr, 2008).

Dominant cultural assumptions

The lived effects of culturally situated assumptions, values and beliefs result in disabled people being stigmatised, excluded and discriminated against in education and society. From its beginnings, Disability Studies scholars have worked to expose and challenge the dominant assumptions underpinning social constructions of disability and their influences on

disabled peoples' lives (Blatt & Kaplan, 1974; Bogdan, 1980; Bogdan & Biklen, 1977; Bogdan & Taylor, 1982; Braginsky & Braginsky, 1971; Fine & Asch, 1988; J. Mercer, 1973; Oliver, 1990). In this section, I base my discussion primarily on later scholars who have drawn many of their central ideas from this earlier body of work.

Assumption One: Disability is an individual problem

The first assumption discussed by Fine and Asch (1988) is that:

... disability is located solely in biology, and thus disability is accepted uncritically as an independent variable... Disability is portrayed as the variable that predicts the outcome of social interaction when, in fact, social contexts shape the meaning of a disability in a person's life (pp. 8-9).

A view of disability as a personal and private matter relieves the rest of society from taking any responsibility for its construction and experience. Individualising views of disability produce uncontested spaces in which exclusionary practices and behaviour can occur. An assumption related to an individualised view is that "when a disabled person faces problems, it is assumed that the impairment causes them" (Fine & Asch, 1988, p. 9). For example, how non-disabled people react towards disabled people, is assumed to be caused by the person and their disability, rather than variables that are outside of disabled person's control (Fine & Asch, 1988; Reeve, 2009). These variables include many non-disabled peoples' discomfort or negative reactions based on a lack of meaningful experiences with disabled people, dominant stereotypes and deficit beliefs about disability (MacArthur, et al., 2000; Rauscher & McClintock, 1996; Reeve, 2009; Veck, 2009).

Assumption Two: 'Ableism'

When a labelled child has difficulty learning to read, do maths, join in, sit still in the classroom or to follow instructions, it is routinely assumed by teachers that these difficulties are caused by the child's 'impairment' (Graham, 2005). This is in contrast to teachers also considering the ways in which the teaching-learning environment and practices may be restricting and influencing a child's ability to learn and participate. A belief that a child's disability is the cause of their problems leads to what Thomas and Loxley (2001, pp. 23-24) describe as "the find-what's-wrong-and-cure it paradigm."

Hehir (2002) discusses the implications of 'ableism' (Bogdan & Biklen, 1977) in education. Hehir (p. 1) states that ableism is underpinned by "...deeply held negative cultural assumptions concerning disability". Ableist assumptions place negative value on disability and difference, which results in denying the identities and rights of disabled children and adults (Bogdan & Biklen, 1977). The assumption that disability is a tragedy to be overcome, supports teaching practices based on a belief that disabled children can and should be made to do things in the same ways as non-disabled children (Hehir, 2002). Hehir argues that ableist assumptions justify normalising practices in education. Such normalising practices include requiring children with significant visual impairments to read print, rather than learn Braille, children with hearing impairments being taught to lip read, use amplification devices and speak, rather than learning to use sign language, and children with dyslexia being expected to spell independently rather than use a spell check. Hehir argues that this restriction on disabled students' access to effective forms of communication negatively affects their learning, achievement, identity and relationships. The teacher time and energy spent on trying to ameliorate and 'fix' perceived deficits, means that less teacher time goes into

supporting positive learning opportunities and accessing the technologies, methods and modes of expression that are likely to be most effective, efficient and rewarding for each child.

Assumption Three: Disabled people and their families are victims of a personal tragedy

A charity discourse positions disabled people as victims and assumes that they and their families suffer from a personal tragedy. It is assumed that professional knowledge, welfare and intervention are necessary to ‘help’ meet families’ ‘need to accept’ and ‘adjust’ to their tragic circumstances (P. Ferguson, 2001; P. Ferguson & Asch, 1989; G. Thomas & Loxley, 2001). Paternalistic thinking underlies much of the literature and approaches embedded within professional responses to disability. Ferguson (2001) discusses professional portrayals of ‘parental reactions’ to having a disabled child and the possible effects of these views. Professional knowledge universalises and typifies parental responses to their children’s disabilities (Brantlinger, 2006; P. Ferguson, 2001). For example, psychodynamic typologies explain parental responses to disability negatively in terms of “...denial, grief, guilt, defence mechanisms of all types, and a positive goal of acceptance...” to normalise and judge parental responses to disability (P. Ferguson, 2001, p. 380). An effect of pathologising family responses to disability is the silencing of counter-narratives. Having no counter-narrative makes it easier for professionals to abdicate responsibility for the negative, or indeed tragic, effects of *their* knowledge and practices on families. Ferguson suggests that professional silencing becomes particularly obvious when parental responses to their circumstances do not conform to what ‘the experts’ expect. In these situations ‘atypical’ parental responses are rationalised as further evidence of pathology. For example, the parent who does not show signs of grieving over their child being disabled or who ‘over-inflates’ their child’s abilities,

are viewed as being 'in denial'. Parental dissatisfaction or anger about the behaviour of professionals can be dismissed as a projection of parents' ('understandable') anger about their child's 'abnormalities' onto others.

Assumption Four: Disability is 'other'

Non-disabled people's interpretations of disability are connected to a view of disability as 'imperfection' and as 'other' Rauscher & McClintock (1996) suggest that:

Deeply rooted beliefs about health, productivity, beauty, and the value of human life, perpetuated by the public and private media, combine to create an environment that is often hostile to those whose physical, mental, cognitive, and sensory abilities...fall outside the scope of what is currently defined as socially acceptable (p. 198).

Discomfort about difference is sometimes expressed as hostility and fear toward the existence of people viewed as 'damaged' or 'imperfect' (Oliver, 1990; Rauscher & McClintock, 1996; Reeve, 2009). Beliefs that position disabled people as 'tragic others' are often expressed through patronising attitudes, pity, embarrassment, discomfort, over-protection and fear of difference (Barton, 1996).

Reeve (2009) discusses the work of Italian philosopher Giorgio Agamben, who was a student of Foucault's. Using Agamben's concept of a 'bare life', Reeve considers how disabled people are perceived and positioned in society. Agamben suggested that disciplinary power is exercised and justified through a view of particular groups in society as living in a "state of exception." (in Reeve, 2009, p. 203). A state of exception involves being positioned outside of the commonly accepted moral codes, and laws that usually apply to every citizen. Existing outside of these protections allows the state, institutions and 'full' citizens to exercise a kind of sovereign power over those deemed 'outsiders and

others' (Reeve, 2009). Reeve's examples of people consigned to a 'bare life' include outlaws, bandits, political detainees, human fetuses, 'severely disabled' unborn babies, disabled people and people committed to psychiatric institutions.

In regards to the positioning and treatment of disabled people, Reeve suggests that non-disabled people can and do exercise a sovereign power over disabled people. This power is implicitly sanctioned through social-political-cultural norms and institutions. Exercising sovereign power over disabled people dehumanises and objectifies them as 'non-people' (Reeve, 2009; Smith, et al., 2009). An example of non-disabled people exercising sovereign power over disabled people is the behaviour of some non-disabled strangers towards disabled people in public settings. Reeve describes acts by strangers towards people with visible impairments - such as intrusive staring, name calling, taking photos without permission and other expressions of hostility - as practices of "psycho-emotional disablism" (2009, p. 210). Acts by strangers span a continuum between impoliteness to open hostility and violence. Hostility creates psychological and emotional barriers to disabled peoples' feelings of acceptance and belonging. Psycho-emotional disablism restricts disabled people and their families' desires, and capacities to participate in daily life without fear and anxiety. Psycho-emotional barriers can lead to disabled people, and/or their families, avoiding or feeling uncomfortable in places and situations that most citizens take access to and enjoyment of for granted.

A view of disabled children and adults as damaged, imperfect or lesser, positions them as different, other, "not like us" and unwelcome (Biklen, 1992; MacArthur, et al., 2000, p. 18). An emphasis on difference as 'other', rather than being a typical aspect of human diversity, rationalises thinking and practices that support the separation and/or

differential treatment of disabled children within education (MacArthur, et al., *ibid*; G. Thomas & Loxley, 2001).

Assumption Five: The person is their disability

A further cultural assumption discussed by Fine and Asch (1988, p. 11) is a view that "...disability is central to the disabled person's self-concept, self-definition, social comparisons, and reference group." From this perspective, a person's disability or impairment is seen as defining their experience of life and who they are. In other words, a disabled person *is* their disability. The authors point out that this view, while pervasive, is simplistic and restrictive to disabled people. All people have varying interests, strengths, characteristics and groups with whom they identify, and the nature of the contexts they are in at any given time will highlight or bring forth particular configurations of these. Although a person's disability or impairment shouldn't be assumed to be irrelevant to their identity, a person's disability or impairment should not be seen as the *most* or *only* significant influence on their experiences and self-perceptions in every situation and context.

An implication of viewing a person's disability as defining who they are and who they can be, is the potential of such reductive thinking to restrict a person's experiences and opportunities, particularly where disability is viewed as synonymous with deficit. This is possibly more the case for young children, who have a greater reliance on adults to structure their lives, and the experiences, environments and opportunities available within them (Allan, 1999; Cullen, 1999; Mayall, 2002; G. Thomas & Loxley, 2001). In addition to considering disabling identities, there are also issues about how 'children' as a social group are defined and constructed and the effects of those constructions on the identity, learning and

participation of all children (Allan, 1999; Farquhar & Fler, 2007; Fler, 2005; Mayall, 2002; G. Thomas & Loxley, 2001).

Discursive ‘adjustments’ in special education: Re-inventing exclusion

Slee (1997) argues that:

The failure of the educational academy and educational policy-makers to apply theoretical analysis to the epistemological foundations of special education practices has been detrimental to the project of inclusion... The beneficiaries of this theoretical, and political, deflection remain those with an interest in traditional special education practice, an unreconstructed school system and the bureaucratic and political imperatives of educational policy makers (p. 407).

The uncritical and a-theoretical approach of special education is a significant barrier to ‘inclusive education’. Critical examinations of how special education conceptualises and responds to ‘disability’, ‘impairment’ and ‘difference’ suggest that the re-configuring of language and methods within special education in response to demands for inclusion has contributed to a false impression that special education thinking and practices are becoming more ‘inclusive’ (Brantlinger, 2006; Slee, 1997, 2001, 2003; Sleeter, 1995; Smith, et al., 2009; G. Thomas & Loxley, 2001). To the contrary, Roger Slee (1997, p. 407) argues that “professional resilience reinvents special education as consistent with inclusive education. This has been achieved through linguistic adjustments which eschew challenges to underlying assumptions about difference and schooling.”

It is strongly argued in Disability Studies that superficial changes in special education rhetoric – in how disability is talked about, and what labels are used to categorise children - obscure the uninterrupted continuity of exclusionary methods and deficit discourses underlying special

education epistemology and practice (Graham, 2005; Slee, 1997; Smith, et al., 2009; G. Thomas & Loxley, 2001). ‘Buzz words’ and concepts invented and/or co-opted by special education such as, ‘inclusion’, ‘celebrating diversity’, ‘special educational needs’, ‘learning disabilities’, ‘trans-disciplinary teamwork’, and ‘partnership with families’ provide a veneer of inclusivity without any accompanying critical reflection about exclusionary deficit discourses and discursive practices (Brantlinger, 2006; Morton & Gibson, 2003; Slee, 1997, 2003). Labels such as ‘Learning Disability’ (Sleeter, 1995), ‘Learning Difficulty’ (Goodley, 2001), ‘Intellectual Disability’ (Rapley, 2004), ‘Emotional and Behavioural Difficulties’ (G. Thomas & Loxley, 2001), and ‘Attention Deficit Hyperactivity Disorder’ (Graham, 2005; Slee, 2001) serve certain purposes and have exclusionary outcomes in education, one of which is the reproduction and maintenance of the dominant social order (Danforth, et al., 2006; Slee, 1997; G. Thomas & Loxley, 2001).

‘Inclusive’ rhetoric and ‘window dressing’ compared with critical pedagogy and radical transformation in education and society are a major concern to those using Disability Studies to critique exclusionary pedagogies. Educational responses to inequality that focus on language and methods in education without a critical consideration of deeply entrenched social-political-cultural mechanisms are not sufficient to transform the material conditions that underlay exclusion in education and society (Bishop & Glynn, 1999; Bishop, et al., 2005; Connor, 2008; Freire, 1998; Neyland, 2005).

2.8 Thesis focus and research questions

My overarching interest in this research is in the relations between family and disabled children’s experiences, and the production and circulation of power, knowledge and ‘truth’ about disability and impairment in education and society. I am interested in the implications of parents’ narratives for

early childhood services, schools and other professionals in supporting the inclusion, learning, participation, contribution and human rights of disabled children and their families. Insights derived from considering the parents' narratives in this thesis may, in some small way, contribute to the realisation of a more inclusive education system and society (Ministry of Education, 1996b, 2007b; Ministry of Health, 2000, 2001). I envisage five main audiences for whom this research will be particularly relevant. These are parents, caregivers and family members of disabled people; teachers; special education professionals; people working in institutions that organise, manage, facilitate, and develop policy, structures, and provision of services related to disabled children and their families and people involved in the disability studies and disability rights movements.

The key research questions for this project are:

- How do the parents in my study make sense of having a 'disabled child'? How do the parents respond to and interact with discourses of disability?
- How are the narratives of the parents embedded in, and resistant to dominant discourses around disability and difference?
- What other discourses are available to, generated and/or constructed by parents through their everyday experiences of living with their disabled child?
- What are the actual and potential effects of dominant, deficit discourses and discursive practices on their children's learning, contributions and participation in public, family and educational contexts?
- What directions and possibilities for professional, structural and pedagogical change do the parents' experiences and narratives indicate?

- How can teachers, early childhood centres and schools, working alongside families and communities, transform exclusionary cultures and practices in ways that develop and sustain inclusive settings, through a consideration of disabled children and their family's experiences and aspirations?

An examination of the research questions that combines a consideration of parents' narratives with a critical 'epistemological curiosity' (Freire, 1998), should create a space for problematising and challenging the taken-for-granted use and privileging of pathologising, deficit knowledge in education and society (Allan, 2008; Bishop, et al., 2005; Brantlinger, 1997, 2006; P. Ferguson, 2001; Fine, 1993; Freire, 1998; Graham, 2005; B Macartney, 2007b, 2008b; Skrtic, 1991). I am hoping that the space created through such an examination may contribute to the project of developing a more clearly articulated and well defined language and discourse around inclusive education (Gergen, 1999; Slee, 1997, 2001).

Chapter Three: Methodology

3.1 Introduction

In the previous chapter I discussed my use of a social constructionist epistemology, and the theoretical perspectives and methodologies I have drawn from in this research. In this chapter, I discuss how I have situated my analysis of participants' data within an interpretive Disability Studies framework and explain how I have used discourse analysis, narrative inquiry, critical inquiry, and auto-biography/ethnography as theoretical tools in this study. I then introduce the research participants and their families. In the methods section, I describe my processes and timeline for gathering and analysing the data. I consider the ethical issues related to this research and how I responded to these. I discuss how I have understood and responded to issues of representation, reflexivity, validity, researcher positioning and reciprocity. I then outline my process and timeline for writing up the thesis and consider the limitations of this study. After concluding the methodology content of the chapter, I outline the structure of three findings chapters that follow.

3.2 Interpretivism and disability research

The research draws on interpretivism which is underpinned by a social constructionist epistemology (Burr, 1995; Crotty, 1998; P. Ferguson, Ferguson, & Taylor, 1992a). An interpretivist perspective is interested in social life as it is constructed and experienced by individuals within their lived contexts (P. Ferguson & Ferguson, 1995; P. Ferguson, et al., 1992a). Researchers working within an interpretivist paradigm use ethnographic, descriptive and narrative detail of people in their everyday contexts as the basis of their data collection, interpretation and analysis (P. Ferguson &

Ferguson, 1995). Interpretivist disability researchers Ferguson & Ferguson (1995, p. 107) suggest that ‘giving’ members of marginalised social groups a voice, through providing opportunities for them to tell and have their stories heard, can have a transformative impact on social relations at the macro level and that: “In its emphasis on complete description of individual cases, interpretivism eventually challenges inequity by legitimating the perspectives of those on the bottom of society...”. They further suggest that interpretivism is a useful approach to researching disability because of the particular questions that it raises, for example:

“What is the experience of disability?”...That is, ask for the context, the social construction through which social reality takes shape. Interpretivism maintains that disability is not a fact – an entity- whose nature is waiting to be discovered. Disability is rather an experience waiting to be described or, more precisely, a multitude of experiences waiting to be described (1995, p.113).

The unique experiences and narratives of families presents an opportunity to explore, deconstruct and understand disability from the ‘inside’ (Ballard, 1994c; Raymond, 2002). Many disabled people criticise accounts and interpretations of their experiences that have been written by non-disabled people (Ballard, 1994c; Barnes, et al., 2002; P. Ferguson & Ferguson, 1995; Gabel, 2005; Oliver, 1990, 1996). Ballard refers to a call in disability studies for:

...direct, personal accounts of disability. Such reports by the disabled themselves and by parents, grandparents and other whaanau will present pictures of disability and of its contexts that reflect actual, lived experiences rather than predetermined categories of experiences that a researcher may think, possibly erroneously, are important. Also, such accounts may help to break down barriers between people with disabilities and others in society by ensuring that the (sic) disabled voice is heard (1994c, pp. 23-24).

Susan Gabel (2005, p.17) suggests that research in disability studies is “primarily concerned with the view of issues and problems as defined by disabled people and as they relate to social exclusion and oppression.” This research, with its emphasis on family stories as a starting place for analysis, can be viewed as a contribution to this emancipatory project.

3.3 Theoretical perspectives and methodologies

This research has combined several different but compatible theoretical perspectives and methodologies (P. Ferguson, et al., 1992c). Because of the multiplicity of perspectives and approaches, the research design is quite complex. In response to this complexity, and for the purposes of organising and combining the range of approaches I had selected, I chose critical discourse theory and analysis as the key methodological foundation on which to build my research structure and link in with the other approaches.

Discourse theory and analysis

Discourse theory and analysis can be used to illuminate the social construction and negotiation of meaning within the wider context of historical, political and cultural relations (Rogers, 2004). The purpose of using discourse as a sensitizing concept and analytical tool in this research was to explore the links between everyday life as it is experienced by families and the wider social-political-cultural context. I have discussed discourse theory, particularly in relation to dominant and resistant discourses of disability and Foucault’s notion of discourse and the mechanisms of bio-power, in the previous chapter. In the data analysis section of this chapter I describe the discourse analytic methods and approaches I have used.

Narrative Inquiry

I have used Clandinin and Connelly's (2000) approach to thinking narratively as a theoretical tool to guide my interpretations and analysis of the parents' stories and document data. The purpose of using narrative is to explore and highlight relational processes through which meanings around disability were constructed and experienced in the everyday lives of the families involved in the study. Narrative thinking provided the starting place and framework in this research for interpreting and describing the experience and construction of disability from the participants' perspectives (Bogdan & Biklen, 1992; Bogdan & Taylor, 1992; Clandinin & Connelly, 2000; P. Ferguson, et al., 1992c; Maynes, et al., 2008). The foregrounding of participant stories is consistent with my intention to value the perspectives and voices of families rather than trying to fit their experiences into preconceived constructs (Ballard, 1994a; Bogdan & Taylor, 1992; Ellis, 2004; P. Ferguson, 2001; Lather, 2003; Lather & Smithies, 1997). I was interested in attending to the participants' own definitions of their situation, and in the influences of general and significant others on the ways that participants perceived, interpreted and described their experiences (Bogdan & Biklen, 1992; Nuttall, 2003a). Furthermore, I was interested in how participants' definitions of their situations contributed to how they constructed and acted on their reality (Ellis & Bochner, 1996; Freire, 1997, 1998; Goodley, 2001; Maynes, et al., 2008; Rapley, 2004). As I began to familiarize myself with the data, I found that a close consideration of the participants' stories revealed many insights about how they viewed and constructed their own identities and the identities of their children.

Critical Inquiry

Combining critical inquiry (Freire, 1997, 1998; Valenzuela, et al., 2000) and discourse analytic theory and analysis (Foucault, 1977; Tremain, 2005), with the micro focus of narrative inquiry (Clandinin & Connelly, 1988, 2000; Maynes, et al., 2008) enabled me to interpret and analyse interactions between personal experience, and the social-political-cultural mechanisms implicated in the construction and experience of disability. In particular I have used Freire's (1998) "epistemological curiosity" as a theoretical tool for noticing and critiquing the workings of power in the families' narratives, images and documents used as data.

Auto-biography/ethnography

As I am a co-participant and the researcher in this study, the research includes an auto-biographical lens (B Macartney, 2005b). I decided to be a participant in the research partly because my personal experiences as Maggie's mum and an early childhood teacher motivated my interest in disability and inclusion. I also felt that my family's participation could create opportunities for the research in relation to providing 'deep' insights or data (Ellis, 2004; Ellis & Bochner, 1996; Harrison, MacGibbon, & Morton, 2001). I felt that our common experiences as mothers of disabled children would help me to develop a connection and rapport as a co-participant with the other participating family. My life is infused with issues around disability and I felt that I would be in a more difficult position trying to keep myself out of the study if I had only chosen the researcher role. I felt that being a participant was a more honest choice.

Over the six year course of this project I have become increasingly aware of disability issues as they affect our family in our daily lives. Mostly this heightened awareness has been positive for me

personally and for the research. My position as an 'insider' has helped to strengthen, deepen and broaden the process of analysis and interpretation. My roles as a parent and a participant in this project have created many more opportunities for reflexivity than if I was an 'outsider'. Most times a question, idea or perspective has arisen from my consideration of the other participating family's experiences, I have reflected on this in relation to myself and my family (B Macartney, 2005b). While there have been potential dangers (to the research and myself) in being an inside participant-researcher, there were also opportunities for developing theory and communicating findings that may have been missed by an outside, naive inquirer (Ellis, 2004).

My participation in this research challenges viewpoints that create boundaries around the roles that parents, and researchers are legitimately allowed to perform, and the selves that may or may not be expressed in that work (P. Ferguson & Asch, 1989; Reinharz, 1997). Being a participant-researcher has had implications for methodology in relation to researcher ethics and positioning, reflexivity and the trustworthiness and establishing the validity of my interpretations and analysis. Although this insider perspective is a strength of the research, it has meant that demonstrating and maintaining a self critical, reflexive approach has been particularly important. A reflexive approach has helped to ensure that opportunities for making meaning from aspects of the data were not missed through taking some insights or information for granted, and that I didn't unintentionally manipulate the research to be more congruent with my own views and experiences.

My intention has not been reduce the data to a tidy picture focusing primarily on congruencies and similarities between the participating families but to also pay attention to areas of divergence, contradiction and silence within and between the narratives. This research

presented opportunities for exploring and working the hyphen between ‘self’ and ‘other’ in ways that recognized the complex interplay between (and within) researcher and participants and their impacts on the research process and findings (Fine, 1998; Fine & Weis, 2002). In the next section I introduce the research participants before describing the research design and methods.

3.4 The research families and parent participants

Two families participated in the study. One of the families was my own. My partner Tony and I both participated in the study. The other family was Fran’s (pseudonyms have been used for Fran’s family and the settings mentioned in this research). In this section I explain the decisions I made about the number of families participating in the study and how I went about selecting and approaching the other family. I also introduce the two non-researcher parents and each family.

Although I was keen to share and learn from my own family’s experiences, I felt that I would learn more and present a deeper and more varied account of disability if I included and considered another family’s experiences and perspectives. I had initially intended to involve three families in the research. However, after gathering and beginning to analyse the data from the interviews with Fran, I decided to limit the research to two families. The interviews with Fran had elicited rich, engaging and interesting data. I felt that there was enough diversity in the two families’ experiences and perspectives to stimulate me to think in more complex ways about disability, inclusion and exclusion. I decided at that point that the research could benefit from a deeper consideration of the two families rather than widening my focus to include another.

Fran's family

Fran and Mark have two children. They are Clare who was four years old when I began interviewing Fran, and her little sister Amber, who was almost one year old. Fran preferred to call Clare 'special' in preference to using the term 'disabled'. Amber was not disabled. I interviewed Fran at her home on four occasions over an 18 month period. Each interview lasted for two hours. Fran and I kept journals between interviews where we could record any issues that came up, things that happened and anything else that Fran or I wanted to discuss at the next interview.

I asked a friend who was teaching in an inclusive education course if she could approach Fran and see if she was interested in participating in the research. Fran and I had met once when we both spoke on a parent panel at the course. My friend approached Fran on my behalf. Fran was interested, so I contacted her and, after talking together about the purpose and focus of my study and sending her an invitation and information letter, she agreed to be a participant in the research (see Appendices 1a and 1b). Fran's husband Mark chose not to be part of the study although he was supportive Fran's involvement. Prior to the first interview, Fran and I went through the consent form together (see Appendix 1b). We each agreed to the conditions before signing the form. The form, which had been sighted and approved by the Ethics Committee of the Christchurch College of Education, outlined Fran's right to withdraw from the study at any time, an assurance of my commitment to maintain her family's confidence and anonymity, my commitment to give Fran a copy of any papers I wrote based on the research, and Fran's agreement for me to use her data from the study for up to three years after completion of the thesis.

Bernadette and Tony's family

My partner, Tony, agreed to being a participant in the study. Tony signed a consent form similar to Fran's but with an additional clause indicating that he understood and agreed to himself and our children being named and identifiable in the research (see Appendix 2). Maggie was seven years old and Sally, our youngest child, was two when the first interview took place. Maggie was nine and Sally four when the second interview took place (see Appendix 3 for a timeline of the research process).

Both families

The document and narrative data about Maggie Rose spans the period from before she was born to when she was nine years old. Fran's narratives about Clare span from before Clare was born to the conclusion of the interviews when Clare was just over five years old. Both families share significant similarities in life experience and cultural positioning. We both planned our first pregnancies and each had a first child who was born 'disabled'. All parents are from the dominant, Pakeha (New Zealanders of European descent) culture, have professional backgrounds, are financially comfortable, began having our children in our thirties and live in heterosexual, nuclear families. While the small number of participants and our similar backgrounds and dominant cultural positioning could be viewed as a limiting factor in this research, I have used this 'insider status', through our membership of generally privileged groups in New Zealand society, as part of the analysis and development of the thesis.

3.5 Design

The data from this project came from semi-structured, in-depth interviews; journal/diary keeping; family, medical, regular and special education records; and autobiographical recollections.

Interviews

Interviews with parents were the main way of generating data. Parents' stories and experiences were the focus and basis of analysis for this project. For each interview with Fran, I developed a series of topics and possible prompts based on the research questions, and preliminary analysis of the previous interview/s (see Appendices 4a – 4d). I was also mindful of the potential for learning from Fran and I talking around our common concerns and unique ways of viewing and experiencing our lives. Our interviews felt conversational and relaxed.

Two interviews with Tony and I contributed to our data for the research. The first transcript was from a two hour interview conducted in our home for a radio documentary about Maggie Rose and our family in 2003 (Ogonowska-Coates, 2003). This was one year prior to enrolling for my thesis. The second interview with Tony and myself was conducted in June 2005 by Amanda, a friend and academic colleague. This interview was at Amanda's workplace, lasted for two hours and came in between my third and fourth interviews with Fran. In preparation for conducting the interview, I discussed the focus of the project with Amanda, and gave her my schedules for the three interviews I had had with Fran. As part of her preparation Amanda also listened to Maggie's radio documentary about our family with which she was already familiar.

Journal keeping

I invited Fran and Tony to keep a journal over the course of the interview period. I wanted to offer participants the opportunity to contribute to the research outside of the interview situations. I suggested that they record any stories, thoughts and experiences that had significance for them in between interviews. Tony decided not to keep a journal because of the time commitment, and because we talked with each other in between interviews about issues related to our family and the research. Fran used her journal as a reminder of any things she wanted to talk about in the interviews. Fran's journal entries became the starting point for her second, third and fourth interviews. In my journal, I wrote my emotional responses to issues that were triggered or highlighted by the research. I also used my journal writing as a space where I could 'be myself', capture my thoughts, and as a possible further source of insight into the sense that I was making about Maggie and our lives. I raised some of my journal reflections during interviews with Fran. Knowing that Fran was keeping a journal helped me feel more relaxed because if either of us forgot something or we got 'sidetracked' during an interview, we could always put it in our journal for next time. Inviting Fran to keep a journal was also an attempt to give her another opportunity to become involved in the research analysis.

Documents and auto-biographical recollections

Relevant documents were identified and collected during the project. These documents came from our family. I asked Fran for examples of documents at times but she didn't supply any. In addition to data from the interview transcripts I used personal recollections, photographic images and texts from our family, and early childhood centre, school, medical and special education 'assessment' documents. I used my recollections and the additional documents to contextualize the interview narratives and to

expand on the apparent layers of meaning and interpretation when analysing the interview data. Using these multiple sources of data, and my ability to include photographic images from my family, meant that my own family's data was perhaps fuller and richer than Fran's family's.

3.6 Methods

Appendix 3 summarises the timeframe for data collection, analysis, chapter drafting, presenting, publishing and the final write-up of the thesis in table form.

Data collection

Between June 2004 and September 2005 I interviewed Fran on four occasions with each interview lasting around two hours. After each interview I collected and transcribed Fran's journal notes. Tony and I were interviewed twice. The first interview lasted two hours and was conducted in June 2003 (Ogonowska-Coates, 2003). The second interview in June 2005 was 1.5 hours in length. My decision to limit our family to two interviews was a way of trying to balance our family's and Fran's contribution to the research.

Transcribing

I employed a person to do the initial transcribing of the interviews which I had digitally recorded. I asked her to transcribe the recordings in as much detail as she was able to hear. After I had received each initial interview transcription, I listened to the recording at the same time as reading the transcript, and made any additions, corrections and comments. I added in any non-verbal contextual information if it was not already included, such as laughter, anger, frustration, interruptions and silences.

I wrote field notes before and after interviews and included these in my data analysis. The field notes contained my thoughts and feelings about the interview and any strong feelings or reactions I felt came from the other participant during the interview. I also included my 'observer comments' on the six interview transcripts in my analysis of the data. During 2006, I looked for and selected materials from our family, Maggie's early childhood centre and school that related to the situations Tony and I had talked about in our interviews.

Data analysis

Analysing and beginning to 'make sense' of the data began in the field. This involved writing field and journal notes; reading and rereading interview transcripts; recording and coding my responses, emerging themes, concepts, and propositions about the data; writing 'analytical memorandums' on aspects of the research methodology and emerging themes; organising and writing up each family's data as a chronological series of narratives; reading and reflecting on relevant research and theoretical writing related to the emerging themes; and writing and presenting academic papers on aspects of the methodology, data and analysis.

Using a narrative approach to analysis involved me being constantly open and attentive to the meanings that Fran, Tony and I made of being parents, of our children, and of disability in our everyday lives (Bogdan & Biklen, 1992; Clandinin & Connelly, 2000; P. Ferguson & Ferguson, 1995). I wanted to understand and respect Tony's, Fran's and my own definitions of our situation, rather than imposing my perspectives onto Fran and Tony (Bogdan & Biklen, 1992). This involved critically reflecting on my responses to our talk through reading and re-reading the interview transcripts, and thinking, writing, and talking more with Fran,

Tony, and my supervisors. I tried to be aware of any judgements I was making about Fran and her family along the way and to complicate my thinking through treating my feelings and interpretations as partial and situated rather than as the 'facts'.

Involving Fran in the analysis

After each interview had been transcribed, I sent Fran a copy and invited her to make any changes and comments to the transcript. Fran never made changes, but enjoyed reading them and referred to them in subsequent interviews. She also appreciated the transcripts as a record of what had been happening in her family.

As Fran was interviewed four times between June 2004 and September 2005 she had some time and opportunities to contribute to the research data and analysis. I invited Fran during interviews and through e-mails to engage in analysis and interpretation of her family's data and with key concepts and propositions from Disability Studies perspectives. At the end of the second interview I gave Fran some reading material about disability, and a audio recording of our family's radio documentary (Ogonowska-Coates, 2003). I provided her with this material as an opportunity for her to hear some of my thinking and our family's experiences and perspectives, and to invite her responses to a 'social model' critique of medicalised views of disability and impairment. This was also a way of trying to develop a feeling of co-participation between us in the project. When I was preparing my 'interview schedule' for each interview, I would e-mail Fran with some of my reflections about the last interview, what I found interesting and any particular issues I would like to talk about during the next interview.

Analysing Fran's interview data

I went through each transcript after each interview and added 'observer comments'. These comments contained my initial responses to, and thinking about, the data. I began to think about the data in relation to my broad research questions and possible emerging themes, issues, contradictions and patterns. I gave Fran copies of the corrected transcripts, minus my observer comments and asked for any feedback, and corrections. Next I read and reread each transcript and made written notes in the margins about possible 'sensitizing concepts', themes, patterns and coding categories. I used my notes in the margins and my observer comments to help me to begin developing coding categories that could be useful in 'chunking', organising and interpreting the data. I created a computer file for each coding category and added relevant excerpts from each transcript to the file that seemed most relevant (Bogdan & Biklen, 1992; Bogdan & Taylor, 1998). The initial categories were based on trying to understand Fran's definition of her situation. Sorting the data into these coding categories allowed me to explore and understand Fran's viewpoint more deeply than if I had begun by devising and applying categories based on what the literature says about parental responses to disability. The codes that I began with were: 'General comments and emerging themes'; 'Clare's participation/inclusion/learning in early childhood education settings'; 'What is the 'perfect child'?'; 'Who is Clare?'; 'Who is Fran?'; 'Talk involving comparisons to others'. Later I added two more categories that became more apparent after the first interview. These were: 'Experiences with experts and the system' and 'Views of and experiences with early childhood centres and schools'.

Fran's definition of her situation influenced the choices I made when developing and refining the initial coding categories. For example, she talked several times during the initial interviews about being Clare 'the

perfect child' when she was a baby and how her view of Clare changed once she realized that Clare was not developing typically. I became interested in what the 'perfect child' meant to Fran, why that concept was important to her and how she used the concept of the 'perfect child' to negotiate and construct meaning around being the parent of a disabled child. In the interviews, Fran linked her experience of losing the 'perfect child' with a process of "grieving". The 'perfect child' category developed into a potentially significant theme around parental responses as 'grieving', 'disability as loss', and normalcy. Although my initial focus was on Fran's use of the concept of the 'perfect child', I became interested in how her talk related to how she saw her role as a mother, and how her experiences were influenced through her relationships with others.

The 'General comments and emerging themes' file became the place where I collected and reflected on most of my developing analytical insights, ideas and questions, which I cross-referenced to specific pieces of data. This file was often the starting place for newly emerging coding categories and themes. It was where excerpts of data that didn't 'fit' the other files were placed. After a while, I would notice a common thread among various pieces of data and develop a new code file.

At the same time as sorting excerpts from transcripts into coding categories, I added my own interpretations and responses to the transcript excerpts within each file. These were in the form of 'observer comments'. Observer comments were based on my interpretations, opinions and reactions, questions and issues to bring up in subsequent interviews, thoughts about the emergence of possible themes, patterns or typologies, contradictions and silences within the narratives, the participants' use of metaphors and analogies and what these might mean, possible literature to explore in relation to a theme or idea, connections to my research questions, and notes about how various stories and concepts might relate to

each other. Although I noted possible discourses being used by participants, I didn't focus my attention on the use of discourses during the early analysis because I wanted to understand Fran's personal perspectives and not narrow my focus too early.

Analysing our family's data

I wanted to do my best to understand, respect and interpret Fran's definition of her situation before closely analysing my own family's data. Apart from my reflections and influence as the researcher and a co-participant in the project, I left my own family's data analysis until after I had finished interviewing Fran and had written the initial draft of her findings chapter. I began analysing our family's data in February 2006 and completed the initial draft of my chapter about our family in February 2007. I used the same process of listening to the recorded interviews, reading and re-reading the transcripts, making observer comments and coding and chunking the data as I had with Fran. I gave Tony copies of our interview transcripts, which he read. Tony and I discussed issues, questions and interpretations of our experiences and his perspectives over the period that I was analysing our data. Through these discussions, he contributed to my thinking and analysis.

Reading through these materials alongside the interview transcripts really began to highlight the workings and effects of competing views of disability within our lives. I began playing around with ways of representing these competing discourses through the text and structure of our family's thesis chapter (Ellis & Bochner, 1996; Lather & Smithies, 1997; Ronai, 2002). At this time, I began writing and presenting papers and inviting feedback on my analysis and approach in regards to our family's experiences and deficit discourses (B Macartney, 2007a, 2008a, 2008b, 2009b).

Discourse analysis (2007 – 2008)

After completing the initial phase of analysis for both families, I turned to a discourse analysis of the interview transcripts, recollections and documents. I applied an ‘epistemological curiosity’ (Freire, 1997, 1998) to each family’s narrative. I used this critical curiosity to systematically look for and interpret the discursive relations experienced by each family. I tried to understand the discourses being used, and rejected, by the participants and the linkages between the discourses and the participants’ and their family’s experiences. I used Foucault’s concepts of ‘bio-power’, self-regulation and disciplinary mechanisms as ‘tools for thinking’ (Slee, 2001; G. Thomas & Loxley, 2001) and ‘sensitizing concepts’ (Bogdan & Biklen, 1992) when re-interpreting each family’s narratives. I looked for traces and evidence of ‘disciplinary practices’ such as surveillance, hierarchical observation, normalising judgements and the examination (Foucault, 1977). I wanted to understand the *effects* of discursive practices on how the parents viewed disability and how individuals and groups were positioned and positioned themselves and others through particular discourses and practices.

I used social-political-cultural perspectives from Disability Studies for thinking critically about the discursive assumptions, meanings and practices in the data. In particular I used Fulcher (1989), and Fine & Asch’s (1988) descriptions of disability discourses and the assumptions underlying them. I was also looking for the presence of alternative or resistant interpretations of disability (Arkwright, 2005; Campano & Simon, 2010; Foucault, 1976; Freire, 1997; Gergen, 1999; Slee, 2003).

Pedagogical analysis (2008 – 2009)

During the data gathering, analysis, and initial drafting of the families' findings chapters my main focus was on understanding how disability was being experienced and constructed by the participants. My emphasis was on understanding, 'naming' and making sense of what was happening. At the same time, I continued to think about what could be done to transform education towards more inclusive thinking and practices. In 2007 I began looking more into literature related to critical, relational and emancipatory pedagogies (Alton-Lee, et al., 2000; Ballard, 2003; Bishop & Glynn, 1999; Bishop, et al., 2005; Brown, 1999; Cannella, 1997; Carr, et al., 2001; Carr, et al., 2000; Dahlberg, et al., 2007; Dalhberg & Moss, 2005; Dunn, 2004; Fleer, 2005; Freire, 1997, 1998; B Macartney, 2007b; MacNaughton, 2005; Rinaldi, 2006).

I had been reading work from U.K., Swedish and Italian early childhood educationalists about a 'pedagogy of listening' that described education and pedagogy in political, ethical and relational terms (Dalhberg & Moss, 2005; Moss & Petrie, 2002; Rinaldi, 2006). I began to consider the lack of an overt critique of inequality and exclusion in New Zealand's curriculum documents and education policy as a key barrier to inclusive pedagogies. I liked the combination of critical and socio-cultural theories in a 'pedagogy of listening' (Valenzuela, et al., 2000). I felt that a 'pedagogy of listening' resonated with New Zealand research based on teachers using 'child's questions' aligned with the strands of *Te Whaariki* to guide curriculum, assessment, planning and critical teacher reflection on practice (Carr, 2001; Carr, et al., 2001; Carr, et al., 2000).

For the third results chapter, I decided to combine a 'pedagogy of listening' approach with the child's questions and apply these in my analysis of each family's early childhood and school experiences. In the

third results chapter, I have interwoven a discussion of a pedagogy of listening, the child's questions, *Te Whaariki* and the *NZC* into my interpretations of the data. Alongside writing chapter six, I continued to develop and seek feedback on my thinking through presenting papers and publishing peer reviewed articles around that topic (B Macartney, 2009a, 2010; B Macartney & Morton, 2009). Presenting and publishing has been a central process for me in articulating, receiving feedback on and refining my analysis and interpretations. From early in 2005 up until the present I have presented and published data and analysis drawing from each family's narratives (B Macartney, 2005a, 2005c, 2007b, 2008c, 2010; B Macartney & Morton, 2009).

3.7 Ethics

In 2004, before proceeding with this research, I wrote a proposal outlining the rationale, focus, methodology, research design and ethical issues relevant to the project. My proposal and ethics applications were accepted and approved by the Academic Standards Committee of the Christchurch College of Education – Te Whare Whai Maatauraka Ki Otautahi with minor changes. When re-drafting the third findings chapter in 2009, I decided to include photographs alongside text from Maggie's baby and early childhood centre Learning Story Books. In 2010 I applied to the University of Canterbury for an amendment to my original ethics application which was approved. I then wrote to the children and their parents who were named in the learning stories and/or present in the images for permission to use their names and images in the final thesis document. Parental permission was granted through the parents filling out and signing a consent form (see Appendices 5a – 5c). An outline and discussion of the ethical dilemmas I have faced in this project follows.

Critiquing other people's words and perspective

After my first interview with Fran, I began to feel uncomfortable about the way Clare seemed to be treated as passive, and even invisible by many people in her life, and about how Fran often described Clare in terms of her 'deficits'. I felt that Clare had been 'short changed' by her early childhood centres, and some family friends. I felt nervous about how I was going to talk with Fran about these issues without offending her or being disrespectful of her as Clare's mother. I found all of this very interesting and relevant to how people construct and view disability but my dilemma was: "How do I use this data, be honest, and not offend Fran all at the same time?" My supervisors suggested that I find some reading and other material about deficit views of disability, and my family's perspective for Fran to engage with if she wanted to. The idea was to ease into a discussion with Fran by giving her the opportunity to discuss relevant issues using the readings as a starting place. The materials I selected were about parent-special education professional relationships (Brown, 1994), my family's early childhood centre experiences with Maggie (Macartney, 2002), the sound recording of our family's radio documentary (Ogonowska-Coates, 2003), and a New Zealand book chapter about the social construction of disability (Ballard, 1994a).

Using some of our family's material was a way to share my perspectives and experiences with Fran. I felt that this might help to balance my relationship with Fran and avoid her feeling that I was either judging her, or withholding information about my own perspectives. In terms of emancipatory commitments within the research, I felt that Fran and her family might benefit from us talking about how people and institutions view and treat disabled children, and alternative ways of viewing the situation. I felt that Fran might enjoy engaging with my early childhood education knowledge and experience, and my perspectives as

Maggie's mum. Another strategy that I developed in considering how to respectfully discuss 'difficult' topics was to use examples from my own experience as a parent to invite Fran to talk about similar things.

Self censoring – dangers and opportunities in exploring influential research spaces

I noticed in response to feeling uncomfortable with some of Fran's perspectives, that even when I was writing my field notes, there were some things I didn't write down and tried to stop myself from thinking. For example, I tried to self-censor my discomfort with how Fran sometimes talked about Clare, the judgements she made about Clare as a learner, and what I considered to be an underestimation of Clare's capabilities. In censoring my thoughts, I was working from the assumption that there were some things I wasn't allowed to think as a researcher and also as a parent of a disabled child because they indicated a disloyalty to Fran.

My supervisor helped me to make a useful distinction between owning and expressing what I thought and felt, and making assumptions based on a (misguided) belief that I understood or could accurately interpret the motives of others without their input. She talked about the strategy or practice of "bracketing" my responses (in the form of 'observer comments', private journal and field notes) so that I could express them and acknowledge that they existed without taking the further step of imputing motives (Bogdan & Biklen, 1992). 'Bracketing' my personal responses was preferable to ignoring them, because it allowed my private thoughts to become available for further analysis in the research in terms of how they related to social constructions and experiences of disability (Harrison, et al., 2001). Not having to share all of my responses helped me to feel more comfortable about being honest in my field notes because I began to interpret my thoughts and comments as belonging to me and as

possibly being useful to the research, and not necessarily as negative reflections of Fran as an individual.

Self-censoring and dominant discourses

The realisation about being tempted to censor my thinking and writing led me to look for other circumstances where this might happen. I began to notice situations where I censored my thoughts and/or actions in relation to how I expressed myself and behaved as a parent of a disabled child (B Macartney, 2005b). Thinking about this self-regulating process, helped me to develop some analytical insights and possibilities about the effects of dominant discourses of disability on my construction of myself as a mother and Maggie as my child. This also led to Fran and I exploring self-censoring, 'hiding' and silencing as issues in our interviews.

Our family being identified in the research

Although Tony and I are happy to be openly involved in a disability project with an emancipatory purpose, we are mindful of the possible impacts this may have on our children and Maggie-Rose in particular. Being Maggie's parents and feeling that she was not able to fully comprehend the implications of agreeing to participate in such a project, meant that we had to make a decision on her behalf about whether to become involved as participants. Having said this, three years after it was broadcast, Maggie was still regularly listening to the CD of her radio documentary. She likes performing and being in the limelight, and enjoys hearing and reading stories about herself. She understands that I am doing work that includes writing about her and she says that's fine, although I think that she would rather I was spending the time with her *or* that she had more access to my computer.

Tony and I made a decision not to include specific ‘negative’ stories in the final write-up relating to Maggie’s classroom teachers and Principal. This was because we didn’t want to compromise our relationships with the school by offending anyone and were keen to keep working on developing constructive and inclusive relationships for Maggie’s and our own benefit. In the next section, I discuss how I have conceptualised and approached representation, validity and reflexivity in this project.

3.8 Representation

Traditionally, ethnographers assumed that their language and research conveyed a neutral and accurate description of reality (Ellis, 2004; Kinchella, 1997). From a social constructionist perspective, there is no such thing as a neutral body of knowledge or interpretation (Bogdan & Taylor, 1992; Crotty, 1998; P. Ferguson, et al., 1992c). Approaching the representation of events, experiences and perspectives from narrative, critical and discourse analytic perspectives has involved arguing that language is *constitutive* of reality, rather than being a straightforward representation or reflection of it (Clandinin & Connelly, 2000; Court, 2004; Crotty, 1998; Foucault, 1980; Freire, 1998; Gee, 1990, 2004; Kinchella, 1997; MacLure, 2003; Rogers, 2004; Slee, 1997). Language and discursive practices produce and express particular world views and relations of power. Researchers are not immune to the power and influence of language and discursive practices (Ellis, 2004; P. Ferguson, Ferguson, & Taylor, 1992b; Harrison, et al., 2001; Oliver, 1996).

Whether researchers choose to pursue their interests overtly or covertly, they are actively involved in crafting and producing texts that they hope will convey some message (Brantlinger, 2006; Clandinin & Connelly, 2000; P. Ferguson, et al., 1992b; Maynes, et al., 2008; Slee, 2001). Kinchella (1997) suggests that hiding the researcher within

qualitative texts denies the power that researchers exercise in the process and production of research. Various writers have suggested that researchers have a responsibility to be reflexive through carefully considering and making visible the influences of their own positioning and perspectives on the research process and the texts that they produce (Fine & Weis, 2002; Kinchella, 1997; Lather, 2003; Richardson, 1998; Riessman, 1993).

Along with a call for researcher reflexivity, Lather (2003) advocates for research to engage in challenging cultural assumptions that mask unequal power relations within society:

Once we recognize that just as there is no neutral education there is no neutral research, we no longer need to apologize for unabashedly ideological research and its open commitment to using research to criticize and change the status quo. The development of data credibility checks to protect our research and theory construction from our enthusiasms, however, is essential in our efforts to create a self reflexive human science (p. 190).

In conceptualising the validity of openly ideological research, Lather (2003) suggests:

...that efforts to produce social knowledge that is helpful in the struggle for a more equitable world *pursue rigor as well as relevance*. Otherwise, just as 'pointless precision' (Kaplan, 1964) has proven to be the bane of the conventional paradigm, the rampant subjectivity inherent in the more phenomenological based paradigms will prove to be the nemesis of new paradigm research (p. 192). (emphasis added)

In the pursuit of rigour, Lather (2003) argues that researchers must take a self-reflexive approach to research design, responsibilities to participants, data collection, representation and analysis. She also argues for catalytic validity in emancipatory research. Catalytic validity involves researchers

being mindful of opportunities for participants to experience empowerment or conscientisation during and as a result of the research.

Layers of representation and meaning

I have used Riessman's (1993) work to consider the representation and analysis of narratives in this research. Riessman offers a framework for understanding levels or layers of representation in narrative research. I agree with her contention that: "Whereas traditional social science has claimed to represent the experiences of populations and cultures, the new criticism states that we cannot speak, finally and with ultimate authority, for others" (p. 15). The layers of representation that I will elaborate on and relate to this research are attending, telling, analysing and reading experience.

Attending

'Attending' involves the choices that researchers make about what they are interested in finding out about and are subsequently attuned to within the participants' stories. This level of representation highlights the role and influence of the researcher's thinking, theoretical interests and their personal responses to participant narratives within the research process. I have outlined my research focus and theoretical positions in the previous chapters. In this chapter I will consider the selves I have brought to this research and the implications of these for how I have attended to and represented the participants' narratives and data (Reinharz, 1997).

Telling

This layer of representation is related to the participants' telling or 'performance' of their stories. People create and communicate their selfhood and identity through telling and retelling stories about their

experiences (Clandinin & Connelly, 1988; Maynes, et al., 2008; Riessman, 1993). The language we use is a *representation and interpretation* of lived experience or reality, rather than an exact reflection of it. Riessman suggests that, although representation rests on a foundation of primary or lived experience, narrative researchers write texts that re-present experience through *retelling* and organising narratives in particular ways. There is “an inevitable gap between the experience as ...lived and any communication about it” (1993, p. 10). As such, Riessman (p. 11) describes all representations as “incomplete, partial and selective.” She discusses possible influences on how and why experiences and stories might be constructed and told by participants in certain ways. Stories are told and experiences relayed within specific interactive and socio-cultural contexts and these contexts will influence the content, form and the meaning of what participants say and how they say it (Clandinin & Connelly, 2000; Goodley, 2001; Rapley, 2004). In my interpretations of the parents’ and document narratives I have considered what knowledge, desires and discourses might have influenced the content and form of the narratives and the intended and unintended effects of that knowledge.

Analysing experience

In representing narrative research analysis Riessman suggests that:

There are decisions about form, ordering, style of presentation, and how fragments of lives that have been given in interviews will be housed. The anticipated response to the work inevitably shapes what gets included and what gets excluded. In the end, the analyst creates a meta story about what happened by telling what the interview narratives signify, editing and reshaping what was told, and turning it into a hybrid story... (p. 13).

Riessman’s description indicates the influence that researchers have on the stories told, and the use and interpretation of those stories in the final

research text. Many of the decisions that researchers make are driven by their research questions, and the theories and literature they have drawn from. Choices about representation and analysis are also influenced by researchers' historical, political, cultural and personal contexts and biographies (Clandinin & Connelly, 2000; Fine, 1998; Maynes, et al., 2008; Richardson, 1998; Riessman, 1993). Richardson (1998, p. 346) suggests that qualitative researchers extend their reflexivity "to the study of our writing practices...Rather than hiding the struggle, concealing the very human labour that creates the text, writing stories would reveal emotional, social, physical, and political bases of the labour." I discuss the choices I made in representing and analysing the participants' narratives in detail in the self-reflexivity and methods sections of this chapter. 'Reading', Riessman's final layer of representation, is discussed later in this section in relation to authorship and multiple interpretations.

Self-reflexivity within this project

There is always the potential for social science researchers to force their analysis and representation of the data to fit in with their own biases and preconceptions. Lather (2003, p. 191) suggests that: "Emancipatory social theory require(s) a ceaseless confrontation with the experiences of people in their daily lives in order to stymie the tendency to theoretical imposition which is inherent in theoretically guided empirical work." In relation to researchers establishing the plausibility of their interpretations, Lather (p. 191) suggests that qualitative researchers engage in "asystematized reflexivity." This involves the researcher considering how their prior theories or assumptions have been challenged and/or changed through engaging with the participants and data. She (p. 191) suggests that reflexivity is important in establishing that the findings of the research are valid, and that the theory developed "will contribute to the growth of illuminating and change-enhancing social theory." An example

of a change in my thinking and assumptions over the six year course of this project is how my interpretations of Fran's narratives and perspectives have changed from when I first met and interviewed her. I initially saw Fran and her thinking as being very different from my own. It was only quite recently, when re-drafting and summarising the three findings chapters, that I began to see the significant commonalities between the two families in relation to our experiences of struggle with dominant views of disability. I realised that, although Fran's perspectives on disability were very different from my own, both families' struggles were about rejecting deficit views and treatment of our daughters and ourselves.

I have engaged in reflexivity in this project through regularly revisiting and expanding my analysis and interpretations of the participants' narratives and related literature. The interpretive writing that I have engaged in, and gone back to, includes my field and personal journal notes, my observer and analytical comments on interview transcripts, on-going analysis and thesis drafting and redrafting, analytical memorandums around particular issues and topics (Bogdan & Taylor, 1998), notes from meetings with my supervisors, writing and presenting papers and publishing articles on aspects of the research (B Macartney, 2005b, 2007b, 2008b, 2009b, 2010; B Macartney & Morton, 2009; B Macartney, Ord, & Robinson, 2008).

One of the intentions and benefits for me of being a participant and researcher has been the opportunity for my own learning and self-transformation. Using a range of different processes and forums for thinking about and making sense of the data and how it connected to my life, has positively influenced my own learning journey as well as strengthening the validity of the research interpretations. Ethical and political issues stemming from the power of researchers in relation to

research participants are present in any research project (Fine, 1998; Lather, 2003; Pugsley & Welland, 2002; Wasserfall, 1997). However, I think that being a participant *and* the researcher made the need for self-reflexivity more obvious and pressing. Because of my dual role in the research there was a danger that I could privilege my family's data and perspectives over Fran's. I thought about this in relation to the weightings and space I gave to each participant's data in the thesis and in my interpretation, and representation of participant stories. Member checks with Fran and Tony of the interview transcripts and my initial analysis, went some way towards ensuring that my interpretations were fair and accurate. However there was no simple measure of what being 'fair' meant in terms of how the research was represented, and my decisions about what to include and exclude from the final write-up. One way I tried to be 'fair' was to write a separate findings chapter for each family, and to draw from both families' data in the third findings chapter.

Transgressive and emotional data

Reinharz (1997, p. 3) describes the qualitative researcher as "the key fieldwork tool" and suggests that researchers bring, and create multiple selves in the field. These potentially influential selves are constructed through relationships and lived experience. Harrison, MacGibbon and Morton (2001) describe researchers' personal and emotional experiences in the field as potential sources of 'transgressive' data. As data, these can be made available for analytical consideration and interpretation. Bruni (2002, p. 32), suggests that "ethno-autobiographical research offers the possibility of generating new understandings of previously 'hidden' situations or events and challenging the boundaries of "ethical research." I have aimed not to silence or marginalize the 'selves' I have brought, and created within this project, but to explore their shifting implications for understanding the social construction of disability. I have been interested in using the

influences of my biography and positioning as an important aspect of the research (Harrison, et al., 2001; Lather, 2003; B Macartney, 2005b; Reinharz, 1993). Treating my intellectual and emotional responses to people as potential sources of data allowed me to analyse emotional data as a potential means of uncovering, disrupting and challenging taken-for-granted constructions and interpretations of experience (Harrison, et al., 2001; B Macartney, 2005b).

Often the emotional data that I recorded was less related to my 'researcher self', and more connected with my identities as Maggie's mother, Tony's partner, and a teacher and my consequent empathy with Fran and Tony's experiences and feelings (Reinharz, 1993). Sometimes there were tensions between myself as a mother and myself as a researcher, particularly when I didn't agree with Fran's views or interpretations. Another, potentially transgressive source of data were my private thoughts and reactions, particularly those that I initially viewed as illicit or not allowable and was tempted to self-censor because they seemed contrary to my position as a researcher (B Macartney, 2005b).

'Reading experience' and multiple interpretations

'Reading experience' relates to the research audience and their engagement with research texts (Riessman, 1993). Riessman describes the reader of a research text as actively engaged in the meaning making process, rather than as a passive recipient of the meaning intended by the researcher/writer. Although researchers intend to convey particular interpretations in their research texts, readers bring their own interests, values and experiences to a text, and any text is open to multiple readings and interpretations (Clandinin & Connelly, 2000; Riessman, 1993). Riessman challenges the assumed legitimacy of authoritative 'master

narratives' about any topic or issue. Instead, she suggests that "all texts stand on moving ground" (p. 15).

A major component of establishing the trustworthiness and validity of interpretations in critical social research involves giving the research audience enough information about the researcher's positioning, reflexivity and thinking to allow the reader to judge and understand how a text and piece of research has been constructed by the researcher (Fine, 1998; Fine & Weis, 2002; Lather, 2003; Richardson, 1998; Riessman, 1993). Making the design, methods and construction of the research visible gives the reader the opportunity to make their own decisions about the trustworthiness and validity of the researcher's analysis and conclusions (Richardson, 1998). In my re-presentation and selection of the data, I have tried to position the reader as an active participant in its interpretation and analysis (P. Ferguson, et al., 1992c; Riessman, 1993). In addition to making my positioning, methods and methodology available for critique, I have tried to include enough 'raw' data so that readers can engage more fully in their own interpretation and analysis and to give them enough information to evaluate my interpretations and draw similar or different conclusions as they see fit (Lather & Smithies, 1997; Riessman, 1993). However, the intention of my thesis is to build and present an argument for the ways I have interpreted the data, and to convince readers of the validity of my analysis as one potentially useful set of ideas for naming, resisting and challenging deficit views of disability and difference.

Writing experience and multiple voices

When representing and interpreting each participant's experiences I have tried to retain and emphasize the multiplicity of voices, selves and narratives that are apparent in the stories (Denzin & Lincoln, 2002; Ellis & Bochner, 1996, 2000; Lather & Smithies, 1997; Muecke, 1994; Reinhartz,

1997; Ronai, 2002). Combining narrative, auto-biographical, critical and discourse analytic approaches in this research has enabled a close examination of the power relations and the interactions between ‘self’ and ‘other’ in the construction of multiple identities and meanings around disability (P. Ferguson, et al., 1992a). Fine (1998, p. 131) describes the space where meanings are constructed and negotiated between people as the “hyphen between the self-other.” This space is rich with interpretative possibilities and insights. Creating a dualism between the self (researcher) and others (participants/subjects) in research and research texts denies the opportunity to explore the shared space between the researcher and participants (Ellis, 2004; Fine, 1998).

Auto- and reflexive- ethnography

When combined with sociological inquiry, auto-biographical approaches are often described as ‘auto-ethnography’ and ‘reflexive-ethnography’ (Ellis, 2004; Ellis & Bochner, 1996; Freire, 1997; Maynes, et al., 2008). Ellis and Bochner (2000, p. 739) describe auto-ethnography as “an autobiographical genre... that displays multiple layers of consciousness connecting the personal and the cultural.” In their discussion of auto-ethnographic representation, Denzin and Lincoln (2002, p. 71) state that “Using the first-person voice, auto-ethnographers, like reflexive ethnographers, blur the usual distinctions between self and other.” Reflexive ethnographers incorporate ways of representing data and analysis that acknowledge the perspectives, experiences, identities and subjectivities of researchers within the research text. Denzin and Lincoln describe reflexive ethnography as a:

writing form now called the layered text, which co-mingles various writing forms and styles. This often includes the use of first person narratives, self commentary, self reflections,

and the voices of others, interspersed with field notes, as well as popular cultural and social science writing (2002, p. 72).

I have used a layered text in this research to retain and represent the multiple voices, perspectives and positioning of participants (Ellis, 2004; Ellis & Bochner, 1996; Lather & Smithies, 1997; Reinhartz, 1997). In representing my own family's data I have juxtaposed and interwoven narratives from the Tony, myself as a researcher and participant, photographic and document data (P. Ferguson, et al., 1992c). Because I did not receive document data from Fran, and photographs could not be used to protect Fran and Clare's anonymity, the representation of my own family's narrative is more varied than Fran's.

3.9 Writing up the thesis

Each time I drafted a thesis chapter, I submitted a copy to my supervisors who provided me with written and verbal feedback. In response to my supervisors' feedback I would edit and re-draft a chapter before moving on to the next (see Appendix Three for a summary of the research process timeline). Between February 2004 and June 2006 I drafted the introductory, theory and methodology chapters of the thesis. This was before and during the time I was collecting interview data. After narratively analysing each family's data, I drafted the two separate 'family' findings chapters, first 'Fran's' chapter (Chapter Four) and then 'my family's' chapter (Chapter Five). I then carried out a discourse analysis of both chapters and incorporated my interpretations from this analysis into each of the family chapter drafts. After completing the second drafts of each family's findings chapter I drafted Chapter Six, the third and final findings chapter.

Late in 2008 I began to work on my discussion and conclusion chapter. I drafted several documents during this period. First I wrote an

analytical memorandum which contained a summary of and reflections on my interpretations and themes across the three findings chapters. I then developed a typology of how education and disability are constructed from special education, *Te Whaariki*, the *NZC*, and pedagogy of listening perspectives. In the typology I considered aspects such as images of children, understandings of learning, teaching and knowledge, assessment, views of disability and diversity, and each approach's espoused purposes for education. I read and re-read the six drafted chapters during this time and significantly extended my review of literature related to policy and curriculum, social-political-cultural understandings of disability and education, narrative inquiry and relationships between knowledge and power, and the individual and society. I then returned to each thesis chapter in view of my deeper and more nuanced understanding of the theoretical frameworks I was using and re-drafted the chapters into final form. When I was writing the summary of the findings chapters for the beginning of the discussion chapter, I began thinking more carefully about the implications and conclusions of the research. During the write up of the discussion chapter I became clear about my major 'take home messages', and I wrote the overall conclusions to and recommendations of the thesis after I had written the final draft of the discussion chapter.

3.10 Limitations of the research

This is a very small-scale study focusing on the narratives of only two families. The small number of participants has enabled a detailed and deep consideration of the families' experiences. However, because of the small number of participants, and our relatively similar social and cultural backgrounds, it should only be viewed as a small snapshot of family experiences and the social construction of disability. The absence of document data for Fran's family limited the possibilities for my interpretation and analysis of her family's experiences. Not having

documents to draw from and consider influenced the strength and surety of my conclusions in relation to Fran and Clare's experiences in their early childhood centres and with medical and special education professionals.

3.11 Outline of findings chapters four, five and six

Chapter Four is based on interviews with Fran. Chapter Five is based on interviews with and documents and images supplied by Bernadette and Tony. The narratives and discussion in each of the two family chapters are organised in four chronological sections. The sections are 'Introducing Clare/Maggie', 'Diagnosis', 'Early Childhood Education' and 'Primary School'.

In Chapter Six I use a pedagogy of listening to critique each family's experiences of inclusion and exclusion in education. Through this analysis I develop some ideas about possibilities for inclusive and critical early childhood and school pedagogies in Aotearoa New Zealand.

The broader analysis and findings in each findings chapter are organised around three themes. The themes are: 'Coming Out of the Closet', 'Disciplinary Mechanisms', and 'Policing Participation'. In Chapter Six, the theme 'Facilitating Participation' is added. Each theme is explored and developed in the findings, discussion and concluding chapters of the thesis.

Chapter Four “...there’s something wrong with that child”: Social constructions of disability and their effects

4.1 Introducing Clare

At the time of the interviews Clare was four and five years old and her younger sister, Amber, was one and two years old. Fran and Mark were a couple for several years before they had Clare. As Mark earned good money in a professional job, Fran left her job to be an “at home mum”. In terms of expectations about having her first child, Fran’s thinking was that:

We’ll have a baby and it’ll fit in and do what I’m doing, and Clare did. That doesn’t always happen. But she just slotted in quite nicely.

Clare was very much adored by her grandparents. She was the first grandchild on Mark’s side of the family and Fran describes Clare as fulfilling that role beautifully:

...she’s so good at everything – good at eating, and good at doing everything grandparents want you to do, like sitting on their knees and having cuddles, and she’ll eat anything you give her, and she’ll sit down and play, and she’ll sit and listen to a story, and she’ll do all those things grandparents want her to...So I suppose she’s a real - that’s one of her advantages. She’s a real grandchild.

When I first asked Fran to tell me about Clare, she said that Clare:

... was supposedly born normal, normal being whatever 'normal' is... she has global developmental delay and she has Myoclonic jerks. ...she was a healthy, chubby baby,...very laid back, ...she was perfect.

A perfect child

Fran's view of Clare being "the perfect child" - partly because she was quiet, contented and undemanding - changed over time. Whereas Fran had initially seen Clare's laid back behaviour as a positive attribute, she began to view it as problematic once she realised that Clare wasn't developing typically. Fran expressed anger about other parents who regularly made comments about her being so "lucky" to have such an "easy" child:

You could take her out – people think we're so lucky. I'm sick of hearing that: "You're so lucky! She's the perfect child – you're so lucky! She just sits down when you put her down." I'm sick of hearing that. If I hear that again, I'm about to boof somebody! She's got her advantages, put it that way, but there are disadvantages as well.

At the same time as expressing cynicism about what is 'normal', Fran articulates a changed view of her daughter as a result of her child's development not adhering to prescribed norms. Fran's perception of Clare as a "perfect child" changed in response to Clare's development being slower than 'normal' children's, and to Clare being medically classified as not normal. Fran no longer felt fortunate or lucky to have an undemanding child because her child was "delayed". Clare's "laid back" temperament, her former positive attributes, had been transformed into deficits through viewing Clare's behaviour through a normalising lens.

Although, on face value, it might appear that Fran had accepted and wholly adopted a deficit view of her child, the situation was much

more complex than this. Fran's rejection of seeing Clare as "perfect" also reflected her wanting the 'best' for her child. The 'best' includes the best possible chances to learn and develop, be accepted, fit into and get on in the world. In a society that prizes normalcy and punishes and ignores difference, the "best" *is* being normal. From this perspective, "perfect" is the same as "normal". To use Foucault's (1980) metaphor of power/knowledge relations as a web, Fran could be described as being caught within a taken-for-granted, pre-scribed, binary social arrangement of normal (perfect) versus abnormal (imperfect). This taken for granted and seemingly unshakeable privileging of 'the norm' required Fran to respond in particular ways.

"Coming out of the closet"

At the same time as Fran's perception of Clare as "the perfect child" had changed, she was resistant to a view that there is something "wrong" with Clare. Fran's awareness of and resistance to a view of something being wrong with Clare had been amplified by Clare's acquisition of a wheelchair. Fran had noticed that Clare being in a wheelchair had increased her visibility as being different or 'other'. Fran became acutely aware of the gaze and scrutiny of others. She talked about the effects of this gaze on her everyday life:

All of a sudden we've got a wheelchair and people are looking and saying: "there's something wrong with that child." Whereas before she could happily sit in the buggy and no one would be any the wiser...

As well as feeling conspicuous, Fran felt that people were looking at her with pity, blame and judgement:

'Cause she doesn't need to be felt sorry for. So I guess that's why I don't like going out—I'm better in the wheelchair now. But for me, the first time going out in the wheelchair, well,

everybody looks. They all have a look and see what's going on. "Why's that little girl in a wheelchair?"...I don't want everybody looking at her and feeling sorry for her because she's happy. She doesn't need anybody to be feeling sorry for her. But anyway, that's that, isn't it? That's life. I've got the wheelchair and we're stuck with it. Although we're not, though, because when I've got two (Amber and Clare) I've got them in the double (pushchair)... We've had a wheelchair for a month, and suddenly we're not in a buggy, and suddenly people are looking...You're insignificant while you're quiet and sitting in the buggy, but once you're out of the closet and in that wheelchair, you are noticed.

For Fran, coming to terms with Clare's disability was interwoven with how her family and Clare were viewed, judged and positioned by others. Fran's choice of hiding Clare's disability when she had the opportunity, such as when she had both girls in the double pushchair, can be viewed as an example of her monitoring and regulating her own behaviour to conform with dominant views of disability. Hiding Clare's disability was also a form of resistance in that Fran was protecting herself and her child from the scrutiny and negative judgements of others.

The metaphor Fran used of "coming out of the closet" indicates that Fran experienced spaces where she felt safe and comfortable and spaces where she did not. She felt comfortable at home and amongst family and some friends, where Clare's differences were not constantly highlighted and were not the only or major focus of attention. The feeling of "coming out of the closet" and Fran's comments about hiding Clare's differences in public indicate that Fran felt pressure as well as a desire to hide. She talked about how she could hide Clare's physical disability by using the double pushchair when she had both of the girls with her. She also talked about not wanting to go out sometimes because of feeling uncomfortable about people looking at and judging her and her child. Fran's feelings and responses can be viewed as effects of discursive practices that construct and convey disability and difference as being

something to feel shameful about, as ‘other’ and as outside of normal. The idea that being different is something bad and shameful invites curiosity about what caused the ‘problem’ and who is responsible (to ‘blame’) for it:

B: And also – is it like maybe in some way – people will think it’s (that Clare is disabled) your fault for some reason?

Fran: Yeah, because, and I guess that’s part of, you know, everybody, first thing people say – or, not first thing, but when you talk to them about Clare, “well, what’s wrong with her?” And you say “Nothing.”

B: Yeah. “She’s got a bit of a cold at the moment, but you know, apart from that...” (shared laughter)

Fran: We had a thing at preschool – a picnic at preschool the other night, and I was talking to a lady whose wee girl is very friendly with Clare, and she said to me: “Well, what is wrong with Clare?” And I said: “Nothing.” And she looked at me as if to say: “What?!” And I said, “Nothing. She’s had muscle biopsies; she’s had MRI scans. There’s nothing wrong with her.” She went “Ohh.” So, yeah, that was a – so I guess my “nothing’s wrong with my girl” is actually out there when she’s in a wheelchair.

This conversation with a parent at preschool illustrates the complexity of circulating understandings about disability. Alongside refuting the view that children classified as abnormal are deficient in some way, Fran used a medical discourse to support her claim that there was nothing wrong with Clare. The other mother’s surprised response to nothing being wrong with Clare indicated her taken-for-granted acceptance of the assumption that if you’re *different*, there *has to be something wrong* with you. Fran’s last statement indicated that she was aware of the contentiousness of saying that someone who is classified as ‘other’ does not have anything wrong with them. At the same time as resisting this view, Fran felt uncomfortable at having found herself in a position where she was at odds with dominant ways of thinking, being and behaving:

Fran: So I guess some people – I mean, you’re probably the same with Maggie Rose – we just cruised along thinking that she would maybe come right one day, and we just took one day at a time, and we do take one day at a time, and integrate it but all of a sudden, we’ve been, it’s like a smack in the head, you know, you have got a – It’s the coming out of the closet thing. We have got a special needs child. So yeah, that’s probably the difficult part of that.

Fran saw Clare being officially diagnosed as having ‘special needs’ as being a big knock – “a smack in the head” - to her and her family. Feeling uncomfortable about being subjected to the judging gaze of strangers was accentuated when Fran and Clare became more visible and therefore less able to ‘hide’ and to get on with life without interference and negative consequences. Official ‘confirmation’ of Clare’s differences through medical diagnosis and labelling included an element of compulsion or coercion for Fran and Clare to come out of the closet. In addition to feeling exposed to the gaze and judgement of strangers, coming out of the closet involved being exposed to the scrutiny and effects of a ‘scientific’, medical and special education gaze.

Visibility and invisibility

As well as experiencing a sort of hyper-visibility amongst strangers, Fran talked about how Clare was easily *ignored* by more familiar people, such as some family friends, and in contexts such as children’s birthday parties and early childhood centre settings. Fran felt that Clare was easily ignored and/or forgotten about because she didn’t make a noise, run around and demand attention like ‘other’ (normal) children. Fran described occasions where family friends and their children would forget about Clare’s presence and treat her as if she was invisible and a non-person. An example Fran gave was when her family would regularly meet up with friends at a café together:

Fran: You know, I used to get frustrated – well, I do get frustrated on the odd occasion – we used to go out, the three of us (families) used to go out, and they'd order a fluffy (a special drink of frothy milk for children) for the other two (children) and not Clare...Mark used to just get up and go and get her one. And one of them (the parents) would know – the supportive one would know, but the others it would just go straight over their head. But just little things like that.

B: And why do you think that was, that they didn't...?

Fran: I think they just forgot. Because the other two were running around, and the other two did things, Clare was sitting, perfect child, they just didn't think she was there. Forgot she was there, maybe. I don't know. You know, if we used to go out for lunch, the other two would have to have – if there were two highchairs – the other two would have to have the two highchairs... and so they would be in the highchairs, where the highchairs were accessible, and she'd be down the other end of the table with Mark and I (in her buggy)... I think they tend to get on and do their own thing and just ...forget that Clare's there. It's not an intentional thing, but because she's the perfect child she just sits down there. She's not demanding... Because she wasn't going to make a noise. Which: "we were so lucky because she wasn't going to make a noise..."

Fran's experiences of Clare being positioned as either hyper-visible and/or in-visible hinged around a view of Clare that honed in on her differences to the exclusion of any other aspects of her as a person. Both Clare's visibility and invisibility were based on her deviation from the 'norm'. Her visibility was based on her being in a wheelchair, her invisibility was based on her not running around and demanding attention. In both situations Clare was positioned as 'other'. The effect of being positioned as 'other' was Clare's exclusion from being related to as a whole and complex person, invited to enjoy social interactions and have her desires, interests, needs and rights considered and respected by others.

4.2 Diagnosis

This section explores the multiple uses and effects of applying medical and special education knowledge to Clare.

“Catching up”

Fran and Mark had assumed that Clare was born ‘normal’. It wasn’t until Clare was four years old that a paediatrician provided Fran with a more conclusive opinion about Clare’s current and future development. From when Clare was a baby the paediatrician had always said that Clare might “catch up” to ‘other’ (normal) children. For Fran, looking for a diagnosis involved wanting some official acknowledgement that Clare did have ‘special needs’ and that she wasn’t going to ‘catch up’. Fran felt frustrated about the paediatrician repeatedly saying that Clare would “catch up”.

Fran: See I always feel sort of, we’ve been a little bit short-changed in the fact that Clare was born normal, she was born with: “nothing wrong with her” supposedly, and then: “she may have had a disability, but no, come back”, “we might have a disability”, and when we come back: “Oh yes, no, she’s definitely slow.” And it’s taken four and a half years for someone to actually say: “Well, actually, yes, she is moderately intellectually disabled.”

Experts can explain everything

Fran expressed relief about Clare having been given a label. She believed that the process of finding a label for Clare’s ‘condition’ would lead to a specific diagnosis that would help her to access information about what she could do to support Clare’s learning and development.

Fran: And so even though we’ve been working that whole time with her, I kind of feel like we’ve missed out on something. Like, a lot of the ones at the early intervention service were referred from hospital when their baby was born and so they’ve started from Day One, whereas we haven’t,

and if we had Down Syndrome we could go and read a book about Down Syndrome, or if we had some other disease we could go and read that up on the internet. But we don't have anywhere to go to look... I suppose Maggie Rose is the same. You don't, because you don't have a label you don't have anywhere to check out what you do or where to go or who to see, and there is no specific support group for your specific disability.

Fran's belief or hope that a diagnosis would provide her with some answers for how to support Clare is compatible with the positivist regime of truth that underpins medical and special education discourses about knowledge and disability. Medical and special education 'regimes of truth' believe that it is possible to create an accurate and discrete body of knowledge about various disabling 'conditions' through scientifically-based processes of diagnosis, segregation and classification. Once the condition is 'named', this body of knowledge can be used to 'treat', fix or 'cure' disabled people. This 'help' and 'guidance' comes from medical and special education experts, research and literature.

Who is Clare?

Fran wanted to find information about Clare's 'condition' so that she could support her. She described her family's approach to Clare in regards to not having a clear diagnosis or label:

Fran: So you either treat it – you pretend it's not there, which is I guess how we work. We work on the fact that "that's Clare" and we treat her like all the other kids treat her, or else you wrap her up in cotton wool and treat her special. So I'm quite keen to read anything I find.

The choices that Fran described about how to view and treat Clare involved three options. She could treat Clare "like all the other kids", she could 'pretend' that Clare was not disabled, or she could treat Clare as "special". In other words, Clare's options were to be treated 'the same', as

‘non-disabled’ *or* as ‘special’. There didn’t appear to be much of a choice for Clare to be accepted as the unique and lovable individual that she was. Fran’s three choices can be related back to the discussion of (hyper) visibility and invisibility. Ignoring Clare’s differences encourages her ‘disability’ or ‘differences’, which are a significant aspect of her as a person and a learner, to be discounted or made invisible. Not recognising a child’s disabilities or differences can be viewed as a ‘fair’ and ethical response by teachers because it involves treating all children “the same” (Rivalland & Nuttall, 2010). Although an orientation that doesn’t highlight or over-emphasise a child’s differences may be positive, it can easily translate into a world view and set of practices based on treating everybody ‘the same’ (Minow, 1990; Rivalland & Nuttall, 2010). This is problematic because everybody is not the same, and what constitutes ‘sameness’ is the dominant group’s culturally situated view of what is ‘normal’ and ‘desirable’ (Rivalland & Nuttall, 2010). Underpinning approaches that treat everybody as ‘the same’ are expectations and assumptions that all people need to and should ‘fit’ in to existing arrangements and ideas about what is normal. In this way, ignoring children’s differences does them a great disservice because, rather than recognising, responding to and valuing diversity, there is a requirement that children will or should conform to and be measured against a set of predetermined standards and expectations. Children who do not conform or act ‘the same’ are variously ignored (invisible) or noticed (visible) or forgotten about because they are seen as not fitting in.

The second possibility Fran talks about is to treat Clare as “special” which she sees as ‘over-protection’ or wrapping Clare “up in cotton wool”. For Fran, treating Clare as special or different involved a level of protection that could deny Clare the same opportunities as other ‘normal’ children. To treat Clare as “special” would increase her visibility

as ‘other’ through positioning her outside of the norm. It seems that both of these choices - pretending “it’s not there” or treating Clare as “special” - continue to reproduce the dualism of not disabled/normal and disabled/special.

Fran was aware that not viewing Clare as having something wrong with her was treated with suspicion or disbelief by other parents and professionals. Her response was to suggest that the way her family chose to view and respond to Clare as “Clare” was an act of pretence. Fran realised that her family’s approach of “pretend(ing) it’s not there” was an ‘officially’ unacceptable way for a parent of a disabled child to think and talk. According to medical special educational discourses, not emphasising Clare’s differences, and treating her “like all the other kids treat her”, is an unacceptable way of responding to disability and difference. Parents’ valuing and unconditionally accepting their disabled child can be viewed by professionals as an indication of ‘parental denial’. Parental denial may be seen as potentially damaging to the child as it could result in parents ‘denying’ their child’s access to the specialist intervention, ‘help’ and treatment they ‘need’.

“Give us the full clobber”: Medical-special knowledge and access to resources

Medical special education discourses of disability and their associated institutions and arrangements rely on classifying and separating ‘normal’ and ‘abnormal’ children to validate and perpetuate their knowledge base. Fran wanted medical acknowledgement that Clare wasn’t going to “catch up” to other (normal) children. She expected that having a label would give her access to more information for supporting Clare’s learning and development.

Fran's other motivation for wanting a more specific diagnosis of Clare's 'condition' was that this could be used in her family's application for access to *On-going Reviewable Resource Scheme (ORRS)* funding (see Chapter One, p. 47 for a description of the *ORRS* scheme). Fran wanted written confirmation from Clare's paediatrician that Clare was disabled and wasn't going to "catch up". She wanted to include this information in her family's application for *ORRS* funding. Fran believed and had been told by Clare's Early Intervention Teacher that, in order to have the best chance of receiving funding, the paediatrician's diagnosis and labelling needed to emphasise Clare's disabilities and weaknesses. Fran telephoned the paediatrician a couple of weeks before their appointment. She told him that she wanted a clear opinion from him about Clare's development and prognosis:

Fran: And I said to him: "Now, look, I'm coming in two weeks time with Clare and we've got *ORRS* reports to fill out and we think it's time that you should, you know, give us the full clobber." ... We're actually going to the paediatrician on Friday to put the hard word on, because we've got to start filling out *ORRS* funding forms in October, for school. And the only way you can get, the most funding we can get is to make her out to be as bad as possible. But we also want to say to him, "Look", we haven't seen him for a long time because she's not a sick child. We don't see him very often, because there's nothing to see him about...

Clare as "Moderately Intellectually Disabled" with "Splinter Skills"

Fran was in a position of requesting or demanding that Clare undergo the disciplinary gaze, observation, examination and judgement of a medical 'expert' (Foucault, 1977). She was asking the paediatrician to make normalising judgements that would demonstrate Clare's deviation from the norm. Foucault (1977) suggested that normalising judgements and the documentation that accompanies them transform a person into a 'case'. Becoming a case, involves the exercise of disciplinary powers through

which a person: "...receives as his (sic) status, his own individuality, and in which he is linked by his status to the features, the measurements, the gaps, the 'marks' that characterize him..." (Foucault, 1977, p. 192). Tremain (2002) suggests that this objectifying process involves individuals becoming attached to particular socially ascribed identities. After Fran's visit to the paediatrician she said:

He (the paediatrician)... for the first time he's actually said that Clare is moderately intellectually disabled. So we've never had that before. All previous to that he's always said "Oh, she'll catch up one day." ... this actually means she'll catch up to what everybody else is doing, but she's not going to get to the same level as them...He called it – because it starts at mildly intellectually, goes to severely (Fran is referring to graph that the paediatrician was showing her). So he's put it 'Moderately', which is in the middle of the line. So he described it as the 'cone effect' of learning. So that meant that a normal child's line goes straight up, and a severely disabled child's line goes sort of very flat, and Clare's is going through the middle. He put her at the middle, so he said when Clare – he put her at about 2, 2½ years, which is what our early intervention teacher put her at, although she does have splintered skills, so she's good at some things and not others, but he said like when she's at the level of a two-year-old she's actually four, so when she gets to be the level of a three-year-old, the other children, she'll actually be six. And same, when she gets to four, she'll actually be eight. So her curve is always going to keep going up, but at a very slow rate. So she's going to be... she's not ever going to— ... ever gonna really catch up... I knew that. So, but it was just this Moderately Intellectually Disabled was probably the word...But, you know, he was very good. He was blunt and to the point... but he's actually said: "she is Moderately Intellectually Disabled."

Fran had mixed feelings about the paediatrician's diagnosis. She seemed to fully accept the paediatrician's explanation of what 'moderate intellectual disability' meant and that this label was appropriate for Clare. The paediatrician's contention that Clare would have 'splinter skills' is relevant to how disability is constructed and the emphasis on deficits in medical

special education approaches to disability. A view of learning, strengths and skills as ‘splintered’ transforms positive qualities and attributes into deficits. The use of the term ‘splinter skills’ has the effect of explaining away behaviours or attributes that don’t fit with a pathological and deficit view of a child. A potential strength or positive learning attribute becomes a ‘splinter skill’, which invokes a deficit interpretation. It is unlikely that the same learning and skills displayed by a child who had not been labelled and was not under the surveillance of special education or medical professionals would be spoken of in this way. Viewed as normalising judgments, having a “moderate intellectual disability” and “splinter skills” were characteristics ascribed to Clare in the process of her being objectified as a ‘case’ (Allan, 1999; Foucault, 1977).

Normalising judgements: Resources, ‘diagnosis’, and documentation

Fran’s descriptions of her experiences highlight how the processes of diagnosis, ‘assessment’ and labelling are subjective and negotiated, and how they serve and do not serve particular groups and purposes. This challenges a medical view of diagnosis as the straightforward application of objective, scientific knowledge applied by ‘experts’ in ‘the field’. One benefit for Fran of having an official label was that she wouldn’t be required to fill out forms each year in order to meet the eligibility criteria for funding for Clare’s Education Support Worker, respite care, equipment, and transition from early childhood education into school.

Fran: ...and he (the paediatrician) will sign her off for her mobility card for the card and her disability allowance until she’s sixteen... But he has said, “No, she will have a disability. I will sign her mobility card and her allowance until she’s sixteen when she legally becomes an adult.” So, for me that was a positive because I’m sick and tired of having to go to the doctors’ and having to fill out these forms for twelve months because she might come right...

There is a strong relationship between having an official/medical diagnosis and the probability of being given easier access to resources on the basis of that diagnosis. The relationship between diagnosis and funding supports and encourages the labelling and classification of children deemed to be far enough outside of the 'norm' so as to become 'a case', worthy of additional surveillance, documentation, attention, 'help' and services. In terms of accessing funding and resources for education, the further away from the 'norm' a child is deemed to be, the better.

Fran was told by Clare's early intervention team members that the best way to get into the *ORRS* scheme was to portray as negative a picture of a child as they could:

Fran: I mean, you can build Clare up, but you can also knock her down...She's got splinter skills-she's good at some things and not good at others, so to write a report, you can actually build her up and make her look great, which is what we'd like to do for West School, but for our *ORRS* funding I want to knock her down again.

Fran's talk indicated her awareness that how Clare was viewed and portrayed, and the implications of different portrayals, was a selective process of social construction. Fran's analysis of her situation indicates a strong and required relationship between how Clare, as a 'disabled child', is constructed as a case in official documents and the subsequent decision making by agencies who provide funding and services to disabled children and their families. Individualised, medical and deficit views of disability dominate the *ORRS* application process and guidelines (Ministry of Education, 2006). The implication that you must paint as negative a picture of your child as possible to have the best chance at receiving funding suggests that the 'system' is working in ways that perpetuate and maintain a deficit view of disability and disabled people.

4.3 Clare's early childhood education

Clare attended early childhood centres part-time from when she was two years old. Her first centre was Crossroads Childcare Centre (CCC). She attended Crossroads for the year she was two to three years old.

Crossroads Childcare Centre: "She was like a little flower..."

Crossroads Childcare Centre was a small, suburban, privately owned and operated childcare centre. Fran's early intervention service (EIS) provided funding to pay an Education Support Worker (ESW) for half a day a week during school term time and so Clare attended Crossroads for that amount of time. Clare also attended half a day a week during the school holidays. During this time Fran was required to stay at the centre with Clare while still paying full fees because the EIS didn't employ the ESW during the holidays.

Two of Fran's friends enrolled their children at Crossroads Childcare Centre at the same time. Although Fran felt that Clare benefited from attending Crossroads, she had some reservations about how she and Clare were treated there. Perhaps the most significant reservations were that the centre staff never spent time with Clare without Sandra her ESW, and that there seemed to be different rules for Clare's attendance at the centre than for her non-disabled peers. Differences in the rules, access to and provision of educational services for Clare as compared to non-disabled children was a situation that Fran was to experience routinely over the next few years.

In relation to that first experience of early childhood education, Fran said:

Fran: ...she was like a little flower I suppose. She sort of opened up a little bit and realised there were other children around her, from there. That was good... but the teachers

never actually took Clare off the teacher aide, and in the holidays, when the teacher aide didn't work, and I still had to pay my money, I would go, and I would go and spend the morning with Clare, and she would never be taken off me... They wouldn't have her by herself (at the centre). Because she was completely dependent. So I either didn't go and Clare didn't go – but I still had to pay - ... so me being the stingy person that I am, decided, “Well, I'm gonna go.” ...And I didn't mind going, but I used to end up sitting, like on a wet day I'd be sitting in the corner with Clare and five other children. And the teachers would go past and say: “Oh, you're great! You should come every week!” But they never thought to take Clare off me. And I was not only looking after Clare, I was babysitting the other five children as well... they'd speak to Clare on their way past, and stuff like that, but I don't think, they didn't really integrate her.

I asked Fran what was discussed at Clare's 'Individual Education Planning' (IEP) meetings:

Fran: Well, she (the head teacher) did the learning – as you have to do at preschool – she did her learning stories, so she would be with her when she did that...So, she just talked about Clare, because at that stage Clare was learning about what other children were doing around her, and becoming more part of the centre, so that was really what she talked about in the IEP meetings and stuff, but, it just never crossed their minds to take Clare off the teacher aide. They never thought about it.

B: I just think that's weird, especially when what they were talking about at the IEP meeting was how she could become more part of the centre. It's interesting, isn't it? I suppose... do you think they just didn't...?

Fran: Well, I guess they'd never had a special needs child there before. And it's quite a small centre, a really small centre, and all they wanted to do was get the kids outside, because it was really quite small inside. And...

B: And Clare was more of an inside person?

Fran: Yeah, there were only certain things she could do outside, like sitting in the sandpit. So... I don't – it wasn't an intentional thing, I just don't think that they had had anybody with special needs and they hadn't dealt with that before.

In addition to Clare always being in the company of Sandra, her teacher aide, Fran talked about how some teachers in the centre were unhelpful and less than welcoming when Fran and Clare arrived at and left the centre each day.

Fran: They had a ramp out in the play area, and the first day I went I asked one of the – because the Supervisor had actually said, you know: “We've got a ramp, we've got all those things.” – and the first day I went I asked one of the teachers to open the gate where the children were, so I could take Clare in through the ramp, and she said: “Do I have to?” She said: “It's too hard to get this gate shut.” And she just didn't want to do it. And so every day I had to go up the stairs and down the stairs...I used to take Clare's floor sitter and her seat, and I used to have to lug it up the steps and then you had to push the bell to get in, and I'd do three trips to the car, to get her up and into the day care centre.

In this situation there seemed to be significant gaps between the philosophy and support that the centre Supervisor said was in place and what actually transpired. Although the supervisor told Fran that Clare was very welcome, the centre teachers made access to the centre more difficult for Fran and Clare through refusing to open the gate to the ramp, and requiring Fran to attend and pay fees when the ESW wasn't employed. The teachers didn't treat or interact with Clare as a fully participating member of the centre, preferring to leave Clare and her ESW in relative isolation. Even when an agreed goal was to encourage Clare to develop relationships with other children and become more part of the centre, the staff behaved in ways that excluded Clare from learning and participating with and alongside other children.

North Preschool: “Sorry, no vacancies for a ‘special needs child’”

After a year at Crossroads, Fran and her two Plunket (pre-school, health and wellness focussed network) friends from Crossroads decided it was time to move and so they started visiting other early childhood centres. Fran’s friend’s children were not disabled. North Preschool is an early childhood centre attached to a private (fee paying) school. Mark, Clare’s father, had attended North School as a child and he and his family still maintained an association with the school. Fran and her Plunket friends went along to an open day at North Preschool. While she was there Fran asked a staff member if they had ‘special needs’ children at the centre. The staff member answered: “No” and suggested that Fran would need to ring the Head Teacher to discuss that.

Fran: ...so I rang and I said I had been to the open day, and I had a special needs child, and she said: “Oh well, there won’t be any vacancies – there’s no point in you coming and having a look around the centre because we don’t have any room for a special needs child and an ESW (because I told her we had an ESW). We don’t have any room for an ESW, our centre’s not big enough to accommodate a special needs child and an ESW.” And she said: “And besides that, we may have a special needs boy coming in to our centre who’s living in America at the moment, and both his parents are lecturers at the university and I taught their other children at a different centre, so if he comes there’s definitely no room for you.”

B: And what did you say, Fran? On the phone? Do you remember?

Fran: Not a lot. I hung up and grabbed my husband and said: “You can stick your old school up your arse!” Literally.

Mark rang the school four times to discuss the matter with the head teacher but she never responded to his messages.

Fran: Yeah. And so he wrote a letter to the Rector and then she (the head teacher) rang back. And she was very apologetic. But there was still no vacancy for Clare there. And that... She was apologetic that she had upset me, but not apologetic that she wouldn't have Clare. And Mark was furious. And the Rector's letter basically said: "sorry but there's no vacancies, but if you want to discuss this any more, come and see me." So we did.

B: You did go and see him.

Fran: And as Mark said, he said all the right things: "Blah, blah, blah, blah, blah." But he never actually grasped the concept that Clare wasn't three. You couldn't go to North Preschool until you were three. She was only two and a half. And you know, his final words were: "We're really sorry this has all happened, but, you know, we don't have any vacancies." She wasn't old enough to go anyway, at that stage. And then he had the nerve to say to me – I said that we were going to South Preschool – "Well, why? What makes South Preschool a better place?" And I said: "I can't tell you, because I wasn't allowed to come and look at your preschool." You know, he just didn't grasp the whole concept. He said all the right things, you know: "We're sorry this has happened, blah, blah, blah, blah, blah," but he just did not have the concept that Clare didn't want to go now, she wanted to go when she was three, and, these other two kids, they sent them application forms, they were accepted.

B: And the other two got in.

Fran: Yeah. So, it was just an excuse.

South Preschool: The 'same' rules for everybody?

Fran contacted another early childhood centre that her Plunket friends had visited to see if Clare would be accepted there. South Preschool is another preschool attached to a private school.

Fran: I actually hung up the phone from her (the head teacher at North Preschool) and rang South Preschool straightaway,

because that was another place that they'd looked at on their open day—I rang straightaway and I got Emma there, and she said: “No, come down tomorrow.” And I said: “Do you want me to bring Clare so you can see her?” She said: “No, you're better off coming and looking around without her.” Went in, looked around, she said: “Yeah, she can come.” No questions asked, none at all. And so that, for me, was great. And she has been fantastic. Emma's not there anymore, but she just didn't even ask. She didn't care. She didn't give two hoots what Clare was like.

Clare began attending South Preschool and Fran was very happy with Clare's experiences there, although she felt that for the first year Clare attended the centre, the parents and other children didn't really notice her so much and would, “just go off and do their own thing” without Clare. Clare attended South Preschool for two days a week when she was three years old and three days a week when she was four. Clare had two half hour periods each day when Sandra, her ESW, was not in the centre or was away on her lunch break.

Three and four year olds at South Preschool eat and play together but they are also regularly separated into the two year-groups that use different rooms. When it was time for the three year olds to move into the four year old group and room, Clare's three year old group teacher asked Fran whether she would like Clare to move on with her age group or to stay in the three year old group. Fran wanted Clare to move on to the next group, especially as her friend's daughter Sammie who spent lots of time with Clare and her family was moving to the next group. Fran recalled Clare's three year old group teacher saying to her:

“I'm quite happy to hold her back,” and I (Fran) said: “Well, no, I'd like her to go on.” And I guess one of the main reasons for that is that she was with Sammie once again, and Sammie was going up, and I didn't see why we couldn't go up (I don't know what we'd be like if we didn't have Sammie, actually), but she was going, so I said: “Well, let's give it a go” and she

has slotted in, it only took her a week, she slotted into all the routines, she was pretty quiet the first week, but all the routines – she does everything when everybody else does it. Some things aren't – she can't do, they're not appropriate, like when they're doing tracing, or things like that, but when she can't do that particular thing, Sandra will take her away and they'll work on her fine motor skills, or she's got her own things.

Fran: ...And they set goals for her – like Stephanie was her new teacher, she said to me: “Now, to be honest, I don't know very much about Clare, because she's been in the other room. What would you like us to work on this year?” And I said, thinking, well, it's not like she can get her to print her name or any of those things, but I said (to the teacher) I would like her to be more mobile and independent in the classroom so she... I said, I would like her to get, say, to go and get a pencil, she's got to go and get it. And so, (Stephanie, the teacher) she was more than happy with that. So her role now is to make sure the other children don't go and get things for Clare. They've got this banging stick – Clare has to go and get it herself. And Clare will shuffle off, Sandra takes her to the toilet three times a day, and Clare will shuffle off to the toilet, Clare will do that – “go” herself. As soon as she sees Sandra (her ESW) walk in after lunch, she heads toward the toilet. So she knows those routines...

Although it is important for parents and whaanau (extended family members) to be consulted about and involved in decision making regarding their child (Ministry of Education, 1996b), the teachers appeared to be asking Fran to make the decisions about whether Clare would change groups and what the focus of the centre's learning goals for Clare should be. Neither teacher overtly shared their thinking or opinions in their discussions with Fran. It is possible that Stephanie, the 'new' teacher, hadn't spoken to the previous teacher about Clare's learning and participation as Stephanie expressed having little knowledge of Clare when she spoke with Fran.

Early childhood teachers are expected to plan a programme which recognises and responds to each child's right to belong in the early childhood setting, reflects the holistic ways in which children learn, enhance the child's well-being, engagement in active exploration, ability to express themselves, be heard and to have their contributions recognised, encouraged and valued (Ministry of Education, 1996b, 1998). The apparent lack of information sharing, reflection and discussion amongst centre staff about Clare's learning and participation, coupled with their reliance on Clare's ESW, and Fran's thoughts to guide them, conveys a missed opportunity to respond comprehensively to Clare as a learner and valued member of the centre community.

Fran: So she has fitted in, into those four-year-olds and that's part of my reasoning on going on to school at five is because we've already given it a go, we've done three steps from the two-year-old with no structure, to the three-year-old with structure, to the four-year-old where it's even more structured, it's not quite all play...so and she's gone up into those four-year-olds and she's fitted in with them. And hasn't been out of place. She's given most of it a go. Which is all that we can ask. And she can now do... draw a "C", she can write a "C", and she can do a circle for an "a", so she's making progress in the direction that she's going, and she's gonna start school better than some kids because she can count to 20 and she can say the whole alphabet.

The focus of the teachers and Fran seemed to be about supporting Clare's capacity to fit in to the existing programme with little acknowledgement and understanding of Clare as an active learner whose participation in the centre might influence the content and structure of the centre programme if there was a desire for and an understanding of how to support this.

'Special' rules for 'special' people and/or 'Normal' rules for everybody?

There was an incident one day at South Preschool where a child pulled Clare's hair and her whole pony tail was pulled out. The teachers and the

child's parent were very upset and apologetic about it, but Fran felt that it wasn't such a big deal. A week later Clare's ESW Sandra was on sick leave from the centre and couldn't work. The EIS didn't provide temporary replacements for absent ESW's. The centre wouldn't take Clare for that day, and the family still had to pay the fees. Fran explained what happened:

Fran: And so I rang the preschool and I got one of the teachers and she said: "Oh, no. Just bring Clare along anyway. She'll be okay. It would be a shame for her to miss out." And I couldn't go that day with her because I was busy. She said: "It would be a shame for her to miss out." So I said: "Okay, well I've just gotta go and do..." Oh, we had a hospital appointment, so I said: "We're going to the hospital, and then I'll bring her in." And by the time we got to the hospital Mark had a phone call from the head teacher to say that they had a teacher away and for Clare's safety they would rather she didn't go. So... she did last year have a day where she had the day by herself, with no teacher aide, and they were okay with that, but I think because her hair had been pulled out the week before and they were a teacher down (although they did have a reliever) they weren't prepared to have her. And I'm not sure whether that would have happened had her hair not been pulled out the week before. Or whether that happened because they don't want her without a teacher aide... So I don't know whether that put a damper on her being there by herself. But it could have happened to any of the other children. It just happened to be Clare.

The head teacher chose not to take responsibility for Clare's access to and attendance at the centre. The EIS provider, who employed the ESW also didn't provide a solution or see a role for themselves in finding a solution so that Clare could attend when the ESW was absent. The outcome of this situation was Clare's exclusion from the centre. In addition to being excluded from the centre, Fran and Mark were still required to pay full fees to the centre for that day. Fran still managed to see an opportunity in what had happened:

Fran: Although, on the other side, because we like quite like looking at both sides of the fence. It will look great on the *ORRS* funding report. (shared laughter) ... I said to our early intervention teacher, if we could put that perhaps in our *ORRS* report, that they weren't prepared to have Clare without her teacher aide because of safety issues, and what happened the week before, that might be in our favour. So possibly not all bad. (laughter) So that was one of our issues.

Summary

Clare's participation in her two early childhood centres was policed and restricted in various ways. Centre teachers and the early intervention service seemed to abdicate and not fully recognise their responsibilities regarding Clare's attendance and participation within each centre. The emphasis of teachers was on Clare fitting into the existing centre culture, environment, arrangements and norms. Staff didn't seem to adequately or deeply focus or reflect on Clare's learning, participation and relationships within each centre. Nor did they seem to plan around her interests, strengths, and abilities (Ministry of Education, 1996b). A consideration of and response to particular issues related to Clare's disabilities and how these might impact on her participation and learning were not addressed as central tasks and concerns.

Some practices were more overtly hostile to Fran and Clare's inclusion in and access to the environment, relationships and curriculum at each centre. These practices included teachers being unfriendly and unhelpful to Fran, discriminatory employment and staffing structures and policies, and punitive and exclusionary rules around attendance and fee payments. These rules and orientations produced exclusionary outcomes in response to disability and difference. An acceptance of difference as deviance seemed to obscure the existence and effects of the discriminatory practices that occurred. Each of the policies, practices and behaviours

discussed above created barriers to Clare and her family's inclusion, contributions and participation within their early childhood centre settings.

4.4 Primary school: "Sorry, no vacancies, we don't want her..."

School at five – Every child's right?

Mark and Fran, like most New Zealand parents, were keen for Clare to start school when she was five years old. Although Fran felt that Clare had learnt a lot from attending South Preschool, she also believed that Clare would continue to benefit from being in a group of children who were the same age as her as they moved through the school system together. Starting school at five years old is a highly valued cultural rite of passage for New Zealand children. It is also a legal right. Fran and Mark had made a choice about where they wanted Clare to go to school, although Clare's place at the school had not yet been confirmed. The school, which was a private, fee paying school, was West School:

Fran: West School is really where I want to go, because they have – all the support is there, they've got a special learning teacher and the high school is there... And West School have got a lot to offer, they, you know the high school kids take the primary school kids swimming, they get in the pool with them... and the whole package, you know, only seven in the class. And her teacher aide that she's got right now is quite keen to go with her... and West School said they'd be open to taking her. That's not going to happen anywhere else. If I can get her in there, there's so much to offer her. Then, we'll be broke for a long time!

There was a lot of uncertainty and stress for Fran and Mark during this time because Clare's *ORRS* funding had not yet been secured, and they didn't know where Clare was going to school.

Fran: You know, we're on tenterhooks about what sort of funding she's going to get for school. We don't know what school she is going to go to because we're still waiting for

West School to do their roll and get back to us, hopefully by the end of this month. And so I'm not really sure.

B: Everything's up in the air.

Fran: Yeah. I'm feeling. This is probably our worst year with Clare. Not that there's anything wrong with her, because she's doing wonderfully, but I'm just thinking...

As it turned out, Fran and Mark were rejected by four schools before they finally found one that would accept Clare and, even then, there were conditions.

South Primary School: "She's not 'ready' to start ..."

When Clare was 4.5 yrs old, the school attached to Clare's preschool rang Fran to see if she was planning on Clare enrolling at the school. They said that they knew about Clare having 'special needs' and that this wasn't an issue for them. Although Clare's name was down to attend St Samantha's School (their local school), and they actually wanted her to go to West School, Fran and Mark thought that they would respond to the school's enquiry by considering South Primary School as another option. Fran and Mark met with the principal of the school.

Fran: They showed us around the school and said they would like to know what *ORRS* funding Clare was to get and they would look into fitting Clare in and get back to us. They then, without our knowledge, - we only found out through the ESW - sent the Year One (junior classroom) teacher in to observe and assess Clare at preschool. The reply we got back from the school was that they didn't think Clare was ready to start school until she was six. And as she wasn't fully funded for an ESW Clare would need a full-time one - because of hygiene, toileting etc...- because Clare wasn't toilet trained. And we would have to pay the shortfall for the ESW, as well as full school fees. Obviously we weren't prepared to do this and really what she was saying is that they don't want Clare at the school.

The South preschool that Clare was attending was on the same grounds as South School. The South Preschool teachers, where Clare had been attending for two years, allowed the new entrant classroom teacher into the centre to ‘assess’ Clare without Fran and Mark’s knowledge, input or permission. This was an act of the centre colluding with the school against the interests, rights and knowledge of Fran and Mark. Fran and Mark didn’t want to risk the South School turning them down when Clare was six.

Fran: But we don’t want to wait until we’re six and then find out that there’s another excuse not to go. So. Yeah. This is my grieving time because my perfect child that everybody loves – everybody likes Clare – isn’t wanted... It’s the coming out of the closet thing. We have got a special needs child. So yeah, that’s probably the difficult part of that.

Fran’s descriptions of her feelings and responses to Clare being rejected and excluded from schools because of her disabilities is indicative of how complex and embedded a deficit discourse of disability is in our society. At the same time as rejecting the idea that Clare should be excluded because she is different, Fran also concludes that they are facing these problems because Clare is: “a special needs child.” One school down, three to go.

West School: “We have a ‘1% policy’”

While their children were still attending South Preschool, Fran had gone to an open day at West School with her two friends. While there, Fran had spoken to a West School staff member who had been positive about enrolling Clare at the school. She told Fran that West School had a practice of topping up any funding shortfall from the *ORRS* scheme for teacher aide hours. After they had met with West School staff, Mark and Fran were asked to wait for the school’s decision about whether they would be ‘able’ to enrol Clare.

Fran: As the school only takes 1 percent special needs and they were waiting to see if any of the disabled high school students were going to leave at the end of the year – they expected one to leave. Unfortunately for us she (the disabled high school student) didn't (leave) and they didn't have a place for us but did agree with us that West School was the best place for Clare and to try again at a future date.

The outcome of West School's '1% policy' was that Clare and her family were once again excluded from access to what is supposed to be a legislated right of all children in New Zealand (New Zealand Human Rights Act, 1993; New Zealand Education Act, 1989). Again, Fran seemed to view the reason for this situation as being about Clare having 'special needs' rather than as an act of illegal discrimination on the part of the school.

St Samantha's: 'We have to say "Yes", but ...'

Clare had been enrolled at St Samantha's, their neighbourhood school, since the age of three. After being refused entry into South and West schools, Fran and Mark decided to go back to their St Samantha's option, assuming that this would be a straightforward process:

Fran: Unfortunately St Samantha's hadn't recorded Clare's special needs and didn't read her registration form properly and accepted one of her friends from the EI Service who was also in a wheelchair. As they had accepted her they couldn't turn her away but we want the best environment for Clare and asked our early intervention teacher to talk to the Principal on our behalf. We asked for an honest opinion, and while she (the Principal) was very apologetic she said they hadn't had any special needs before and didn't think they would cope with two at once and especially not in the same class. So Clare would have to go into the Year 2 class. Clare couldn't cope with Year 1 let alone Year 2, so we said: "No" and that we would look elsewhere.

Sammie, Clare's friend from Plunket group, was also accepted to St Samantha's. Because Clare was turned away, Sammie's family also declined their place at the St Samantha's. In this situation Clare had the opportunity to have two familiar children, Sammie and Clare's friend from their early intervention group, in her first school and classroom. But any opportunities were denied when the situation was constructed as a problem by the school. Although Fran sounded partially sympathetic towards the school, she also indicated that they didn't fully swallow the school's line and neither did Sammie's family.

St Phoebe's: "We let them off the hook..."

Fran: So three down. Getting desperate. So I was still keen on the Catholic school, because we are Catholics, so we went to St Phoebe's. The principal was very nice there too and while he couldn't say no, he had two children in wheelchairs in Year 1. So we let him off the hook too and said, "Don't worry, we'll try somewhere else."

At the same time as feeling "desperate" to find a school for Clare, Fran and Mark's seemed resigned to being excluded yet again and to reluctantly accept the principal's reason of not wanting to be 'over burdened' by children in wheelchairs. Fran's comment that they had "let" the principal "off the hook" indicates their awareness that Clare did have a legal right to be enrolled at the school. In this and the other situations, this legal right, is not enough to deter schools from discriminating against children and their families on the grounds of disability.

North School: "You're welcome, but..."

Fran: Because of the private school delays, we were now early December which is close to Clare's birthday and no school for the following year! So we went to the closest school we could find (to our new house) only to discover we were to be zoned and their ballot was the very next day and we were out of their

new zone. However the school had made the decision not to commence zoning until January, so they would take her. Then we had to tell the principal that Clare had special needs. The lovely man never blinked and started reeling off all the things we needed to do to get Clare settled. One of which was to build a new disability toilet block as there wasn't one in the block that she would be in for the next couple of years. Lots of paper work which I apologised for the inconvenience of. His reply was that he did the best for all of his students and that Clare was no different, he would do his best for her also. So she was in. The school was also good enough to employ Clare's ESW that she has had since she was two years old. So the transition to the new school was actually very easy with our old friend Sandra there with us all the way... She commenced the first term mornings only. Then term two, 2 full days and 5 mornings. Term three, 3 full days and 5 mornings and term four, 5 full days. While the school must take Clare full time we agreed to this arrangement and have decided to fund the school to give Clare a full time teacher aide. It's still cheaper than private school fees.

It wasn't until this fifth school that Clare was accepted, although this acceptance also involved different rules for Clare's attendance and participation. For example, the expectation that Clare would attend on a part-time basis for most of the first year differed to the arrangements for 'typical' children starting school. Fran and Mark believed that Clare having a full time teacher aide was important for her to get the most out of her learning environment. They 'chose' to top up the teacher aide hours to full-time due to the gap between state funding and the employment of a full-time teacher aide. It is unlikely that parents of non-disabled children would ever be in a position where they felt compelled to subsidise their child's education to such an extent.

Fran's response to school rejection and exclusion

Fran talked about the process and effects of trying to find a school that would accept Clare and constantly being knocked back. She related these experiences to a process of 'grieving':

Fran: And I suppose our grieving period is coming now, when schools don't want her. This problem has been my hardest. Because everyone looks at her as normal. And at preschool, she's not allowed to hit and kick because the others aren't allowed to hit and kick, she doesn't get any special treatment.

B: The same rules for her as for everybody else.

Fran: Everybody else, yeah and if they've got to go and get their balls, well she's got to shuffle over and get them as well. That's how we kind of have approached her. And now, all of a sudden, schools are saying, "Oh, no, sorry, no vacancies, we don't want her." And that's probably been my hardest part.

At this time Fran directs her anger and grief at how unfair it is for Clare and their family not to be wanted and to be rejected. She is trying to make sense of how 'sameness' and 'difference' are understood by herself and others in this situation. Fran finds it difficult to accept Clare still being positioned as other when Fran and her family are committed to playing by the 'same' rules as everybody else.

When enrolling Clare at school, Clare was treated as "special". A "normal" response was not offered to her family. Each school based their rules for Clare's participation on an unquestioning acceptance and privileging of 'the norm'. The rules were not "normal" or the same for Clare precisely because she was "special"/not normal/not going to "catch-up". The series of rejections by the primary schools represented overt and illegal discrimination against Clare and her family because of her being viewed through a dehumanising and pathologising language of 'special needs'. Even though it is illegal for New Zealand schools to refuse entry on the grounds of disability, it was relatively easy for each school to succeed in 'convincing' Fran and Mark that they were unwilling and/or unable to adequately provide an education for Clare and that they were better off looking elsewhere. It seems inconceivable that these blatant instances of

illegal exclusion would be successful or left unchallenged if the schools had so overtly refused entry because of ethnicity, economic status, religious beliefs, sexuality or gender for example. A view of disability as deficit and grounds for exclusion has strong currency, power, dominance and taken for granted acceptance in New Zealand education and society (Grant, 2008; IHC, 2008; Ministry of Health, 2001).

4.5 Summary of chapter and themes

This chapter contains many examples of how Fran and Clare were positioned, and how Fran positioned herself in interaction with dominant, deficit discourses of disability. Central to their positioning and experiences were processes of ‘othering’ based on constructions of Clare as ‘disabled’, ‘special’ and therefore ‘other’. Because negative assumptions and beliefs about disability were largely taken for granted and accepted as ‘the truth’, the workings and exclusionary effects of deficit theories and practices were both obscured and legitimised. This unquestioning acceptance of a deficit based ‘regime of truth’ about disability and difference indicates the need to explore the effects of particular discursive patterns on disabled people and their families (Alton-Lee, et al., 2000; Leithfield & Murray, 1995; Rietveld, 2005; Tihi & Gerzon, 1994). The restrictive effects of deficit views on how Clare was positioned emphasise the importance of critiquing learning, participation and power relations at a lived, micro and intersubjective and level (Foucault, 1982; Freire, 1998; Maynes, et al., 2008).

‘Disciplinary Mechanisms’

In the introduction to this chapter, I described ‘disciplinary mechanisms’ as being the instruments or tools of power-knowledge production. One key mechanism that influenced Clare and Fran’s lives was the pervasive ‘gaze’ or surveillance that they experienced because of how people responded to

Clare's differences. The gaze was perhaps most explicit in the normalising judgements of health and education professionals. However, normalising judgements and the 'gaze' were a fairly constant presence in Fran and Clare's everyday experiences and interactions.

Not surprisingly, at the same time as feeling resistant to and angry about Clare's visibility and people's negative judgements, Fran expressed views of Clare that were consistent with deficit discourses. In particular, Fran attributed the blame or reason for her situation of hyper-visibility and judgment, on Clare's 'special needs'. A focus on disability as a 'problem' contained within Clare was intensified through processes of diagnosis, assessment and labelling that further differentiated and separated her from others in terms of how she was viewed and treated (Allan, 1999; Foucault, 1976). Clare was primarily regarded by most people and settings according to her perceived differences. In addition, her differences were emphasised to the exclusion of many other possible attributes and qualities that were part of her identity as a person and a learner. Normalising judgements were an explicit requirement of funding and resources being accessed for Clare. Clare's 'differences' seemed to provide the rationale for many influential or potentially influential people and places in her life to respond to her in exclusionary and limiting ways. Through pervasive disciplinary mechanisms involving surveillance, normalising judgements and hyper-visibility/invisibility a deficit regime of knowledge-power and exclusion was maintained and perpetuated.

'Coming Out of the Closet'

A key effect and process of the disciplinary gaze for Fran was a feeling of 'coming out of the closet' as a parent of a 'special', 'not perfect', abnormal child. Fran's use of this 'coming out' metaphor for her experience as Clare's mother indicates the powerful exclusionary forces that were

operating. Fran felt so judged and blamed by others that she sometimes chose to hide her child, and her differences, from public view and scrutiny.

The ingrained and culturally taken-for-granted notions of ‘normal’ and ‘not normal’ are at the centre of Fran’s experiences of not being accepted and being an outsider. Fran and Clare were constantly interpreted and treated as ‘other’ by ‘virtue’ of Clare’s differences. It seems that exclusionary processes involving ‘othering’ act as a disciplinary mechanism that supports and perpetuates a restrictive knowledge-power regime that has many negative consequences for disabled children and their families. One of these negative consequences is a narrowing and restriction of disabled children’s participation and ability to contribute. The policing of participation is the focus of the third and final theme from this chapter.

‘Policing Participation’

A key instrument and effect of deficit discourses on Clare and her family was the policing of their participation in social and educational settings. Clare’s participation within family, social and educational situations was policed and restricted by others. At times Clare’s ability to participate was restricted through her being forgotten about and/or ignored. Her participation was also restricted through interpretations of her that emphasised her differences and perceived deficits. These influences and restrictions on Clare’s participation and the kinds of participation she was allowed to experience appeared to be based on what was acceptable to and comfortable for others. Sometimes Fran felt pressure to restrict Clare’s participation in order to conform to her own and other’s ‘needs’ for comfort.

There were several instances of outright exclusion and refusal to allow Clare to participate and attend early childhood centres and schools. Equally common however were situations where Clare's presence was accepted or tolerated but in which she was either ignored by others or treated markedly differently to how other children within that situation were treated. This raises serious questions about Clare's rights as a person, a group member and a learner and how differential treatment and not being noticed restricted her opportunities and ability to belong, participate and learn with and alongside others. The 'policing' of participation by family, friends, strangers, teachers, special educationalists and institutions led to restricted and limited subject positions being available to Clare in comparison to children who are viewed as being 'normal'. Also indicated is a narrow and limiting conflation of 'inclusion' and 'participation' with mere physical presence. For example, it was assumed that Clare being in the room alongside her ESW or mother at Crossroads Childcare Centre meant she was participating to an adequate level.

It may be that special education involvement in Clare's early childhood education created tensions and confusion about who was responsible for planning for and responding to Clare's access to, learning and participation in educational contexts. This may have contributed to the situation in which nobody took responsibility for facilitating, advocating and ensuring access for Clare and her family to what they wanted and needed within an early childhood education centre. The only advocates for Clare's full participation appeared to be her family and possibly her ESW. At the same time as being an advocate for Clare, Fran was struggling to make sense of and explain what was happening at Crossroads Childcare Centre. She felt unable to communicate her concerns about how she and Clare were being treated to the centre. Fran often didn't share her insights, opinions and struggles with Clare's early childhood teachers, special

education professionals or school staff. In addition to Fran and Mark, teachers and early intervention staff were charged with and should have been sharing responsibility for Clare's access, learning and participation. Clare and her family, as 'special' and 'other', were effectively silenced and denied the ability and opportunity to honestly and safely contribute to realising inclusive views of and education for Clare and her peers.

Chapter Five ‘Disabled by the Discourses’

5.1 Introduction

The data in this chapter comes from interviews with Tony and I, excerpts from an article that I wrote about our family’s early childhood centre and early intervention experiences (B Macartney, 2002), family photographs, entries in Maggie’s baby book, stories and photographs from her ‘Learning Story Books’ and my personal recollections. Because of these multiple sources and kinds of data, I have been able to explore a more complex array of perspectives than I was perhaps able to in Chapter Four.

Family and early childhood centre narratives are juxtaposed with written materials from medical and special education professionals, and recounted experiences of our interactions with medical and special education personnel. I have used a ‘split text’ to juxtapose medical/special education narratives with family narratives (Lather & Smithies, 1997). The text is divided into two columns, one medical-special educational, and the other family-educational. Each column can be read as separate *and* related pieces of writing. I juxtapose the data as a strategy for identifying and exploring the differences and relationships between medical-special education approaches to disability, and our family and early childhood centre experiences. Juxtaposing the data highlights the characteristics of each worldview and is intended to take the reader on a journey through the terrain that our family has covered through the experience of having a child labelled as having “special needs”.

Multiple narratives, positioning and selves

In the methodology chapter I presented the idea of the ‘multiple selves’ researchers bring to and create in their research (Reinharz, 1993, 1997). The selves that are particularly relevant to this study are my ‘selves’ as the researcher, a research participant, a teacher, a mother and member of my family. I discussed the tensions and possibilities that this multiple positioning could create, particularly in relation to interpreting the data. I suggested that, rather than trying to ignore or hide any aspect of my ‘selves’ within the research process, I would use this multiple positioning as a tool for interpreting the data using an ‘insider’s’ perspective.

The data and discussions that follow represent an interweaving of both my own multiple positioning and Tony’s. Tony and I both have professional backgrounds and each of us use and invoke a professional discourse in our talk. Tony’s background is in mental health and mine is in education. We use our professional knowledge in ways that challenge and resist the professional discourses we have experienced as limiting and negative. We use our ‘professional selves’, knowledge, status and language as a tool for resistance and change when communicating our experiences. Although our use of professional discourses to resist negative views may seem obvious in the data, it is not always a conscious process for Tony or me when we are speaking. We tend to base our analysis and framing of our experiences on our professional study and work as well as on our position of being Maggie’s mum and dad. As parents, our talk comes from a loving, relationship, family based discourse. As such, our connections as a family also provide the impetus and inspiration to challenge and resist limiting views and practices.

Each of our ‘selves’ are expressed at different points in the data and to varying degrees. At times particular selves and discourses compete


and appear contradictory both within and between the narratives. These tensions and contradictions are identified and interpreted as potential discursive sites for the analysis of the social construction and negotiation of meanings around disability.

Re-presenting the data

The data are presented in the same chronological order as Fran's chapter. The narratives are presented in four sections which are: 'Introducing Maggie Rose', 'Diagnosis', 'Early Childhood Education', and 'Primary School'. Each section is followed by a discussion that 'disrupts' the narratives through contextualising, examining and interpreting the data in terms of the various ways of viewing and positioning Maggie and our family. I have attempted not to constantly interrupt the reading of the split text with immediate analysis. Although I agree that data does not and cannot 'speak for itself', I am wary of approaches that read a lot into a few short statements without also building a picture that communicates the nuances and complexities of the contexts and topics that the researcher is trying to understand and represent.

The discussion at the end of each chronological section identifies and develops tensions, processes and themes in the data. This includes a critique of developmentalism, 'expert' status and power-knowledge; what discursive practices such as assessment and labelling might achieve; barriers to family involvement in education; barriers to inclusive pedagogies; the role of 'silence' in maintaining dominant discourses; and resistance to deficit discourses.

5.2 Introducing Maggie Rose

<p>Medical/Special Education Narratives</p> <p>Apart from this note, the medical/ special education column contains no text in the first section 5.2 'Introducing Maggie Rose'. This has the effect of the reader initially having nothing to contrast the family story with. This format is intended to be a visual mirror of our family's process of getting to know and learn about Maggie before she was officially 'diagnosed' as 'disabled'. The family narrative stands alone as the introduction to Maggie and,</p>	<p>Family Narratives</p> <p>Paine – Margaret Rose Macartney (Maggie – Rose), born in a southerly storm at home in Diamond Harbour, at 1.44am on Monday May 27, 1996, 5lb 8oz and growing. Julie and Viv – your love, support, ice packs and hot towels were perfect. Thanks to Julie Richards for her love and awesome midwifery skills, and to the Christchurch Home Birth midwives. From Tony (Dad), Bernadette (Mum), and Maggie (baby).</p> <p>(Birth Notice, The Christchurch Press)</p>  <p>Excerpts from Maggie's Baby Book:</p> <p>7 weeks</p> <p>Maggie-Rose likes looking at fires, going for walks in her front pack and went on her first holiday to Akaroa and Little Pigeon Bay. Starting to smile.</p>
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it is hoped, that in some small way, the reader gets to know her, as we did, without any (overt) medical-special education intervention, interpretation or labels.



3 months

Smiling quite a lot – mainly to herself! Is starting to notice her hands which she raises up to her face like she's drinking from a jug. At one week old Maggie-Rose drank from a sherry glass because she hadn't quite worked out what breasts were for – perhaps she remembers.



Maggie-Rose is extremely kissable and we can't imagine life without her lovely presence. She's very inquisitive in a crowd e.g. a café, party, with visitors etc... Weighs 10lbs!



3.5 months

Maggie is vocalising heaps – she likes to blow bubbles and has discovered that she can move the objects on her ‘hanging frame’ with her hands. She especially likes her felt toy which is a little white cloud with a smiley face and 6 ribbons hanging from it. Maggie goes to sleep at 8pmish and wakes between 3-4.30am. Goes back down till 7-8am – mum and dad are very impressed!

Her raising her hand to her mouth is definitely an attempt to get her thumb into her mouth. She seems to enjoy the practise which is momentarily successful every now and then. Has got a ticklish neck!

4 months

Maggie went for her first ride on the ferry to Lyttelton yesterday, she really liked it – was looking around heaps, smiling and seemed comfortable with the whole experience...She smiles a lot if you kiss her hand and likes being cheek to cheek while we talk into her ear. She is very happy and a joy to spend the days (and nights!) with.

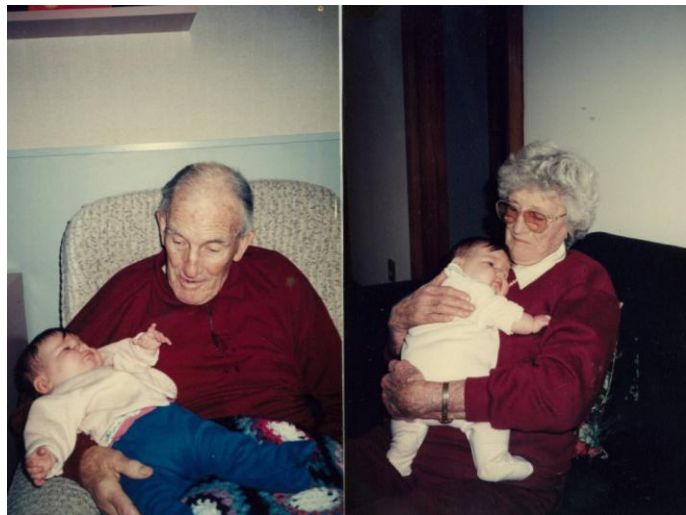
4.5 months

Cousin Jessie (11 years) came and stayed for a week. Maggie really loved her – Jessie taught Maggie how to kiss. Maggie went for her first ride punting down

the Avon, stayed the night at Arthur's Pass and went to the snow at Porter Heights.

5 months

Maggie-Rose and I (Mum) went on an aeroplane to Wellington. Maggie smiled during take-off and was fine on the flight. In Wellington Maggie met Aunty Sharon, Uncle Stephen, Aunty Deborah, Uncle Peter, cousin Immie, Grandad (Birdie), her Great Grandparents, and heaps of great aunties and uncles and cousins. She saw Nanny again too and had five days of non-stop cuddles! Maggie especially loved Frank (Great Grandad) who held her in his one good arm while they looked into each others eyes and talked – Grandad was much more animated with Maggie than any one else in the room – good taste!!



5.5 months

Maggie has an ABR hearing test on Friday as we have been concerned about her hearing for a couple of months now. Lately Maggie has been falling in love with soft toys and teddies – she's a real snuggler!

Maggie has normal hearing in her right ear and a 50% loss in her left one. May not be permanent and won't affect her language acquisition or comprehension

Yeh!! A great relief for Mum and Dad.

Maggie went to Australia! Highlights – lots of groovy cafes, tram and train rides, first sand castle made on the coast up from Bermagui, stretching out in a port-a-cot instead of squishing in her pram, first swim in a swimming pool, meeting her cousins Ben and Tim in Aussie.



6 months

Maggie is almost 6 months old – had her first solids today – about 1 tsp of pureed kumara – very enjoyable. Maggie has finally got that thumb into her mouth! She is a thumb chewer rather than sucker and either thumb will do!

7 months

Maggie-Rose is as delightful as ever – very into blowing bubbles and raspberries – loves the elephant mobile she got from the Horwoods for Christmas – 4 elephants with bells on – she reaches up and whacks the elephants, delighting in the movement and sound, she also talks to them in excited tones.

Has solids each day – kumara is still her favourite, also eats a little apple and cereal – still only one

	teaspoon at the most each time. Likes the ritual of a bib, new taste etc... Is very interested in me writing this beside her.
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Figure 1: Introducing Maggie Rose

A ‘new’ family

Maggie-Rose was our first child. I was 32 years old and Tony was 36 when she was born. Tony and I had been in a relationship for eight years before Maggie was born and had lived together for seven of these. After fifteen years working in early childhood education, I was really looking forward to having my own baby. Tony was much more nervous about the prospect of being a first time parent, at the same time as feeling excited about it.

When I was pregnant I remember people asking me if I knew the sex of the baby. I would usually reply along the lines of: “No we don’t. But just so long as it has ten fingers and ten toes, we’ll be happy.” I made this comment in response to a colleague’s question one day. My colleague was a Speech Language Therapist who taught our early childhood students in the area of language and communication. She said: “But your baby might not have ten fingers and ten toes, it might have disabilities.” At the time I thought: “What a joy germ! Fancy criticising a pregnant mother for wanting a normal baby.” After my experiences as Maggie’s mum, although I am probably too polite to say something like that to an expectant mother in a similar situation, I do think exactly the same thing.

So, like Fran and Mark, we were expecting a ‘normal’ baby and a ‘normal baby’ is what we assumed we had when Maggie was born. Tony took nine weeks parental leave after Maggie’s birth and, although we had

the usual challenges and adjustments to having a new baby, we also had a lovely time settling into our new family and getting to know the little person we had created, and ourselves as parents. We were very proud parents and loved introducing Maggie to our friends and family, going on holidays together and generally embraced our new life together as a family.

Recognising Maggie as a ‘whole’ person

The entries in Maggie’s baby book communicate an observant, accepting, inquisitive and ‘doting’ mother. Maggie was seen as a member of a wider network of friends and family, a ‘good’ baby in terms of sleeping well, being happy and content and making others happy, a sociable, active and engaged little person with her own interests, goals and preferences.

Our concerns about Maggie’s hearing and arranging for her to have a hearing test indicated that we had some early questions about her development. I expressed relief in response to being told that any hearing loss wasn’t going to affect Maggie’s language development. Her possible hearing loss was communicated as a concern alongside stories and experiences that celebrated Maggie as a person. The news that she may have a hearing ‘impairment’ didn’t detract from our view of her as a participating, competent, welcome and valued member of our family. At the same time, the expression of relief indicated a preference for her to be ‘normal’ and ‘unimpaired’. Our feelings of concern and relief were underpinned by dominant assumptions and beliefs about disability. Our relief in being told that Maggie’s level of hearing wouldn’t affect her ability to learn to communicate normally is relevant to a number of things that were happening, but not discussed openly, in our family at the time.

Silencing and self-censoring of experience

Tony was concerned about Maggie's development from when she was quite young and would ask me (as the 'early childhood expert' in the family) if I was also concerned. For the first few months, and for a short time after Maggie had her hearing test, I would respond by using my professional knowledge as a teacher and 'explain' that developmental milestones ('ages and stages') gave a general indication of a child's level of ability and progress and that there is a wide range of time within which children reach 'normal' developmental milestones. This explanation served to allay Tony's worries, although they didn't disappear. As time went on, I became more concerned about Maggie and less convinced by my own explanation, but still subscribed to it in conversations with Tony. Tony and I talked about how some family members, colleagues and friends' were concerned about Maggie, although no-one apart from Tony and I actually said anything over Maggie's first 7 months.

From when Maggie was about 2 months old, I was aware that she wasn't responding or behaving in ways typical of her age and 'acceptable' level of development, but I didn't talk with anyone about this. I did, however, feel anxious about it and would try and encourage Maggie to do what was 'expected' of babies of her age, such as reaching for and grasping objects. Although her baby book mentions concerns over her hearing, there is a strong measure of silence within the book in relation to my concerns about her development. During this period of silence it was obvious to Tony and me that a number of people, including ourselves, had concerns about Maggie's development. Keeping the silence was, for me, partly to do with wanting to get to know Maggie for who she was, rather than who she was 'supposed' to be. As Maggie's Mum, I loved who she was and what I saw. I wanted other people to see and feel that love and

value her like I did and, like Fran, I wanted to protect Maggie from the negative judgements of others.

I would feel annoyed and affronted when I was in situations where I was aware of someone else's concern about Maggie. I felt defensive on Maggie's behalf. The 'positive' diary entries, with their descriptions of what Maggie could and was beginning to do, can partly be read as a personal reaction to my concerns or anxieties about how she was developing. By writing and providing a chronicle of Maggie's achievements, I may have also been trying to convince or reassure myself that she was progressing and developing 'normally' at least to some extent. It was also a way of defending Maggie and valuing who she was as a person. An effect of hiding my concerns was that my experience and perspective were silenced. Therefore, although my reluctance to engage in any discussion about Maggie's 'abnormal' development can be viewed as an act of resistance to dominant cultural expectations, it also had the effect of silencing, ignoring and negating what I was experiencing and who Maggie was as a person.

Parental defensiveness and dominant discourses

There are three key cultural assumptions or beliefs in Western Society that seem to help produce those feelings of defensiveness and my reaction of wanting to hide or ignore any concerns. The first belief is that there is a proper, preferred, normal timeline and way for babies and children to develop. The second is that, if a baby does not conform to these normal developmental expectations, there is something 'wrong' with the child and it is/they are a problem. The third is that a child who is not meeting those expectations for development is 'impaired' and that this is a tragedy for them and their family.

Who wants their precious baby, and maybe especially their first baby, to be viewed as a tragedy and a problem? I certainly didn't. My defensiveness can be read as a reaction against those dominant constructions or 'truths' about difference in a situation where that thinking contained a threat of negative consequences for my child and family.

As discussed in Chapter Two, professionals working from a psychodynamic theoretical perspective, construct defensive parental reactions as a 'normal' response to their child's 'impairment', rather than as a reaction against negative views about disability or difference. Concepts or 'states' such as 'hostility', 'grief', and 'denial' are constructed as stages or phases on the way to accepting what professionals often assume to be a personal tragedy for the child and family (P. Ferguson, 2001). An alternative interpretation is that family resistance is often a reaction against attempts by professionals to cast a child and family into a negative light (P. Ferguson, 2001). Defensiveness that is motivated by love and protectiveness against negative views of disability and difference are easily dismissed or redefined to fit a personal tragedy view, thus keeping professional knowledge and practices unchallenged and intact.

5.3 Diagnosis

Medical/Special Narratives	Education	Family Narratives
		<p>A friend came to visit us at home one day when Maggie was about 7 months old. She rang me that night and told me that she was concerned about Maggie's development and thought we should have her examined by a specialist.</p>

<p>‘Assessment’ & ‘Diagnosis’</p> <p>This (abridged) letter was written by the paediatrician to our family doctor, not to us. We received a copy a few days after our appointment with him. He</p>	<p>Excerpt from interview with Tony, Bernadette and Amanda 2005</p> <p>B. I was quite upset when I got off the phone.</p> <p>A. Can you remember what those feelings were about?</p> <p>B. Yeah, I think it... it’s feeling protective. Just feeling really protective of Maggie and thinking “Oh, God. What are we in for?” And I suppose in some ways I probably felt relieved as well, because I’d been going through months of – you know, in the circle that I move in, although, because I was at home and it was winter with a little baby, I wasn’t out and about heaps, but whenever I sort of spent time with my early childhood friends... Well, I was very aware of people being concerned about her development and things.</p> <p>T. And you do feel defensive about that, don’t you, it’s like... this is our little baby, of course she’s perfect.</p> <p>B. Yeah, yeah—“Butt out.” And: She is perfect, thank you very much.”</p> <p>7 months (Maggie’s Baby Book)</p> <p>We took Maggie to a Paediatrician a couple of weeks ago because we have been concerned about the slowness of her development e.g. she is not as responsive socially as many infants, does not roll, or lift her head easily</p>
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also sent the letter to an early intervention service of his choosing without our permission,

“Thank-you for referring Maggie who is delayed with her development and is of short stature as well...

Maggie was a floppy baby and she was also jaundiced, she was slow to suck and establish breast feeding which did not really get going until she was 3 – 4 weeks old. After that weight gains have been steady and have taken off recently with a marked increase in weight so that now Maggie is quite obese. This is accentuated by her short limbs and short length...

when placed on her tummy, is not reaching for objects...

The paediatrician was quite concerned after meeting and examining Maggie-Rose and she will be having tests soon to x-ray her skeleton, scan her brain and check out her chromosomes. Apparently her limbs are disproportionately short and as a whole she is very short for her age (60cms). Of course she is still our lovely wee Maggie-Rose... We will start checking out early intervention services for her and have been talking to family and friends about her having a/some disabilities.



She may have an intellectual impairment of some sort too because her social, motor, and intellectual development are delayed. She'll certainly get every opportunity to reach her potential and is a motivated wee possum.

She did not smile until 9 weeks old and this was only occasional, more smiles came at 12 weeks of age, but she has been slow in her social development, not interacting with other people and not showing a great deal of eye regard even to her parents.... She is not able to hold her head up when prone and she is certainly not sitting, she does not support her weight when held upright...

Maggie shows significant delay in her development, motor, social and cognitive. She is also short, she needs further investigations..."

Maggie is turning into a rough and tumble girl – loves flying up in the air, being bounced etc... Also loves music – especially Tony playing the guitar – she stops whatever she is doing, eyes open wide and she listens.



8 months (baby book)

Maggie-Rose is enjoying making 'silly' noises like frog sounds and other animal sounds – the ones that tickle her fancy change each day and when you 'hit the spot' – she giggles. Saying "mummm-mummm-mum" a lot in the last few days. Talks to us and to herself.

We talked in our interview with Amanda about the question marks that arose over Maggie's development and her future:

B. And so, did you (Tony), like after Maggie Rose, after we went to the paediatrician, did you feel differently about her?

T. No, because I, like you, when we went away to Hanmer, we sort of had that epiphany the next day, it was just like, well, nothing's changed. I do feel – I shared that feeling. But it was just, the question marks, there were just suddenly a million question marks that weren't there before—maybe they kind of were there before, but if Maggie Rose had been “normal” those question marks wouldn't be there. So it just sort of adds a whole layer of doubt.

A. A different layer. Did you feel differently once you'd been to the paediatrician?

B. Ummm, I don't think I felt – I didn't feel differently towards Maggie, but I think that in some ways nothing had changed and in some ways everything had changed. And it was to do with, I suppose in some ways, sort of like having to share her more, having her being the...

T. The subject.

B. Yeah, the subject, or the object of other people's interest and intervention and all of that sort of thing. It made me feel a bit tired... (sighs)

T. And we both knew, because of our work, you know, because I had worked in mental health, how badly the world treats people with

	<p>disabilities. So immediately as well as all those questions about what she's going to be like when she's 21, was "How's the world going to treat her?" and being aware of the crap the world deals out towards people with disabilities. That sort of adds some anxiety that you don't necessarily...</p> <p>A.that you wouldn't have had otherwise.</p>
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Figure 2: Diagnosis

'Diagnosis': A personal tragedy or a force to be resisted?

Tony and I were very upset when we left the paediatrician's office. It was also a relief to feel that we were able to talk about what had been a pretty much unacknowledged concern for both of us for many months.

We had arranged to visit a close friend after the paediatrician visit, but we just wanted the three of us to be together and to go home and that's what we did. We decided that we would go away together for a few days, to 'collect' ourselves, before having to tell friends and family about Maggie's 'diagnosis'. When we got up the next morning in our motel, we went to get Maggie out of her cot, as we did every morning. There was Maggie, cute as ever, awake and happy to see us as usual. It was at this moment that Tony and I realised that nothing had changed, or at least the most important things hadn't changed. Maggie was still the person she had been the morning before and we were still her doting Mum and Dad.

This realisation, although the fact that Maggie hadn't changed might appear obvious, was significant for Tony and I because it helped us

to recognise what *had* changed. What had changed was how Maggie would be viewed and positioned by ‘others’ as a result of having this new label of ‘global developmental delay’. The trepidation and sadness we felt was about how people would view and treat Maggie from now on and throughout her life and what impact this would have on her.

There was also uncertainty and anxiety about how she would develop, particularly the ‘big’ things like: “Will she walk?” and “Will she talk?” Tony and I both found that this anxiety reduced over time, as some of our questions were answered through seeing her develop and through getting to know and understand her more as a person. I knew that she had a home environment that was conducive to learning and relating to others, so I tried to relax and not worry about what the future might hold. I made a conscious effort to trust her processes of development and to enjoy and value who she was rather than constantly comparing her to ‘normal’ children and wanting her to be more like them. It was my experience that there was a lot to like, love and enjoy about Maggie-Rose and I tried to communicate that to everybody else.

Making and ‘breaking’ the silence

Our feelings of relief about being able to talk about Maggie’s development and the relative silence that had existed before it, indicates that we had been keeping her differences a secret. This raises questions about why we felt that it was necessary or best to keep such a secret. I think that one answer lies again in the ‘fact’ that, in the dominant discourse, to be identified as developing ‘differently’ in our society is equated with being lacking, damaged, not as good as ‘normal’ children, deficient and delayed. This negative positioning and subjectifying is invoked when the labels of ‘impaired’ and ‘delayed’ are used to describe and classify particular children and adults. An example of the entrenched relationship between

‘disability’ and ‘deficit’ is the language that I used to talk about Maggie having ‘disabilities’ in her baby book. My entry is full of deficit comparisons to ‘normal’ infants and development. I used this language of comparison and ‘lack’ even though I didn’t agree with deficit views of disability or Maggie.

Classifying, labelling and pathologising

The paediatrician’s letter reads as a chronicle of Maggie’s perceived ‘deficits’ and is replete with markers of the particular ways in which she was deemed to deviate from the ‘norm’. Any of Maggie’s positive qualities and achievements were either absent or re-inscribed as deficits.

One example of this re-inscription process that I found particularly upsetting was the statement that Maggie was “quite obese”. At the time we took Maggie to the paediatrician, breast milk was her sole source of nutrition. I had never thought and still don’t believe that it is possible for a fully breastfed infant to be ‘obese’. As the paediatrician pointed out, Maggie (and I) took a while to establish successful breastfeeding. Working hard on and succeeding in getting Maggie established with breast feeding was one of my first challenges and triumphs as a mother. As a result I was very proud of her ability to feed from my breasts, thrive and grow into a chubby, healthy baby. I also experienced breastfeeding as the major process through which Maggie and I engaged in loving, mutual interactions.

I felt affronted by the paediatrician’s repeated statements about Maggie’s ‘short stature’ and ‘disproportionate’ limbs. At the time I couldn’t see why her height should be relevant and of such significance to him that he felt he needed to refer to it at all, let alone in almost every paragraph. I was later informed by him that he ‘suspected’ Maggie’s

differences could partly be due to having the ‘condition’ of achondroplasia or ‘Dwarfism’. Soon after, this was ‘ruled out’ by the “further investigations” that we underwent with Maggie Rose at the hospital.

Medical testing: For what purpose?

The visit to the paediatrician was followed by several months of regularly going to the hospital with Maggie for tests. Initially, neither Tony nor I thought to question the need for medical tests. In fact, Tony was relieved to have ‘the experts’ on the ‘case’. None of the results from the tests ‘found’ anything that could medically explain Maggie’s differences or point to any ‘treatment’ that she might benefit from.

Secretly, Tony and I enjoyed the fact that they couldn’t find a label for Maggie or a pigeon hole to fit her into. For a while we coined the term ‘Maggie Syndrome’, until we decided that we couldn’t think of any benefits of ‘having’ a syndrome. Eventually we got to the point where the paediatrician suggested that Maggie have an MRI scan on her brain. For this she would need a General Anaesthetic. When Tony and I asked why the paediatrician thought that this procedure would be useful or was necessary he said that they may be able to come up with a prognosis about her potential to develop language by looking at her brain. We were very sceptical about any prognosis being valid and we didn’t want to hear a prognosis even if we had decided that we weren’t going to believe it anyway. We didn’t want an opinion that we mistrusted to be spoken, written down or niggling away at the back of our minds. Tony then asked him if the results from an MRI scan would lead to any treatment or suggestions for ways in which we could intervene to support Maggie’s development and learning. The paediatrician’s answer was: “No”. After that we couldn’t see any benefits and only risks for Maggie in such a procedure. This was when the ‘penny dropped’ for us in relation to what

we were doing at the hospital. We began to question why we were having all these tests when Maggie obviously wasn't sick or in need of a cure.

We realised that what we wanted was to let Maggie's development unfold 'naturally' without medical intervention or opinions influencing her future and how other people perceived her and her capabilities. Even though we had 'doubts' or questions about her future, we preferred living with uncertainty to having it 'all sewn up'. That is when we stopped going to the hospital for tests and we stopped looking for a label.

5.4 Maggie's early childhood education

Early Intervention/Special Education Narratives	Family and ECC Narratives
<p>In the process of choosing an early intervention service we met with an EIS social worker. A comment from this social worker that stuck in our minds was: "We get 110% out of our children". This was given as a reason for choosing that particular EIS.</p>	<div data-bbox="853 1032 1382 1503" data-label="Image"> </div> <p>We checked out three early intervention services before choosing one for Maggie and our family. I wrote about this and our early childhood centre experiences in First Years, a NZ Early Childhood Journal (B Macartney, 2002)</p>

<p>This service involved travelling an hour each way once a week to an institution where three different therapists would spend time with Maggie separately and give three different lots of suggestions for intervention that we would be required to make sense of and implement in our family setting.</p> <p>At the same meeting with the social worker I made a comment about how Maggie seemed to be taking more time reaching developmental milestones, but that is was great to see that she was reaching them. In response, the social worker said that as Maggie got older, the ‘gap’ between Maggie and ‘normal’ children would become much wider and more pronounced. It felt to me at the time that she wasn’t open to recognising the positive achievements that Maggie had made and our enjoyment as parents in celebrating these.</p>	<p>“We didn’t want to get 110% out of Maggie Rose. We wanted to help her evolving sense of self to emerge and unfold, to keep getting to know her and to help her reach her potential in ways that responded to what felt right and comfortable for her. The 110% approach we felt was too pushy, and disrespectful. Maggie’s efforts to communicate were very subtle and she seemed to us to have quite a fragile sense of herself and the world. We didn’t want to ‘lose her’ in an effort to maximise the speed of her development. We were more interested in valuing and respecting who she was than in trying to make her fit as close to the ‘normal’ developmental path and time frame as possible.”</p> <p>“We chose a service that involved a team who would visit our home every two weeks, where the specialists came together and I could discuss Maggie’s development and various strategies for supporting her development with them... We felt that it made much more sense for people to come to the place where Maggie was most happy and comfortable, and that everybody could talk together...”</p> <p>“When she was two and a half we started attending our local parent-led ECC, where she has an Education Support Worker (ESW) who was also a family friend. Our EI service was a bit worried about “boundary issues”, but again we</p>
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Excerpts from ‘Observation Guidelines for Development’ given to us by the Early Intervention Teacher:

Sensorimotor Development

Physical appearance

(1) Is there anything unusual about the child’s body?

(2) When plotted on a chart, are the child’s height and weight appropriate for age?

Motor activity

(1) Is the child able to get from one play area to another alone?

(2) Does the child appear to move more or less often than other children?

(3) Are there any motor skills that the child seems to avoid

wanted what would be most comfortable and secure for Maggie. The idea that people who have a close relationship with a child and family are not appropriate as an ESW is one that we believe needs challenging.”

“One reason we chose Playcentre was because of the high level of input and involvement we could have as a family into what was happening for Maggie Rose. We also wanted other parents and children within our community to get to know her.”

“The early intervention team changed at this point and so did their approach to Maggie. The EIS people almost exclusively visit the centre, where Maggie is much quieter and more reserved than at home. They ask lots of questions each time they come about what Maggie is and isn’t doing. We (the ESW and myself) find ourselves trying to convince the EI people that she is ‘doing well’ in relation to what they are interested in. It is a situation where we feel defensive, always responding to their agenda and there is sometimes little relationship between what we are trying to achieve and what they are interested in.”

“We are interested in responding to and building on Maggie’s interests and supporting her and others to develop relationships with her. We see this as the path to her development, being accepted,

<p><i>Muscle Tone</i></p> <p>(1) Do body parts on the right and left side look and move the same?</p> <p>(2) Does the child assume a wide variety of positions?</p> <p>(3) Does the child look co-ordinated when moving from one position to another?</p> <p><i>Sitting</i></p> <p>(1) Does the child need to be held in sitting?</p> <p>(2) How much support does the child need when held in sitting?</p> <p>(3) Is the child able to hold the head up?</p> <p>(4) Is the child able to freely turn the head? (to both sides, up and down?)</p> <p>(5) Is the (sic) back rounded or straight?</p> <p>(6) Is the child able</p>	<p>and being influential in the centre. Their approach focuses more on deficits relating to what she “should” be doing next, rather than valuing the learning that we can see taking place and building on that.”</p> <p>“We want to know what is happening for our child in the centre. Sometimes people from outside will come in and do assessments that we have not discussed or given permission for, or behave in ways that we don’t think are okay. For example, not introducing themselves to Maggie or telling her why they are there and what they would like to do. Or they try to get information from her that is already available through asking a centre adult or us. The result is that her play is unnecessarily interrupted. Sometimes what they want to know relates to a developmental checklist or other information that either we don’t see as necessary or is not the focus of what we are trying to achieve.”</p> <p>Once Maggie’s ESW and I suggested that the EIS personnel didn’t come to the centre unless we requested them to because we felt that everything was going fine. The EI teacher’s response was to say that visiting fortnightly was in her job description and that receiving funding for the ESW was dependent on her being involved. So we left it at that and continued to ‘put up’ with them.</p>
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<p>to sit by propping on the arms?</p> <p>(7) Does the child sit independently without support?</p> <p>(8) Can the child bring the hands together in front of the body?</p> <p>(9) Can the child use the arms and hands to play with toys in sitting?</p> <p>(10) Does the child turn the upper body to reach for or watch objects, keeping the lower body stationary?</p> <p>(11) Is the child able to cross the centre of the body with the arms when reaching for a toy?</p> <p>Social-Emotional Development:</p> <p><i>Adaptability</i></p> <p>(1) What is the child's <i>initial</i> response to new stimuli?</p> <p>a) Shy, timid, cautious</p>	<p>Excerpts from Maggie's early childhood centre Learning Story Book.</p> <p>The stories were recorded at home and in the ECC by Maggie's ESW, centre parents and Mum/Supervisor. Maggie was aged between 3.5yrs and 5yrs when they were recorded.</p> <p>First day back at Playcentre after the holidays today. Maggie said: "Can I help you make the playdough?" before we left home this morning! She enjoys tipping cups of flour and salt in as well as mixing it up now. I'm teaching her the recipe! She got into making prints in the dough with her chin, saying: "Maggie made a chin print!" laughing and giggling and then doing it again. Elliot made dough 'scones' and Maggie liked: "The sugar on top" (flour).</p> <p>Elliot, Maggie and I went outside, we walked over to the shingle pit, which is a favourite of Maggie's at the moment. Maggie enjoyed making a "bell tower", "sprinkling the stones" and, of course, eating them. She asked to play: "Goldilocks and the three bears" before morning tea, but we had left our run too late.</p> <p>Later in the morning, I asked Maggie if she wanted to do a painting and I became distracted before she has responded to my question. After a while she prompted me by saying: "Do you want to do a painting?" Great reminder!</p> <p>When we got home I said: "What</p>
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<p>b) Sociable, eager, willing</p> <p>c) Aggressive, bold, fearless</p> <p><i>Reactivity</i></p> <p>(1) How intense does the stimuli presented to the child need to be in order to evoke a discernable response?</p> <p>(2) What type of stimulation is needed to interest the child?</p> <p>(3) What level of affect and energy are displayed in response to persons, situations, or objects?</p> <p>A. Characteristics of child in interaction with the parent</p> <p>(1) What level of affect is displayed by the child in interaction with the parent? Does the child appear to find the interactions pleasurable?</p> <p>(2) How does the child react to the emotions expressed</p>	<p>did you like doing at Playcentre today?” Maggie said: “We went to Playcentre. We washed our hands.” (Written by Mum)</p> <p>You seemed to have had a really good time today Maggie Rose! You just about managed a bit of everything. The highlight, I would say, would have been the rubber glove filled with water in the water trough – what great fun – squishing the water around it with both hands and your mouth!</p> <p>You had a wee bump on your forehead in the yellow swing after you said: “A bigger swing! A bigger swing!” and went quite high – but you were very brave and didn’t mind having Arnica put on.</p> <p>You are becoming very independent now Maggie and getting better and better at communicating your needs. Great to see you so happy! (Written by Justine, Early Childhood Centre (ECC) duty parent)</p> <p>Mary read ‘Goldilocks’ to Isaac and Maggie. Maggie likes holding the Duplo Goldilocks and following the story. She put Goldilocks in the places during the story (e.g. the big bed, the middle sized bed etc.). Isaac helped make the Duplo stairs for Goldilocks to climb up and down. (Written by Mary ESW)</p> <p>What a busy day! Maggie enjoyed</p>
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<p>by the parent?</p> <p>(3) How does the child respond to vocal, tactile, or kinaesthetic stimulation by the parent?</p> <p>(4) What type of cues does the child give the parent (vocal, tactile, kinaesthetic?) How easily are these cues interpreted?</p> <p>(5) What percentage of the time is the child active versus inactive in the play time with the parent?</p> <p><i>Characteristics of dramatic play in relation to emotional development</i></p> <p>A. Structure of Play</p> <p>(1) To what degree is there continuity and logical sequence versus fragmented thought presented in the child's play?</p> <p>(2) To what degree is there a linkage or recognition of past, present, and future?</p>	<p>using the little oven at the playdough table and called it "the Griller". She liked opening and shutting the door and cooking bowls of porridge for the 3 bears. Sasha joined in too and we had the Duplo Goldilocks story. (Written by Mary)</p> <p>We have been working on a production of Goldilocks and the Three Bears. Today we listened to the story on a tape of Maggie's – she had a Big smile when the story began and at the end she said: "Thanks for doing Goldilocks and the three bears!"</p> <p>Maggie tried on the bear costume (t-shirt with bear face) and said: "I'm a bear! I'm a bear!" She continued saying this through most of the session. We had a bear hunt later and Maggie was the bear which we found at the end of the hunt. She chased all the bear hunters away, saying "I'm a bear!" very loud. (Written by Mary)</p> <p>Jasmine and Sasha were dressing up and Maggie and Mary walked over. Mary put a purple cape with gold trim on Maggie. Maggie looked in the mirror and said: "Goldilocks". She stood looking at herself in the mirror and I asked her if she'd like her face painted – she nodded. She nodded "yes" to being Goldilocks. Later Maggie was searching the dress-ups. She found the bear shirts and then reached up for the 'Goldilocks' puppet on a high shelf and said: "Hello myself!! (Written by Mary)</p>
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<p>(3) To what extent does the child's play demonstrate rigid or inflexible thought patterns?</p> <p>B. Content of play</p> <p>What are the dominant themes of the child's play?</p> <p>a) Dependency</p> <p>b) Loss</p> <p>c) Power/control</p> <p>d) Fear/anxiety</p> <p>e) Self-image</p> <p>Does the child recognise the boundaries between reality and fantasy?</p> <p>Maggie 4.6 years</p> <p>EI teacher and Speech Language Therapist visited today. They suggested that we focus on before their next visit:</p> <p>(1) Sequence play – dramatic play e.g.</p>	<p>Maggie was in the dress-up area. She said: "Listen to the heartbeat" and was looking around for the stethoscope. She found it, put it on and said: "Doctor Maggie" while looking in the mirror. Mary asked: "What does your heart sound like?" Maggie said: "Boom-chicka, boom-chicka, boom-boom-boom!" Mary brought the rubber drum over and played the rhythm of the words. After a while Maggie copied.</p> <p>Maggie was reaching her hands up high towards where some beads were stored. Mary asked if she would like some help to get them down. Maggie said: "Ask a grown up."</p> <p>We walked outside, Mary asked if Maggie wanted to walk onto the 'stage' (set of wooden steps and cubes). Maggie did and said: "We went to the house of three bears". Mary asked what we did there and Maggie replied: "And Goldilocks sat down." Maggie enjoyed retelling the story with Mary (filling in words and what happened next). Later Maggie chose the magnetic Goldilocks story and put pictures on the board with Isaac while Mary told the story. (Written by Mary)</p>
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<p>bathing dolls etc. using words like First, Then, Next, Last</p> <p>(2) Activities @ kai (food) table and collage table to encourage interaction with one other child. Being at the tables mean the children are at the same height therefore Maggie is equal</p> <p>(3) Maggie initiating change of activity – clear the activity away and wait for Maggie to choose a new one.</p>	
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Figure 3: Early Childhood Education

Early intervention: ‘Making a difference’

The ways that Maggie Rose, the centre community, Maggie’s family and the special education personnel are positioned and position themselves and the effects of these positionings can be highlighted and explored through a critical examination of this data.

The special education staff positioned themselves as ‘experts’ in relation to knowledge about ‘normal’ child development and how to

support the development and learning of a ‘disabled’/ ‘abnormal’ child. The developmental assessment checklists that we were given contain pre-determined markers for ‘normal’ and ‘abnormal’ development. The language used in these checklists and the assumption that an assessor will be able to determine the ‘answers’ to the questions indicates a belief that this approach to learning and assessment is based on a valid, scientific, technical and objective process. The official purpose of such assessment methods is to show where a child ‘is at’ developmentally so that interventions can be designed to help the child ‘progress’.

Are the experts there to create, maintain or fix ‘the problem’?

This checklist-comparison approach relies on ‘helping’/making children who are different to be and/or behave more like typically developing children. Part of what is involved in this process was the expectation from the EIS social worker that ‘these children’ have to work harder than ‘normal’ children to ‘catch up’. Fran, and Clare’s paediatrician also drew from an assumption that disabled children need to “catch up” to normal children. Thomas Hehir (2002) argued that an ableist focus detracts attention away from supporting labelled children’s communication, learning and participation.

Special education early intervention is supposed to ‘close the gaps’ and help the child to “catch up” as Fran and the paediatrician expressed it. The information in developmental checklists is supposed to help them do that. However, many of the checklist items aren’t about actually ‘fixing’ the ‘problem’. Instead they seem more relevant to establishing a profile of the child using comparisons to what is deemed ‘normal’, to look for and identify perceived deficiencies, and to label the child as different, behind and lacking. It is primarily a tool for classifying and labelling, and doesn’t point to positive teaching strategies. If the

checklist was intended to contribute to intervening in the learning and teaching process, why should the first item - how a child looks in comparison to 'normal' children - be relevant? How can and why should early intervention change a child's physical appearance, and what inclusive educational reason would you have for collecting quantitative information about such things as a child's frequency of movement to others?

The effects of the myth of objectivity

The developmental checklist approach takes it for granted that a child's behaviours and characteristics can be accurately pre-defined and objectively measured. Part of this claim to objectivity is a belief in the moral and value neutrality of the contents and processes of assessment. However, this claim to the scientific, objective and value neutral status of developmental norms is open to critique through considering the effects of those claims on how children, families, teachers and 'experts' are positioned and how 'disability' is constructed.

For example, what is the effect of 'knowing' that you can 'objectively' assess whether a child's play 'represents': "continuity and logical sequence versus fragmented thought"? "Continuity and logical sequence" and "fragmented thought" are subjective categories that communicate a particular, rational, worldview and orientation in relation to how people *should* think and behave. Consider this criterion in relation to Maggie-Rose and her love of books, stories, acting and imagination. A rational, logical orientation *requires* a negative value judgement about and a narrowing of what is deemed acceptable and relevant in Maggie's play, thinking and ways of interacting with the world.

Maggie uses her book and musical worlds to make sense of the world, 'develop working theories' and connect with her experiences.

Maggie's ways of viewing and interacting with the world were not recognised, positively valued or understood from a 'special education' perspective. On the contrary, using the checklist given to us by the EIT, Maggie's way of constructing and communicating her understandings of the world could be used as 'evidence' of difficulties in recognising "the boundaries" between "fantasy" and "reality". Maggie's world was seen as 'other' and as a barrier to her engaging in 'reality' and 'real' learning which involved understanding and using linear cultural constructs such as "first, then, next and last."

Maggie Rose's resistance to 'expert' involvement

When the EIS people came to visit Maggie at her early childhood centre, she would often 'thwart' our efforts to 'present' her in a competent light, by refusing to 'perform' the tasks she was given by them. Instead of co-operating with them, Maggie would choose not to say or do very much at all. I began to interpret this as her resistance to her play being interrupted and to being the focus of so much adult attention. After a while the ESW and I began asking the EIS people not to talk about Maggie in front of her and to observe her from a distance. We began trying to give the EI people the information they wanted about Maggie ourselves instead of them interrupting her play.

We also began to refuse the use of any assessments in the centre that weren't consistent with our *Te Whaariki*-based philosophy and approach. This had the effect of ending situations in which Maggie was removed from her peers and tested by therapists. If the information that they sought seemed of interest and relevance to us, we would gather narrative assessment information and share it with the EIS team. The ironic, but perhaps unsurprising, thing was that unless they saw or 'tested'

something for themselves, they were sceptical about anything we reported and didn't refer to it again.

There seemed to be a strong dynamic related to maintaining a deficit focus that involved 'diagnosing' differences rather than a focus on learning and progress. The outcome of our lack of co-operation was that Mary (Maggie's ESW, centre parent and friend) and I were positioned as 'difficult', misguided and as over estimating Maggie's capabilities. Maggie continued to be seen as 'lacking' and 'deficient' and the EIS staff retained their jobs and their 'expert' status. We were always positioned by the early intervention staff in relation to their agenda (their questioning, surveillance and checklists). They seemed to operate under the assumption and belief that by virtue of being labelled, 'disabled' children need the leadership and specialist interventions of 'experts'.

The 'whole child' within a social context

In contrast with an individual and de-contextualised special education approach, at Maggie's early childhood centre we used narrative assessment methods that began with the child's strengths, interests and participation and positioned every child within a learning community and in relation with others (Ministry of Education, 1996b). As other New Zealand research has found (Dunn, 2004; MacArthur & Dight, 2000) the approaches of the early intervention staff and of the parents and teachers in the centre were very much at odds. At the ECC, the stories, photos, and examples of the children's artwork in their Learning Story Books were used as a starting place for planning and reflecting on the curriculum, programme and environment. The Learning Story Books were also intended to be a celebration of each child's interests, learning and achievements. They were living, changing documents that belonged to the children and their families. Rather than beginning with a textbook or

checklist for knowledge about children's learning and development, we saw ourselves as parents and teachers as the 'experts' on the children in our care and our methods and orientation also communicated a belief that the children were 'experts' about themselves.

The suggestions from the EI staff that we focus on "dramatic play" and feed in the concepts of 'first', 'then', 'next', 'last' seemed an impoverished and banal response to Maggie's developing interest in stories and imagination and the pleasure, skills, dispositions, relationships and learning that she and others were gaining from those interests. Our centre's response was to find a favourite story of Maggie's (Goldilocks and the Three Bears) and to provide lots of opportunities for all of the centre children and families to join with that interest through providing resources and planning events, activities and occasions that would encourage and respond to the exploration and learning that was happening. We would find out about what learning was taking place through observing, documenting and discussing what was happening and use this information to further plan in response to the learning we believed was occurring. Our approach positioned the centre adults as both 'experts' and 'learners', Maggie and her peers as competent learners and members of a community, and the early intervention staff as an impediment to and distraction from our way of working.

5.5 Primary school

Special Education Narratives	Family Narratives
<p data-bbox="379 465 884 573">Special Education Therapy Plan “Communication Goals” (Maggie nearly 9 years old)</p> <p data-bbox="419 674 596 707"><i>Present Skills</i></p> <p data-bbox="419 759 762 1122">“Maggie has functional expressive language skills... Encouragement is often required for Maggie to maintain the topic during conversations as she can sometimes either, not answer the question, or supply an answer that is “off the topic”.”</p> <p data-bbox="419 1173 639 1207"><i>Goals/Outcomes:</i></p> <p data-bbox="419 1258 762 1364">”Maggie-Rose will maintain the topic for up to four turns when she is:</p> <ul data-bbox="469 1417 762 1839" style="list-style-type: none"> • Having a conversation • Reading a book • Playing a game • Asking a question • Recalling a story” 	<p data-bbox="906 465 1490 573">Interviews with Tony and Bernadette for Radio Documentary (Maggie 7 years old), & with Amanda (Maggie 9 years old)</p> <p data-bbox="906 611 1362 645">Tony talked about how he thinks of</p> <p data-bbox="906 685 1484 719">Maggie in relation to the label of ‘disability’:</p> <p data-bbox="946 759 1370 1563">T. Most of the time I just feel like she’s just Maggie Rose. And her issues are... because she’s different, we need to learn her language, or learn her culture even. Maggie Rose... I want to spend more and more time with Maggie Rose because that’s who she is, that’s how you can relate to her. And I want to make sure that the world goes there as well, that who she bumps into at school will ... our philosophy, our vision as she goes to make her way in the world, but it will also be how we approach, and I don’t think it was that way before she was born, I’ve had to learn things, and you’ve (Bernadette) helped teach me that, and she’s helped teach us that.</p> <p data-bbox="946 1615 1370 1939">B. I think that what’s different for parenting Maggie is that we, and I feel like we do, we need to take a much more active role in things like her developing friendships and following her interests, although she seems to, Maggie gets into a topic or a particular field of</p>

<p><i>Strategies</i></p> <p>“If she is choosing not to answer:</p> <p>Guide and repeat the question, then wait for her to answer.</p> <p>If her responses are off the topic, respond with, “that was interesting”, then repeat or clarify original remark that is requiring a response.”</p> <p>School Individual Education Plan (IEP) (Maggie 9 years old)</p> <p><i>Present skills and needs</i></p> <p>“At times Maggie will spontaneously greet people and initiate conversations. She has favourite topics that she enjoys recounting. She can need lots of prompting to contribute in conversations initiated by others. She needs plenty of time to consider her responses and can need</p>	<p>interest and she goes for it, she just sort of really embraces it, and so that’s quite easy, just feeding stuff in and taking her to shows, and she’s into jazz at the moment and things...</p> <p>T. We’ve had to be an advocate with the system and be kind of consumers of the system with Maggie Rose in a way which is uncommon for most kids, you don’t have that kind of verbal engagement with the prodders and the pokers and the early interveners and the teachers.</p> <p>B. I’m just thinking about that sharing thing, like, it’s related to that as well, like, you feel like—well, it’s not even so much sharing, it’s just that your child is so much under the gaze of other people and it’s called early intervention or whatever, intervening, but sometimes it feels like interfering. You know, like you have all these people and they’ve got this right to...</p> <p>T. And there’s that kind of “expert” thing as well, isn’t there. It’s like, there are a whole lot of people with expertise that they want to offer to this process, and we have to work very hard to evaluate whether we are going to agree with that expertise or not, and to give our own points of view about those issues.</p> <p>A. In particular, I’d imagine,</p>
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<p>instructions/questions repeated. Maggie will sometimes ask questions to gather more meaning. She makes use of a rich vocabulary when speaking which is often based around her current favourite literature. She needs plenty of encouragement to maintain the topic of a conversation.”</p> <p><i>Goals/Outcomes</i></p> <p>“For Maggie-Rose to work towards achieving more reciprocity in her communication with peers, family and other adults.</p> <p>Listening and responding, turn taking, maintaining the topic, maintaining attention, initiating interactions.”</p> <p><i>Strategies and Resources</i></p> <p>“Classroom programmes and the language of the classroom;</p> <p>Involvement in daily oral language focus;</p> <p>Class and group</p>	<p>where that expertise is being offered from a very different philosophical basis.</p> <p>T. Yeah. And sometimes it hasn't seemed particularly expert, I'd have to say. Sometimes it seemed pretty unrobust, the quality of people we've had offering that advice, or intervening with Maggie and not even involving us in that intervention. It's coming to school and doing a test and making some conclusions as a result of that test and then feeding that back to the teacher aides, and we become totally...left out of the loop.</p> <p>T. Because it's like that control thing, it's like you want to be involved in what's happening with your child, and apart from just wanting to be involved, we've just got so much to offer that process. Because we live in Maggie Rose-ville more than anyone else, and so we know how to talk her language better than anyone else. Not that we're that good at it, but it's sort of we know that stuff better than anyone else...</p> <p>T. ...every time we'll go along to an IEP meeting there's bloody twelve people in the room. That you have to have that same kind of conversation with, about “listen to us.”</p> <p>A. So that's been the hardest</p>
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<p>discussions;</p> <p>Understanding that Maggie needs plenty of time to communicate her thoughts/feelings;</p> <p>Retelling favourite stories;</p> <p>Helping hand to language strategies;</p> <p>Maggie to be regularly involved in organised group games in the classroom and during break times;</p> <p>Teacher aides supporting Maggie in developing her repertoire and use of communication skills while at the same time encouraging her independence in all areas of school life;</p> <p><i>Peers and adults to:</i></p> <p>Ask Maggie to say something again if not understood;</p> <p>Prompt Maggie to speak louder;</p> <p>At times planned ignoring remarks that are off the topic;</p> <p>Repeat requests,</p>	<p>one for you. Is it hardest for you?</p> <p>B. Yeah, I think that I would agree that that's been the most difficult thing, is trying to participate meaningfully in her education and her experience at school...</p> <p>B. And I mean, we've had situations—I've been in meetings with people where I've started talking about Maggie Rose's friendships – because there seems to be this thing about 'adults shouldn't intervene in the social/emotional development' of young children – seems to be really strong. So I might say something about, you know, her friendships, and the children that I'll be talking about are the same children that are in that classroom, that the teacher sitting there is teaching those children, and she just, every time I started talking about what we were trying to do outside of school to help facilitate those relationships, she'd sort of stare blankly out of the window, like there was a big switch that had been switched off.</p> <p>B. But we went through – it was probably about a year – of quite, I think I got quite depressed, because it was just like coming up against a brick wall and nobody seemed to understand what our problem was, and everybody saw us as being difficult and antagonistic,</p>
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<p>instructions...wait;</p> <p>Respond to Maggie's initiations;</p> <p>Encourage children from school to play at home;</p> <p>Develop situations where Maggie Rose can play at other children's homes without her family;</p> <p>Maggie's Learning Story Book to be used to record some of her interactions with peers and adults. Focus on situations where Maggie is engaged in positive reciprocal exchanges. Regularly share these recordings with Maggie Rose."</p> <p>When she was six, a Speech Language Therapist (SLT) visited her at school. She did two "screening assessments" that she used as the basis of a plan for Maggie. The first assessment was called the 'Renfrew Action Picture Test' (RAPT) and consisted of showing Maggie a series of pictures and asking her questions about them. The other assessment was called 'CAOS' and it consisted of a predetermined checklist in the areas of 'communication, attention,</p>	<p>and all sorts of things, and I felt that we had been so – I mean, we were honest and things, but we had tried to be so strategic and conciliatory and nothing seemed to work. But it's all good at the moment.</p> <p>Maggie's Learning Story Book</p> <p>At times I have tried to respond to the 'assessment' information professionals want and the questions they ask by providing them with stories and observations from home. My intention has been to try and challenge their way of thinking about Maggie and her learning by giving them information about what they are interested in but in a way that is more meaningful and relevant to Maggie's learning and experiences and our lives as a family. So far, no-one has ever shown any interest in, taken account of or used the information we have given them to improve Maggie's learning and teaching environment:. Although Maggie's teacher aides and her .1 teacher would sometimes write in her Learning Story Book, no classroom teacher ever did. We discontinued Maggie's LSB after a few years at school.</p> <p>Following are stories recorded by Mum at home in response to a special education focus on Maggie's understanding and use of questioning:</p> <p style="text-align: center;"><i>'Feeding the goldfish'</i></p> <p>Mum: I wonder where the snail has gone. Can you see it Maggie?</p> <p>Maggie: No. The snail has gone</p>
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organisation and sequencing skills’.

Maggie didn’t know the Speech Language Therapist SLT very well and the SLT would withdraw her from her classroom for the ‘tests’. The SLT wrote a report in which some of the: “findings suggested that”:

“Maggie-Rose’s ability to maintain attention to task was limited. The test was abandoned after the 7th card was presented as she became fixated and very amused by the previous card (A picture of a girl who had fallen down some stairs and broken her glasses)...Maggie-Rose demonstrated that she was able to maintain the topic when asked a question. However, this linked with her attention span. When presented with the remaining three pictures left over from the previous session, Maggie-Rose once again became fixated on the picture that she found amusing. Consequently the test was abandoned.”

The .1 teacher from school who had responsibility for co-ordinating Maggie’s programme etc... was concerned about how Maggie became

back to Animates!

Mum: Let’s feed your fish Maggie.

Maggie: Would that be alright Mummy?

Mum: Yeah, let’s feed them.

Maggie feeds the fish.

Mum: I think they were hungry Maggie!

Maggie: (to the fish): Are you eating your food fishies?

‘Where do things come from?’

Maggie: Where do guitars come from? Could I fly up in the sky?

“Maggie is frequently asking where things come from at the moment. She listens intently to the answers. Is especially interested in where various musical instruments come from.” (Mum)

‘Brushing teeth time’

Maggie: I’m going to brush my teeth. Can you help me? Would that be alright?

Mum: Yip, sure. Hey, have you seen Sally’s toothbrush Maggie? I can’t find it anywhere.

'fixated' on the illustrated picture card of the child falling down the stairs. She asked me if Maggie reacted in a similar way when people hurt themselves around her. I talked about how Maggie found other people hurting themselves and crying upsetting for her.

I also talked about how laughing at other people's misfortunes is common in our culture and that we encourage and support this through rhymes such as Humpty Dumpty.

I suggested that an alternative interpretation of Maggie's response to the picture card could have been that she is developing a great sense of humour! I also told her that, like most people, Maggie didn't seem to have much trouble attending to things that she found relevant and related to her interests and that she was enjoying.

In relation to the CAOS checklist, the SLT 'found' that:

"This determined that Maggie-Rose is at the pre-literacy, pre-numeracy level... Therefore the current recommended speech and language therapy targets for

Maggie: It's in Holland!

'Maggie's Jokes'

Q. Where do baby apes sleep?

A. In apricots!

Q. What do cows have for breakfast?

A. Moooslie!

Q. What do cows listen to?

A. Mooooosic!

"Last night when she was getting into her pjs, Maggie made up a new joke:

Q. What do Teletubbies wear to bed?

A. *Pojamas!* (Po is a Teletubbie character)

She has been delighting in telling this frequently!" (Mum)

T. And so there's this huge team of adults you know, sort of around Maggie and on one level that's great because there's a huge amount of resources and a huge amount of expertise and good will in that team and on another level it's quite bizarre that you've got all these kind of people intervening in this one little life. I've got very mixed

<p>Maggie-Rose consist of:</p> <ol style="list-style-type: none"> 1. To match a 2-part pattern 2. To continue a 2-part pattern <p>To identify the days of the week; and to identify what day it is today, what day was it yesterday, what day comes after and what day comes before.</p> <p>To match single words to pictures</p> <p>To answer “what” and “why” questions when presented with pictures. This task assists with functional communication development and relates to problem solving, prediction, explanation and reporting skills. These skills are the precursor to higher language skills necessary for literacy and numeracy.</p> <p>To write the letters of the alphabet (template provided).</p> <p>To write her name</p> <p>To facilitate Maggie-Rose to remain on-task it is recommended that a visual schedule be</p>	<p>feelings about that because it has to unfold naturally and that’s...for me that’s a much more important challenge than the challenges of her learning to walk or write or read or you know, whatever. I think those things will come in good time and they’ll come to a certain level and that will be ok but it’s the one... The important things are about her making her way in the world as a kind of emotional being, you know, and being loved and being able to give love herself and all those kinds of things.</p> <p>A. Do people find that challenging?</p> <p>T. It’s a challenge because it’s hard. I think it’s much easier to teach someone to wipe their bum or write nice letters on a page than it is to teach someone those skills... to learn how to be a good friend. I mean our experience has been that there are really limited resources both in terms of time. You know, everyone involved with Maggie is really busy. I’m sure that there are huge caseloads of all those people sitting in that room and others, and there are teachers that have got full-on lives with huge classrooms. And money is short. There is not enough money for Maggie to have as much support as we think would be ideal, all that kind of stuff. So in the face of that resource shortage that</p>
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<p>implemented to support and enhance organisation, functional communication and attention skills. Further, that she be expected to remain “on task” for a given amount of time e.g. 5 minutes, then she is allowed to choose an “off task” activity for a given period of time. Once this time is up she will be expected to return, “on-task”, for a given (achievable) period again.”</p>	<p>makes it even harder so it’s a challenge for everyone.</p> <p>And I think it’s also been a challenge for us too you know. It comes back to that point we were making about the similarities between our experience and the experience of any parent. She’s our first little girl going off to school, you know, and that’s... I think every parent, all parents must find that hard and just learning to kind of let go. A little bit of letting go happening there.</p>
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Figure 4: Primary School

Starting school – barriers to family participation and involvement

Tony and I began experiencing problems having our aspirations for Maggie met within the primary school setting before Maggie started attending her local school at the age of six. Our first problems were related to the employment of staff that would be working with and on behalf of Maggie and our family. The key decisions that we wanted some input into were who would be her teacher aides, and the .1 ‘special needs teacher’ who would work with the classroom teacher, teacher aides, our family and specialists from the special education service provider to support Maggie’s learning and inclusion in the classroom and school. The school employed a person that we had told them we didn’t want working in the .1 teacher role because we believed that she came from a deficit viewpoint. The school also refused to employ one of Maggie’s ESWs from her early childhood

centre as a teacher aide. In addition to having a wealth of knowledge about and experience in working with Maggie, this person also had a teaching qualification.

Family disempowerment, frustration and marginalisation

The situation was one where we felt disregarded - left out of important decisions regarding Maggie and what was happening for her on a day to day level in the classroom and playground. This was despite the promises four years earlier of meaningful partnerships between families and school staff within the *Special Education 2000 Policy Guidelines* (Ministry of Education, 1999). Tony and I voiced our concerns through discussions and meetings with various members of the school staff, and eventually letters to the school principal, teachers, and the Board of Trustees. It wasn't until the .1 teacher resigned her position after two years, and the person that we had initially recommended as the .1 teacher was successful in securing that job that things became more open and easy for us as a family. This was after two years during which we felt left out and isolated and concerned that much of what was and wasn't happening for Maggie at school was not in line with our experience and knowledge about an inclusive, positive learning environment.

There was a lot that we didn't know about because we were not kept informed about what the adults in the setting were thinking and doing and how this was for Maggie. This was a big contrast from our early childhood centre experience where we were very involved and informed. It seemed that the school saw themselves as, the 'experts' and that our desire to be involved and contribute were interpreted as outside of their boundaries of what was acceptable and comfortable for them.

The outcome of feeling left out for me was on-going anger and frustration at the situation which led to a period of quite significant depression. During this time I sometimes got Tony to go to the IEP meetings because I couldn't face them. I didn't see the point in attending if I wasn't going to be heard and I didn't like the way that they planned around subject areas of the curriculum rather than Maggie as a learner and participating member of a learning community. Partly I think my perspectives and reactions were influenced through having an early childhood education background and my study and learning about inclusive education at university during the same period. Because of my background and study, I found it painful to sit through a process that reflected none of what I saw as being possible to achieve in an inclusive educational setting. I also felt very anxious about sitting in a room with all of those people who had the 'right' to discuss and make decisions about my child. I suppose that the overall feeling and effect of the situation on me, and consequently Maggie, was one of disempowerment.

Special and inclusive educational approaches: The 'problem' of context

The 'Primary School' split text can be used to conceptualise the differences between our family-centred approach to Maggie, and special education, and school approaches. The special education column focused on data related to Maggie's learning and development around language and communication. I chose this focus because Maggie's ways of communicating and her ability to engage in reciprocal relationships with others are central aspects of her learning and participation to us as a family and because the data seemed to highlight some key areas of difference and departure between a 'special education' and 'inclusive education' approaches.

Our talk as parents, in the interview data, emphasises the importance that we place on people getting to know Maggie through deep engagement in and learning about her world and what ‘turns her on’ as a developing, interesting and valuable person. As Tony said “we need to learn her language, or learn her culture even.” The Speech Language Therapist’s response to Maggie’s ‘communicative development’ was focused on her performance of pre-defined communication ‘skills’ such as ‘turn taking’ in a conversation, ‘asking a question’ or ‘recalling a story’ (pp. 220-223 split text). The way these skills were referred to indicated a marked disinterest in the contexts in which expressive skills are used and developed. The method of ‘assessment’ was to measure these ‘skills’ in relation to their *frequency of occurrence*, rather than their content. *What* was talked about in conversations and *who* was involved was not of interest or relevance. What ‘counted’ in this situation was Maggie increasing the number of ‘conversational turns’ she took. A prejudice for judging learning in solely quantifiable terms indicated a belief in the subordinate position of the learning and relational context.

One of the ‘teaching strategies’ in the ‘speech language therapy plan’ involved the intentional denial and active discouragement of Maggie’s interests and personal agency (pp. 226-227 split text). Where Maggie’s ‘turn’ in a conversation was judged to be ‘off the topic’ by the conversational partner, it was recommended that that other person tell Maggie that what she said was “‘interesting” and then to proceed to ignore it by going back to their ‘original remark’. The suggested goals and strategies positioned the adults as ‘expert’ and ‘on the topic’ and Maggie as ‘inexpert’ and ‘off the topic’. Other potential conversational partners (those who would be encouraged to ignore comments they viewed as irrelevant) were positioned as active while Maggie was positioned as the passive/obedient object. The focus of the speech language therapy plan was

on Maggie, as an individual, developing a set of ‘skills’, rather than on Maggie actively participating, contributing and developing the ability to express herself through participating as a respected and valued member of her classroom and school community.

Sharing family knowledge and perspectives

In an attempt to demonstrate the ways in which Maggie *was* using her language and communication there are excerpts from conversations at home, and of her enjoyment in telling and making up jokes at the time. I recorded and showed these stories to teachers and therapists as a way to share aspects of who Maggie was as a person, what her skills and interests were and how she was engaging in these and communicating them within our family context. Tony and I tried to encourage teachers, teacher aides, special educationalists, families and children to enter Maggie’s world, enjoy, share and learn from it. Our emphasis was learning *in context*. We assumed that once people got to know Maggie and how ‘she ticked’ they would be in a better position to encourage her learning and participation. The speech language therapist’s approach was to ignore and pathologise Maggie’s world and ‘communication style’ because it didn’t fit with pre-defined expectations about what is ‘normal’. From a deficit or special education worldview, if something/someone is not ‘normal’ then it/they need fixing.

Pathologising ‘difference’

Processes that pathologise children through defining perceived differences *as* deficiencies seem central to the thinking and practices of ‘special education’ and result in the exclusion of groups of children from equitable access to educational opportunities. Maggie’s laughter at the illustration of a child falling down the stairs was inscribed as some sort of weird

‘fixation’ that might be worth further investigation. Her ‘creative conversational style’, sense of humour and ways of responding were interpreted as “off the topic” and therefore of little interest or relevance to her learning and participation. In fact, her tendency to talk “off the topic” (split text, p. 223 - 225) was seen as getting in the way of the ‘real work’ she should have been doing. Pathologising Maggie drew attention away from her status as a person with rights, preferences and desires. A deficit focus on Maggie created barriers to adults and peers learning from and with her. One of the key messages communicated to Maggie was that who she was and how she expressed her thoughts and feelings was not important or okay, and that she should change herself to fit into other peoples’ (often near strangers) expectations.

Individualising ‘disability’ as a personal ‘problem’

The belief in disability being a ‘problem’ contained within individuals, and the implication that any questions, goals, interventions and outcomes be focused on that individual is evident in both the special education therapy plans and the school IEP. Although the school IEP does refer to other children, it is always in relation to what Maggie can learn or develop from those interactions or that situation with peers. The goal: “For *Maggie-Rose* to work towards achieving more *reciprocity in her* communication with peers, family and other adults” is a good example of this positioning of Maggie as being solely responsible for her growth and change, even when the particular aspect of learning is around communicating with others (pp. 220-223 split text). What is missing here, that is present in the ‘family column’, is a consideration of the relational context and interactive ‘nature’ of learning and communication. What was not considered in any detail in both Clare’s early childhood and Maggie’s school contexts were the influences and importance of how everybody else (her peers, teachers, teacher aides) thought about and related to and with *Clare and Maggie*.

The impacts of the socio-cultural, relational and affective environment on Maggie, Clare and their peers' learning and social inclusion was not central within the teachers' pedagogical approaches.

5.6 Summary of chapter and themes

Like Fran and Clare's experiences, this chapter contained many examples of how Maggie and our family were positioned, and we positioned ourselves in interaction with dominant, deficit discourses of disability. The juxtaposition of deficit-developmental discourses with 'credit' and socio-cultural discourses was used to examine and interpret the knowledge and processes relevant to these orientations and their potential and actual effects on Maggie's life, learning and participation.

In this section I summarise and further develop the three themes of: 'Disciplinary Mechanisms'; 'Coming out of the Closet'; and 'Policing Participation' that were introduced in the previous chapter. I also consider the nuances between Fran's perspectives, positioning and experiences and those represented in this chapter. I want to retain and explore the complexities of this topic and to avoid the assumption that all families with disabled children respond to and interpret their experiences in the same ways.

Disciplinary mechanisms

Fran and Clare experienced a kind of 'hyper-surveillance' that led to normalising judgements and the reproduction of deficit discourses and responses. This gaze directed and restricted the social positions that Clare and her family were able and likely to take up. Tony, Mary (ESW) and I tried to resist a deficit gaze and judgments because we wanted Maggie to be accepted and valued and to be offered the same opportunities to learn, belong and participate as her (typically developing) peers in our

community. This was perhaps different to the ways Fran described her resistance to a deficit gaze as a rejection of pity and blame, and discomfort about being the focus of other people's negative judgement and attention. Fran tended to describe, and perhaps view Clare, in relation to her differences or 'specialness' whereas we tended to try and emphasise Maggie's commonalities with others. There were examples in this chapter of our attempts and preference to view and position Maggie as more like, than different to, others. This positive positioning was often discounted by professionals using a deficit gaze. For example, positive parental interpretations of Maggie were discounted as a denial of her 'problems' and 'delays' and as an unrealistic view of her.

Although we expressed resistance to a deficit gaze, our tolerance of normalising labels such 'developmentally delayed' or having 'special education needs' for Maggie was required in order to gain access to funding, resources and access to the curriculum. Along with those labels and resources came special education personnel, processes, and normalizing knowledge and judgments. The outcome of this compulsion for Maggie to be classified, labelled and tested was that she was positioned as significantly different from most of her peers and experienced differential treatment as a result. A key aspect of this differential treatment was the regular, close surveillance and intervention of special education 'experts'. This involved Maggie being closely monitored, scrutinised, judged and consequently, interrupted by adults imposing their knowledge and agenda with the outcome of influencing her experiences, play, relationships and life.

A critical reading of both chapters Four and Five indicates that, although adult observation, intervention and judgement is a typical feature of many children's experience of education, assigning 'special education' labels to Clare and Maggie greatly intensified the 'disciplinary gaze'. The

influence of adults in their education settings produced negative consequences for their learning, contribution and participation.

Coming out of the closet

Although we gave different reasons for doing so, both Fran and I hid our children's differences and tried to 'keep them in the closet'. My motivation for hiding or remaining silent about Maggie's differences early on was my desire for her to be accepted and valued for who she was. I hid early concerns in a bid for our family and others to get to know and value Maggie without what I believed would be restricting labels and interventions. Hiding Maggie's differences was a form of resistance to deficit views and 'coming out of the closet' involved being forced to 'accept' or at least tolerate the gaze and involvement of professionals who drew from a deficit, personal tragedy power-knowledge regime of truth. Fran also hid Clare's differences, mainly in public situations, in an effort to avoid being stared at and judged negatively. Fran also wanted to de-emphasise Clare's differences when approaching West School about enrolment.

Fran, Tony and myself all experienced feelings akin to 'coming out' in response to being subjected to the disciplinary gaze and judgments that positioned ourselves and our children as 'other'. Fran described her difficulties with 'coming out of the closet' in relation to how she personally felt about acknowledging she had a child who wasn't going to 'catch up' to normal children, and feeling uncomfortable about being the focus of others' attention. Our feelings were associated with wanting to protect Maggie from the scrutiny and negative judgments of others and the potentially limiting consequences of those judgments for her. Fran also shared a strong desire for Clare to be valued and included.

Because of our conscious and partly professionally based resistance to deficit views of Maggie, coming out of the closet involved Tony and I becoming advocates for Maggie's rights to be respected and to learn with and alongside others. Our perspective was at odds with deficit discourses that sought to quantify Maggie's 'deviations' and treat her in ways that separated and positioned her as not 'normal' and, therefore, 'other'. Our advocacy involved constantly trying to explain her interests, strengths, and abilities in an effort to get others to notice, recognize, and respond to these as their key focus. This advocacy was often ignored, discounted and marginalized by professionals and 'experts'. Our perspective would be countered by chronicles of Maggie's perceived 'deficits', and how to 'fix' them.

Although our resistance and advocacy didn't remove Maggie from a deficit gaze and judgments that positioned her as 'other' and 'lacking', we *were* able to influence what happened for her in her early childhood centre. As her parents we were also able to make choices such as calling a halt to 'diagnostic' testing and invasive procedures at the hospital. Our advocacy and awareness minimized some of the exclusionary processes that Maggie would have otherwise experienced.

Policing participation

Rules and provisos of participation

Special education personnel made it clear to us that if we wanted to receive funding for an Education Support Worker in Maggie's early childhood centre, the involvement of early intervention, special education professionals was required. The belief that 'expert' knowledge is necessary to help 'special' children develop and participate in 'regular' educational settings is enshrined in policy, curriculum documents and embedded in

funding structures. A major influence on Maggie Rose and her participation in her early childhood centre and classroom was the monitoring and scrutiny of special education ‘experts’ whose focus was on identifying and disciplining her deviation from typically developing children. Although special education rhetoric was about ‘minimising differences’, many interventions and recommendations appeared to maximise them. The outcome was that Maggie’s participation with and alongside others in her early childhood centre and school was influenced and regularly interrupted by adults using a deficit disciplinary gaze.

Policing parental participation

At her primary school, our participation as her parents was actively marginalized by school and special education staff who positioned themselves as the experts and us as an interruption to their way of working. Our exclusion from being involved in meaningful exchanges of information and perspectives with school staff meant that our ability to know about and influence Maggie’s involvement and participation was limited.

Another way our participation was marginalized was through being a minority in situations such as IEP and other planning meetings we were expected to attend. Although our input as Maggie’s parents into the IEP process was required, the process, structure and focus of IEPs were already set. There was little room to consider the influences of others on Maggie’s participation and belonging and what they could gain from Maggie’s contribution to the classroom and school. Instead, the emphasis was on Maggie’s learning and achievement as an individual in specific subject and skill areas. In this way, a consideration of her participation was reduced to how she did and didn’t fit in to existing arrangements. If she was deemed unable to fit in with the rest of the class, then separate

alternatives and adaptations such as carrying out activities on her own with a teacher or teacher aide were devised. Similar to Clare's experiences in her early childhood centres, this represented a view of 'participation' as 'fitting in' to existing structures and arrangements rather than participation being about influencing and contributing to what happens in the classroom and curriculum.

'Participation' as de-contextualised

A view of disability as a problem of individual impairment influenced the de-contextualising of responses to Maggie's learning and participation at school. 'Expert' special education approaches to assessment and planning, such as those adopted by the speech language therapist, did not treat Maggie's home, school and classroom contexts as relevant and, therefore, of primary importance. This construction of disability as an 'individual's problem', alongside a developmental universalising of the experience of disability, translated into an absence of reflection and planning related to Maggie's actual communication, participation and relationships within the school and classroom settings. Largely ignoring her participation within relational contexts represented a missed opportunity to recognise, understand and remove any barriers to participation within those contexts. It also meant that there was little discussion and information gathered within the context that could help adults understand, build on and encourage the on-going development of relationships and co-participation.

Participation as 'fitting in' and/or physical presence

It appears that many of the adults involved in Maggie's education were using an understanding of 'participation' as 'fitting in'. This understanding and goal of 'fitting in', which could also be expressed as 'being normal or behaving normally', conflicted with our family's understanding of

participation as recognising, valuing and responding to what each child brings to the centre and classroom. Defining participation as physical presence and/or fitting in is restrictive and limiting to learners. Superficial understandings of disability and differences involve a non-recognition of each child's qualities and rights to be valued as a person, and to belong.

Facilitating Participation

How Maggie was viewed, and her participation facilitated in her early childhood centre, is examined more closely in relation to inclusive and emancipatory pedagogies in the next chapter.

Chapter Six “If You Don’t Know Her, She Can’t Talk”: Teacher Obligation and a Pedagogy Of Listening

6.1 Introduction

In this chapter I focus on both families’ experiences with special education, early childhood centre and primary school personnel and settings. In the first section of this chapter, I outline ethical and critical approaches to pedagogy. These approaches are broadly conceptualised as a ‘pedagogy of listening’ (POL). A POL, which was briefly introduced in Chapter One, is an ethical approach to education based on a teacher orientation of obligation, connection and responsibility to others (Dahlberg, et al., 2007; Dalhberg & Moss, 2005; Moss & Petrie, 2002; Rinaldi, 2006; Veck, 2009). I then consider a POL in relation to current New Zealand approaches to curriculum and pedagogy. In particular I discuss pedagogical research from the New Zealand early childhood sector that developed into a *Learning and Teaching Story Framework* (Carr, 1998; Carr, et al., 2001; Carr, et al., 2000). In the remainder of the chapter I use a POL and the *Learning and Teaching Story Framework* to interpret Clare, Maggie and their families’ experiences in education. I primarily draw from New Zealand early childhood pedagogy in this chapter because it is useful and relevant to a consideration of both early childhood and school-based pedagogy (G. Moore, et al., 2008). As outlined in Chapter One, the NZC makes strong statements about compulsory education being underpinned by a respect for diversity, social justice, inclusion, responsiveness and reflective teaching.

These aspirations are embedded within the pedagogical approaches I have drawn from and used in this chapter.

6.2 Educational settings as sites of ethical and political practice

Unlike situated and relational conceptions of teaching and learning, dominant Western approaches are underpinned by a belief that education is primarily a technical and objective enterprise with a focus on individual learning and the application of universal methods, rules and codes (Dalhberg & Moss, 2005; Fleer, 2005; Neyland, 2005; Valenzuela, et al., 2000). From such a viewpoint, universal ethics (one size fits all) are assumed to be a straight-forward matter of the application of set codes (Dalhberg & Moss, 2005). However, moral decisions and actions that do not consider or acknowledge differences within and between the groups of people, tend to default to the dominant group's beliefs, norms and stereotypes (FourArrows-Jacobs, 2008; Rivalland & Nuttall, 2010; Veck, 2009). Universal approaches, therefore, are underpinned by an unquestioned assumption that everybody should or does benefit from conforming to the dominant group's ways of thinking and being. The outcome of this thinking is that non-dominant groups are silenced and marginalised, and the dominant group retains its privilege.

Dahlberg and Moss (2005, p. 2) argue that rather than being neutral, preschools (and schools) are social-political-cultural institutions and “can be understood, first and foremost as forums, spaces or sites for ethical and political practice – as ‘loci of ethical practices’ and ‘minor politics’”. My interest is in exploring ways that teachers can be supported to engage *ethically* and *critically* with curriculum frameworks that already acknowledge the importance of the diverse qualities, values, beliefs and experiences that teachers, children, families and communities can contribute within their educational settings (Ministry of Education, 1996b, 2007b). In addition to the emphasis in *Te Whaariki* and the *NZC* on

responsive learning and teaching, an ethics-based approach emphasises the power relations that are circulating within every educational setting. As such, ethics-based approaches to pedagogy involve teachers developing a critical and political awareness of their role, work, relationships and institution (Dalhberg & Moss, 2005; MacNaughton, 2005).

Critical-ethical pedagogies open the way for the diversity and complexity that exists within education and society to be recognised and responded to rather than marginalised and ignored (Bishop & Glynn, 1999; Dalhberg & Moss, 2005; Ministry of Education, 1996b; Robinson & Jones Diaz, 1999). Dahlberg and Moss (2005, p. 2) argue that ethical pedagogies create possibilities for early childhood institutions to operate as “...places where the Other is not made into the Same, but which open up instead for diversity, difference and potentialities.” An implication of situated and relational pedagogies is the need “...to recognise, and learn to live with ambiguity and ambivalence” (Dalhberg & Moss, 2005, p. 70).

6.3 Pedagogy as listening

As discussed in Chapter One, a pedagogy of listening (POL) is based on an ethic of care for, and obligation to, ‘others’. A POL shares with New Zealand’s early childhood and school curriculum documents (Ministry of Education, 1996b, 2007b) an image of children (and adults) as diverse, social beings, active agents and competent learners. Teaching and learning are viewed as relational and co-constructed. In a POL ‘learning’, ‘truth’ and ‘knowledge’ are viewed as:

...a process of construction...The learning process is certainly individual, but because the reasons, explanations, interpretations and meanings of others are indispensable for our knowledge building, it is also a process of relations – a process of social construction. We thus consider knowledge to be a process of construction by the individual in relation with others, a true act of co-construction (Rinaldi, 2006, p. 125).

A pedagogy of listening works in *conscious resistance* to an epistemology that constructs teaching and learning as linear, objective, predictable, normative and universal (Dahlberg, et al., 2007; Rinaldi, 2006). It challenges images of children as ‘other’, passive, needy, weak and as lesser than adults and replaces this with an image of children as full citizens and participants in society (Rinaldi, 2006).

Rinaldi (2006, p. 70) describes ‘listening’ as being embedded within relational processes and contexts in which the expectations and behaviour of teachers are “*orientative*” and responsive, rather than pre-determined and prescriptive. In order to orient themselves to the learners within their contexts, Rinaldi (2006) suggests that teachers must analyse and interpret children’s experiences from an open, questioning and curious stance. This orientation challenges the dominant perception of teachers as the experts and knowers regarding children’s learning, aspirations and participation. Dahlberg and Moss (2005, p. 101) suggest that: “In radical dialogue, based on listening, as a teacher you have to participate together with the child, entering a space together where both teacher and child are actively listening and trying to construct meaning out of the situation.” Teachers orienting themselves as learners involves them acknowledging and inviting the:

...doubt and uncertainty (that permeate the teaching and learning) context... Herein lies true didactic freedom, for the child as well as the teacher. It lies in this space between the predictable and the unexpected, where the communicative relationship between the child and teachers’ learning processes is constructed (Rinaldi, 2006, p. 70).

Teaching becomes an ethical pursuit in which listening is used as a process for understanding, respecting and responding with openness to the other.

Pedagogy as the transformation of participation

Drawing from socio-cultural theorist Barbara Rogoff (2003), Carr (2001, p. 176) describes learning and development as “sited in action, in the relationship between the workings of the mind on the one hand and the cultural, historical and institutional setting on the other... development and learning are about transformation of participation.” Social transformation and the emancipation of ‘others’ within an ethic of care and obligation, are based on relations facilitated through radical dialogue and attentive listening. Rinaldi (2006, p. 184) links ‘dialogue’ with “having a capacity for transformation... It is an idea of dialogue not as an exchange but as a process of transformation where you lose absolutely the possibility of controlling the final result.” She suggests that when people consciously strive to connect with the ‘other’ there is hope for humanity and a more socially just world.

Documentation, assessment and radical dialogue

Margaret Carr (2001), a key author of the New Zealand early childhood curriculum (Ministry of Education, 1996b) and Carlina Rinaldi (2006) each emphasise the central role that context, documentation, critical reflection and dialogue have within pedagogy that is grounded in ecological and socio-cultural theories of learning and participation. They describe documenting children’s learning and experiences as a process for making teaching, learning and participation visible and therefore available for interpretation, critique and transformation. Rinaldi suggests that the value of documentation is in providing ‘traces’ of learning and teaching. This resonates with Carr’s description of learning stories, or narratives of learning in action, as documented fragments or threads of connected experience. Documenting, sharing and reflecting on ‘learning in action’ makes children’s learning and teacher practice open to changing

interpretations over time through reflection, discussion, dialogue and action (Carr, 2001; Rinaldi, 2006). The participants' narratives and excerpts from Maggie's Learning Story Book provide traces of Clare and Maggie's learning and participation and these traces make their experiences available for critical reflection. Within a *Te Whaariki* based approach to documentation, assessment and critical reflection, children, families and teachers all have the opportunity to document, discuss, interpret and contribute their perspectives and insights about learning and participation (Carr, 2001; Ministry of Education, 1996b, 2005).

6.4 A POL and education in Aotearoa-New Zealand

The principles and strands of *Te Whaariki* provide a foundation for consensus about children's (and adults') rights and teachers' responsibilities and obligations in early childhood settings in Aotearoa-New Zealand. As outlined in Chapter One, the principles require teachers to recognise and foster the *empowerment* of *all* young children as they learn and grow; to draw from *holistic* conceptualisations of learning and development; to recognise and value the integral place of the *wider world, community and family* in children's learning and participation; and to approach learning as an intersubjective process where children: "... learn through *responsive and reciprocal relationships* with people, places and things" (Ministry of Education, 1996b, p. 14). (emphasis added)

The principles of *Te Whaariki* are ethical statements that focus on what is expected of teachers within early education settings (Ministry of Education, 1998). The strands further emphasise learning and education as situated and responsive. Their focus is on children having experiences that are characterised by belonging, well-being, engagement, exploration, communication, self expression, contribution and responsibility to and for each other. The orientation and practice of 'attentive listening' as a process for teaching, learning and transformation is reflected in New Zealand's

narrative, ‘learning and teaching story’ approaches to assessment, documentation and critical reflection (Carr, 1998, 2001; Carr, et al., 2003; Carr, et al., 2000; Greerton Early Childhood Centre, 2010; Ministry of Education, 2005; Te One, et al., 2010). As such, *Te Whaariki* can be approached as an ethical framework that communicates an emancipatory vision for diversity and social justice as central to New Zealand early childhood education environments, pedagogy and society.

The ‘Learning and Teaching Story Framework’

Carr, May, Podmore and Mara (Carr, et al., 2001; Carr, et al., 2000; Podmore, et al., 1998) have developed a theoretical and practical, *Te Whaariki* based framework for New Zealand early childhood pedagogy. This ‘*Learning and Teaching Story Framework*’ was designed as a guide for teachers in ‘assessing’ children’s learning and ‘evaluating’ teaching practices. It was informed by in-depth, narrative inquiry and participant observation within a diverse range of New Zealand early childhood centres (Carr, 1998; Podmore, et al., 1998). The purpose of the research was to consider how the principles, strands and goals of *Te Whaariki* were lived and enacted within diverse ECE contexts.

The researchers identified key ‘features of participation’ and ‘dispositions for learning’ through considering how the curriculum principles and strands were reflected in action within the research centres and how the children, families and teachers approached learning and participation within those contexts (Carr, 1998; Podmore, et al., 1998). The key features of participation seemed to centre on children: ‘taking an interest; being involved; persisting with difficulty, challenge and uncertainty; expressing a point of view or feeling; and taking responsibility’ (Carr, et al., 2000, p. 9). The research also suggested that children’s (and adults’) capacity to participate evolved alongside key

dispositions or ‘habits of mind’. These dispositions included children developing courage, curiosity, trust, playfulness, perseverance, confidence, empathy and responsibility within their settings (Carr, 1998; Carr, et al., 2003; Carr, et al., 2001; Carr, et al., 2000; Ministry of Education, 2005; Podmore, et al., 1998). The researchers suggested that these features of participation and dispositions could provide a framework for teachers to use when listening and responding to, documenting, discussing and interpreting children’s learning and participation (Carr, 2001; Carr, et al., 2000).

The following page contains an outline of the learning story focus of the *Learning and Teaching Story Framework*. This centres on understanding individual children’s learning and experiences within a relational context. The table identifies the potential connections between the strands of *Te Whaariki*, children’s learning dispositions, and features of participation. The Framework, like the Curriculum, is underpinned by the four guiding principles of *Te Whaariki*.

A Learning Story Framework

Curriculum Strand		Learning Dispositions	Features of Participation
Belonging - Mana Whenua	Children and their families feel a sense of belonging	Courage and Curiosity To find something of interest here	Finding and taking an interest
Well-being – Mana Atua	The health and well-being of the child are protected and nurtured	Trust and Playfulness	Being involved
Exploration – Mana Aoturoa	The child learns through active exploration of the environment	Perseverance To tackle and persist with difficulty or uncertainty	Persisting with difficulty, challenge and uncertainty
Communication – Mana Reo	The language and symbols of their own and other cultures are promoted and protected	Confidence To express an idea, feeling, a or point of view	Expressing a point of view or feeling
Contribution – Mana Tangata	Opportunities for learning are equitable, and each child's contribution is valued	Responsibility and Empathy For justice and fairness, and the disposition to take on another point of view	Taking responsibility

Figure 5: A Learning Story Framework

Based on: (Carr, et al., 2000, p. 9; Ministry of Education, 1996b)

The Teaching Story Focus of the Framework

The *Teaching Story* focus of the Framework connects children's learning and participation with teachers' capacities to listen to children and families, and to critically reflect on their practices and environment (Carr, et al., 2000). The inclusion of *teaching* stories in the Framework was intended to encourage teachers to take responsibility for their influence on children and families and to make positive changes to enhance the learning, participation and empowerment of children and families within their settings (Carr, et al., 2001; Carr, et al., 2000; Ministry of Education, 1996b; Podmore, et al., 1998).

The Child's Questions

The starting place for developing teaching stories was a set of hypothetical 'child's questions'. These were also developed from observational, narrative inquiry into how infants, toddlers and young children were experiencing their early childhood education environments (Carr, et al., 2001; Carr, et al., 2000; Podmore, et al., 1998). Like the 'features of participation', and 'dispositions', the child's questions were also closely aligned to the principles, strands and goals of *Te Whaariki* in action (Podmore, et al., 1998). The child's questions, in short form, are 'Do you know me?', 'Can I trust you?', 'Do you let me fly?', 'Do you hear me?' and 'Is this place fair?' Their purpose was to encourage teachers to orient themselves to each child and family's perspective (Carr, et al., 2001). The following page contains an outline of the *Learning and Teaching Story Framework* including the 'child's questions'.

A Learning & Teaching Story Framework (Carr, et al., 2001; Carr, et al., 2000; Ministry of Education, 1996b)

Curriculum Strand		Learning Dispositions & Features of Participation	Long question	Short question
Belonging - Mana Whenua	Children and their families feel a sense of belonging	Courage and Curiosity Finding and taking an interest	Do you appreciate and understand my interests and abilities and those of my family?	Do you know me?
Well-being – Mana Atua	The health and well-being of the child are protected and nurtured	Trust and Playfulness Being involved	Do you meet my daily needs with care and sensitive consideration?	Can I trust you?
Exploration – Mana Aoturoa	The child learns through active exploration of the environment	Perseverance Persisting with difficulty, challenge and uncertainty	Do you engage my mind, offer challenges, and extend my world?	Do you let me fly?
Communication – Mana Reo	The language and symbols of their own and other cultures are promoted and protected	Confidence Expressing an idea, feeling or point of view	Do you invite me to communicate and respond to my own particular efforts?	Do you hear me?
Contribution – Mana Tangata	Opportunities for learning are equitable, and each child's contribution is valued	Responsibility and Empathy Taking responsibility	Do you encourage and facilitate my endeavours to be part of the wider group?	Is this place fair? Is there a place for me here?

Figure 6: A Learning and Teaching Story Framework

The urgent need for a focus on teaching stories

Anne Meade (2002), a respected New Zealand early childhood leader, researcher and writer, suggests that there has been an over-emphasis in New Zealand early childhood thinking and practice on the narrative assessment of individual children's learning and an under-emphasis on theories and practices of teaching. She argues that, since the introduction of *Te Whaariki*, professional resources, development and energy have focused on assessing individual children's 'learning' and 'progress' much more than on supporting teachers to engage in critical reflection about the theoretical, ethical and practical implications of the curriculum for their teaching. The Teaching Story concept and the 'child's questions' seem to have largely disappeared from or not to have entered teacher and teacher educators' consciousness and practice.

The child's questions can be used critically to develop stories with a focus on learning *and* teaching within educational contexts. They can be used as a critical tool for encouraging teachers to recognise and transform relations of power where these are restricting children and excluding them from equal opportunities to learn and participate (Carr, et al., 2000). Teacher reflection and dialogue using the child's questions may provide a pathway for teachers to value and work within the spaces between themselves and others (children and family members) (Gordon-Burns, Purdue, Rarare-Brigs, Stark, & Turnock, 2010; Ritchie, 2010). When used critically, the *Learning and Teaching Story Framework* can help teachers to understand and use a listening based pedagogy to recognise, challenge and transform normalising, exclusionary discourses, practices and arrangements in their settings (Podmore, et al., 1998).

6.5 Applying a pedagogy of listening to the family narratives

I now consider each family's experiences with early childhood and school personnel and settings. I use a 'pedagogy of listening' orientation, and the *Learning and Teaching Story Framework* for interpreting how Clare and Maggie were constructed as learners and participants in their educational settings. Because I am applying a different lens to the data, I have chosen to revisit and re-examine some of the narratives from the previous two findings chapters as well as introducing some additional data in relation to Clare and Fran's experiences. Maggie's data comes from the existing split text in chapter five. The excerpts I have selected were not interpreted in-depth and detail in that chapter. The section examining Maggie's experiences includes photographic and document data, personal recollections and excerpts from interviews with Tony and I. Because of this variety of data, it is more multi-layered than Fran and Clare's section. As with the two previous findings chapters, I have placed my representation of Fran's narrative first. I acknowledge that the greater variety of data for my family and the absence of a range of data for Fran's creates an imbalance in the presentation and interpretation of each family's experiences. I have chosen to live with this imbalance in the interests of doing as much justice as possible to each family's narrative.

6.6 Fran and Clare: "If you don't know her, she can't talk."

During our first interview, Fran told me a story about her midwife making incorrect assumptions about Clare's ability to communicate based on the midwife's informal observations of Clare during a meeting with Fran. When Clare was two years old, Fran met with her midwife to ask her to write a referral so that she could involve a specialist in her care during her pregnancy with Amber. The midwife wrote in her referral letter that Clare wasn't able to talk. Fran was upset about and disagreed with the midwife's assessment saying that during the visit Clare was busy observing and

taking in the new environment. Fran believed that Clare didn't talk during the visit because she didn't have a relationship with the midwife and the setting was unfamiliar. Fran's comment in response to the midwife's assumption that Clare couldn't talk was that "If you don't know her (Clare), she can't talk."

My aim in representing and interpreting these narrative excerpts is in listening and being open to Fran and Clare's experiences through applying a 'gaze' which is attentive (Veck, 2009) and responsive (Ministry of Education, 1996b) and grows from an ethic of obligation, care and responsibility to the 'other'.

Crossroads Childcare Centre

Crossroads was the childcare centre that Clare was enrolled at for one morning a week during the year she was two years old. Sandra, her ESW, was only employed by Clare's early intervention service (EIS) during school term time and so Fran stayed with Clare at the centre during the school holidays when Sandra was absent. I base my analysis on Fran's descriptions of Clare's participation, relationships with teachers and teacher responses to planning for Clare and her inclusion in the centre. Fran talked about when Clare started at Crossroads:

Fran:...she didn't even know that other children existed, really. She was none the wiser as to what was going on around her, she just sat, really...They had their mat time, as most places do, I suppose, and they had songs, morning tea and-play lunch, but it was all free play, there was nothing structured about it...

Fran looked forward to Clare learning about and developing relationships with other children, and with the teachers at the centre. She wanted the centre teachers to welcome, invite and encourage Clare to learn and participate. When applying an attentive gaze to Fran's perspective I would

suggest that the teachers' based their practices on a universalised image of 'the child' as independent, and that their subsequent "free play" approach to children's participation became problematic for Clare because she wasn't independently mobile or skilled and experienced at interacting with other children.

Because Clare wasn't able to walk and move around the centre independently, she needed support to physically explore and engage within the environment. She wasn't able to go and join other children at play in the same ways as her other peers in the centre. Fran suggested that, because of the small size of the indoor space at the centre, the children and staff often spent a lot of time outside. She said that there were not a lot of things that Clare could do independently and without support in the outdoor environment. Fran was concerned about the teachers not spending time with Clare without the presence of her ESW. She interpreted this as the centre teachers being disinterested in Clare. Fran's perception of the teachers' disinterest was reinforced by their unwillingness to help Fran and Clare with their access into and out of the centre building each time they attended.

Formal planning for Clare was arranged by and held at the Early Intervention Service. Only the head teacher from Crossroads attended these meetings. Although Fran said that the teachers did record "learning stories" about Clare in the centre, their 'assessment' documentation didn't seem to be used formatively in terms of it influencing or increasing the teachers' engagement and relationship building with Clare over the year she attended the centre. Fran said that, at the 'Individual Education Planning' meetings, the head teacher talked about "What the other children were doing around Clare, and her becoming more part of the centre", but this awareness didn't translate into inclusive practices.

Clare's experiences at Crossroads and a pedagogy of listening

The teachers and early intervention personnel appeared to have a restricted understanding of their obligations towards and responsibility for Clare's involvement in the centre. It could be that the teachers viewed their responsibilities to other children in the centre in a similar way. That is, they may have primarily seen their role as setting up the environment and then 'standing back' and observing the children's play (May, 2001; Meade, 2002). If this was the case, then Clare may not have been the only child who could have benefited from deeper connections with the adults in the setting. However, the teachers' lack of sensitivity and openness to Clare as a learner and a person, and their lack of responsiveness to Fran's aspirations for Clare's inclusion, acted as additional barriers to her participation. Rather than listening attentively to Clare, viewing her *holistically* and seeing it as their role to foster her *empowerment* within the setting, Clare's 'otherness' became a disincentive or reason for her not to be fully included (Ministry of Education, 1996b; Veck, 2009).

Do you know me?

The strand of Belonging – 'children and their families experience a sense of belonging' and the critical, reflective question 'Do you know me'? – are central to Fran and Clare's experiences at Crossroads. *Te Whaariki* and the *Learning and Teaching Story Framework* interweaves children and families' sense of belonging and well-being with each child developing the dispositions to *take an interest* in the people, places and things in their environment, and to *become involved* in the relationships, happenings and life of the centre. Fran's description of Clare opening up "like a little flower" when she "realised there were other children around her" at the centre, indicates that Clare was disposed to taking an interest in what was happening around her. Although Fran was aware of the significance of

Clare's discovery and interest in the people in her new surroundings, the teachers' behaviour didn't indicate their awareness of being obliged to get to know and include Clare within the life of the centre.

Clare's sense of belonging as a fully participating member of the relational and learning context was also influenced by her attendance at Crossroads for only half a day each week. Fran based her choice about the number of hours that Clare was enrolled for on the limited funding that had been allocated by the EIS for an ESW for Clare. Had Fran not spent the mornings during school holidays at the centre with Clare, the amount of time she was there would have been even less. The teachers' actions, and Fran's interpretation of what was happening, indicated that the teachers saw Clare as being the responsibility of someone else - her ESW and her parent when the ESW wasn't present. In this way Clare's identity as 'special' became a reason for teachers not to get to know her or to see it as their role to include her, even partially, in the relationships and life of the centre (Veck, 2009).

Fran's understanding, that Clare not knowing someone limits her ability to communicate, is reflected within a pedagogy of listening and *Te Whaariki*. Without the benefits of being heard and developing reciprocal and meaningful relationships Clare's opportunities to learn, contribute and participate to the best of her ability were impaired by her environment. Developing connections and relationships are central to experiencing a sense of belonging within a early childhood setting (Ministry of Education, 1996b). It is ironic and concerning that this situation was allowed to occur and continue given that a stated goal of the teachers was for Clare to become more part of the centre. It appears that Fran and Clare's voices were not listened to or considered in these planning discussions and reflections.

In addition to asking the question, ‘Do you know me?’, this situation prompts me to ask: ‘Do you *want* to know me?’, ‘*Why* don’t you want to know me?’ and ‘Why do you *say* you want to know me and for me to be part of the centre, and then *do nothing different* to encourage my influence, participation and connections with others?’ Without attention to responsive, reciprocal relationships between a child and her family, ESW, teachers, and peers, the possibilities for learning and participation within a context are significantly diminished. In the absence of teachers exercising their obligation to develop a respectful and reciprocal relationship with a child, the answer to the questions – ‘Can I trust you?’, ‘Do you let me fly?’, ‘Do you hear me?’, ‘Is this place fair?’ and ‘Is there a place for me here?’ – must be no.

South Preschool

Clare attended South Preschool for two days a week when she was three years old, and for three days a week when she was four years old. Sandra, Clare’s ESW, was at the centre when Clare was in attendance except for two half hour periods each day. Fran talked about the times when Sandra wasn’t present in the centre, starting with a daily group time in the mornings. Note that Fran described Clare as being “by herself” when Sandra wasn’t present with her in the centre.

Fran:...and they do a dance or a song or whatever, and I’ve watched all the teachers in there with her through the door, and they grab her hands and wiggle with her or they do whatever. But she pretty much sits on the mat and they do their thing, so that’s a safe time because the teachers and all the children are on the mat. So it’s safe to leave her by herself, and then Sandra comes in at 9:30 and then lunchtime, after Clare’s eaten, Sandra goes and has half an hour, and that’s usually sort of rest time where the children read books or – they’re inside and they’re having a... it’s quiet time. So she has that quiet time by herself then, and she doesn’t – we don’t seem to have had any problems with her being by herself. And

I don't think that she will have any problems (at school) being by herself at certain times.

Apart from the incident where Clare's hair was pulled out and the centre subsequently refused Clare's attendance when Sandra was away, Fran mainly spoke in positive terms about Clare's and her own experiences with South Preschool. In particular, Fran felt that the teaching staff invited and were responsive to her input as Clare's mother, that they valued Clare as an individual and celebrated Clare's achievements in the centre.

Clare's experiences at South Preschool and a pedagogy of listening

Using a lens of attentive listening and the child's questions to critique Fran and Clare's experiences at South Preschool, and also my experiences as an early childhood teacher and a mother, perhaps encourages a different and more critical interpretation of Clare's experiences, than Fran's. My interpretation of Fran's narrative in Chapter Four suggested that the South Preschool teachers abdicated their obligations to, and responsibility for, Clare's learning and participation to Fran. My view was that, although they invited and were responsive to Fran's input, the teachers followed Fran's lead without contributing and negotiating any knowledge, observations or insights as Clare's teachers themselves. In this regard, the teachers may be described as listening to *Fran*, but as not exercising their full obligations and responsibilities to listen to Clare. They also didn't seem to listen to or consider the theoretical underpinnings and practical implications of their guiding curriculum document, *Te Whaariki* in their responses to Clare's learning and participation. The outcomes of this situation for Clare appeared to be an emphasis within the centre's programme and relationships on Clare developing self help and independence skills and fitting in to the existing norms, expectations and arrangements of the centre as much as possible.

I am interested in considering the potential outcomes for Clare's learning and participation, had the South Preschool teachers taken a more active, holistic, relationship and empowerment based approach to assessment, planning and reflection (Ministry of Education, 1996b). Learning (assessment) and teaching stories (critical reflection on teaching practices) did not seem central to the teacher's discussions or thinking about Clare in the centre. From Fran's description of the centre's planning and the dialogue she had with them, there was little or no consideration of, or responsiveness to, Clare's lived participation, interests and developing dispositions within the centre. For example, there didn't appear to be a consideration of Clare's relationships and interactions with others. Respectful relationships and communication are central to a socio-cultural view of pedagogy in general and *Te Whaariki* in particular (Carr, 2001; Dahlberg, et al., 2007; Ministry of Education, 1996b; Rinaldi, 2006). Similar to my conclusion about the teachers at Crossroads Childcare Centre, it is possible that the teachers at South Preschool did not attend closely to children's relationships, cues and interests as the basis for their pedagogy. Although this raises questions about what early childhood teachers are basing their pedagogy on for *all* children (Carr, 2001; Meade, 2002; Rinaldi, 2006), the negative implications of an absence of attentive listening for children who don't conform to 'normal' expectations are perhaps greater than for typically developing children from the dominant culture and worldview (Fleer, 2005).

Fran described Clare regularly being removed from her group to work in isolation with her ESW when the rest of the children were engaged in activities that were 'too hard' and therefore deemed 'inappropriate' for her. The learning that Fran described and valued involved Clare learning to recognise, recite and write the letters of the alphabet, and to count to 20. Fran associated this learning with supporting Clare's preparation for

school. Fran was also keen for Clare to conform to the centre's rules (e.g. not hitting), exercise independence (get to the bathroom and fetch things by herself) and be familiar with the centre routines. Whilst most of these activities and goals, with the exception of being removed from her group to work on "her own things", may be viewed and justified as acceptable within a *Te Whaariki* based curriculum, they don't appear to have originated from teacher's listening and responding attentively to Clare as a learner.

The child's questions

It appears that the teachers at South Preschool relied on Fran's knowledge of Clare to plan for her within the centre, rather than also developing an understanding of Clare's interests and abilities through attentive observation and listening. Based on Fran's assertion that Clare was happy to go to Preschool and, "she'd go seven days a week if she could", it can be assumed that there was at least one adult in the centre that Clare felt safe with and trusted. Clare's key relationship was with Sandra, her ESW, who was employed by and responsible to the EIS rather than the early childhood centre. It seems probable that Sandra, who was present except for two half hour periods each day, was mostly responsible for meeting Clare's "...daily needs with care and sensitive consideration" (Carr, et al., 2000, p. 9). Clare being asked not to attend "for safety reasons" on a day that Sandra was unable to be at the centre indicates that she was seen as Sandra's responsibility.

Clare being expected to fit into the centre programme and being removed to spend time with Sandra when she was unable to 'fit in' suggests that the teachers did not see themselves as responsible for 'engaging Clare's mind, offering challenges or extending her world' in ways that responded to her as a fully participating member of the centre

community (Carr, et al., 2000). In regards to the child's question, 'Do you hear me?', the teachers appeared to hear and perceive Clare in terms of her label, differences, and otherness, and typically responded to these with a disciplinary rather than attentive gaze (Veck, 2009). Clare was expected to 'take responsibility' in terms of fitting in with and following the rules and routines of the centre, but these were not reflective of or responsive to her as a person and a learner. In that regard, the teachers didn't seem to "encourage and facilitate (her) endeavours to be part of the wider group" (Carr, et al., 2000, p. 9).

In terms of the centre programme, relationships and activities, Clare's presence and participation didn't seem to influence what the teachers did or how things happened in the centre. In this regard the answer to the child's question, 'Is this place fair?' must be no. In regards to the question, 'Is there a place for me here?' the answer appeared to be that there was a place for Clare if she, her family and her ESW conformed to expectations of how they were to fit in to the existing, normalised arrangements. At times there were different rules for their participation. In situations where the teachers were required to take full responsibility for Clare, her place in the centre was regarded as negotiable rather than as a right.

Summary

Clare and Fran's experiences in both early childhood centres indicated a difference in how Clare's learning, participation and rights were viewed by the teachers compared with how they would typically view their role and responsibilities in relation to non-disabled children. In each of Clare's early childhood centres, the teachers' actions and inactions indicated a lesser or different sense of responsibility and obligation regarding her learning, contributions and participation than they did for 'typically developing'

children. For Fran, people developing a relationship and shared connections with Clare, was an important aspect of getting to know and understand her. As Fran said about Clare: “If you don’t know her, she can’t talk.” A barrier to Clare’s learning, participation and inclusion, was that the teachers didn’t get to ‘know’, or develop a responsive and reciprocal relationship with her (Ministry of Education, 1996b).

6.7 Maggie, Bernadette and Tony: “we need to learn her language”

In relation to getting to know Maggie Rose, Tony said:

...most of the time I just feel like she’s just Maggie Rose. And her issues are... because, because she’s different, we need to learn her language, or learn her culture even. Maggie Rose... I want to spend more and more time with Maggie Rose that’s who she is, that’s how you can relate to her. And I want to make sure that the world goes there as well, that who she bumps into at school will ... that’s our philosophy, our vision as she goes to make her way in the world... and I don’t think it was that way before she was born, I’ve had to learn things, and you’ve (Bernadette) helped teach me that, and she’s helped teach us that...It’s such a beautiful – I mean, she is so interesting, she’s fascinating.

B. She’s such a cool person, and she has got a really unique outlook on life and the way that she experiences life, and it’s very enjoyable.

T. It’s interesting trying to get a sort of metaphor for Maggie Rose, and I do like that one, that she comes from a different culture, and then you try to learn as much about that culture as you can. That’s quite a good way of looking at it...That would rely on finding teachers who are interested in engaging with children and getting into their worlds... And I’m very very clear now that I don’t think of Maggie Rose as having a disability. Maggie Rose is different, and Maggie Rose is interesting, and fascinating... – but I don’t think of her as having disabilities, I don’t think of it in a way ... most of the time I just feel like she’s just Maggie Rose.

Tony's emphasis on others needing to reach out to get to know and connect with Maggie as a person before she can fully 'be' and express herself is similar to Fran's view of others needing to know Clare before she is able to communicate. In his description of Maggie, Tony acknowledges the complexities of understanding her as a person at the same time as the 'simplicity' ("she's just Maggie Rose") of his relationship with and understanding of her. He acknowledges his 'inability' to 'grasp' Maggie because, "she's different". He describes her differences or 'otherness' as "interesting", "beautiful" and "fascinating" and rejects a view of her as 'disabled'. This is perhaps similar to Fran's preference for referring to Clare as "special" rather than 'disabled'. To Fran, 'special' didn't always mean needy, it also meant interesting, happy and lovable.

A pedagogy of listening embraces ambiguity and uncertainty and encourages an open and listening orientation that expects and invites the unpredictable and inexplicable in our relationships with others. Being open to differences and complexity helps us to learn about and engage with others, to get "into their worlds". Deep engagement invites radical dialogue and radical dialogue creates the possibility for the transformation of teachers, children, families and learning communities or institutions (Dalhberg & Moss, 2005; Moss & Petrie, 2002; Rinaldi, 2006).

Rather than trying to fit or perceive Maggie Rose in terms of dominant expectations for what is 'normal', Tony expresses a desire for himself and others to recognise Maggie's differences and to orient themselves towards her world or her "culture even". He suggests that from his experience as Maggie's Dad, when we enter her world we are likely to learn new things and expand our understanding of our world and ourselves within it.

Following is an examination of two assessment experiences involving Maggie Rose and an interpretation of each from a pedagogy of listening perspective and the child's questions. The first experience was school based and relates to a special education assessment situation, report and recommendations. The full narrative of this situation and report are in the Chapter Five, 'Primary School' section of the split text (see pp. 222-225). The second assessment experience consists of excerpts from Maggie's early childhood centre Learning Story Book and a review of the centre's pedagogical approach to interpreting, discussing, planning and teaching using Learning Stories. I have reversed the order in which the situations are presented (school and then early childhood), so that I can continue using a pedagogy of listening and the child's questions as a tool for exposing and critiquing exclusionary practices, and follow this critique with a positive exemplar of employing a pedagogy of listening alongside the child's questions.

Listening attentively to special education perspectives at school

The assessment situation that follows raises issues about what counts as valuable learning, what is seen as important in terms of a child's learning and the particular goals we set for children in our early childhood centres and classrooms.

Not long after Maggie had started school, a speech language therapist (SLT) came to school to carry out an 'assessment' with her. Maggie had previously met this person at school on one or two occasions. The 'assessment' was referred to as a "test" by the therapist. It consisted of Maggie being shown and asked questions about a series of illustrations. According to the SLT's report, the purpose of showing and asking Maggie questions about each illustration was to:

Determine Maggie's ability to maintain attention to task, ...gain some knowledge of her expressive language abilities in connected speech, and gauge Maggie's ability to maintain the topic when asked a question.

The SLT took Maggie out of her classroom with Maggie's teacher aide to carry out the test. The teacher aide sat quietly and observed and was not involved except for her physical presence in the room. These were the recorded "results" of the "test":

Maggie-Rose's ability to maintain attention to task was limited. The test was abandoned after the 7th card as she became fixated and very amused by the previous card. (A picture of a girl who had fallen down some stairs and broken her glasses).

"Testing" and a pedagogy of listening

Rather than approaching assessment as attentiveness to Maggie's learning and abilities within her classroom context, the SLT was *listening for* the performance of specific behaviours and 'abilities' that she had pre-determined as of interest and importance (Carr, et al., 2003). Using Veck's (2009) Foucauldian based analysis of listening, the SLT was using a 'disciplinary', rather than an 'attentive gaze'. The SLT's use of the term "fixated" to describe Maggie's response to the illustration of a girl falling down the stairs suggests an interpretation that assumed and positioned Maggie and her behaviour as pathological and 'abnormal'.

An orientation of responsiveness, openness and sensitivity towards Maggie within the situation makes other interpretations possible. For example, it is possible to understand Maggie's reaction as an expression of interest and amusement rather than a "fixation". Rather than listening attentively, the SLT judged Maggie in relation to her perceived differences or deficits. It could also be suggested that it was the situation

and context, not Maggie, that was unusual or abnormal. If the context of the situation was changed, it is quite possible to view Maggie's behaviour as appropriate, creative and acceptable. For example, if I had been reading Maggie a nursery rhyme book and reciting 'Humpty Dumpty' with a picture of him falling off the wall and she had laughed when I said: "Weeee! Bang!" when Humpty fell down and Maggie had wanted to read it over and over, I would not have interpreted her behaviour as evidence of a 'fixation'. On the contrary, I would have interpreted the situation as one of Maggie and I experiencing a period of joint attention that involved sharing a joke.

I am not surprised that Maggie wasn't that keen on answering the speech language therapist's questions. She had been removed from her classroom to answer questions about some pictures by a near stranger. Maggie's reluctance to focus on and respond to the SLT's questions was interpreted as evidence of her being unable to 'maintain attention to task'. This didn't mean that Maggie was unable to concentrate and engage when a topic was meaningful and of interest to her. In fact, Maggie's "fixation" with one of the picture cards was an example within the assessment situation of her ability to 'maintain attention to task'.

The SLT's return visit

A few weeks later, the SLT returned to school to repeat the picture "test" with Maggie. After this session the SLT wrote:

Maggie-Rose demonstrated that she was able to maintain the topic when asked a question. However this linked with her attention span. When presented with the remaining three pictures left over from the previous session, Maggie-Rose once again became fixated on the picture she found amusing. Consequently the test was abandoned.

The conclusions from both visits demonstrate the SLT's inability or unwillingness to listen to and interpret Maggie's attention to the 7th picture card as evidence of Maggie's ability to maintain attention. Rather than approaching assessment as a process involving listening to and learning about Maggie, the SLT's approach to assessment was about listening for pre-determined evidence of 'ab/normal' behaviour, in order to "determine" and 'treat' Maggie's deviation from those norms.

On the basis of the assessment, the SLT wrote a report for the classroom teacher. The report included a recommendation to Maggie's teacher that:

To facilitate Maggie-Rose to remain on-task it is recommended that a visual schedule be implemented to support and enhance organisation, functional communication and attention skills. Further, that she will be expected to remain "on-task" for a given amount of time e.g. 5 minutes, then she is allowed to choose an "off-task" activity for a given period of time. Once this time is up she will be expected to return "on-task", for a given period again.

Thankfully, Maggie's classroom teacher discounted and ignored the SLT's conclusions and her recommendations. However, it is still concerning to me that the SLT was able to remove Maggie and her teacher aide from her classroom to conduct the tests and make her judgements and recommendations.

Other results from testing

Maggie's .1 'special needs teacher' at school *was* interested in the SLT's results and recommendations. After the SLT had been the second time, the .1 teacher talked with me about Maggie's reactions to other children when they were visibly unhappy or had hurt themselves at school. She suggested that Maggie's reaction, which was often to become very focussed on the

child and to giggle, was unusual or abnormal. She used Maggie laughing at the picture of the girl falling down the stairs in the 'test' as an example of Maggie's 'tendency' to become 'fixated' and react 'strangely' to other children's misfortunes. I explained that Maggie laughing and being focused in situations where a child was upset, was her way of expressing her curiosity, uncertainty and discomfort about what was happening. I suggested that, in situations where another child was upset, teachers could explain what had happened, and also reassure Maggie to help her feel less anxious. In relation to the illustrated card and Maggie's reaction, I talked about the tendency in Western culture to find other peoples' misfortunes humorous. The interpretation that I shared with Maggie's .1 teacher was that Maggie's response to the picture card could be viewed as evidence of her developing sense of humour rather than as evidence of her deviation from the 'norm'. I don't think that the .1 teacher accepted my interpretation.

The 'assessment' situation and the child's questions

Maggie's interests and abilities were not considered relevant or important within these 'assessment' situations. 'Knowing' Maggie was reduced to looking for and constructing ways in which she was perceived to deviate from the 'norm'. In terms of Maggie being able to trust that the adults in her environment would, "meet (her) daily needs with care and sensitive consideration" (Carr, et al., 2000, p. 9), allowing Maggie to be removed from her classroom by a stranger was a problem. The situation counteracted orientations to assessment as a process for developing understandings about Maggie that would help adults to "engage (her) mind, offer challenges and extend (her) world." For example, the SLT seemed disinterested in finding out about Maggie's interests, strengths, or abilities or how she communicated in various situations. From a view of learning and knowledge as predictable, and of education as the

transmission of pre-determined knowledge to an individual, *who* Maggie was as a person and a learner within her family and classroom contexts was probably not very relevant.

Rather than teachers and therapists inviting Maggie to “communicate and respond to (her) own particular efforts” and “facilitate (her) endeavours to be part of the wider group”, she was expected to conform to normalising expectations and her efforts to find something of interest in the situation were interpreted negatively. In response to the child’s question ‘Is this place fair?’ I would suggest that it was unfair and stigmatising to remove Maggie from her usual context and subject her to normalising judgements and a disciplinary gaze. Although there was *a* ‘place’ for Maggie at school, it appeared that her position and placement in relation to the wider school group and community was viewed and treated differently. The classroom teacher’s tacit acceptance (through allowing Maggie to be removed and tested) of the SLT’s emphasis on Maggie’s disability or difference as her defining characteristic, acted as an invitation to the .1 ‘special education teacher’ to look for and find further ‘evidence’ of Maggie’s behaviour as deviant.

This situation reinforced for me the dangers posed by the intensified and narrowed scrutiny or ‘gaze’ that labelled children are under (Allan, 1999; Veck, 2009). Coupled with ‘disability’ being viewed as a person’s defining characteristic, the disciplinary gaze can lead to situations where a child’s attributes, interests, and strengths are transformed from positive and productive of learning to negative, pathological and something that needs fixing (Hehir, 2002). It can be argued that this pathologising process is what was occurring when Maggie’s enjoyment and developing sense of humour was re-interpreted as a limiting ‘fixation’.

6.8 What is knowing?: Listening attentively

In this section, I present and discuss images and written narratives from Maggie's early childhood centre Learning Story Book in relation to a pedagogy of listening, *Te Whaariki* and the child's questions. All of the children and adults, have been asked for, and have given, written permission to be named and have their images reproduced in this section of the thesis (see Appendices 5a – 5c).

Background to Maggie's early childhood education

Maggie's early childhood centre was a parent-led early childhood service in our local community. The centre was a not-for-profit service managed by families on a voluntary basis and affiliated to a nation-wide umbrella organisation. The centre was open part-time and was sessional. Each session was facilitated by a co-ordinating Supervisor with an early childhood education qualification and three 'duty parents' or other adult family members. The centre parents were involved in on-going education opportunities to support them in their teaching and parenting roles. Maggie attended the centre for three, three hour sessions a week from when she was 2.5 yrs to when she turned 6yrs old. The centre was licensed to operate with a maximum number of 19 children attending at one time.

The Learning Stories that follow were recorded over the period when Maggie was aged between 3.5 and 5 yrs old. During that time I was the centre Supervisor. Maggie's Education Support Worker, Mary, was employed by the early intervention service. Mary was a trained teacher, lived in the community and was a close friend of our family. Her three children had all attended the centre, and at the time the Learning Stories were recorded, her youngest child, Molly, was still attending.

The Children's Learning Story Books

Every infant, toddler and young child at the centre had their own Learning Story Books. Although the children each had an individual book that focussed on their learning and participation, many of the narratives involved the child's learning in relation with adults and other children in the centre and their wider lives. Centre parents, extended family members, teachers and children contributed stories, images and other artefacts to the books. A child's Learning Story Book often became a valued and treasured possession to the child and their family.

A Narrative of Learning: 'Goldilocks and the Three Bears'

I have selected excerpts and images from Maggie's 'Learning Story Book' around a particular interest and learning story that developed in response to her dispositions and interests as a person and learner (pp. 207-211 of split text). The Learning Stories illustrate the "threads" (Carr, 2001; Ministry of Education, 1996b) and "traces" (Rinaldi, 2006) of Maggie's learning, contributions and participation around her interest in and uses of literature.



Figure 7: Sarah, Maggie and Delcie making the dough

First day back at Playcentre after the holidays today. Maggie said: “Can I help you make the playdough?” before we left home this morning! She enjoys tipping cups of flour and salt in as well as mixing it up now. I’m teaching her the recipe! She got into making prints in the dough with her chin, saying: “Maggie made a chin print!” laughing and giggling and then doing it again. Elliot made dough ‘scones’ and Maggie liked: “The sugar on top” (flour). (Written by Mum)



Figure 8: Elliot, Karen and Maggie in the gravel pit

Elliot, Maggie and I went outside, we walked over to the shingle pit, which is a favourite of Maggie's at the moment. Maggie enjoyed making a "bell tower", "sprinkling the stones" and, of course, eating them. She asked to play: "Goldilocks and the three bears" before morning tea, but we had left our run too late. Later in the morning, I asked Maggie if she wanted to do a painting and I became distracted before she has responded to my question. After a while she prompted me by saying: "Do you want to do a painting?" Great reminder! When we got home I said: "What did you like doing at Playcentre today?" Maggie said: "We went to Playcentre. We washed our hands." (Written by Mum)



Figure 9: Maggie being baby bear with mum

What a busy day! Maggie enjoyed using the little oven at the playdough table and called it “the Griller”. She liked opening and shutting the door and cooking bowls of porridge for the 3 bears. Sasha joined in too and we had the Duplo Goldilocks story. We have been working on a production of Goldilocks and the Three Bears. Today we listened to the story on a tape of Maggie’s – she had a Big smile when the story began and at the end she said: “Thanks for doing Goldilocks and the three bears!” Maggie tried on the bear costume (t-shirt with bear face) and said: “I’m a bear! I’m a bear!” She continued saying this through most of the session. We had a bear hunt later and Maggie was the bear which we found at the end of the hunt. She chased all the bear hunters away, saying “I’m a bear!” very loud. (Written by Mary)



Figure 10: Maggie in bear shirt on the swing

You seemed to have had a really good time today Maggie Rose! You just about managed a bit of everything. The highlight, I would say, would have been the rubber glove filled with water in the water trough – what great fun – squishing the water around it with both hands and your mouth! You had a wee bump on your forehead in the yellow swing after you said: “A bigger swing! A bigger swing!” and went quite high – but you were very brave and didn’t mind having Arnica put on. You are becoming very independent now Maggie and getting better and better at communicating your needs. Great to see you so happy! (Written by Justine, duty parent)



Figure 11: Maggie, Elliot and Jenny sharing a story

Jenny read 'Goldilocks' to Elliot and Maggie. Maggie likes holding the Duplo Goldilocks and following the story. She put Goldilocks in the places during the story (e.g. the big bed, the middle sized bed etc.). Isaac helped make the Duplo stairs for Goldilocks to climb up and down. (Written by Mary)



Figure 12: Maggie, Emma and Sasha face painting



Figure 13: Sasha and Maggie Rabbit sharing some food together

Emma, Sasha and Maggie love to paint their faces at the moment. When I asked the girls who they were, Maggie said: “Rudolph the Red Nosed Reindeer!” Emma said she had a: “Christmas Face” and Sasha was: “Father Christmas.” Merry Christmas girls! (Mum-Bernadette)



Figure 14: Maggie as Goldilocks looking at herself in the mirror

Figure 15: Goldilocks

Jasmine and Sasha were dressing up and Maggie and Mary walked over. Mary put a purple cape with gold trim on Maggie. Maggie looked in the mirror and said: “Goldilocks”. She stood looking at herself in the mirror and I asked her if she’d like her face painted – she nodded. She nodded “yes” to being Goldilocks. Later Maggie was searching the dress-ups... She found the bear shirts and then reached up for the ‘Goldilocks’ puppet on a high shelf and said: “Hello myself!!” (Written by Mary)



Figure 16: Playing Doctors: Isaac, Maggie, Ed and Islay. Jenny is the patient.



Figure 17: Doctor Maggie with her stethoscope

Maggie was in the dress-up area. She said: "Listen to the heartbeat" and was looking around for the stethoscope. She found it, put it on and said: "Doctor Maggie" while looking in the mirror. Mary asked: "What does your heart sound like?" Maggie said: "Boom-chicka, boom-chicka, boom-boom-boom!" Mary brought the rubber drum over and played the rhythm of the words. After a while Maggie copied. Maggie was reaching her hands up high towards where some beads were stored. Mary asked if she would like some help to get them down. Maggie said: "Ask a grown up." (Written by Mary)



Figure 18: On the ‘Goldilocks stage’ playing ‘Speckled Frogs’

We walked outside, Mary asked if Maggie wanted to walk onto the ‘stage’ (set of wooden steps and cubes). Maggie did and said: “We went to the house of three bears”. Mary asked what we did there and Maggie replied: “And Goldilocks sat down.” Maggie enjoyed retelling the story with Mary (filling in words and what happened next). Later Maggie chose the magnetic Goldilocks story and put pictures on the board with Isaac while Mary told the story. (Written by Mary)

Goldilocks and the Three Bears Show

On the last day of centre before the school holidays the children performed the Goldilocks and the Three Bears show for friends and family. Two of the children had made and distributed an invitation to families and lots of families and friends came to the show. The name of the show changed on the day to ‘The Three Goldilocks and the Nine Bears’ to accommodate everybody who wanted to perform and what character/s they wanted to be. Maggie’s dad Tony played the electric guitar for the songs and the adults and children joined in with percussion instruments, singing and dancing. Afterwards we had a picnic, a cake and birthday celebration for Molly who was turning five.



Figure 19: The Goldilocks' with 'baby bear' (Maggie) singing 'Here Come the Bears'

Figure 20: Breakfast time at the bears' house.

Figure 21: Singing 'We're Going on a Bear Hunt' with 'baby bear' leading

A Learning Story approach and a pedagogy of listening

The centre's focus on 'Goldilocks and the Three Bears' was initiated and developed by the centre adults in response to Maggie Rose's observed interest in books, stories, dressing up and imaginative play. The focus came from centre adults listening attentively to and engaging in dialogue about Maggie as a person and a learner and asking how we could engage with and extend her learning through responding to her particular interests, ways of expressing herself and understanding the world (Carr, et al., 2000; Ministry of Education, 1996b).

We had observed that Maggie was quite isolated from her peers within the centre in terms of the children and some parents including her in their conversations and play. One of our central aims or hopes was to empower Maggie and others to develop deeper relationships and connections with each other through supporting a shared interest in stories and imaginative play.

Over the several months of the 'project', many of the centre families contributed and became involved. Rather than beginning with fixed ideas about what would happen and be achieved through the project, we developed and changed our thinking in response to listening attentively to, documenting, discussing and negotiating our interpretations of what was happening (Carr, 2001). On-going dialogue amongst the centre adults and children, generated ideas along the way for how to further the project and the children's learning and relationships. In this way, the centre adults embraced ambiguity and uncertainty within the project. Being open to and engaged within what was evolving created an atmosphere of anticipation, enjoyment, excitement and possibility.

A Learning Story approach and the Child's Questions

The 'Goldilocks' project was supported and guided through the collaboration of Maggie's family, her Education Support Worker, the centre Supervisor and parents. The contributions and participation of all of these people in listening to, observing, documenting and sharing their perspectives produced a rich and multi-dimensional view of Maggie and the other children as people and as active learners. 'Knowing' Maggie depended on who each person and family was in relation to her participation in the centre, family and wider community. Every person had different knowledge, relationships and stories to share about Maggie's learning and contributions. Having a group of people committed to her interests indicated to Maggie that she could trust that others would hear, recognise and respond to her preferences and needs. In terms of the child's question, 'Is this place fair?', even though the impetus of the project stemmed from Maggie's interest and the adults' concerns that Maggie become more involved in the life and relationships of the centre, her 'needs' and 'differences' were not the primary focus of the project. The emphasis on building connections and relationships and the focus of the project on a shared interest in imaginative play and stories positioned Maggie as an equal member and integral "part of the wider group" (Carr, et al., 2000, p. 9). There was certainly a place for Maggie in the centre and that place was learning, contributing and participating "with and alongside others" (Ministry of Education, 1996b, p. 70).

6.9 Chapter summary

Using a pedagogy of listening perspective and the child's questions to evaluate Clare and Maggie's experiences helped to expose how possibilities for their learning and participation were restricted by deficit views. The stories of learning and teaching from Maggie's early childhood centre provided an example of how a pedagogy of listening and a *Learning*

and Teaching Story Framework might be used to resist exclusion and support inclusive practices. Rather than *policing* participation, interwoven learning and teaching stories from Maggie's centre indicated how listening pedagogies can be used to *facilitate* children's learning and involvement. In the other narratives of their educational experiences, Clare and Maggie's differences were often over-emphasised (hyper-visible) or ignored (rendered invisible). In a pedagogy of listening approach, what might be seen as Maggie's differences from many of her peers were recognised, valued and responded to in ways that enhanced her own and others' learning. A recognition of her differences was included as an aspect of who Maggie was as a person and a learner. Maggie's differences were not used as a distraction from viewing her as a unique, integral, equal, active and contributing member of the centre community. The complexities and ambiguities arising from a construction of Maggie, her peers and their families as being the same *and* different were maintained and celebrated (Ministry of Education, 1996b, 2007b).

Chapter Seven: Discussion and Conclusion

7.1 Introduction

In this thesis I have argued that social-political-cultural contexts shape human experience, how we view the world and the opportunities made available and denied to us. Exclusion from full participation in society is underpinned by unequal power relations. Western cultural knowledge and ways of being dominate and marginalise disabled people and other groups who deviate from its narrow norms and values.

Reforms and changes in education must consider and address power relations if they are to have the potential to support positive and sustainable change in the lives of disabled children and their families. I have tried to make sense of discourses that disable and how deficit, normalising assumptions interact with experience. In particular I have looked for mechanisms that sustain deficit beliefs, and what the effects of pathologising thinking and practices have been on the two participating families. I wanted to know how and why exclusion persists in education when the rhetoric contained within government policies, legislation and national curriculum documents seems to go quite a way towards supporting human rights, 'inclusion' and valuing diversity. I wanted to understand why it appears acceptable to label people as other and then to exclude them socially-politically-culturally and economically in education and society.

I wanted to listen to and re-present the stories of people who live with and close to 'disability' and to foreground parents' voices in considering issues around disability and disablement. Examining disabling

discourses as part of my analysis provided a vehicle for understanding the interactions between macro and micro influences on social and cultural constructions of disability. Considering the experiences of two families with disabled children provided possibilities for developing insights into the workings and effects of disabling discourses.

At the outset of this research, I had some experience and insights into the problems and issues that affect disabled people. However I had little idea of how we might go about addressing exclusion in education and society. Learning to ‘name’ and understand disabling language, practices, beliefs, ‘truths’, assumptions and knowledge within lived contexts helped me to find and consider possibilities for challenging disabling barriers. I have continued to draw from a pedagogy of listening, the *NZC*, *Te Whaariki* and the *Learning and Teaching Story Framework* in the discussion, recommendations and conclusions of this thesis.

The research focus questions

In this chapter I address the questions that guided my focus and interpretations of the narratives throughout the project:

- How did the parents in this study make sense of having a ‘disabled child’? How did they respond to and interact with discourses of disability?
- How were the narratives of the parents embedded in, and resistant to, dominant discourses around disability and difference?
- What other discourses were available and/or generated by parents through their everyday experiences of living with their disabled child?
- What were the actual and potential effects of dominant, deficit discourses and discursive practices on their children’s learning,

contributions and participation in public, family and educational contexts?

- What directions and possibilities for professional, structural and pedagogical change did the parents' experiences and narratives indicate?
- How can teachers, early childhood centres and schools, alongside families and communities, transform exclusionary cultures and practices in ways that develop and sustain inclusive settings, through a consideration of disabled children and their families' experiences and aspirations?

Learning from the intelligence of experience

In this chapter I focus on what the parents' narratives and related literature tell us about the workings and effects of deficit discourses, and how we might work to transform educational settings into inclusive places of learning and participation for all children, families, teachers and communities. I present and explore two key arguments. The first argument is that we must develop the ability to recognise and critically interpret disabling discourses and practices in personal, local, and societal contexts. The second argument is, that alongside developing skills for recognising exclusion, we must learn to exercise ethically and contextually based resistance to inequality in education and society. Ethical and contextual responses to inequality must aim to dismantle the barriers to the access, learning and participation of *every* child and their family.

The voices and perspectives of disabled people and other marginalized groups must be central in naming exclusionary practices, strategising for transforming unequal relations of power and informing visions of an inclusive society. However, non-disabled people and otherwise privileged individuals and groups must not wait for people from

marginalised groups to tell us what to do or how to think. Non-disabled individuals must take responsibility for co-creating and maintaining inclusive contexts. This includes actively seeking the information, feedback and relationships necessary to allow inclusion to become a reality (Ritchie, 2010). Teachers, teacher educators, families, policy makers and politicians must form an understanding of the localized workings of exclusionary discourses and their effects before we can develop our capacities to do something about creating and sustaining ‘inclusive’ contexts where all citizens share influence and have a voice.

7.2 Summary of findings

The three themes I developed to make sense of the central influences on Clare, Maggie and their parents’ experiences were ‘Disciplinary Mechanisms’, ‘Positioning as Other’ and ‘Policing Participation’.

Theme 1: ‘Disciplinary Mechanisms’

I take up Foucault’s definition of ‘disciplinary mechanisms’ as processes that enforce and reproduce normalising, power and knowledge.

Visibility, the ‘gaze’ and normalising judgments

A key disciplinary mechanism was the pervasive ‘gaze’ and surveillance that both families experienced ‘because’ of Clare and Maggie’s discernable deviations from the ‘norm’ (Foucault, 1977). A ‘disciplinary gaze’ invoked limiting, deficit discourses of disability. The ‘gaze’ delineated and restricted the identity and subject positions that Clare, Maggie and our families were encouraged, and therefore likely, to take up. The gaze evoked deficit judgements and labels such as ‘developmental delay’, ‘obesity’, ‘splinter skills’, ‘short stature’ and ‘intellectual disability’. The gaze was perhaps most obvious in the application of labels through

‘diagnosis’ and ‘assessment’. Clare and Maggie’s perceived ‘deficits’ provided the rationale for many influential people and places in their lives to respond to them in exclusionary and limiting ways. A deficit regime of knowledge-power was perpetuated through taken-for-granted, and consequently unquestioned, disciplinary mechanisms involving surveillance, normalising judgements and visibility/invisibility. Deficit assumptions permeated many of the relationships and experiences of both families in and with early childhood centres and schools.

Limiting judgments about disability and difference were also tolerated and used by family members. We were all engaged in negotiating meanings around disability and difference as a part of our daily lives. For example, at the same time as feeling resistant to people negatively judging Clare, Fran communicated deficit based views of her. Fran attributed the reason for her situation of visibility, judgment and blame on Clare’s ‘special needs’ and she also described Clare and her differences in terms of her being ‘imperfect.’ I also tolerated a deficit view of Maggie in agreeing to on-going early intervention involvement in her early childhood centre. Tony and I both talked about needing to learn to value and be accepting of Maggie and her differences.

Dividing constructs of ‘normal’ and ‘not normal’

Medical and ‘special’ education surveillance reinforced a view of disability as a private ‘problem’ contained within the individual. Processes of ‘diagnosis’, ‘assessment’ and ‘labelling’ separated Clare and Maggie from ‘normal children’ in terms of how they were defined, judged and consequently treated. Foucault (1982, p. 208) argued that normalising judgements and “dividing practices” objectify people. There were many situations where each child was only or primarily seen and treated according to their perceived ‘deficits’ and deviations from ‘the norm’.

Clare and Maggie's 'deficits' were routinely emphasised to the exclusion of their personal strengths, interests, qualities and identities as people and as learners. Clare's deviations from 'the norm' meant that her early childhood teachers could largely abdicate their responsibility for her to her ESW and mother. Because of her label of 'special needs', four schools denied Clare's right to participate. Maggie's feelings, interests, and ways of being were defined as 'off the topic', 'fixations' and problems at her primary school. To use Tony's turn of phrase: "Maggie-Roseville" was 'out of bounds' at school. Maggie was expected and pressured to deny significant facets of her identity in order to fit in.

The outcome of being classified, labelled, tested and monitored was that Maggie and Clare were positioned as significantly different from most of their peers and experienced differential treatment as a result. Along with labels and 'resources' came a raft of special education personnel, processes and deficit knowledge. A key aspect of this differential treatment was the regular, close surveillance and intervention of special education 'experts'. A critical reading of Chapters Four and Five indicates that, while adult observation, intervention and judgment is a typical feature of many children's educational experiences, assigning labels to Clare and Maggie greatly intensified the 'disciplinary gaze' and influence of a range of adults in their education (Allan, 1999). Furthermore, this influence was often negative in relation to their learning and participation with and alongside their peers and 'regular' teachers.

Although Fran described, and viewed Clare often in relation to her differences or 'specialness', and we tried to emphasise Maggie's human rights and her commonalities with others, each family felt pushed outside of dominant expectations about acceptable ways to live and to be. Both families felt and were resistant to 'the gaze' and being cast as 'other'. Our resistance was motivated by our desire for our children to be accepted and

valued and to be given the same opportunities to learn, belong and participate to the same degree as their so-called ‘typically developing’ peers. Fran’s resistance was also a rejection of pity and blame and a reaction to the discomfort she felt about Clare and herself being subjected to other people’s close scrutiny and attention. In order to receive the funding and resources that we believed might support our children’s access to the curriculum, both families were compelled to ‘tolerate’ normalising labels such as ‘globally developmentally delayed’, ‘moderately intellectually impaired’ and ‘special education needs’. Ironically, those resources were often used to exclude our children through making them the responsibility of ‘special’ rather than ‘regular’ education personnel.

Turning the ‘gaze’ in on itself

Applying reflective questioning and attentive listening to the narratives of families in this study showed how an ethical-critical approach can be used as a starting place for noticing and responding to inclusion and exclusion in education settings. In Chapter Six, I used the rhetorical reflective question: “Do you know me?” to understand and interpret teacher pedagogy and Clare and Maggie’s experiences in educational settings (Carr, et al., 2001; Carr, et al., 2000; Podmore, et al., 1998). As a result of exploring teachers’ knowledge, understanding and relationships with Clare and Maggie, I expanded the question to consider “What do you *want* to know about me?” and “What *don’t* you want to know about me, and why?” Questioning from a child’s perspective helped expose the assumptions and beliefs underlying particular (disciplinary) practices, and their exclusionary effects. An absence of critical reflection seemed to limit the possibilities for teachers to notice, question and challenge exclusionary thinking and practices. Using rhetorical questioning to examine ‘the gaze’ revealed the power of taken for granted assumptions and beliefs like: a child’s disability is a problem that needs fixing, disability is the child’s defining characteristic, and

disabled people are ‘not like us’ and they are ‘needy’ (Biklen, 1992). The tacit nature of these beliefs is likely to continue excluding disabled children from opportunities because the presence, transmission and effects of deficit discourses are not recognized or understood.

Theme 2: ‘Positioning as Other’

A key question of this research was about the nature of and extent to which deficit discourses affected Clare and Maggie’s learning, participation and contribution. Chapters Four and Five contained many examples of how Fran, Mark and Clare, Tony, Bernadette and Maggie Rose were positioned, and positioned themselves in relation to deficit discourses of disability. Central to their experiences were processes of ‘othering’ that constructed Clare and Maggie and their families as outsiders.

‘Coming out of the closet’

For Fran, a key effect and process of being positioned as an outsider was what she described as “coming out of the closet” as a parent of a ‘special needs’ child. Fran’s use of a ‘coming out’ metaphor for her experiences indicates the power of exclusionary forces that were operating in her life. Fran felt so judged, positioned and blamed by others that she sometimes ‘chose’ to regulate her behaviour through hiding Clare and her differences from public view and scrutiny. That is, she (and Clare) stayed ‘in the closet’ in an effort to avoid the normalising spotlight. Underneath Fran and Clare’s experiences of non-acceptance and rejection are the dividing concepts of ‘normal/perfect’ versus ‘abnormal/imperfect’. Fran and Clare were constantly interpreted and treated as ‘other’ by ‘virtue’ of Clare’s differences. The key consequences were limited opportunities for Clare to contribute to and fully participate within educational settings and her community. Clare and her family were denied ‘choices’ such as deciding

what school Clare would attend and what opportunities she would have to learn alongside familiar children in her life. These illegal and unethical acts of exclusion pushed Fran, Mark and Clare back out of sight and mind and into ‘the closet’.

My early silence and reluctance to talk about Maggie’s differences were motivated by wanting her to be accepted and valued for who she was. I hid early concerns in a bid for our family and others to get to know and value Maggie without what I feared would be negative judgements. For me, ‘hiding’ Maggie’s differences was also a form of resistance to being positioned as ‘other’. ‘Coming out’ involved being compelled to accept or at least tolerate the gaze and involvement of others drawing from managerial, medical, deficit, and charity-personal tragedy discourses. Although Fran and I possibly had different motivations for hiding our children’s deviations from the norm, both of our situations involved a reluctance to share particular aspects of our children’s identities with others for fear of negative consequences.

Resistance to deficit views

Because of our resistance to situations where Maggie was viewed and cast in a deficit light, ‘coming out of the closet’ compelled Tony and I to become advocates for Maggie’s rights to be respected and to learn with and alongside others. Our perspectives were at odds with deficit constructions that sought to classify Maggie and separate and define her as ‘other’. Our advocacy involved constantly trying to explain Maggie’s interests, strengths, abilities and *value* in an effort to get others to notice, recognize, and respond to these as their key focus. Often our views and interpretations of Maggie were ignored, reinterpreted, not believed and marginalized by early intervention and special education professionals. Our perspectives

were countered by chronicles of Maggie's perceived 'deficits' or 'otherness', and how to 'fix', reduce or manage them.

Being advocates for Maggie was hard work and has had personal and emotional costs. For periods of time, like Fran, I would, and still do, go back and hide in the closet because the barriers to Maggie's participation seem insurmountable. Rather than being a safe haven, the closet can be a sad and isolated place for disabled people and their families. Although our resistance and advocacy didn't remove Maggie from a deficit gaze and judgments that positioned her as an outsider, Tony and I were able to influence what happened for her in her early childhood centre, and to make decisions such as calling a halt to her having 'diagnostic' tests and procedures at the hospital. Our influence has perhaps acted to minimize some of the exclusionary effects that Maggie would otherwise experience.

Fran, Tony and I view this research as an act of resistance to the marginalization and othering of our children. Fran's stated motivation for being a participant in this research was her desire to have her and Clare's stories heard by teachers. She hoped that teachers would learn about being inclusive through listening to her perspective and experiences. Fran's perspectives were based on her expectation that Clare should be given a "fair go". I think that Fran really struggled with understanding why Clare wasn't allowed to fit in. She saw and felt the double standards and contradictions between what people said and how they behaved towards Clare and her family. Perhaps because of the prevalence of their experiences of exclusion, Fran was grateful when they were given a chance to participate, even when the rules and expectations were different for Clare's participation than for other children. The third theme, 'Policing Participation', raises an important question about what kind of education and society we want our children to be 'included' into (Graham & Slee, 2008).

Theme 3: ‘Policing Participation’

The focus of this theme is on the effects of deficit views on how Clare and Maggie were positioned, and the subsequent opportunities and *kinds of participation* that they were allowed and denied. If disciplinary mechanisms are the tools and tactics of dominant power-knowledge production, then the policing of disabled children and families’ participation are primary processes and outcomes. Clare’s participation within social and educational situations was often policed and restricted by others. These restrictions relied on processes of ‘othering’ where Clare was understood primarily through her differences and perceived deficits. Opportunities for Clare to express herself and participate were restricted when other children, and adults routinely forgot about and/or ignored her presence. Davies (1991, p. 43) argues that it is difficult to make sense of the world outside of discourse: “...we can only ever speak ourselves or be spoken into existence within the terms of available discourse.” As well as being spoken into existence, ways of being and participating in the world can be, and are ‘spoken out of existence’ (Rivalland & Nuttall, 2010; Veck, 2009). In addition to the gaze highlighting and emphasising Clare’s differences, the gaze was also *averted*. This aversion led to Clare’s presence being rendered invisible. The result of Clare’s invisibility to others was that she was often, or even routinely, ignored.

Kinds of participation

Acceptable ‘kinds of participation’ are influenced by Western ‘regimes of truth’ such as developmental psychology, medicine, special education, and the presumption of Western cultural superiority (Bishop, et al., 2005; Brantlinger, 1997; Erevelles, 2006; Fleer, 2005; FourArrows-Jacobs, 2008; Graham, 2005; MacNaughton, 2005; Skrtic, 1991; Tuhiwai Smith, 1999). The restrictions that deficit regimes of truth place on particular groups in

society must be exposed in order to create spaces for more inclusive and equitable participation (Dalhberg & Moss, 2005; Moss & Petrie, 2002). The narratives about Clare and Maggie's experiences in education indicated traces of the relationship between deficit assumptions about disability, and the effects of these deficit assumptions on learning, contributing and participating. These effects included views of participation as: 'tolerated physical presence', 'divided between regular and special', 'peripheral or irrelevant', and as 'fitting in'. These restricting views of participation supported and sustained inequality and exclusion within Clare and Maggie's education settings. The *kinds of participation* Clare and Maggie experienced appeared to be largely based on what was comfortable and desirable for others.

(1) Participation as tolerated physical presence

There were several instances of overt exclusion when early childhood centres and schools refused to seriously consider allowing even Clare's physical presence. Equally common, however, were situations where Clare's presence was tolerated, but in which she was largely ignored by others and/or treated differently. The 'policing' of participation by family friends, strangers, teachers, special educationalists, and institutions led to restricted and limited subject positions being available to Clare in comparison to those made available children viewed as 'normal'. Being ignored and treated differently restricted Clare's ability and capacity to belong, participate and learn. As Fran said about Clare's ability to contribute and express herself: "If *you* don't know her, *she* can't talk." Participation being reduced to a tolerance of Clare's physical presence at Crossroads Childcare Centre meant there were limited opportunities for her to develop relationships with her peers and teachers, and to contribute. Being in the room alongside her ESW or mother were taken to mean that she was participating to a level that was acceptable to others. At South

Preschool, Clare wasn't even allowed to be present when it wasn't convenient or comfortable for the teachers. The rules for Clare's participation were different.

(2) Participation as divided between special and regular

Special education knowledge and involvement in Clare and Maggie's education settings contributed to confusion, unspoken disagreements and tensions around whose responsibility it was to plan for and respond to Clare and Maggie's learning and participation. There was little connection in Maggie's early childhood centre between how the centre viewed and approached her learning and participation, and how she was perceived and positioned by special education personnel. Fran's experience was that nobody at Crossroads took responsibility for facilitating, advocating for and accessing what Clare and her family wanted and needed to belong and fully participate in the centre and curriculum. Although Fran had concerns about issues at Crossroads, such as the teachers only interacting with Clare in passing, and having to attend with Clare and pay fees during the school holidays, she didn't communicate these concerns to centre staff. Neither teachers nor special education personnel invited Fran's perspective or listened to her in ways that allowed for a productive discussion of how Clare's participation and learning in the centre could be enhanced. That this situation continued, even within the context of a documented and agreed upon IEP goal about Clare becoming more part of the centre, is testament to the power of dividing concepts in education such as 'regular' and 'special'.

Fleer's (2003) concern about what is highlighted and passed over in 'the many voices' of *Te Whaariki* is relevant when considering disabled children and families' participation in early childhood education. *Te Whaariki* is perhaps implicit in a divided view of participation. The

curriculum distinguishes between what it terms “children”, and “children who have special needs” (p. 11). *Te Whaariki* mandates divided assessment requirements for ‘special needs’ children in the form of requiring that: “An Individual Development Plan or Individual Education Plan (IDP or IEP) ...be developed for any children who require resources alternative or additional to those *usually provided* within an early childhood education setting” (Ministry of Education, 1996b, p. 11) (emphasis added). Support for the intervention of “additional” special education ‘experts’ in the education of ‘special needs’ children is assumed in this curriculum statement. The inclusion of such a statement raises questions about what is emphasised and reinforced in relation to labelled children. Does an emphasis on resources and processes that are “alternative or additional to those usually provided within an early childhood setting” encourage teachers to assume the primary and ethical responsibility for labelled children? It can be argued that dividing practices for the assessment and participation of labelled children runs counter to the aspiration “for children to grow up as competent and confident learners and communicators...secure in their sense of belonging and in the knowledge that they make a valued contribution to society” (Ministry of Education, 1996b, p. 9). In this regard, the early childhood curriculum sanctions a view and treatment of children with ‘special educational needs’ as ‘other’. This and other research suggests that what labelled children and their families *need* is a learning community in which *their* rights to be valued, belong and fully participate are actively protected (Ballard & Macdonald, 1998; MacArthur, et al., 2003; B Macartney, 2011). Rather than highlighting ‘regular’ and ‘special’ resources and ‘needs’ as the pathway to inclusion, teachers should focus on every child having access to the relationships and experiences that they often assume to be “*usually provided* within an early childhood setting” (Ministry of Education, 1996b, p. 11) (emphasis added).

(3) Participation as peripheral or irrelevant

A view of disability as an individual's problem strongly influenced the de-contextualised responses to Maggie and Clare's learning and participation. With the exception of Maggie's early childhood centre, Clare and Maggie's ability to enhance and contribute to the learning and participation of others was seldom considered in planning and assessment discussions. 'Expert' special education approaches to assessment and planning at school didn't treat Maggie's home, school or even her classroom relationships and context as relevant or worthy of more than passing consideration. Largely ignoring Maggie and Clare as active participants within relational contexts limited opportunities to understand and remove barriers to their participation.

The involvement of early intervention teachers and specialists was required for Maggie's early childhood centre to receive government funding for Mary, Maggie's ESW. In other words, the disciplinary gaze of special education was compulsory. I assume that this requirement was based on the belief that 'expert' knowledge is necessary to 'help special children' develop, and 'participate' in regular educational settings. However, in our centre special education involvement was experienced as a barrier to Maggie's learning and participation. Special educational involvement was a distraction from and interruption to Maggie's participation with and alongside others. It was not a 'legitimate' option for the early intervention staff to respect the centre's wish that early intervention involvement was no longer necessary or required and that Maggie would be more fully included without it.

A major influence on Maggie's participation in her early childhood centre and school was the monitoring and scrutiny of special educationalists. 'Disability' was treated as her defining, and perhaps her only, characteristic. Maggie's 'deviations' were much more important than who she was as a learner and a person. Identifying and minimizing her 'deviations' from 'the norm' was treated as more important than ensuring Maggie's full and meaningful access to the curriculum. Maggie's 'deficits' were treated as more relevant than ensuring her access and full participation within the 'regular' curriculum (Biklen, 1992; Hehir, 2002). How and what she was learning with and alongside her peers, teachers, family and community was treated as peripheral and irrelevant. The 'learning' focus of special educationalists was about how to get Maggie to conform to acceptable identities and ways of being.

As a consequence of being pathologised, central aspects of Maggie Rose and Clare as learners and potential contributors were ignored, marginalized and at times actively discouraged. What was often emphasised for both Clare and Maggie was fragmented, pre-determined, 'functional' skills and concepts. 'Functional' knowledge was privileged over relationships, learning and participation. At school, Maggie's personal qualities and ways of being were routinely judged as being unproductive, off 'the topic', and lesser than others. Her ways of being were defined as an impediment to her learning.

(5) Participation as fitting in

Their IEPs did not consider the influences that Maggie and Clare's relationships with other people and the social and physical environment had on their learning, participation and sense of belonging. Maggie's school IEP emphasised her learning and achievement as individual, isolated, and related to fragmented subject and skill areas (see split text pp.

219-221). Maggie's participation and planning at school were often reduced to devising ways for her to comply with existing norms and arrangements. When Maggie and Clare 'weren't able' to fit in with their peers, separate alternatives were devised. These usually involved them carrying out activities with a teacher aide or by themselves. Clare was expected to fit into the pre-existing arrangements and expectations of her early childhood centre environments to the extent that she was rarely noticed by anyone other than her family and ESW, except in passing.

An understanding of participation as 'behaving normally' conflicts with the approaches articulated within New Zealand's curriculum documents (Ministry of Education, 1996b, 2007a, 2007b). Each mandated curriculum states it as the responsibility of early childhood settings and schools to recognise, value and respond to every child and family as people first. Participation as 'physical presence' and divided between 'special' and/or 'regular', 'peripheral and/or irrelevant', and 'going somewhere else and/or fitting in' are oppressive. Restricted views of participation exclude and place limits on children and their learning (Farquhar & Fler, 2007; MacNaughton, 2005; Purdue, 2004; Rutherford, 2009). Each of the above views of participation involves a non-recognition and denial of *every* child as a citizen with unique and complex qualities, strengths and interests. Most kinds of participation offered to Clare and Maggie denied their rights to be treated equitably, with respect and to belong (Ministry of Education, 1996b, 2007b).

Facilitating participation and inclusion

Maggie was respected as a valued member of her community in her early childhood centre. The adults in this setting took their obligations to enact the curriculum for every child and family seriously. Every child's participation was recognized as the path to learning and was encouraged

and facilitated by the adults. This contrasts with early childhood and school pedagogies that police the participation of children and families.

Maggie's rights, interests and qualities were recognized, valued and responded to positively in her centre. Rather than being viewed as an impediment to her learning, Maggie's 'differences' were assumed to be an integral part of who she was as a person. Any problems related to her inclusion and participation were seen as the responsibility and interest of the group, rather than as private, individual and insurmountable issues. Maggie's differences were not ignored, nor were they highlighted to the exclusion of viewing her as a valued individual. She was treated as a learner with the same rights as others to participate and belong. Maggie's centre was engaged in telling and weaving stories of teaching and learning together. There was a relationship-based culture that encouraged listening, critical dialogue, reflection and documentation (Ministry of Education, 1996b).

The combination of my knowledge of *Te Whaariki*, my loving relationship and acceptance of Maggie as my daughter, and being in a leadership position within the centre contributed to the positive approaches we developed in ensuring Maggie's learning and inclusion. In addition to this we lived within a small, mutually supportive and 'close knit' community. Another enabling factor may have been the parent co-operative structure and philosophy of the early childhood service. Unlike the teachers in Clare's early childhood centres, the families knew and regularly related to each other within family and community settings outside of the early childhood service. Centre adults' primary motivations and perspectives came from their relationships as parents, family and community members. This probably influenced the adults and children developing a holistic and complex view of each other. Unfortunately, although Maggie's school was in the same community as the early

childhood centre, the early childhood education pedagogical approaches and culture couldn't be transformed into equally inclusive experiences for her at school. Deficit, technicist and 'expert' approaches to teaching and learning prevailed and were harder to transform in the school setting, where children and families had less of a voice and influence.

Each family was constantly engaged in a process of positioning ourselves and being positioned in relation to dominant, deficit discourses. The number and value of roles and subject positions that were available for us were restricted in many situations. Disciplinary mechanisms such as 'the gaze' and normalising judgments restricted who Clare and Maggie could be in their education settings. They produced exclusionary outcomes for each of our children.

7.3 Naming exclusion

Identifying exclusion at all levels of society is vital in creating possibilities for inclusion and transformation. My first conclusion is about what can be gained through naming the problem of exclusion. I suggest that we need to 'make sense' of exclusionary discourses and *how* they operate. Without a critical understanding of deficit discourses it will be difficult to transform and change knowledge-power relations in sustainable and meaningful ways (Alton-Lee, et al., 2000; Flear, 2005; Foucault, 1982; Freire, 1997, 1998; Graham & Slee, 2008; Linton, 1998). The exclusion and marginalization of disabled children in education is about more than placement, although the existence of a dual model for education is part of the problem. Even changing our personal views about disability will not make exclusionary practices disappear. To transform exclusion, we need to understand the processes and effects of an unquestioned loyalty to the assumption that any departure from Western cultural world norms and behaviour should be treated as 'exceptional', 'other' and problematic (Graham & Slee, 2008).

In advocating for the contribution and full participation of ‘disabled’ people and others with marginalised identities we must acknowledge unequal power relations. Efforts to ‘include’ marginalised people within existing power relations will inevitably reproduce deficit enactments of ‘inclusion’ (Graham & Slee, 2008; Ministry of Education, 2010; Slee, 2001). Practices built on a view of ‘inclusion’ as ‘fitting in’ will continue to naturalize and hide exclusion which will remain largely ignored (A. Moore, 2004; Rivalland & Nuttall, 2010). In Clare’s early childhood centres and Maggie’s school there were hidden and complex rules about how and to what extent the girls were allowed to participate. The exclusion of disabled children from opportunities to learn and participate are not noticed or seen as problematic by many teachers and special educators (B Macartney, 2008b, 2008c; Purdue, 2004; Rietveld, 2010; Rivalland & Nuttall, 2010; Rutherford, 2009). Isolation and rejection in education *is* noticed by those who experience it, and it is disabled people and their communities whose voices need to be sought and listened to in naming and resolving the problems of exclusion (Barrkman, 2002; Biklen, 1992; Connor, et al., 2008; P. Ferguson, 2009; P. Ferguson, et al., 1992b; Linton, 1998; MacArthur & Dight, 2000; B Macartney, 2007b, 2008b; Raymond, 2002; Veck, 2009).

The problem of ‘the centre’

The idea of there being a centre, norm, meta-story or grand narrative that is true and relevant to ‘human society’, is a myth of its own making. The centre/norm is variously constructed as Western, white, male, English speaking, middle-class, heterosexual and able bodied. Western norms are more often named and critiqued from outside perspectives. People who identify fully or partially with ‘the centre’ find it much harder to name their own and other people’s experiences as anything other than normal. Indigenous (Bishop & Glynn, 1999; Bishop, et al., 2005; FourArrows-

Jacobs, 2008), migrant (MacNaughton, 2005; Rivalland & Nuttall, 2010), minority culture (Erevelles, 2006; MacNaughton, 2005) and disabled people's experiences (Connor, 2008; Graham, 2005; Graham & Slee, 2008; Linton, 1998; Rietveld, 2010; Slee, 2001) provide powerful critiques of Western colonialist perspectives and practices. Dominant socio-cultural understandings maintain the centre and thrive on a lack of experience and awareness of inequality among groups privileged by the norm (Linton, 1998). This 'naive privilege' results in an uncritical acceptance of, and loyalty to, what is assumed to be an accurate description and reflection of 'how things just are'.

Mann (2008) critiques Western-Pakeha knowledge and thinking from an indigenous perspective. She argues that a central barrier to indigenous and 'other' ways of knowing is the propensity in Western academic and popular culture to engage in what she calls "one thinking" (Mann, 2008, p. 42). 'One-thinking' describes Western culture's disinclination and learnt inability to see reality in complex, multiple, ambiguous and contradictory terms. Mann (2008) says:

It finally dawned on me that Euro-Americans cannot see two of anything without immediately assuming that one of them must be the deadly enemy of the other. Only one can be legitimate for them; the other is flawed, an impostor that must be rooted out. This "One-thinking" as I call it... is in profound conflict with the cooperative binaries of native American cultures (p. 42)

The European concept of 'pedagogy', and the indigenous Maori concept of 'ako' and 'akonga' view teaching and learning as connected aspects of one overall process. 'Ako' and 'pedagogy' are examples of 'co-operative binaries' in education. 'One-thinking' creates and imposes a preferred set of norms and reality by which everything 'other' is judged and measured as outside and 'exceptional' to the centre/norm (Graham, 2005; Graham &

Slee, 2008). One-thinking maintains competing binaries between social constructs such as normal/abnormal and same/special, learning/teaching and separates processes such as assessing children's learning and critically reflecting on teaching. These binaries create exclusion and restrict teachers' thinking.

Disability Studies researchers argue that it is the *centre/norm* and its positioning of 'deficit/exceptionality' at its edges that creates and maintains exclusion (Graham & Slee, 2008; B Macartney, 2010). Further, they argue it is the *centre*, and not the 'margins', that needs deconstructing. An attentive gaze needs to be turned inward towards the dominant culture in order to understand the history, forces and workings of oppression (Foucault, 1976, 1977, 1980, 1982; Freire, 1997, 1998). Teachers must exercise curiosity about how power and exclusion work in our contexts and what role we play in enforcing normalcy and exclusion (MacNaughton, 2005; Rivalland & Nuttall, 2010). We have to start naming and changing exclusion for ourselves and 'others' (Freire, 1997, 1998).

The *centre/norm* both constructs (makes visible) and ignores (makes invisible) experiences of disability. Through a view of disabled people as 'less than human', and a 'disabled' life as a 'bare life', the value of disabled people and their lives disappears (Bogdan & Taylor, 1992; Graham & Slee, 2008; Reeve, 2009). Rivilland and Nuttall (2010) examined the approaches and thinking of mostly white Australian early childhood centre teachers and managers who were loyal to dominant cultural norms. They interviewed new migrant parents, centre managers and teachers about their experiences of each other. Rivilland and Nuttall observed that centre staff worked from the assumption that treating all people 'the same', and therefore not 'highlighting differences', was the path to equity for 'minority culture' children. This discourse obscured unequal power relations, because the teachers believed that they were

“doing the best possible ethical work they could *within the discourses that were available to them*” (p. 30). The teachers believed that they were fulfilling their ethical obligations and responsibilities to the migrant families through treating them like ‘everybody else’.

Rivalland and Nuttall (2010, p. 30) described the teachers’ approach as a “sameness as fairness discourse.” The teachers and managers’ sought to minimise differences through privileging ‘sameness’ over difference. Most teachers and managers who were interviewed had sought very little or no information about the families’ countries of origin, experiences prior to settling in Australia and cultural norms and practices. Centre staff were not aware of or engaged with the new migrant families’ experiences and perspectives. In terms of teaching practices, non-migrant children were discouraged from noticing and commenting on differences between themselves and migrant children.

New Zealand research in early childhood centre and school settings has noticed teachers ignoring, and working actively to minimize, differences between students with Down Syndrome and their ‘typical’ peers (Rietveld, 2005, 2010). A ‘sameness-as-fairness’ discourse was apparent in the ways that the New Zealand teachers regularly ignored, and responded in dismissive or deficit ways to non-labelled students’ curiosity about their classmates with ‘Down Syndrome’ (Rietveld, 2005). Discouraging children’s curiosity about difference and ignoring and playing down differences in preference for ‘sameness’ and appears to teach majority culture peers to develop negative, fearful and/or dismissive attitudes towards ‘difference’ or ‘otherness’ (Rietveld, 2005, 2010; Rivalland & Nuttall, 2010).

Labelled by the centre

Labels provide a mechanism which diverts attention and responsibility away from the disciplinary centre (Graham & Slee, 2008). Labels assign limited identities to children and their families and lead to exclusionary processes and responses. Clare's label of 'special needs' allowed schools and early childhood centres to feel justified in refusing her and her family access to their services. The attitudes and behaviour expressed towards Fran and Mark by these institutions indicated that, had Clare been allowed to 'participate', she and her peers would not have experienced an inclusive education. Veck describes labels as "signifiers for who we are" (p. 144). Labels significantly influence how we see ourselves and how we are viewed. Labels name and construct what is made visible (Biklen, 1992; Foucault, 1980). What is not widely named or understood is rendered invisible and irrelevant (Graham, 2005; Graham & Slee, 2008; Veck, 2009). Indigenous education researchers Bishop, Mazawi and Sheilds (2005) observe that:

...over time, as the labelling process persists and those closest to the persons labelled begin to accept and support the labelling, the "patient" suffering the "pathology" also begins to internalize the definitions. Especially if others believe that acceptance of the labelling offers a solution to the perceived problem, a common alternative chosen by those so positioned is resistance, which again may be seen as deviance (p. 8).

Veck (2009) argues that labels such as 'special educational needs' and 'learning difficulties' create barriers to teachers listening attentively to labelled children. He suggests that labels and stereotypes take on:

... a 'master status' (and) become(s) the lens through which the labelled student is viewed...When we speak but are not listened to within an educational institution, when who we are is reduced and shaped by the labels applied to us, we are

excluded from entering into equal and reciprocal relations with others in that institution (pp. 143-144).

Veck concludes that “If educators are to turn an attentive gaze to learners, then they will need to resist attaching any significance to generalized labels” (p. 147).

Fran expected a diagnosis and label to bring some resolution, access to resources, and information that could support Clare’s learning and development. However, deficit discourses shut down multiple possibilities for understanding Clare as a person and learner able to and interested in exercising agency. Whilst labels do represent a significant barrier to how society views and positions disabled people, the treatment of labelled people as deficient and as ‘less than human’ is not inevitable (Biklen, 1992). Labels, and even critiques of labelling, reinforce a belief that there is little or no alternative to these negative views of disability and difference (Bogdan & Taylor, 1992). As the narratives of family members and people who have intimate relationships with labelled people continue to demonstrate, negative labels can be rejected as a serious distraction from unconditional love, respect and acceptance.

Conclusion

A critical approach to pedagogy and social justice requires more than tinkering with the centre/norm (Graham, 2005; Graham & Slee, 2008). The ‘centre’ demonstrates great skill for naming, absorbing, integrating, assimilating and colonising the ‘other’ (Allan, 2008; Bishop & Glynn, 1999; Brantlinger, 2006; MacNaughton, 2005; Skrtic, 1995; Slee, 2001; Tuhiwai Smith, 1999). Part of naming the problem of deficit discourses and exclusion must involve teachers recognizing knowledge-power relations as ever present in their lives and work (Foucault, 1980; Freire, 1997, 1998). Teachers must exercise curiosity about whose knowledge

counts and is privileged in this setting and what the *effects* of using that knowledge are on the contributions and participation of *every* individual and group (Alton-Lee, et al., 2000; Freire, 1997, 1998; Raymond, 2002; Rivalland & Nuttall, 2010). Critical pedagogies must be contextually and ethically grounded and involve on-going relationships, openness, curiosity, and dialogue about knowledge-power and its effects (Dalhberg & Moss, 2005; Fler, 2003; Moss & Petrie, 2002; Rinaldi, 2006; Rivalland & Nuttall, 2010). The next section explores possibilities for transforming education to facilitate, rather than police, the participation of every child, family and community.

7.4 Emancipatory discourses and pedagogies

Many individuals and groups are working to visualise and enact ethical and emancipatory approaches to diversity and inclusion in education and society (Biklen, 1992; Bishop & Glynn, 1999; Bogdan & Taylor, 1992; P. Ferguson & Ferguson, 1995; Fler, 2005; Ministry of Education, 1996b, 2007b; Ministry of Health, 2001; Moss & Petrie, 2002; Rinaldi, 2006; Ritchie, 2003; Rogoff, 2003; Slee, 2003; Smith & Barr, 2008; Smith, et al., 2009). Emancipatory pedagogies must intentionally and systematically challenge technical-rational discourses and expose social inequalities (Freire, 1997, 1998). Emancipatory approaches involve teachers and institutions listening to and learning from diversity and experience. Rather than treating inequality and the status quo as inevitable, emancipatory approaches retain an outlook of hope and optimism for a better world. In this section I discuss how teachers might work in ethical and transformative ways to create and sustain inclusive environments in which *everybody* is valued, has a place and belongs. This work involves supporting teacher educators, student teachers, teachers and others to recognize and resist exclusionary discourses with emancipatory intentions.

A pedagogy of listening and the role of teachers

In a pedagogy of listening (POL) teachers work to relinquish their traditional identity as expert knowers. A belief that teachers can and should know everything of importance or relevance to their students restricts teachers' motivation and capacity to listen attentively (Compano & Simon, 2010; Veck, 2009). In a POL an 'expert' status is replaced with an image of teaching as an exercise of humility, obligation and wisdom situated in relationships. Teachers' wisdom grows from listening and showing humility in the face of life's infinite variation, diversity, complexities and opportunities (Dalhberg & Moss, 2005; Freire, 1998; Van Hove, et al., 2009; Veck, 2009). Wise teaching involves attentive listening, collaboration, co-construction and interpretation (Ministry of Education, 1996b, 2007b). Education is an ethical and political endeavour precisely because humans are social beings who exercise influence on each other through the sense we make of social experience and reality (Dalhberg & Moss, 2005). Teachers are constantly engaged in constructing meaning and making sense of their own and others' experiences (Carr, 2001). Regardless of whether teachers develop a critical awareness of the effects of their thinking and actions on their students, the sense that they make of experience has lived consequences for themselves and others (Clandinin & Connelly, 1988; Dalhberg & Moss, 2005; Gallagher, 2005; G. Moore, et al., 2008).

Although we may not be able to control how others make sense of and act towards us, as teachers we can and should take responsibility for how we perceive and act towards others (Bogdan & Taylor, 1992; Ministry of Education, 1996b). Bogdan and Taylor's research into the perspectives of non-disabled people with long standing, intimate relationships with severely disabled people, shows how dehumanising constructions of disability and their consequences are not inevitable. They suggest that:

“Whether or not people with severe disabilities will be treated as human beings, or persons, is not a matter of their physical or mental condition. It is a matter of *definition*” (p. 291) (emphasis added). Teachers, families and communities have the power to define and value disabled people as unique, contributing individuals or as a pitiable, less than human set of ‘resource implications’. The stories we believe and tell about life connect our thoughts with our experience, our theories with our practices (Clandinin & Connelly, 1988, 2000; Freire, 1997, 1998; G. Thomas & Loxley, 2001). The ‘stories we live by’ can provide a pathway to inclusion and social justice or to exclusion and inequality (Ballard, 2003; Bogdan & Taylor, 1992; Brantlinger, 2006; Carr, et al., 2003; Clandinin & Connelly, 1988; P. Ferguson & Ferguson, 1995).

In a pedagogy of listening, teachers consciously work from an ethic of care and obligation to ‘others’, rather than unconsciously relegating anything that doesn’t fit to the margins. An inclusive pedagogy must acknowledge *every* child and family’s right to be recognized and valued. ‘Acceptance’ and ‘belonging’ must be more tangible and ‘evidence based’ in education than teachers having an intellectual commitment to ambiguous ideals such as ‘being inclusive’ and ‘valuing diversity’. If we only rely on inclusive intentions and beliefs without critical reflection and action, ‘inclusion’ may start and stop in the often well intentioned hearts and minds of those responsible for care and education (Allan, 2006; Booth, 2003; Gallagher, 2005; Millar & Morton, 2007; Morton & Gibson, 2003; Rivalland & Nuttall, 2010; Slee, 2003; Stromstad, 2003; Valenzuela, et al., 2000).

In a POL teachers work hard to support and *understand* rather than *control* the experiences, identities and aspirations of others (Dahlberg & Moss, 2005; Rinaldi, 2006). Veck (2009, p. 147) makes a distinction between a “disciplinary gaze” which “...marks the end of listening”, and

an “attentive gaze” which seeks understanding of others through engaging with them. He suggests that every child’s ability to contribute and belong is dependent upon a relational ethic of care and attentive listening:

If attentive listening offers us the opportunity to include others as contributors to the educational spaces we share with them, then it does so by enriching relationships within those spaces. When there is attentive listening within a classroom, educators and learners are taken beyond a ‘technology of teaching’..., and to a tenderness in teaching (Veck, 2009, pp. 147-148).

Gallagher (2005) suggests that in technical-rational approaches to teacher education, student teachers are taught to search outside of themselves for prescriptive methods and programmes that will help them become more effective transmitters of knowledge as facts. A POL encourages teachers to look *within* themselves and to practice reflexively within their contexts. Learning and teaching are viewed as socio-culturally and ethically based, rather than objective, individual and transmitted.

Aotearoa-New Zealand Curriculum Approaches

Although the tensions between technical-rational and emancipatory discourses are much greater in the *NZC* than in *Te Whaariki*, a respect for multiplicity and diversity does have a significant presence in the *NZC*. I believe we are in a fortunate position in Aotearoa-New Zealand to live in an environment where pedagogical approaches, such as those contained within *Te Whaariki* and the *Learning and Teaching Story Framework*, offer an emancipatory methodology based on ethical, critical, and situated understandings of teaching and learning (Carr, et al., 2001; Carr, et al., 2000; Podmore, et al., 1998; Reedy, 2003; Ritchie, 2003). *Te Whaariki*, the *NZC* and the *Learning and Teaching Story Framework* provide teachers with potential lenses for learning from, listening to and developing relationships alongside *all* children, families and communities.

Recognising indigenous rights and voices

A significant aspect of our social-political-cultural context in Aotearoa-New Zealand is in the increasing recognition of the indigenous people, their rights to self-determination over, and access to their lands, resources, cultural knowledge, language and ways of being. It can be argued that the history, format and contents of *Te Whaariki* position it well to support early childhood centres acknowledging, entering and working within spaces of obligation between the ‘self and other’ (Dalhberg & Moss, 2005; Fine, 1998; Moss & Petrie, 2002; Ritchie, 2003). The process of developing *Te Whaariki* and the document’s bi-lingual content and format reflect a reciprocal power sharing relationship between the tangata whenua (indigenous people of the land) and the manuhiri (visitors) or tauiwi (new peoples) of Aotearoa (Carr & May, 1994; May, 2001; Reedy, 2003; Ritchie, 2003; Te One, 2003). *Te Whaariki* contains a separate indigenous curriculum based on Maori language, culture and knowledge. In addition, the principles and strands of *Te Whaariki* are articulated in both Maori and English languages. It is acknowledged within *Te Whaariki* that the English and Maori language sections and concepts are not direct translations of each other because they come from different cultural worldviews. The intention is to encourage the principles and strands to be interpreted using both cultural frameworks within regular education settings (Ritchie, 2003).

The bicultural and bilingual framework of *Te Whaariki*, and its view of pedagogy as a process of actively weaving diverse strands, provide two powerful metaphors for inclusive approaches to pedagogy. In early childhood education in Aotearoa, central Maori cultural concepts and practices such as ‘ako’ (teaching/learning), manaakitanga (hospitality towards, caring for and obligation to others), tuakana/teina (sisterly and brotherly support and mentoring), and whanaungatanga (kinship ties and family relationships) are encouraged (Ministry of Education, 1996b). Each

of the above concepts resonate with Western based ecological and socio-cultural theories. Each shares an emphasis on learning and teaching as distributed and embedded in relational, historically and culturally situated community contexts. Concepts and practices such as manaakitanga, tuakana/teina and whanaungatanga also resonate with an ethic of care, hospitality, reciprocity and mutual obligation.

I believe that New Zealand's curriculum documents provide fertile ground for weaving and growing a climate of hope and optimism within education in Aotearoa-New Zealand and elsewhere (Fleer, 2003; G. Moore, et al., 2008; Te One, 2003). Through working ethically and reflexively to enact our curriculum documents we can demonstrate that there *are* emancipatory alternatives to exclusionary discourses and regimes of truth (Clandinin & Connelly, 1988; Compano & Simon, 2010; Freire, 1997, 1998).

A foot in both camps

Each curriculum document, however, has 'a foot in both camps' in regards to technicist, developmental and normalising approaches to education and responsive, emancipatory approaches. This is hardly surprising given that deficit, normalising discourses circulate throughout education and society. It is likely that many New Zealand teachers, like our Australian colleagues, continue to operate from a belief that to treat everybody 'the same' is an ethical and responsible way to approach difference (Ballard, 2004; Farquhar & Fleer, 2007; Fleer, 2005; Purdue, 2004; Rietveld, 2005; Rivalland & Nuttall, 2010). Despite progressive approaches to pedagogy within our early childhood education and school curriculum documents, local research and policy continues to provide evidence of widespread deficit thinking and practices (Bishop & Glynn, 1999; Gordon & Morton, 2008; Gunn, et al., 2004; Higgins, et al., 2006; IHC, 2008; MacArthur, et

al., 2000; Mutch, 2003; Purdue, 2004; Rietveld, 2005, 2010; Ritchie, 2003).

The promise of narrative approaches

Interpretive, storied approaches to pedagogy have the potential to help teachers identify, challenge and dismantle deficit thinking and practices. Through their focus on recognising, listening to and communicating with others they have the capacity to assist in the generation of new understandings and interpretations of reality (Clandinin & Connelly, 2000; Court, 2004; P. Ferguson & Ferguson, 1995; Freire, 1997, 1998; Gergen, 1999; B Macartney, 2002; Maynes, et al., 2008; Van Hove, et al., 2009; Veck, 2009). The purpose of learning and teaching stories is to encourage teachers to attune themselves towards children and their family's voices and to weave family, children's, teachers' and community perspectives throughout the curriculum (Carr, et al., 2003; Carr, et al., 2000; Greerton Early Childhood Centre, 2010; Te One, et al., 2010). Emancipatory pedagogies must consciously and actively aim to transform inclusive ideals into tangible thinking, practices, methodologies and outcomes (Booth, 2003). Inclusive education can be sustained through teachers exercising a critical and ethical commitment to every child's learning, contribution and full participation (Freire, 1997, 1998; MacNaughton, 2005; Ministry of Education, 1996b, 2007b; Rivalland & Nuttall, 2010). Learning and teaching stories were intended to support teachers and other adults to situate themselves critically and ethically within educational, family, community and broader contexts (Carr, 2001; Podmore, et al., 1998). As yet the promise and potential of teaching stories have not been fully realised (Meade, 2002). A focus only on individual children's learning without a consideration of the influences of teachers and the social-political-cultural context will not lead to educational transformation

(Danforth, et al., 2006; Flear, 2003; Graham & Slee, 2008; Meade, 2002; Nuttall, 2003a; Rivalland & Nuttall, 2010; Slee, 2003).

Given the widespread acceptance amongst New Zealand early childhood teachers of narrative methods of assessment, Clare and Maggie's experiences contain a warning about assuming that solutions to educational exclusion will come about through the adoption of particular teaching methods or approaches (Bishop & Glynn, 1999; Brantlinger, 2006; Dalhberg & Moss, 2005; Gallagher, 2005; Smith, et al., 2009). Learning stories can be, and often are used and interpreted without any attention being paid to unequal power relations within educational contexts (Cullen & Carroll-Lind, 2005; Dunn, 2004; L. Lyons, 2005; MacArthur, et al., 2003; Ministry of Education, 2005; Nuttall, 2003a; Ritchie, 2003). Without a critical and ethically-based understanding of knowledge and power, it is unlikely that narrative approaches to assessment will avoid or dismantle deficit discourses (Alton-Lee, et al., 2000; Dunn, 2004).

New Zealand teachers and researchers continue to explore the promise and use of narrative approaches to inform critical understandings of teaching, learning and participation in early childhood and school environments (Ballard, 1994b, 2003; Carr, et al., 2003; Dunn, 2004; B Macartney & Morton, 2009; G. Moore, et al., 2008; Rietveld, 2005, 2010). One project involved the staff of an early childhood centre carrying out action research over a two year period with professional mentoring and support around improving their understanding and use of learning stories (Carr, et al., 2003). Within this project the centre teacher-researchers reported "many examples of parents, families and members of the wider community experiencing the transformative effects of narrative" (Carr, et al., 2003, p. 194). The teacher-researchers talked about a transformation in how they viewed their role as a result of the project. The transformation

involved their role shifting from “planning *for* to planning *with* children and families” (Carr, et al., 2003, p. 206).

Action research using learning story approaches in New Zealand ‘special’ and ‘regular’ primary school settings found that combining professional mentoring and support with using learning stories led to increased teacher understandings of, and engagement with, disabled children’s learning and participation (G. Moore, et al., 2008). In this school-based project the teachers also reported that using learning stories as the basis for assessment and planning improved their connections and relationships with families. The teachers talked about how they became increasingly excited and inspired by the possibilities for learning and teaching through using a learning story approach. They found that their teaching and the children’s learning took on a positive momentum through using learning stories as the basis for their assessment, planning and teaching. The teachers contrasted learning stories with the norms-referenced assessments they had been using. On reflection, they realised that standardised approaches had done little more than measure and highlight each child’s perceived deficits. They further concluded that summative and norms-referenced approaches had distracted them from focussing on the children’s interests and abilities, and on the learning that was and could have been taking place. Prior to trialling learning stories, the children’s and their families’ voices had been peripheral or absent from assessment and planning. The contributions of children and families to documenting, discussing and interpreting the learning stories were a major benefit reported by both teachers and families. Considering the child and their learning from multiple perspectives and contexts contributed to new learning for both teachers and families about the child as a person and active learner.

Dunn's (2004) research explored the interactions between early childhood teachers, family members and special education personnel assessing and planning for children labelled as having 'special educational needs' attending their early childhood centres. Her findings showed how deficit interpretations and practices can swiftly and easily transform a learning story approach from an ethical and emancipatory tool into a dividing and disciplinary mechanism.

I have suggested that, while they might represent a positive move in the right direction, changes in teachers' orientation towards learners through using narrative, do not *necessarily* translate into exclusion being noticed and challenged. However, narrative approaches do have the potential to help teachers notice and respond to inequality and exclusion. This seems particularly the case when teachers are supported or guided by mentors to consider power issues in their observations and interpretations of centre or school life (MacNaughton, 2005; G. Moore, et al., 2008). Combining narrative approaches to pedagogy with professional support and action research methodologies appears to be one way of creating spaces for transformation to inclusive pedagogies (Carr, et al., 2003; Carr & May, 2000; G. Moore, et al., 2008; Nuttall, 2003a, 2003b).

Combining critical and narrative approaches

Transformation can be sparked by the questions teachers ask and what they are curious about when reflecting on the curriculum in action (Carr, et al., 2001; Carr, et al., 2000; Freire, 1998; Ministry of Education, 1996b; Podmore, et al., 1998; Valenzuela, et al., 2000). When teachers recognise and involve multiple sources and perspectives in developing their interpretations, they are much better positioned to understand and know how to respond to what is happening for children and families in their settings. The *Learning and Teaching Story Framework*, and many of the

reflective questions within *Te Whaariki* encourage a critical consideration of issues related to inclusion and participation. The ‘child’s questions’ can encourage adults to reflect on their images of children and to draw from multiple perspectives in making sense of teaching and learning (Carr, et al., 2001). They can also draw teachers’ attention to the influences of peers, teachers, other adults and the physical environment on children’s learning and participation and attune teachers to the child and family’s rights to be heard, accepted, learn and participate (Carr, 2001; B Macartney, 2010; B Macartney & Morton, 2009; Ministry of Education, 1996b, 2007b; Rinaldi, 2006; Wansart, 1995).

The importance of context and relationships to teaching and learning

In this research I have suggested that cultivating inclusive educational environments starts with developing a situated and critical approach to our narratives and practices of teaching. An ethical viewpoint is needed that acknowledges the complexities of social-political-cultural forces within education, and that takes a lot less for granted as a result (Allan, 2008; Foucault, 1977; Freire, 1997, 1998). Critical reflection and dialogue must include thinking about how teachers are positioning the children and families within our settings. This will involve teachers being curious about the *lived effects* of the curriculum on children and families (Alton-Lee, et al., 2000; Carr, 2001; Fler, 2005; MacNaughton, 2005; Ministry of Education, 1996b, 2007b; Nuttall, 2003a; Rinaldi, 2006; Rivalland & Nuttall, 2010). Being attentive to the lived curriculum allows teachers to make sense of learning, teaching and participation (Carr, 1998; Clandinin & Connelly, 1988; Dalhberg & Moss, 2005; Gallagher, 2005; Wansart, 1995). Listening to, documenting, telling and discussing stories emphasises the centrality of meaning making and relationships to teaching and learning. New Zealand research demonstrates that *Te Whaariki* and the *Learning and Teaching Story Framework* have the potential to support an

ethical and systematic understanding of teaching and learning in ways that inspire inclusive pedagogies (Carr, et al., 2001; Carr, et al., 2000; Greerton Early Childhood Centre, 2010; MacArthur, 2004; MacArthur, et al., 2003; B Macartney, 2002; G. Moore, et al., 2008; Podmore, et al., 1998; Ritchie, 2003, 2010; Te One, et al., 2010). Maggie's early childhood centre experiences also demonstrated how the principles and strands of *Te Whaariki* can be used to resist deficit narratives and facilitate inclusive practices.

7.5 Implications for future research and action

Inclusive education is about more than addressing the exclusion of labelled children (Allan, 2008; Ballard, 2003; Gallagher, 2005; Slee, 2003). Developmental, technical-rational approaches to education marginalise and restrict many groups and identities albeit to greater and lesser extents (Farquhar & Flear, 2007; Gallagher, 2005). It can be argued that the experiences of children from more privileged groups in society are also limited and restricted by approaches to education that view all children as passive, and teaching as the transmission of narrow and predetermined knowledge (Gallagher, 2005). Teachers and researchers need to be vigilant and engage in sustained and critical effort, to expose and understand exclusion, and to transform education (Allan, 2008; Brantlinger, 1997, 2004, 2006; Connor, 2008; Freire, 1997, 1998; Gallagher, 2005; MacNaughton, 2005; Slee, 2001). In working to create an inclusive education system and society (Ministry of Health, 2001), more qualitative research needs to be undertaken within micro-contexts. Families' and children's voices must be central within this research. In addition to learning more about how exclusion operates within early childhood centres, classrooms and schools, research should focus on positive stories of inclusion in action, and projects that support teachers to develop critical, ethical and inclusive pedagogies (Alton-Lee, et al., 2000).

Teacher education

To be part of the solution, researchers, teacher educators, professional mentors, policy makers, politicians and teachers need to acknowledge and value diverse ways of knowing, and recognise the potential of different realities and perspectives for informing inclusive thinking and practices (Brantlinger, 2006; Morton & Gordon, 2006). An implication of recognising the social construction of disabled identities must include a shift from teacher education courses that prepare teachers to develop the (special education) knowledge and skills assumed to be ‘required’ to work with students with particular ‘conditions’ to, “...studies of difference and identity politics” (Ferri, 2006; Slee, 2001, p. 174; Ware, 2006). Recent research on ‘inclusive education’ in New Zealand teacher education programmes shows a high degree of inconsistency between education providers in terms of how they understand the inclusion of disabled learners in education and whether their teacher education courses reflect and support New Zealand curriculum-based inclusive pedagogies (Morton & Gordon, 2006).

Resisting the separation of teaching from learning

Interpretive, action-research projects such as those trialling learning stories should sharpen their focus on using a critical lens to address and transform exclusionary power relations. One obvious avenue is to deepen our understanding and use of critical pedagogies through combining ‘learning stories’ *with* ‘teaching stories’ as a tool for critical reflection and action (Carr, et al., 2001; Carr, et al., 2000; Meade, 2002; Podmore, et al., 1998). Action-research projects in centres and classrooms should be supported by professional development and mentoring, and be long enough to give teachers time to develop confidence and skills in embedding ethical, critical approaches within their work (Carr, et al., 2003; Carr & May, 1993;

Carr, et al., 2000; Compano & Simon, 2010; Cullen, 2003; Greerton Early Childhood Centre, 2010; G. Moore, et al., 2008; Te One, et al., 2010).

Exploring experience alongside discursive structures and practices

In order to recognise and resist simplistic and presumptive conclusions, an interest in the relationships between personal, lived experience and social-political-cultural processes and structures should be combined. Emancipatory research methodologies need to be collaborative and work reflexively to explore micro and macro influences. As with inclusive approaches to pedagogy, documentation and assessment, emancipatory research should listen *to and with* participants, rather than listening *for* evidence of preconceived theories (Carr, et al., 2003; Lather, 2003; G. Thomas & Loxley, 2001). Disability Studies research also needs to spread the net wide in terms of drawing from multiple sources and perspectives in developing knowledge and insights about disability, exclusion and inclusion in education and society (P. Ferguson, et al., 1992c).

Policy

Even though The New Zealand Education Act (1989) has ‘protected’ every child’s legal and ethical right to attend their local school for over twenty years, many individual centres and schools and the Ministry of Education are unclear and often resistant to realising and supporting inclusive education and collaborative partnerships between teachers, families and communities (Gordon, 2009; Gordon & Morton, 2008; Higgins, et al., 2006; IHC, 2008; MacArthur & Dight, 2000; Morton & Gibson, 2003; Purdue, 2004). There is no overarching Ministry of Education policy in New Zealand about what inclusive education means and the implications of those meanings for how education is structured, resourced, and practiced (Higgins, et al., 2006). Instead, there is confused rhetoric and a growing

‘special education industry’ with very little inclusive commitment and action evident on the part of the state (Ministry of Education, 2010). As Booth argues of England’s education context:

The sheer number of initiatives and the different principles on which they are based make it difficult for staff in schools and colleges to become familiar with them all, let alone put them into practice. If they have serious intent, policies have to be linked to clear implementation strategies (2003, p. 35).

There is no clear or adequate system of advocacy and accountability in New Zealand education to ensure that families’ and children’s voices are heard and that government policies and directives are understood, supported and enacted by schools (Grant, 2008; IHC, 2008; Ministry of Education, 1999; Wylie, 2000). Even in the most basic interpretation of inclusion, that every disabled child has the same legal right as a non-disabled child to their neighbourhood school, disabled children and their families are regularly excluded (IHC, 2008). The Ministry of Education continues to support the provision of segregated, ‘special’ education placements and interventions for disabled learners and justifies these using a discourse of ‘parental choice’ (Millar & Morton, 2007; Slee, 2010). However, retaining special education language, practices and structures justifies exclusion and distracts teachers and the general public from a view of education as a vehicle for transforming New Zealand from a disabling to an inclusive society (Graham & Slee, 2008; Ministry of Health, 2001).

Advocacy and alliances

In Aotearoa-New Zealand we are perhaps fortunate in having curriculum, policy, legislation, international human rights agreements, research and pedagogical frameworks that go some way towards supporting inclusive education. We can and should use these frameworks to justify and guide inclusive stances and practices. Emancipatory education could benefit

greatly from building alliances within and across groups, sectors, disciplines and social-political-cultural interests (Millar & Morton, 2007; Ware, 2005). Alliances create opportunities for attentive listening and dialogue between diverse perspectives and groups on an issue. Millar and Morton (2007, p. 174) suggest that in an effort to transform education we need to create "...ways of disrupting boundaries, and of bridging worlds" such as those of 'regular' and 'special' education. One alliance that has perhaps been realized more in early childhood education than in the compulsory school sector in Aotearoa-New Zealand, are research and epistemological connections between educationalists and activists who draw from socio-cultural, emancipatory theories, disability studies and Kaupapa Maori (Tuhivai Te Rina Mead, 1997). Each of these groups shares a resistance to the dominance of traditional Western normalising discourses.

There is no state funded system of advocacy in New Zealand for ensuring that disabled children and their families receive the inclusive education they are entitled to. Short of advocating for themselves and taking complaints to the Human Rights Commission disabled children and their families have little opportunity for redress and change (IHC, 2008). If successive New Zealand governments were serious about their stated commitment to "changing New Zealand from a disabling to an inclusive society" they would pay people to advocate for and support this undertaking, and they would widely publicise/advertise it (Ministry of Health, 2001, p. 1). Early intervention and special education structures and personnel are typically part of the problem. They act as gatekeepers to deficit discourses and government funding (Skrtic, 1991; Slee, 2003). 'Special' education funding would be better spent on advocacy, professional development opportunities for early childhood centres and schools to develop and enact inclusive pedagogies, providing more

‘regular’ teachers and preparing teacher educators and student teachers for inclusion.

7.6 Thesis conclusion

Intellectual and relational alliances are necessary for understanding, exclusion and deciding what to do about it. *Te Whaariki* is an example of meaning making and action that was consciously informed by the humility, intelligence and wisdom of lived experience. The bicultural and ethical framework of *Te Whaariki* offers an example of what can be achieved when marginalized and dominant social groups engage in a collaborative process. The development of *Te Whaariki* was a process in which contributions were invited and respected from multiple perspectives, aspirations and worldviews with a shared aim of improving life and education for diverse families and communities (Carr & May, 2000; Fleer, 2003; Reedy, 2003; Te One, 2003). The journey of *Te Whaariki* demonstrates that where there is critical awareness, commitment and a desire, transformation based on respect and reciprocity can and do happen (Dalhberg & Moss, 2005; MacNaughton, 2005; Mandela, 2009; Moss & Petrie, 2002; Rinaldi, 2006; Te One, et al., 2010). Inclusive education remains a possibility in every centre, classroom, school and community.

It is regularly assumed that all or most New Zealand children experience the benefits of early childhood and school pedagogies underpinned by a view of learning and teaching as relational, social and cultural processes. We assume and/or are told that schools and early childhood education services are places where all children belong. This is often not the case for disabled children. The teacher’s role as a facilitator of responsive, reciprocal relationships is a taken for granted tenet of New Zealand early childhood policy (Ministry of Education, 1998), and pedagogy (Carr, 1998, 2001; Carr, et al., 2000; Greerton Early Childhood Centre, 2010; Ministry of Education, 1996b; Te One, et al., 2010). The

New Zealand Curriculum also emphasises teaching as being about listening and responding to diversity, children's identities, interests and abilities. The need to re-visit and negotiate taken for granted fundamentals such as 'reciprocal, responsive relationships' and 'teaching as inquiry' when it comes to labelled children is alarming. It suggests that positioning disabled children as 'other' is having powerful exclusionary effects on how early childhood centres, schools, teachers and other adults think and behave towards disabled students. It appears that, even though the curriculum documents may state that their curriculum is equally inclusive of *all* children, in practice, it is not.

The disjuncture between our espoused practices and beliefs and some of the assumptions that are actually guiding our behaviour must be treated as an urgent and serious concern for us to address as teachers, parents and a society. It is unethical and dangerous to assume that our teaching practices and their effects reflect our espoused curriculum, philosophies and theoretical bases. There is little possibility for recognising or challenging dominant discourses and their potential to restrict learning, participation and inclusion if we do not critically attune ourselves to the experiences of those in our care. Without on-going critical reflection on our practice in relation to how *every* child is participating, we cannot claim to be enacting an inclusive curriculum. The tendency to assume that all children are experiencing an 'inclusive' curriculum because they are physically present is politically and ethically naïve. Superficial understandings of inclusion and participation divert teachers' attention from seeking the information they need to critique and question their practices, attitudes, knowledge and beliefs.

Conceptualising ethics as the exercise of responsibility and obligation to the 'other' positions a concern for inclusion, justice and emancipation as central to education (Dalhberg & Moss, 2005; Rinaldi,

2006; Slee, 2001; Smith, et al., 2009). An orientation of obligation to the 'other' constructs people as interdependent and as living and learning in relation with and to each-other. An ethic of care and obligation to others challenges developmental, neo-liberal and individualistic views of children and adults as autonomous subjects who are personally responsible for their position in society. Rather than viewing individuals as rational, autonomous creators of their own situations, the exercise, operation and effects of unequal power relations within society must be recognised and viewed as problematic. In order to do this, teachers need support to develop a historical-cultural awareness of Western knowledge-power traditions and how that knowledge influences their views of teaching, students, education and society. We need to learn to name, resist, question and transform practices that are based on technical-rational and deficit discourses.

A key process in disrupting deficit discourses and 'one thinking' is for those of us from privileged groups to recognise that privilege and the responsibilities that come with it (Mann, 2008). With privilege comes the responsibility and obligation to expose ourselves to and learn from different ways of understanding, knowing about and engaging with the world. 'Ethical engagement' involves acknowledging the limits of our ability to fully understand the other, at the same time as fulfilling our obligations to listen and respond in ways that do not colonise the experiences, rights and needs of people who we perceive to be different from ourselves (Bishop, et al., 2005; Dalhberg & Moss, 2005; Veck, 2009). Through thinking and practicing in ways that communicate a sense of obligation to others, teachers are well positioned to recognise, resist and remove barriers to other's learning, participation and inclusion (Dalhberg & Moss, 2005; MacNaughton, 2005; Robinson & Jones Diaz, 1999; Slee, 2003; Stromstad, 2003; Veck, 2009). This research has attempted to take a

critical and ethical stance through listening to the voices, knowledge and experiences of two disabled children and their families. We must develop ways to listen to, hear and respond positively to the voices and aspirations of those who the dominant cultural framework constructs as ‘others’. This requires recognising and resisting responses that ‘absorb’ ‘differences’ into the ‘mainstream’ and/or push difference to the margins of education and society, or out altogether.

I have suggested that the *Learning and Teaching Story Framework* may be one potential vehicle for identifying exclusion and creating and sustaining inclusionary spaces. What appears to be lacking and needs re-emphasizing in the New Zealand education sector is the importance and potential of ethical and critical approaches to learning and teaching (Meade, 2002). Critical pedagogies require us to think about our lived contexts historically, socially, politically, culturally, ethically and materially (Freire, 1997, 1998; Smith, et al., 2009; Valenzuela, et al., 2000). They provide an alternative to traditional Western, deficit frameworks. Like life and learning, teaching is not and should not be viewed as a technical, predictable and universal process (Carr, 2001; Gallagher, 2005; Meade, 2002).

To live and work inclusively we must step outside of our comfort/normal zones. This will involve learning to name our dominant ways of knowing and to acknowledge the consequences and effects of our knowledge on others. As Graham and Slee (2008) have argued, we must question our loyalty to ‘the centre’. We need to visualise what kind of education and society we want our children to be included into. This requires hope and optimism about creating emancipatory possibilities for the future. Creating new language and generative discourses that take account of people’s diverse embodied experiences, cultures, lives and aspirations should be the work of progressive teachers and inclusive

education systems (Freire, 1998; Gergen, 1999; Ministry of Education, 1996b; Slee, 2001; Smith & Barr, 2008). We must open ourselves and the spaces we are responsible for up to the differences, contradictions, ambiguities, power relations and possibilities that are circulating (Ministry of Education, 1996b, 2007b; Rinaldi, 2006). We must learn to approach knowledge as provisional and as open to multiple interpretations rather than a given. Learning to teach every child and creating inclusive environments and pedagogies are on-going projects, not short-term destinations (Dalhberg & Moss, 2005; Slee, 2003). We have to resist being seduced and seducing ourselves with quick fix, technical 'solutions' to complex, historical and systemic problems (Gallagher, 2005; Gordon, 2009; Gordon & Morton, 2008; Grant, 2008; IHC, 2008; Millar & Morton, 2007; Slee, 2001; Smith & Barr, 2008; G. Thomas & Loxley, 2001).

As people, family and community members, teachers, teacher educators, local and global citizens, we have got to turn an attentive gaze towards Western-Pakeha culture, our contexts and ourselves (Ellis, 2004; Gallagher, 2005; Graham & Slee, 2008; Ministry of Education, 1996b; Reinharz, 1997; Rinaldi, 2006; G. Thomas & Loxley, 2001; Veck, 2009). We are capable of co-constructing inclusive environments through engaging with and listening to ourselves and 'others' in ways that enable all of us to learn, contribute and participate (Carr, et al., 2000; B Macartney, 2002; Ministry of Education, 1996b; Ministry of Health, 2001; Rinaldi, 2006; Veck, 2009). We should reject fatalistic beliefs such as there being no alternatives to the status quo, and that the pursuit of equality for every person is unrealistic and destined to failure. To accept this argument is to fail ourselves, our children and our humanity. I would rather embrace an ethical and morally responsible struggle, than resign my family and others to a future of unreasonable compromise and exclusion.

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Appendices

- 1a. Fran's invitation letter
- 1b. Fran's consent form (2004)
- 2. Tony's consent form (2004)
- 3. Timeline
- 4a-d. Fran's 4 interview schedules
- 5a. Parents' letter
- 5b. Children's letter
- 5c. Consent form for photographs (2010)

Appendix 1a: Participant invitation letter

Bernadette Macartney
PO Box 17
Diamond Harbour
Christchurch 8030
Ph 3294-561
Email: Bernadette.mac@paradise.net.nz

Dear Fran

Thank you for considering participating in my study concerning the experiences of families of children with a disability. Sharing your experiences would contribute to a greater understanding of how disability is viewed and the issues it raises for families. I am carrying out this project as part of my study at the Christchurch College of Education. Throughout the study, I will be supervised by Missy Morton and Kerry Purdue, who work at the College of Education.

My study is interested in how particular families view disability from the perspective of having a child with a disability themselves. I am interested in looking at the different ways that disability is viewed in our society, particularly in education, and how dominant views are similar to and different from family's views. I am hoping that the project will contain some insights for people, such as teachers and therapists, working with children with disabilities and their families. My interest in this area comes from having a young child with disabilities myself, and being an early childhood teacher.

There will be three families taking part in the study. One family is my own. The study will consist of a series of up to four 1-2 hour interviews. In addition, it would be useful for each family to keep a diary in between interviews to record any stories or issues that come up. Families could choose to use a Dictaphone to record diary entries if that would be more convenient than writing. During the project, I would send you copies of transcripts of our interviews, and your diary entries and ask you for comments on them. We would use this as part of our discussion during interviews. I am keen to develop a relationship with participating families that values your ideas and insights about where the research is heading and what we are learning.

All data that I gather will be strictly confidential to myself, my supervisors and a typist transcribing the interviews. The names of any people, places or services mentioned in the research will be given pseudonyms, except for the names of my family members who will be identifiable because I am also the researcher. Because the research sample and community of families who have young children with disabilities is a small one, there is a limited but real chance that your contribution may be recognised despite the precautions we take. As this research is part of a thesis, a copy of the thesis will be disseminated and placed in the College library.

The College requires that all participants be informed that if they have a complaint concerning the manner in which a research project is conducted, it may be given to the researcher, or, if an independent person is preferred, to:

The Chair
Ethical Clearance Committee
Christchurch College of Education
PO Box 31-065

Christchurch
Phone: 343-7780, ext 8390

If you have any questions regarding the study please contact one of my supervisors (ph 343-7780) or myself. Thank you for your interest. I look forward to hearing from you.

Yours sincerely,

Bernadette Macartney

Appendix 1b: Consent form for participants

'Difference or Deficit: Parents' narratives and discourses of disability in education'

I understand that by participating in this study, I agree to:

Up to four interviews that will last approximately 1 – 2 hours;

The opportunity to keep a diary to record stories and issues in between interviews;

Diary recordings being audio-taped, or written, and then transcribed;

Interviews being audio-taped and transcribed;

The opportunity to read, comment on and return transcripts in between interviews;

The opportunity to participate in discussions with the researcher about the direction and content of the research.

I understand that by being involved as a participant in this study:

My participation is voluntary and I can withdraw from the study at any stage;

The data I give will be treated confidentially;

The data I give will be retained by the researcher for up to three years during which time it can be used by the researcher for any conference papers, journal articles or reports drawn from the data;

My identity will be protected. Neither my name nor those of my family members will be published or attributed to any quotes or comments used in publication;

All information will be stored securely, and available only to the researcher, the supervisors and the transcriber.

I have read and understood the information about the project contained in the letter accompanying this consent form.

Name: _____ Phone: _____

Address: _____ Email: _____

Signature: _____ Date: _____

Please return to: Bernadette Macartney, PO Box 17, Diamond Harbour, CHCH 8030.

Email: Bernadette.mac@paradise.net.nz Phone: 3294-561

Appendix 2: Consent form for researcher family participant

'Difference or Deficit: Parents' narratives, and discourses of disability in early childhood education and early intervention services'

I understand that by participating in this study, I agree to:

Two interviews that will last approximately 1 – 2 hours;

The opportunity to keep a diary to record stories and issues in between interviews;

Diary recordings being audio-taped, or written and then transcribed;

Interviews being audio-taped and transcribed;

The opportunity to read, comment on and return transcripts in between interviews;

The opportunity to participate in discussions with the researcher about the direction and content of the research.

I understand that by being involved as a participant in this study:

I can withdraw from the study at any stage;

The data I give will be treated confidentially;

The data I give will be retained by the researcher for up to three years during which time it can be used by the researcher for any conference papers, journal articles or reports drawn from the data;

My identity will be known, and I and my family members will be named in the research;

Where it is not necessary to use the name of a person quoted in the text, neither my name, nor those of my family members will be used;

All information will be stored securely, and available only to the researcher, the supervisors and the transcriber.

Name: _____ Phone: _____

Address: _____ Email: _____

Signature: _____ Date: _____

Appendix 3: Timeline	2003	2004	2005	2006	2007	2008	2009	2010
Fran								
4 Interviews:		June 04 -	Sept 05					
Journal keeping		June 04 -	Sept 05					
Narrative analysis		2004 -	2005					
Draft findings chapter					2007			
Tony & Bernadette								
2 Interviews	October 03		June 05					
Journal keeping		March 04 -						
Narrative analysis				2006				
Document collection				2006				
Draft findings chapter					2007			
Discourse analysis								
Both families					2007	2008		
Writing								
Introductions etc		Introduction, Theory, Methodology						I, T, M,
Findings chapter 4					Fran			
Findings chapter 5					T&B			
Findings chapter 6						P.O.L*		
Discussion						Discussion		
Conclusion								Conclusion
Final write up								July - Sept
Presenting & publishing								

Data collection		Final Write-up	
Analysis		Presenting & Publishing	
Drafting Chapters			

* Pedagogy Of Listening

Appendix 4a: First interview guide

Stories about the family:

Tell me about yourself, and your family. Prompts/possible directions – What has your working life involved? Who is in your family? Ages, personalities, interests... What does your family enjoy doing together? How do you arrange responsibility for day to day caregiving in your family?

Stories about parenting hopes and expectations, and responses to having a child with a disability:

Tell me about how having a child with disabilities has been for you.
Prompts/possible directions – were you planning on having a child? Hopes and expectations before, during pregnancy? Any big events in the family over this time e.g. more children, change of jobs, travel, finding an early childhood centre etc...? How did you discover your child had a disability. What was your response? What were other people's responses? Has your response changed over time? In what ways? How do you think about your child's disabilities now?

Stories about (child with a disability)

What was (child's name) like as a baby/ toddler/ older preschooler, now? How would you describe (child's name)? How would you describe (child's name) needs or disabilities? Do you think of (child's name) as having disabilities? What are your child's strengths, passions, interests?

Stories about (child with a disability's) relationships

How would you describe your relationship with (child's name). How does (child's name) get on with other members of your family, with other people? What important relationships does (child's name) have outside of your family?

Research Diary

Discuss keeping a diary with participant. Have a Dictaphone that they can borrow, and a notebook to give them if they would like to use one. Suggest that they make recordings about any of the issues raised in this interview. Could include things that they felt they left out, further information they want the researcher to have. Ask that if they have time, it would be really useful to have them record some stories about what they see as being a 'typical day' in their family before the next interview.

Appendix 4b: Second interview guide

Feedback re Interview One Transcript – changes, comments, things that leapt out etc...

How was process of being interviewed for you?

Feedback how it was for me.

Interview transcript and what I'm finding:

About how it is for Fran parenting Clare, her struggles, joys, role/s;

Who Clare is and how Fran views: her learning, rights, relationships and participation;

Lots about how Clare is viewed by others.

Ideas about disability from various viewpoints;

Raises questions about what is normal, what is perfect, how do people respond to and develop their ideas about difference?;

Thought provoking for me as Maggie's mum.

Catch-up re what's been happening – Journal and anything else Fran wants to talk about.

Emerging Themes we could discuss –

'Perfect child' – what is the perfect child? What is 'normal'?

Comparing process in responding to disability.

Is this related to the grieving process? A coming to terms process?

How do you think other people view Clare?

How are Clare's capabilities and her learning framed?

Is Clare more 'on to it' than people give her credit for?

What is that about?

Idea of treating Clare as normal, the same, fitting in – how does this work, what are the 'results'? Maggie example – school sports.

Self-censoring – e.g. I realise that I do this so as not to be disloyal to Maggie. I don't tell specialists or any people, except for Tony, what I find difficult about parenting Maggie because I think they'll grab onto it and view Maggie in terms of what I have talked to them about (deficits and difference).

Do you do this? For example, are there some things you wouldn't say to some people? Like specialists, teachers, your parents etc...?

Things to ask for/collect: newspaper article, learning story and other assessments.

Readings: Ask Fran if she would be interested in listening to Maggie's CD and reading some articles re disability: Intro to Ballard's book, plus Chap on parent/professional relationships, my article about Maggie and ECE centre and EI services. Ask her if there's any area she would like me to source info for her on.

To do: Give Fran new journal and collect old one for transcribing.

Appendix 4c: Third interview guide

(1) Transcript of Interview 2:

Changes, comments etc...

Anything you want to talk about further or pick up on from the interview/s,

Your journal etc...

(2) Grieving and/or adjustment processes

Realisation I had from talking with a colleague about how I don't say negative things about Maggie or any negative feelings I have for fear that people will focus on that and feed into that deficit, personal tragedy way of looking at her. It's a contradiction on the one hand you're expected to grieve but on the other hand I don't do it in public or even allow myself to talk about or recognise it because people might take it the wrong (deficit) way.

This is linked to a process of self-censoring – thoughts that I do or don't let myself have in regards to Maggie and other people. Do you notice times where you don't let yourself say or even think things in relation to Clare? Or where you are careful about how you say things? Does this depend on who you are talking with? Like do you not say some things to specialists when you think them – like if you disagree with them? Maybe your feelings about 'coming out of the closet' are related to a sort of censoring?

(3) How has the interview process and being part of this research been for you so far?

In what ways has it been positive?

Has it been enjoyable in some ways? How specifically?

Has it affected your thinking or feelings? About?

About what, can you give me an example?

How is it reading through a transcript for you? What is that process like? How do you react to what you have said, what I've said? Examples?

In what ways has it been negative?

Have you had any worries or concerns?

For example – about what I'm going to say in the write-up about what you have been telling me?

Or questions?

Have you disagreed with, or not liked things I've said? Can you give me an example?

Have you felt like I've shut down particular things that you've been talking about – e.g. when you started talking about feeling that you could have done more for Clare had you had a

clearer diagnosis earlier – I tried to reassure you, and suggested that that may have not made much difference. It occurred to me when I was reading the transcript that me saying these things might have had the effect of silencing your feelings of regret.

Have you got any questions for me?

(4) Feedback from me re the interview/research process:

I am quite an inexperienced interviewer and you have been a real gift!

You have been very generous with your time and the stories and experiences you have shared with me.

There is so much richness in your stories and perspectives that it's going to be quite hard to decide exactly which way to go, what to focus on!

I've found that a lot of what you say connects with my experiences as a parent and it's got me thinking a lot about what I think and feel – like the grief thing.

One thing that has struck me has been how there seem to be lots of connections between Clare and Maggie in terms of what they are like and how they learn.

Sometimes, particularly in the last interview, I've found it challenging to work out how I should respond to some things. Like, should I say what I think, or will that inhibit you from saying what you want to say. I don't want you to have to be second guessing me all the time or feel like I'm expecting you to share everything with me and I'll just keep my thoughts to myself. So issues around me being honest and a real person in our conversation at the same time as not taking over or over influencing what you have to say.

(5) Responses to the readings and Maggie's radio documentary:

What were the important or interesting aspects for you?

What jumped out?

Did 'it' get you get thinking about anything in particular?

Would you like me to find you some more material? About what sorts of things?

Pull out some of the aspects that are significant for me:

Models and approaches to disability – Medical/Personal tragedy & Social and the assumptions underlying them.

Do these 'ring true' for you? Discuss.

Specialists etc... having a different view of your child – e.g. her capabilities, what will support her development (how Maggie used her eyes) – something about accepting who Maggie is, rather than trying to change aspects that are part of her as a person, not an impairment as such, or part of the impairment and therefore not able to be changed.

Making assumptions – about your child’s capabilities, based on limited knowledge of them – mid-wife, schools...

Needing to be advocates for our children – have you felt this need? Story telling as a way of increasing people’s valuing of your child?

The difference between ‘inclusion’ being viewed as a child being expected to fit in or a valuing and recognition of diversity among learners.

Suggested reading:

Keith Ballard’s (1994) book: ‘Disability, Family, Whaanau and Society’. The Chapters were:

Chapter One, ‘Disability: An introduction’ by Keith Ballard. Introduction to some ‘key’ issues:

what meanings are given to disability;

experiences of disability as discrimination;

language and values surrounding disability;

difference between family and professional perspectives re disability;

experiences and ideas associated with intellectual disability;

research and disability

Chapter 12 by Colleen Brown: ‘Parents and professionals: Guidelines for the way ahead’. Colleen is a parent of a child with disabilities.

Her changing views of disability;

Her experiences of coming to terms with having a child with disabilities;

Negotiating relationships with professionals;

Parents facing barriers to their child’s acceptance and inclusion in educational settings;

The fight for inclusion and the positive and negative outcomes for herself and her family.

‘Maggie-Rose: A Parent’s Story’ (2002) which discussed:

Our responses to having a child with disabilities;

Our experiences of early intervention and early childhood education for Maggie;

How we viewed partnership with professionals and those involved with her education; What we wanted for her and from her early childhood centre.

'Meet Maggie-Rose' (2003) radio docu about Maggie and our family:

What messages would you to come across about disability in this research.

Who would you like to influence, what do you want them to hear?

Appendix 4d: Fourth interview guide

Catch-up

How has it been going? Any journal entries you would like to share? Responses to the last interview?

What happened with your ORRS application and getting into school? You didn't end up with the school you were wanting Clare to attend at our last interview. What happened?

ECE

What sort of relationship did you have with centre staff? How would you describe your relationship/s? Do you tell them stories about Clare? (Like achievements, learning, being 'switched on', interests etc...) What is their response? How involved were you in talking about Clare, planning, having input into what she does, learns, what they do in the centre?

Did your early Intervention Service fund a maximum number of teacher aide/ESW hours? Would you have chosen for Clare to attend for longer if Sandra was paid for more hours?

Special Education/Specialists

How do specialists, teachers, EI people respond when you tell them stories about Clare, what she can do, things she's done etc... Can you think of any examples?

Has Clare being given the label of moderately intellectually disabled made a difference to you? In what ways? How you see her? Relate to her? Talk about her? What you do with her?

Society

How's the wheelchair going? How is it feeling being out and about with Clare. Have you noticed, felt like other people are watching? Judging? Try to unpack what this 'gaze' is about.

Test out, discuss the "society disables" idea again. Link to Fran's description of life with Clare and the wheelchair as "coming out of the closet".

Relationships/Friendships

What does "knowing Clare" mean. What do you want in terms of people having relationships with Clare?

How do you see relationships in terms of their importance and value? Maybe as compared to other aspects such as learning to count, read, respond to routines etc...

How has parenting Clare affected your relationship with Mark?

How has parenting Clare affected your thinking about disability e.g. Have your attitudes etc... changed as a result of your experiences? In what way/s.

Research Project

How has the interview process impacted on your thinking, feelings? What messages do you have for others, as part of the research?

Appendix 5a: Parents' letter

August 16, 2010

Dear

As per our conversation on the phone, I'm writing to ask you if I can include photographs and/or names from Maggie's (XX) centre Learning Story Book that include your family in a section of my Doctoral thesis. Enclosed is a letter for your child/ren to give them some information and ask for their permission too. Would you mind going through the letter with your child/ren and talking with them about whether they want to be in the thesis? One or more of the photos I'd like to use have you and/or one or more of your children in them. Some of the stories refer to particular parents and children by name. Some of the stories are written by centre parents and have their names at the end. If you don't want yourself or your child's name or photo to be included I won't select photos with members of your family in them. If you don't want yourself or your child to be named, I can take the names out or use a pseudonym instead.

My thesis is about the lives and experiences of two young disabled children and their parents. It is based mainly on interviews with the parents, but I wanted to include some examples of assessment and teaching in there too. The stories are about a project you might remember about Goldilocks and the Three Bears. In that section of the thesis I use the project to show how Maggie was included at XX centre and what she learnt from being involved in that project. I particularly focus on Maggie's interactions and relationships with centre children and adults which is why I'd like to include the photos as well as the written stories.

I'd like to send you a copy of the Learning Story section of the thesis as a thank-you if you decide to give permission for your family to be included. Aside from talking about Maggie, I refer to other children as a whole but don't talk about adults or children as individuals in the thesis. I'd also like you to consider giving me permission to use the images and names in future presentations and publications and again, wouldn't talk or write about you as individuals in those or any other public forums.

I've enclosed a consent form that asks you for your permission to use photos and/or names from your family for the purposes I've outlined in this letter. You can decide to allow your own and/or your child's image to be reproduced in the thesis. You can also decide whether I use a pseudonym or your real names to identify you. You can also decide to be included in the research but not in any further presentations or publications.

I'd appreciate it if you could send back the consent form in the stamped, addressed envelope a.s.a.p. Please sign and send the form back to me even if you decide that you don't want yourself or your child/ren to be viewed or named in Learning Story section of the research.

Please don't hesitate to contact me if you require any further information. If you have any questions or concerns that you don't want to talk with me about, you can contact one of my Supervisors Missy Morton (03) 3458312 or Nicola Surtees (03) 345 8349 at the University of Canterbury, College of Education.

If you need to make a complaint about any aspect of my request or the manner in which I have conducted the research, you can contact either me or:

The Chair,
Educational Research Human Ethics Committee,
University of Canterbury,

College of Education,
PO Box 31-065,
Christchurch.

I'm looking forward to hearing from you and hope all is going well for you in the XX.

Take care,

Bernadette Macartney
23 Wilton Rd
Wadestown
Wellington 6012
Phone: (04) 9386757
Bernadette.mac@paradise.net.nz.

Appendix 5b: Children's letter

Dear

It's Bernadette Macartney here, from XX centre (a while ago!). I am writing to ask you if I can include photographs with you and Maggie Rose in them and your name in my Doctoral thesis. A thesis is a book written about some research. It's like a big assignment or project. When it's finished, I hand it into the University of Canterbury in Christchurch to get marked. A copy also goes into the University library where people training to be teachers can read it and hopefully learn something about how to include and respect people with disabilities. I will also keep a copy for Maggie and our family and give away a few copies of my thesis to special people.

My thesis is about the lives of two young disabled children and their families. One of the children you don't know, and the other one is Maggie Rose. As you know, your family went to XX centre with Maggie Rose. As part of telling our family's story, I talk about Maggie's time at XX centre. I'd like to include some stories and photos from her XX centre Learning Story Book. Most of the stories are about the project we did on Goldilocks and the Three Bears. You might have some of the same photos in your Learning Story Book/s.

One or more of the photos I'd like to use have you in them, and some of the stories have the names of children and parents from XX centre in them. Some of the stories are written by centre parents and have their names at the end. If you don't want your name or photo to be included I don't mind choosing photos without you in them. I also don't mind either taking your name out of stories or making up a pretend name for you if you decide that you don't want your name in my thesis.

I have asked your parents if it's okay with them for your name and/or picture to be in my thesis, but I also want to know whether that's okay with you too. The reason I want to include photographs is that I think they tell the story as well as and sometimes better than words. They bring the words to life so people can relate to them better. I especially think that the photographs show how much Maggie was included as a valued person in the XX centre community.

If you decide that you would like to be in the photos I choose, I will send you a copy of the stories and photos for you to keep. I am also wondering if you and your parents will let me show the photos when I'm talking to people about my thesis, and when I write articles to go into journals or magazines. Talk with mum and/or dad about it, and they'll let me know what you decide. I hope everything is going well for you. Maggie is looking forward to starting high school next year and she's still really into drama and music. Say hi to your families for me and Maggie,

Bernadette

Appendix 5c: Parental consent form

‘Difference or Deficit: Parents’ narratives and discourses of disability in education’

My child/ren and I have read, discussed and understand the letters informing us about this research project and inviting us to decide whether to be named and/or included in photographic images within the ‘learning story’ section of the research thesis document.

I understand that it is entirely my child/ren’s and my own decision regarding whether to be involved in the project in the ways outlined in the letters we have read.

I understand that I have the right to withdraw permission for myself and/or my children to be included in future presentations and/or articles at any time by contacting the researcher and informing her of my withdrawal of permission.

I understand that any permission given to have my own and/or my child/ren’s image/s included in the thesis document may not be withdrawn at a later time and that our anonymity cannot be guaranteed.

I understand that the thesis document will be available to the public through the University of Canterbury Library, and the distribution of a small number of copies to other people by the thesis author.

I understand that I can choose for myself and/or my child/ren to be given pseudonyms to help protect our privacy.

I understand that, if I choose for my child/ren or myself to be named only our first names, and not our family name/s, will be used.

I understand that, aside from being named, neither my child/ren nor myself will be referred to or discussed as individuals in the thesis document or subsequent presentations and articles based on the research.

My child/ren and I have read and understood the information about the project contained in the letter accompanying this consent form.

Please indicate your responses to the following statements by circling the appropriate answer and then fill in the details and sign in the space provided below.

I agree / do not agree to being named in the research thesis

I agree / do not agree to my child/ren being named in the research thesis

I agree / do not agree to my image being reproduced in the research thesis

I agree / do not agree to my child/ren’s image/s being reproduced in the research thesis

I agree / do not agree to my child/ren being named in future presentations or articles based on the research

I agree / do not agree to being named in future presentations or articles

I agree / do not agree to my image being reproduced in future presentations or articles based on the research

I agree / do not agree to my child/ren's image being reproduced in future presentations or articles based on the research.

I request that pseudonyms be used for myself and my children **YES / NO**

Name: _____ Phone: _____

Address: _____ Email: _____

Signature: _____ Date: _____

Please return to: Bernadette Macartney, 23 Wilton Road, Wadestown, Wellington 6012

Email: Bernadette.mac@paradise.net.nz Phone: (04) 9386757