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**Wellbeing for children with a
disability in New Zealand:**

A search for meaning

by

Maree Kirk

2006

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Abstract

This thesis explores the meaning of wellbeing for children with a disability in New Zealand, an area of social policy that has been largely unexamined. Focusing on the school environment, three questions are addressed: *What does wellbeing mean for children with a disability? What factors influence it? Are current policy frameworks which address child wellbeing relevant to the wellbeing of children with a disability?* The research involved qualitative data collection from nine purposively selected participants: children with a disability, their parents and key informants involved in service provision and policy development.

A critical review of international and national literature on definitions of wellbeing and disability, and on existing data sources, is followed by a socio-demographic profile of children with a disability in New Zealand. Qualitative findings are interpreted in relation to current New Zealand social policy initiatives and frameworks - *New Zealand's Agenda for Children*, the *Whole Child Approach* and the *Key Settings Model* – as well as the theoretical perspectives of social solidarity, wellbeing, the ecological theory of human development and discourses of disability.

Findings indicate that the concept of wellbeing as applied to all New Zealand children is also relevant to children with a disability. The difference however, lies in the factors which ultimately influence whether the various dimensions of wellbeing will actually be experienced by children with a disability. For these children, communication as a dimension of wellbeing for example, is influenced by language skill acquisition, which in turn depends upon allocation of appropriate and adequate resourcing of the child's learning environment.

The conclusion drawn is that policy frameworks, principles and social indicators addressing child wellbeing, are inconsistently applied with regard to children with a disability. *New Zealand's Agenda for Children* which promotes an ecological approach to child wellbeing would benefit from further adaptation to reflect the needs of this specific child population. The notion of wellbeing for children with a disability needs further development for the purpose of knowledge building, and to ensure clearer articulation between processes of policy development, service provision, and resource allocation.



Another turning point, a fork stuck in the road
Time grabs you by the wrist, directs you where to go
So make the best of this test, and don't ask why
It's not a question, but a lesson learned in time
It's something unpredictable, but in the end it's right.
I hope you have the time of your life

(Green Day, 1997).

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Acronyms

Acronym	Meaning
CCS	Crippled Children Society
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairments, Disabilities and Handicaps
IDP	Individual Developmental Plan
IEP	Individual Education Plan
IHC	Intellectually Handicapped Children
GSE	Group Special Education
NZDSRF	New Zealand Disability Survey of Residential Facilities
NZHDS	New Zealand Household Disability Survey
NZHS	New Zealand Health Information Service
NZPMP	New Zealand Poverty Measurement Project
OECD	Organisation for Economic Co-operation and Development
ORRS	Ongoing and Reviewable Resourcing Scheme
QPEC	Quality Public Education Coalition
SEG	Special Education Grant
SENCO	Special Education Needs Coordinator
SE2000	Special Education 2000
UNCROC	United Nations Convention on the Rights of the Child
UNESCO	United Nations Educational Scientific and Cultural Organization
UPIAS	Union of the Physically Impaired Against Segregation (UK)
WHO	World Health Organisation

Chapter 1. Introduction

1. Social policy and wellbeing for children with a disability: thesis purpose and background

Children are children - except when they are children with a disability. The way in which we consider the wellbeing of children reflects how we value, prioritise, and promote the day-to-day experience of childhood within our society.

The experience of wellbeing for children with a disability in New Zealand has been largely unexamined, yet according to New Zealand's 2001 census, approximately 90,000 children, that is 11 percent in the 0 - 14 age range had a disability, of which about 17 percent were found to be in need of some kind of additional health service (Statistics New Zealand, 2001). From a policy perspective this suggests a shortfall that merits further examination across other sectors.

As part of its *Agenda for Children* strategy, the New Zealand Government has developed the *Whole Child Approach* a framework designed to examine how children and young people are affected by policies, and to inform policy and service development. The *Whole Child Approach* is acknowledged as a tool aimed at ensuring quality of policy advice within and across any sector (Ministry of Social Development, 2004e). The *Children and Young People: Indicators of Wellbeing in New Zealand* (Ministry of Social Development, 2005a) is a current report that arose from the *Agenda for Children* strategy. It aims to establish a research dimension and information base for cross-sector policy development for children. While both documents identify information gaps, neither establishes a clear conceptual definition of wellbeing for children in New Zealand, nor do they consistently include the specific population of children with a disability.

So how can we examine what wellbeing means for children with a disability in New Zealand?

The thesis will address this issue by focusing on three questions:

1. What does wellbeing mean for children with a disability?
2. What factors influence wellbeing for children with a disability at school?

3. As the basis of child policy and service development in New Zealand: are current policy frameworks relevant to the wellbeing of this specific population of children with a disability?

The thesis has involved the development of a small-scale, exploratory study, which draws partially on a grounded theory approach to data collection and analysis:

Grounded theory is an analytic *inductive* technique (going from observed instances to the development of a law or model of action in a rigorous manner), based in the interpretive tradition, with emphasis on individual power, choice and construction of meaning (Znaniecki, 1934 cited in Grbich, 1999:171).

This approach is used because of its relevance to research focusing on issues of empowerment such as *children's voice*. Adopting a research perspective which acknowledges the importance of listening to children's voice means an approach focused on what children have to say as competent and reliable witnesses to their own lives (Clark & Statham, 2005; France, 2004). It is also for this reason that this study does not develop the interpretation of findings in terms of pre-existing frameworks or concepts such as *objective* and *subjective* wellbeing.

The relevance of the thesis' questions to policy is threefold. First, there is an increasing emphasis on the need to inform policy based on considering children's rights and children's voice. Second, in the social sector, an evidence-based approach to policy work and service provision is being promoted which should draw on qualitative or quantitative research and should also involve children in the research process. Third, a fundamental perspective to child wellbeing is now recognised as one which considers the needs of children in relation to their whole life circumstances, and which avoids single-sector solutions (Ministry of Social Development, 2002; 2004e:16). These considerations are reflected in New Zealand's *Whole Child Approach* which promotes the key settings model and the ecological model of development, which have also informed the study's research approach. The thesis addresses children's voice by seeking their perceptions of what wellbeing might mean, which in turn provides an evidence-base of the day-to-day reality of what wellbeing actually means for children with a disability. The specific setting in which I examine these questions is the social institution of the school, an environment

identified in New Zealand's *Key Setting Model* as crucial to child development and wellbeing (Ministry of Social Development, 2004e: 25).

The study has involved the collection and analysis of qualitative data, an acknowledgement that understanding human experiences is a central objective of social science research (Davidson & Tolich, 2001; Holloway, 1997; May, 2002). Data have been collected from a purposively identified study population of nine individuals, seven of whom are directly involved with the schooling environment of children with a disability, the remainder in the broader national policy field: services users - children with a disability and their parents; service providers - teachers and special education providers¹; policy professionals - policy and national service development providers.

The thesis' third question is addressed by relating these findings to the broader policy context, with the purpose of asking how well existing data, policy frameworks and their applications in the area of child wellbeing reflect consideration of the needs of this specific group of children - those with a disability.

The definitions of disability are expanded on in later chapters, but for the purpose of this thesis I broadly define the specific population of children with a disability aged from 0 to 19 years as those with a physical, intellectual, psychiatric/psychological, or sensory impairment which limits a child, or young person from actively participating in society due to either physical or social barriers in their environment.

2. Background: a focus on children's needs

In New Zealand there is an increasing amount of evidence to suggest that children as a population group do not fare well. Government and non-government organisations measure the impact of welfare reform and other social policies on children and their families through developing indicators of child wellbeing (Child Poverty Action Group, 2003; Davies, Wood & Stephens, 2002). The variables of ethnicity, employment status, parental educational qualifications, housing tenure, and family type are strongly correlated with restricted living standards for households with children (Krishnan, Jensen, & Ballantyne, 2002). Research points to discrepancies in

¹ In New Zealand, the title of special education services is now called *Group Special Education* and forms part of the Ministry of Education.

health, education and social opportunities for children from impoverished homes, with 21 percent of New Zealand children living in poverty in 2005 (Callister, 2004; Krishnan et al, 2002; Ministry of Social Development, 2005b; Waldegrave, Stephens, & King, 2003). These findings lend support to the importance of addressing the needs of children as a specific population group.

Recent legislative and policy changes in New Zealand have been the precursor to a broader reconsideration of the adequacy of services provided to children and their families; for example² the *Education Act 1989*, the *Child, Young Persons and their Families Act 1989*, the *Human Rights Act 1993*, the *Children's Commissioner Act 2003*, and the *Care of Children Act 2005* to name some of the more salient changes. The latter change is particularly significant for children with a disability because for the first time it allows a designated role of advocate to facilitate communication for children with a disability. From the policy field, examples of change include the *1998 Child Health Strategy*, the *New Zealand Disability Strategy 2001*, and the *Early Childhood Strategic Plan 2002*. In social policy probably one of the most significant responses has been the *Working for Families* package (Ministry of Social Development, 2004f), and undoubtedly of most consequence, *Special Education 2000* (1996) a policy outlining all funding related to children with a disability in New Zealand schools, as well as the ratification of the *United Nations Convention on the Rights of the Child* (1993) because it led to *New Zealand's Agenda for Children* (2002).

The notion of children's voice has also been strongly endorsed in New Zealand policy and legislation which informs policy decisions on issues of child participation in decision-making processes, and has appeared as part of the implementation of the *Agenda for Children*, the *Youth Development Strategy Aotearoa 2002* and the *Care of Children Act 2005*. This approach is considered to be in line with New Zealand's obligation under the *United Nations Convention on the Rights of the Child* (UNCROC). Article 12 requires that children have the right to express their opinion

² In chronological order: *Education Act 1989*; *Child, Young Persons and their Families Act 1989*; *New Zealand Bill of Rights Act 1990*; *Human Rights Act 1993*; *Code of Health and Disability Consumers' Services 1996*; *Education Standards Act 2001*; *Children's Commissioner Act 2003*, and the *Care of Children Act 2005*. Some child policy examples are: the *Child Health Strategy*, 1998; *Family Assistance 1991*; *Strengthening Families Strategy*, 2000; *New Zealand Disability Strategy*, 2001; *Youth Development Strategy Aotearoa*, 2002; *Early Childhood Strategic Plan*, 2002; *Agenda for Children 2002*; *Working for Families 2004*.

freely and to have that opinion considered in decisions that affect them. Article 13 protects the right of children to seek, receive and give information and ideas of all kinds (Gray, Barwick, Martin, & Asiasiga, 2002).

The Government's policy framework *New Zealand's Agenda for Children* (Ministry of Social Development, 2002) represents a collaborative process stemming from a number of years of consultation with government agencies, child and family services providers, community organisations and children and their families. The *Agenda* is a guide for multi-service and sector development to enable inter-agency provision for children in New Zealand and to promote positive childhood attainments. It is based on ten principles for Government policy and practice, prioritised into seven "Action Areas" with a commitment to monitoring specific progress in each area. The *Agenda* recognises specific child population groups (Ministry of Social Development, 2002: 34).

The initiative originated from the Office of the Commissioner for Children's 1990 seminar *Towards a Child and Family Policy in New Zealand* and culminated in the *Seminar on Children's Policy in July 2000*. The *Agenda* arose from growing Government and community agency concern regarding the disproportionate numbers of New Zealand children represented in data relating to adversely affected childhood outcomes. As an example, the *Social Report 2001* highlighted that for the 1997/98 period, 29 percent of children were living in poor families³ compared to 16 percent a decade earlier (Ministry of Social Development, 2001b).

The 1993 ratification of the *United Nations Convention on the Rights of the Child* (UNCROC) gave further impetus for the development of a child-centred focus to provision of services in New Zealand. The *Strengthening Families Strategy* (2000) and the *Youth Development Strategy* (2002) were precursors of the *Agenda for Children* framework. The adoption of the *Whole Child Approach* to child policy and service development was established as the basis of this Ministry of Social Development strategy. This is discussed in section 3 of this chapter.

In New Zealand whilst these legislative and policy changes clearly demonstrate a fundamental changing commitment to the wellbeing of children, it is not clear

³ Poor families are defined as families with incomes below 60 percent of the median, adjusted for living costs (Ministry of Social Development, 2002).

whether children with a disability are adequately considered. Concern has been expressed for example by practitioners and researchers alike, that these children may be disadvantaged when demand for scarce resources is high and service provision criterion are not consistent with a holistic approach to considering children's needs across the life course (Bourke et al., 2001; MacArthur & Kelly, 2004; Quality Public Education Coalition, 2004; Wylie, 2000). The review of provision of services to children with special education needs (Wylie, 2000) and the *Families Today* report (Ministry of Social Development, 2004a) both identify the fragmentation of service provision and the difficulties of service access for families and children with a disability.

The research undertaken by the Quality Public Education Coalition (QPEC) also highlights the concern that the *Special Education Grant* (SEG) funding for educational resources in New Zealand schools is inadequate in meeting the educational needs of children with a disability, particularly in low socio-economic areas (QPEC, 2004:1). In addition, the QPEC research identifies two major shortfalls in special education services in New Zealand; first there is a general lack of resources including teacher training, teacher aide training, professional development and educational resources; second, only 1 percent of children are eligible for additional educational support, regardless of research-based evidence supporting the need for a minimum 2 percent requiring support to achieve capabilities at school (Ministry of Health, 1998:51; QPEC, 2004).

Finally, the New Zealand Human Rights Commission has identified the disparity in service provision for children, including those with a disability:

Some children encounter problems in accessing education, including disabled children, children who speak English as a second language, children with severe learning difficulties, and children living in poverty (Human Rights Commission, 2004: 66).

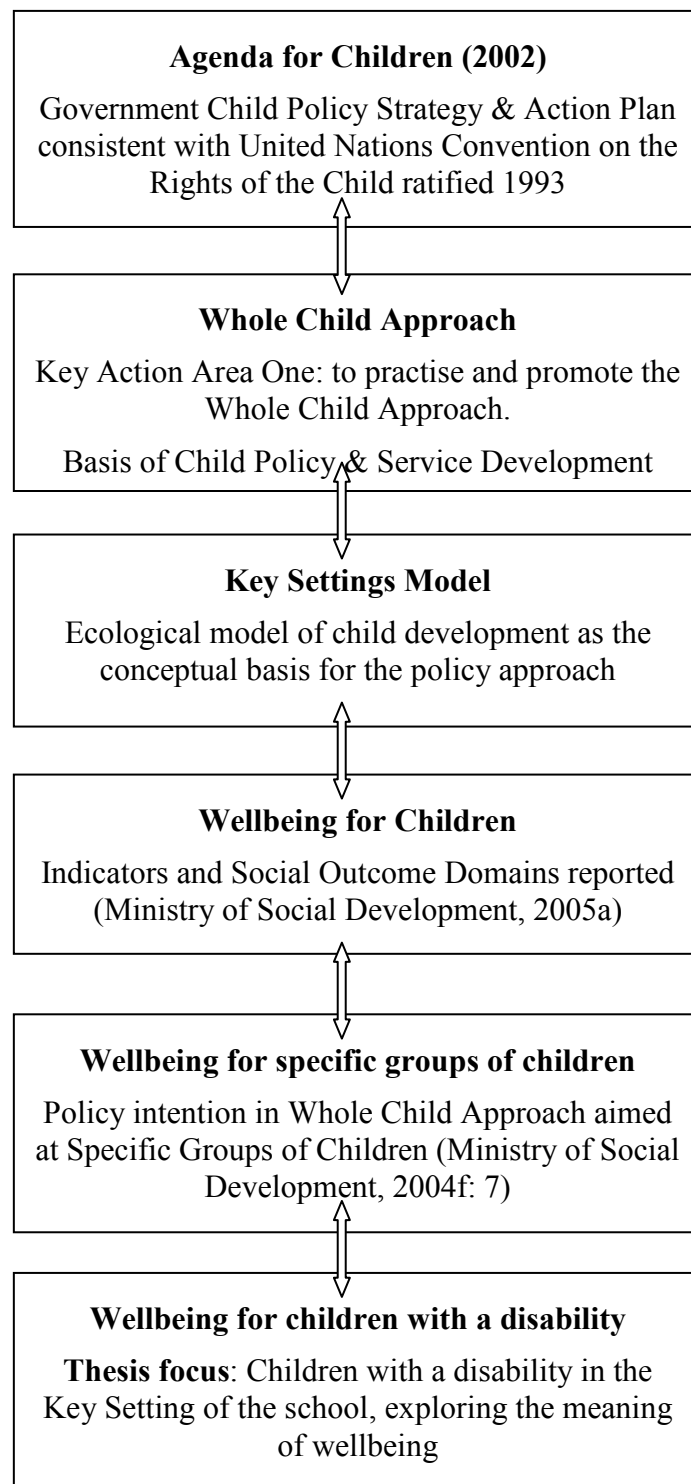
There are therefore grounds to indicate that the place of children with a disability, and the clarity of what is meant by wellbeing in relation to this specific child population, need further examination in the context of existing policy frameworks and educational provisions.

3. New Zealand policy in the area of children and wellbeing

New Zealand's Agenda for Children established a framework to direct and implement a range of initiatives to address child outcomes which were broadly portrayed as the principles of wellbeing for children. The principles directing the framework are briefly described as the need for love, protection and support, with opportunities to thrive during childhood, to grow up healthy and happy, to acquire the skills to form positive relationships, and to fully participate as adults; with the right to be treated as respected citizens and to be valued for who they are (Ministry of Social Development, 2002:6).

Stemming from the *Agenda for Children* is the *Whole Child Approach* (see Figure 1) a policy orientation seen as central to policy development and service delivery by both government and non-government agencies (Ministry of Social Development, 2004e: 5).

Figure 1. Social policy initiatives for children in New Zealand 2005



The *Whole Child Approach* embraces a holistic perspective to policy and service development, delivery and evaluation, by attempting to avoid isolating the child from its broader environment, recognising that they cannot be separated from the key settings or environments in which they live and grow. In practice this means that the

focus of policy should be on addressing children's needs and problems by considering their lives as a whole and their links with others. In its application, the *Whole Child Approach* implies the need for coordinated action across different sectors, and interventions at multiple levels including family and whanau, friends and peers, and wider communities, including schools. At the heart of the *Approach* is the importance given to children themselves. This translates into a need to recognise the implications that policy will carry for children, seeing them as individuals capable of making valuable contributions to the development of policies which affect them, and actively seeking ways in which to include them in decision-making (Gray, Barwick, Martin, & Asiasiga, 2002; Ministry of Social Development, 2002: 41; 2004e: 6).

Underpinning the *Whole Child Approach* is the *Key Settings Model* (see Figure 1), the conceptual foundations for the policy approach which draw heavily on the ecological model of human development, initially proposed by Urie Bronfenbrenner (1979). This perspective of human development and learning views child functioning as multiply determined, where the practices influencing behaviour and development originate from different settings, and the inter-relationships between the settings in which children are participating members. According to Bronfenbrenner (1979), the aim of an ecological science of human development is:

Systematic understanding of the processes and outcomes of human development [...] where variations in developmental processes and outcomes are considered a joint function of the characteristics of the environment and of a developing person (ibid: 197).

Adapted to the policy environment, the *Key Settings Model* identifies key settings or environments which enable the child to be situated within the context of a number of interlinking settings or systems of influence (Ministry of Social Development, 2002: 14; 2004e: 25; see Appendix 3).

The concept of wellbeing for children (see Figure 1) has been operationalised as social outcome domains of wellbeing, which are measured by appropriate indicators (Ministry of Social Development, 2005a: 136). These data provide the basis for development of policy and services, and in the context of this thesis, are linked to the *Whole Child Approach* which aims to develop policy and service provision for

specific groups of children (see Figure 1), including those with a disability (Ministry of Social Development, 2004e: 7).

The thesis has therefore evolved against this policy background, and focuses specifically on the specific group of children with a disability, in the key setting of the school⁴, exploring the meaning of wellbeing.

1. The school setting: education and the ecological model in New Zealand

School service provision is directed by education policy, and as such reflects the social policy principles and theoretical basis of the ecological paradigm through the core national curriculum *Te Whariki - Early Childhood Curriculum* and *New Zealand Curriculum Framework*. Children with a disability are identified in the curriculum framework in the *Special Education Policy Guidelines* (Ministry of Education, 1993, 1996b, 2004d) which underscore service provision rationale for this specific population.

In New Zealand there is a two tier education system which it can be argued, runs contrary to a holistic approach to service provision for children. The Ministry of Education *Special Education Policy and Guidelines* (2004), *Special Education 2000* (1996) policy and the *Education Act 1964; Education Act 1989; Education Standards Act 2000* and the Ministry of Health *New Zealand Disability Strategy* direct education service provision for children with a disability in New Zealand (Ministry of Education, 2004d)⁵. These policy and legislative documents give the definitions of entitlement to education and the principles which underpin New Zealand education. The overarching guiding principle often quoted as the foundation of New Zealand education, is Peter Fraser's 1939 Ministerial Objective that every person, whatever the level of academic ability, has a *right* as a citizen to a free education [emphasis added] (Beeby, 1992; Olssen & Matthews, 1997).

The Education Act 1989 Section 8 is of particular significance:

⁴ As this is a Master's thesis, it has not been possible for me to undertake the examination of all dimensions of the *Key Settings Model* such as the family or broader social influences.

⁵ The policy guidelines and strategy objectives are available online from the Ministry of Education website <http://www.minedu.govt.nz>.

People who have special education needs (whether because of disability or otherwise) have the same rights to enrol and receive education in state schools as people who do not (Ministry of Education, 1989).

Of the *New Zealand Disability Strategy*'s fifteen objectives, eight are promoted as applicable to special education (Ministry of Education, 2004d). In this study, the policy guidelines and strategy objectives are drawn on because of their relevance to the key setting of the school, for children with a disability.

4. Thesis structure

Chapter One of the thesis sets out the purpose and background of the study, and presents an overview of recent key policy initiatives relevant to the theme of children, disability and wellbeing.

Chapter Two offers a descriptive, socio-demographic profile of children with a disability in New Zealand, based on the collation of data from a range of published data sources. The chapter outlines the definitions of children, disability and wellbeing as they are applied in data collection and used to inform social policy reports; it also highlights some of the shortcomings of existing data sets which provide key sources of information for children with a disability.

Chapter Three outlines the dominant discourses of disability - medical, charity, lay, and rights - arguing that they are clearly influential in shaping contemporary social policy and service provision for children with a disability. It then relates these discourses to two dominant models used in the field of disability, the medical and the social models of disability.

Chapter Four presents an overview of the theoretical perspectives relevant to the social policy dimension of the thesis: the concept of wellbeing, the ecological theory of human development, and the theory of social solidarity and inclusion.

Chapter Five describes the research rationale for adopting a small-scale, qualitative inquiry, and the research processes involved in identifying key informants, interviewing and data processing.

Chapter Six addresses the thesis' three research questions by presenting findings from the key informants on their perceptions of wellbeing for children with a disability, what factors they consider influence this wellbeing and how relevant they consider the

Key Settings Model and the established outcome domains of wellbeing for children in New Zealand are to children with a disability.

Chapter Seven provides a discussion of the research findings, setting them against broader theoretical perspectives and highlighting their link to broader social policy applications.

Chapter Eight concludes the thesis summing up the inferences drawn from the research and the broader literature. There are recommendations for data collection and the need to link data with social policy applications. The research findings highlight implications for policy development, service planning, resource allocation, and service provision to meet the needs of children with a disability at school.

Chapter 2. Disability and wellbeing: definitions, data and child profile

Well the situation is that they might not meet the criteria for the resourcing but it is very clear to you as professionals and as a school that those children aren't able to access the curriculum [...] but it is anticipated that we would have whole children. (Extract of interview with Service Provider).

1. Introduction

This chapter provides a socio-demographic profile of children with a disability in New Zealand based on a review of published data⁶ from both government and non-government reports⁷. It also highlights the complexities of identifying issues in relation to children with a disability because data for this population group are fragmented across various government departments and publications. In addition, the chapter shows that policy and service provision documentation do not provide a consistent application of a standard definition of children, disability nor of what constitutes *special needs* for children. The argument underpinning this chapter is therefore that without adequate and comprehensive data, it will be difficult to document, monitor and evaluate how New Zealand is addressing the social wellbeing needs of children with a disability.

2. Children in New Zealand: an overview

For most children the family provides the context within which they are nurtured and socialised. It can also have a major bearing on life chances in education, health and future socio-economic status. In New Zealand, the make-up of families is changing and there is a growing number of sole-parent and de facto-couple families (Brown, 1999).

In 1971, 32% of the population were children, but by 2001, they represented only 23%, a proportion that has remained unchanged in the past three censuses. In the next 50 years their numbers are projected to decrease, so that from the 2040s onwards they

⁶ At the time of publication of the Thesis, no data from New Zealand's 2006 Census were available.

⁷ The age range covered in these reports normally spans birth to 14 years, with quinquennial age group distributions.

will represent approximately 16% of New Zealand's total population (Khawaja & Dunstan, 2000). In 2001, apart from the 35 - 39 year age group, children in the 10 - 14 year age group were proportionally the largest of all age groups (Pink, 2002), a structural aspect which in the near future will have important ramifications for the transition to employment, particularly amongst children with a disability.

There is evidence of increasing diversity amongst New Zealand's child population. This stems from two influences: an increasing number of children born overseas and an increasing number identifying with more than one ethnic group. The proportion of children living in New Zealand but born overseas has increased from 1.9% in 1951 to 9% in 2001; of these, about a third, a quarter and a fifth respectively were born in the Pacific Islands, Asia and Europe. Secondly, the increasing ethnic diversity of children is illustrated in part by the fact that a greater proportion of children than adults - 18% and 6% respectively - identify with more than one ethnic group (Smillie, 2002).

In 2001, close to 70% of all New Zealand children under 18, lived in urban areas but their proportions vary between regions, with Gisborne having the highest concentration of children (32%), and Otago the lowest (23%) (Ministry of Social Development, 2002:47).

Children's family circumstances are also changing, particularly in terms of family structure. Between 1986 and 2001 the proportion of children living in mother-only families rose from 14% to 23% and the proportion of dependent children under the age of 18 living with one parent increased from 16% to 27%. These changes were most pronounced for Māori (16% to 44%) and Pacific Island children (19% to 31%) (Ministry of Social Development, 2002:48). Children are also more likely to have lived in blended families by the time they reach their late teens, more so for Māori than non-Māori children (29% and 18% respectively) and for children whose mothers have few or no educational qualifications (Dharmalingam, Pool, Sceats, & Mackay, 2004:73).

Children living in low income families are identified as experiencing disproportionate disadvantage depending upon family type, ethnicity, household tenure and income⁸

⁸ The specific variables include: by sole - parent families, families with a Māori, Pacific or 'Other' adult (defined as apart from New Zealand European), families with an income - tested benefit as the

(Ministry of Social Development, 2004c:68). In 2004, the proportion of families below the threshold ranged from 51% for families reliant on income tested benefit (62% in 2001) and 43.3% of children in sole-parent families (60.7% in 2001) (Ministry of Social Development, 2005b). According to the 2005 *Social Report* families with three or more children are also disproportionately represented in low income families (Ministry of Social Development, 2005b:64), and although data do suggest some improvement, a significant proportion - about one fifth - of children in low income families remain under the New Zealand poverty threshold ⁹ (Ministry of Social Development, 2005b:64).

3. Definitions of disability applied for data collection: their relevance to children

Definitions of *disability* vary depending upon context and use. There are conceptual issues in defining disability which reflect whether they have been developed from either the traditional medical model or the social model of disability (Beatson, 2004b; Marks, 1997; Oliver, 1996; Taylor, 2004). The debate around the theoretical foundations of these models is discussed in detail in Chapter Three. Briefly then, the medical model locates disability within individuals where interventions to optimise function¹⁰ and adjustment are targeted at the individual (Ministry of Health, 1998). The individual's impairment is seen as the cause of the restrictive life experiences of the disabled person. The impairment is identified as stemming from limitations of function or utility [functional limitation] or psychological losses which are assumed to arise from disability (Taylor, 2004). The social model of disability is reflective of human rights and equality. The individual's impairment is seen as compounded by the physical and social barriers in society which restrict life experiences and are therefore disabling.

main source of income, and families who are renting their accommodation (Ministry of Social Development, 2004a).

⁹The Ministry of Social Development uses one of three thresholds: 60%, 50% and 40% of median disposable family income to measure the distribution of low income (Ministry of Social Development, 2004c:66,164:).

¹⁰ *Function* is the individual's ability to interact with the environment. Dr Elizabeth Spellacy, Lecture 10.11.2004. Disability Services Advisory Committee, Bay of Plenty District Health Board.

1. International definitions of disability

The most recognised definition of disability is the World Health Organisation (WHO) *International Classification of Impairments, Disabilities and Handicaps* (ICIDH) (World Health Organisation, 1980). This definition makes the distinction between three terms: *impairments* refer to biomedical status and disturbances at the organ level; *disability* refers to the consequent restriction or lack of ability to perform activities applicable to the whole person such as tasks, skills and behaviours, and indicates functional limitation [impairment] expressed in the reality of everyday life; *handicap* refers to any social consequence of disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual (adapted by the author from Doyal & Gough, 1991; World Health Organisation, 1980)¹¹.

The difficulties of collecting and recording disability statistics are recognised internationally (United Nations, 2001) and have recently led to reviews of statistical collection and questionnaire design procedures. This has included a revision of the ICIDH to the *International Classification of Functioning, Disability and Health* (ICF), and an important dimension of this has involved the incorporation of the social context, a change which has significant implications for data collection on the wellbeing of children with a disability (United Nations, 2001: 9; see Appendix 1).

Despite this progress however, the ICF has yet to be universally adopted, compatibility with census data remains problematic (ibid), and the classification still lacks a child focus (Childhoods 2005, 2005; European Committee for Social Cohesion, 2004; Organisation for Economic Co-operation Development, 2002).

2. New Zealand definitions of disability

New Zealand still relies on the ICIDH (1980) definition for the *New Zealand Disability Surveys* (Statistics New Zealand, 1996, 1997, 2001). These surveys use a functional¹² concept of disability for adults which is justified for its comparability with international standards for data collection on disability (Statistics New Zealand,

¹¹ Official Population Census Survey (OPCS) has advanced its assessment of disability in Britain by modifying the WHO classification. OPCS, 1988 *The prevalence of disability among children*. HMSO.

¹² Function in terms of physical or psychological ability being limited by health status and requiring some form of assistance to perform tasks (author's own definition).

2001). This said, New Zealand disability data have not consistently been included in the OECD indicators of disability data sets (Kirk, 2004; Organisation for Economic Co-operation Development, 2002).

The definition of disability for children aged less than 15 years relies on a broader definition¹³, which also includes the use of Special Education services, use of specific types of equipment and support needs (Ministry of Health, 2005a; Statistics New Zealand, 1997). In the *New Zealand Disability Surveys*, children are classified as having a disability if they have one or more functional limitations, chronic conditions, are attending a special school or special class, and / or use a technical aid. The limitation had to be for a minimum of six months and not eliminated through the use of simple corrective devices such as glasses (Ministry of Health, 1998; Statistics New Zealand, 1997). A further category “other” records use of special education, learning needs, an Individual Education Plan (IEP) or Individual Developmental Plan (IDP); attendance at special school, special unit or class at a regular school; speaking difficulties and other (Statistics New Zealand, 1997, 2002b:129). Of note is the total reliance on data from parents who act as proxy respondents for the child, indicating a lack of representation of children’s voice in the data source.

These definitions of disability for children and adults, which rely on functional limitation and the use of special education services, are broader than the definition that determines eligibility for government-funded disability support services:

A person with a disability is a person who has been identified as having a physical, psychiatric, intellectual, sensory or age-related disability (or a combination of these) which is likely to continue for a minimum of six months and result in a reduction of independent function to the extent that ongoing support is required (Ministry of Health, 1998:12, 2002:6).

The *New Zealand Disability Strategy* (2001) defines disability from a social and ecological, rather than a medical perspective:

Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric,

¹³ This excludes the *New Zealand Disability Survey of Residential Facilities Survey* (1997; 2001) which focused on adults aged 15 and over.

intellectual or other impairments. Disability is the process which happens when one group of people create barriers [...]. Disability relates to the interaction between the person with the impairment and the environment (Ministry of Health, 2001:3).

However, this definition has yet to be directly applied to data collection in New Zealand and as such, existing data sources will still reflect the influence of the medical model. From a policy perspective, this suggests that service development and provision will continue to be based upon medically-oriented conceptualisations of wellbeing and disability, with little room for exploration of its broader social dimensions which has life course ramifications for children with a disability.

4. Key data sources

Key primary sources of data available on disability are the *New Zealand Census*, and the *New Zealand Disability Survey* undertaken by Statistics New Zealand. The *New Zealand Household Disability Survey* (NZHDS) is a household survey and a companion survey of the population living in residential facilities, the *New Zealand Disability Survey of Residential Facilities* (NZDSRF) (Ministry of Health, 2005a:1). Other government agencies that collect primary data in relation to disability are the Ministry of Education, the Ministry of Health and Sport and Recreation New Zealand.

The main problem with these sources is that they are collected and compiled by various Government agencies, using different definitions of disability (as discussed earlier) and child populations and therefore pose problems of accessibility and comparability.

An illustration of the definitional inconsistency in age of child population is the *New Zealand Disability Survey*, which considers the population of children with a disability to include those aged 0-14 years (Statistics New Zealand, 2002b). A person aged 15 years or more is considered an adult in the NZHDS and the NZDSRF (Ministry of Health, 2005a:92). This has an impact on the types of data collected because different survey screening questions and questionnaire content vary for adults and children. This creates the impression that the needs of children with a disability beyond the age of 15 can be assimilated with those of an adult and this is often compounded by the fact that published secondary source data do refer to population groupings of people with a disability such as 15 – 24 years, 15 - 44 years and 15 – 64

years (Ministry of Health, 2005a: 84;-85). In contrast, the Ministry of Education considers that a child becomes an adult student only once they reach the age of 19 or over (Ministry of Education, 2004e). This anomaly needs to be further explored in terms of the notion of dependency, which may be linked to assumptions of social outcomes for young people with a disability.

The New Zealand Ministry of Education collects comprehensive data from all schools in March and July each year. Within the July data, questions cover data by type of student, regular students by type of school and nature of attendance; and *Ongoing and Reviewable Resourcing Scheme* (ORRS) students¹⁴ by number of students, age, ethnicity, funding category, gender, institution, fund-holder and city district (Ministry of Education, 2004c). However, these data have a major disadvantage because they are not readily available for analysis and are not published regularly.

The population of children with a disability is not covered in the *New Zealand Health Survey 2002/03*. This is the third national population survey of its kind, but is restricted to the population of those aged 15 years and over and do not contain data related to disability (Ministry of Health, 2004).

In contrast to the lacuna of health and education data on disability, a primary source which does include data relating to people with a disability is from the *New Zealand Sport and Physical Activity Surveys*. Data are readily available, and cover people with a disability, including young people with a disability aged 5 - 17 year olds and adults with a disability aged 18+¹⁵ (Sport and Recreation New Zealand, 2002).

The problems of inadequate, incomplete and fragmented data sources on children with a disability are to some degree also reflected in published data. Only recently have certain Government reports featured a profile of people with disability¹⁶. For example the *Living with Disability in New Zealand: Summary* (Ministry of Health, 2005a) reports data on age, gender, ethnicity and medical pathologies, but is the first Government report to include a section on children with a disability and education,

¹⁴Ministry of Education Special Education criteria of eligibility to educational support due to designated special need; children are then verified as ORRS students (Ministry of Education, 2004).

¹⁵ The definition of disability used in the *Sport & Physical Activity Survey* is: any physical or intellectual disability or condition (lasting six months or more), which would put a person at a disadvantage relative to able - bodied people. This excludes any condition resulting from poor health or illness (SPARC, 2002).

¹⁶ For example the 2005 Social Report (Ministry of Social Development, 2005:20).

support needs and household composition. However, the current reports *Children and Young People: Indicators of Wellbeing in New Zealand* (Ministry of Social Development, 2005a) and the *Social Report* (Ministry of Social Development, 2005b) do not contain any detailed data but a simple paragraph or table summary of the number of children aged 0 - 14 with a disability by ethnicity and gender (Ministry of Social Development, 2005a: 24; Ministry of Social Development, 2005b: 20).

In addition, Government reports which would be anticipated to contain data in relation to children with a disability but do not, are for example, *New Zealand Families Today* (Ministry of Social Development, 2004a). This report does not delineate family care or support of a person with a disability by age so that intergenerational patterns are difficult to identify. It appears that the focus is on older family members with a disability, focusing on the prevalence of disability with age.

Inter-group comparisons are limited in secondary source publications to Māori and non-Māori groups or Pacific and non-Pacific groups. No published data are available for European/New Zealand and Asian/other ethnic groups, so inter-group comparison of disability by cause and type amongst the general child population is not possible. Nor is it possible to clearly identify issues of disability cause or type for the child population group European/New Zealand or Asian/other (Ministry of Health, 2005a:68; 78).

An exception to this apparent lack of published data in government sources is a non government report *Children and young people in New Zealand: key statistical indicators* (Melville & Van Rutte, 2003), produced by Barnardos which identifies critical issues affecting children and young, integrating data relating to children with a disability.

In short, the data which have a direct bearing on children with a disability come from a variety of sources. However, the majority of publications rely solely on the disability surveys as the primary data sources¹⁷, although other sources are clearly available. This suggests that current publications will only provide a partial

¹⁷ For example, the current report *Living with Disability in New Zealand: Summary* (Ministry of Health, 2005a) is a descriptive summary of the 2001 *New Zealand Household Disability Survey* and the 2001 *Disability Survey of Residential Facilities*.

contribution to the ways in which the wellbeing of children with a disability might be addressed, evaluated and monitored.

5. A socio-demographic profile of children with a disability in New Zealand

Ministry of Health statistics show that 22 percent of adults aged 15 years and over and 11 percent of children below that age living in households reported a disability in 2001. In actual numbers, this was an estimated 626,500 adults and 90,000 children – a total of 716,500 people. Focusing on the defined child population, disability was more prevalent amongst the 5 - 9 and 10 - 14 age ranges, and more pronounced for males in both age groups (Ministry of Health, 2005a:8).

The profile of children with a disability in New Zealand draws on the statistical data base of the *New Zealand Disability Surveys*, in which disability is defined as outlined in Section 3.2 of this thesis, and a child is defined as a usual resident of New Zealand aged between 0 - 14 years (Statistics New Zealand, 2002b).

1. Cause and type of disability for children

The most prevalent cause of disability reported for children (41%) was disability existing at birth. For a quarter the cause is not specified, or not known, for another third it is due to disease or illness, about a fifth report “other”, but only a small proportion (3%) identify cause as a result of accident or injury (Ministry of Health, 2005a:20; Statistics New Zealand, 2002b:16).

For children with a disability identified as part of the 1996 and 2001 *Disability Surveys*, nearly sixty percent had a single disability only. Amongst children aged between 5 - 14 years half had a disability that limited their participation at school, including affecting their ability to make friends (22%), play (25%), participate in sport or games (30%) and go on school outings (15%) or camps (Statistics New Zealand, 1999, 2002:16; Ministry of Health, 2005a:33).

Of those with a disability, 58% classified the type of disability as “other”¹⁸. Over one-third reported sensory difficulties and chronic health problems, a quarter psychiatric

¹⁸The classification “other” included those with a speaking limitation, learning and developmental difficulties or requiring special education due to a limitation. The type of disability reported does not add to 100% due to the reporting of multiple disabilities.

or psychological disabilities and 14% reported intellectual disabilities. An estimated 5% had a limitation requiring the use of a technical aid (Ministry of Health, 2005a:16; Statistics New Zealand, 2002b:16).

2. Children with a disability: variations by gender, ethnicity and age

Disability varies by gender: prevalence amongst those aged 0 - 14 is higher among boys (13%) than girls (9%), and is higher in the 5 - 9 and 10 - 14 age ranges (Ministry of Health, 2005a:7). These data have implications for planning service provision particularly in relation to transitions from education services to the workforce. The *Disability Survey* data do not clearly identify the population age range 15 – 21, a group eligible and provided for within education services – again this has implications for policy, service planning and service provision.

There are also ethnic variations in disability: prevalence is higher among Māori (24%) compared with non Māori (17%). Compared to the national level of prevalence which was 11 percent, the disability rate for Māori children was higher at 15%, but lower for Pacific Island children at 8%. A key explanation of these ethnic differences resides in the younger age structure of New Zealand's Pacific population¹⁹ (Ministry of Health, 2005a:64,74; Statistics New Zealand, 2002a:1).

There are also notable variations of disability by type and ethnicity. Comparing types of disability for children, Māori had markedly higher rates of hearing disability, chronic conditions/health problems and speaking disability than non-Māori (Ministry of Health, 2005a:68). Chronic conditions/health problems, use of special education and hearing disability were the most common types of disability reported for Pacific Island children (Ministry of Health, 2005a:78).

When comparing the tables in the published data it may be inferred that speaking, vision, intellectual and psychiatric/psychological disability types are more representative of the European/New Zealand, Asian/Other ethnic groups. However, there are no published data to identify any pattern for these ethnic groups.

Furthermore, there are no New Zealand published data available on the socio-economic profile of families with children with a disability. The Poverty Child Action

¹⁹ Further detail of the ethnic differences in levels of prevalence by type of disability is available from Kirk, M. (2005) *What counts? Disability, children and the data source in New Zealand*. Unpublished manuscript: University of Waikato.

Group does however acknowledge the link between poverty for children in New Zealand and disability (Child Poverty Action Group, 2003). The published data from the *Disability Survey* do not document the additional costs to families of having children with a disability, even though this information is available internationally such as educational supports/resources; technical aids; housing/living adjustments; additional clothing/household maintenance expenses; transport variations; parental employment (Baldwin & Carlisle, 1999; Ballard, 1998).

3. Children with a disability by education and education services

There is relatively limited published data available on children with a disability and their access to, and participation in education. The Ministry of Education Statistical Data identified earlier is available via application to the National Operations Division. The Barnardos commissioned report identifying issues affecting children has a section relating to education, as does the QPEC report.

Of the 11 percent of children with a disability, three quarters of those aged 0 - 4 years were enrolled in an early education facility, and nearly all of the 5 - 14 years group were enrolled in some type of primary or secondary education (Ministry of Health, 2005a:30).

Of those aged 5 - 14 years of the total child population, an estimated 2% were receiving Special Education services (approximately 12,400 children), and this has been estimated as 17% of children with a disability (Ministry of Health, 2005a:31). However, this percentage would reduce were the data to include the group 0 - 4 years (the age group requiring early intervention special education services) and the 15 - 19 group, who remain eligible for special education services in New Zealand.

Although the estimate is for children receiving special education services, the published data do not detail the degree of service provision. Again, of those aged 5 - 14, 74% attended only regular mainstream classes and were *not* receiving special education services, with no explanatory information (Ministry of Health, 2005a:31 *footnotes*).

A significant proportion of parents (45%) reported that disability had a negative effect on the education of children aged between 5 – 14, notably having to change schools (20%) and long interruptions to education (17%) (Ministry of Health, 2005a:33). In comparison to non-disabled children, children with a disability were taking fewer

subjects (8%); taking courses by correspondence or home - schooling (7%); beginning school later than other children (6%) or changing subjects/courses (5%) (Ministry of Health, 2005a:33).

6. Summary

Are the existing disability data in New Zealand adequate in ensuring the effective monitoring and evaluation of social policy objectives addressing wellbeing disability?

Although the *Disability Survey* has collected data comparable with New Zealand's national census, which has allowed the calculation of prevalence and population estimates, when looking at international applications, the way in which data have been used is limited. It would therefore appear that New Zealand has yet to fully exploit the data sources available.

There also appears to be a problem of integration of data on disability into mainstream social policy reports. Even though New Zealand's *Social Report 2005* purports to promote an inclusive society (vision statement), it has only recently included a profile of people with a disability. The same information gap appears for children with a disability. Data sets of educational attendance and qualification are commonly applied internationally in social policy analysis, but not in New Zealand.

With the concern for children's voice in mind, all data appear to have been gathered from parents or caregivers to the exclusion of the children themselves.

There may be scope for further development in the collection and analysis of data so that inter-group comparisons by disability cause and ethnicity for example are more detailed. No obvious link is made to indicators of wellbeing for children reported in social policy reports, and surprisingly, not even in those which report on children's wellbeing.

In short, there is room for progress in improving the relevance of existing disability data to ensure that social policy effectively addresses the wellbeing needs of children with a disability.

7. Wellbeing for children with a disability: concepts and data sources

When sound, non partisan, quantitative evidence is not accessible to decision makers, children get short-changed. Useful indicators can serve as a lever to advance positive action for child wellbeing, support based programming, and stimulate investment in children's care and development. Things that cannot be measured or tracked over time do not garner public support, scientific understanding, sustainable investment, or comparable outcome information to stimulate best practices (Davidson & Pollard, 2001:33).

There is a growing body of literature on the concept of wellbeing and how it is identified as an operational definition and applied for social measurement. Applications of the concept however remain limited when it comes to thinking specifically about the wellbeing of children.

An extensive review of the literature on the concept of wellbeing as it relates to children revealed a lack of definitions in this area (Kirk, 2004). In the United States of America, the Centre for Child Wellbeing has adopted the following formal definition of child wellbeing:

Wellbeing is a state of successful performance throughout the life course, integrating physical, cognitive and social, emotional function that results in productive activities deemed significant by one's cultural community, fulfilling social relationships and the ability to transcend moderate psycho - social and environmental problems. Wellbeing also has a subjective dimension in the sense of satisfaction associated with fulfilling one's potential (Davidson & Pollard, 2001:8).

This definition identifies the significance of an ecological approach in community participation and relationships encompassing developmental stages across the life course. The authors assert that elements of wellbeing represent fundamental strengths of an individual's physical, social, emotional and cognitive domains, and they recognise both its subjective and culturally specific dimensions (Davidson & Pollard, 2001). A strengths-based approach is recommended, focusing on cultivating

children's assets, positive relationships and capacities that give them the resources they need to grow successfully across the life course.

Historically, the concept of wellbeing in New Zealand as it has been applied in the policy context describes aspects of life that contribute to individual happiness, quality of life and welfare. These aspects or dimensions of wellbeing which are currently set down in the *Social Report 2005* were initially documented by the *New Zealand Royal Commission on Social Policy* (1988). This definition represents what New Zealanders agreed constituted wellbeing in the late 1980s:

The Commission concluded that New Zealanders have said that they need a sound base of material support, including housing, health, education and worthwhile work. A good society is one which allows people to be heard, to have a say in their future, and choices in life... [They] value an atmosphere of community responsibility and an environment of security. For them, social wellbeing includes that sense of belonging that affirms their dignity and identity and allows them to function in their everyday roles (Ministry of Social Development, 2005b:6).

This definition has been adopted and applied to adults and households in New Zealand, and very recently to children.

1. Measuring wellbeing

The New Zealand *Social Report*, first published in 2001, is an annual report which identifies ten domains of social wellbeing: health; knowledge and skills; paid work; economic standard of living; civil and political rights; cultural identity; leisure and recreation; physical environment; safety; and social connectedness (Ministry of Social Development, 2004c:10). The domain *recreation and leisure* was added in 2004, but the intention to add a further domain of *overall social wellbeing* has yet to be finalised (Ministry of Social Development, 2004c). Each domain is represented by indicators²⁰

²⁰ An indicator is a summary measure related to a key issue or phenomenon that can be used to show positive or negative change. The evaluative nature of an indicator distinguishes it from the descriptive nature of statistics. Indicators are measurable aspects of a project/environment/society that can be used to monitor its progress and direction (Statistics New Zealand Guidelines, 2004).

which enable measurement and monitoring of trends to provide a summary of information on desired social outcomes in that particular domain²¹.

The *Social Report* acknowledges an evolving process of knowledge building in the conceptualisation of wellbeing. For example, religion and spirituality and different ethnic perspectives are yet to be recognised (Ministry of Social Development, 2004c:6; 2005b:6). Interestingly, in a recent international review of wellbeing, New Zealand's emphasis on cultural wellbeing was identified as unique (Galloway, Bell, Hamilton, & Scullion, 2006), but this aspect does not feature in the *Social Report 2005*, although it does appear in current knowledge building on wellbeing debate in New Zealand (Love, Malaulau, & Pratt, 2004). The definition relied on remains that of the New Zealand Royal Commission on Social Policy 1988 (Ministry of Social Development, 2005b:6).

In the New Zealand context, the concept of wellbeing for children is not defined but is measured by a set of indicators of wellbeing. These represent ten domains, documented in the *Children and Young People: Indicators of Wellbeing in New Zealand* report: health, care and support, economic security, safety, education, civil rights, justice, culture and identity, social connectedness and environment (Ministry of Social Development, 2005a:136). The impetus for the development of these indicators came from the *Agenda for Children* which documented the lack of reporting on indicators of wellbeing for children (Ministry of Social Development, 2002). The domains of wellbeing and the indicators for each of these domains of wellbeing for children in New Zealand are listed in Appendix 2 of this thesis.

The use of an indicator framework to operationalise the concept of wellbeing is not unique to New Zealand. Bramstedt and O'Hare (2003) note that an alternative approach to achieving an international consensus on the meaning of child wellbeing is to move from various conceptual definitions to a consensus of an operational definition through the establishment of appropriate indicators. The OECD (2002) recommends that indicators should reflect aspects of health, education, access to resources and a stable basis of social interactions – particularly in terms of child or

²¹ For a complete list of the 42 *Social Report 2005* indicators, see Ministry of Social Development, 2005. *Social Report 2005*. (p 10-11) Wellington: Ministry of Social Development or <http://www.msd.govt.nz/publications/2005/socialreport.html>.

student populations and future economic growth (Organisation for Economic Co-operation Development, 2002:11).

However, when a selection of international and national indicators currently used as operational measures of child wellbeing were reviewed for their relevance to children with a disability, the finding was that this specific population was remarkably unrepresented (Childhoods 2005, 2005; European Committee for Social Cohesion, 2004; Kirk, 2005b). For example, the New Zealand Paediatric Society review of child health/wellbeing indicators recommended for adoption by the Ministry of Health (Craig, 2004) clearly reflects the medical model approach to health and wellbeing and does not include indicators for children with a disability (Kirk, 2005b).

2. Wellbeing and data sources

Again as reflected in the disability data, the *Social Reports* since 2001 combine data from various sources to provide measurement of the domains of wellbeing and indicators of social outcomes. The *Children and Young People: Indicators of Wellbeing in New Zealand* (Ministry of Social Development, 2005a) relies on the same data source as the *Social Reports*.

The majority of primary data used for the indicators as measurement of wellbeing in New Zealand are from Statistics New Zealand *New Zealand Census* data and household surveys such as the *Household Labour Force Survey* and the *Household Economic Survey* (Ministry of Social Development, 2005b). Additional primary data is sourced from Government departments' statistical records pertinent to indicators within each outcome domain²².

In sum, for children with a disability the indicators of wellbeing should arguably be the same or consistent with the indicators of wellbeing for all children. As identified earlier, children with a disability are not represented as a specific population in the *Children and Young People: Indicators of Wellbeing in New Zealand* report and only a summary profile is provided (Ministry of Social Development, 2005a).

²² Such reports include *Fetal and Infant Deaths 1999* (New Zealand Health Information Service, 2003); *NZ Food, NZ Children: Key results of the 2002 National Children's Nutrition Survey* (Ministry of Health, 2003); *A Portrait of Health: Key results of the 2002/2003 New Zealand Health Survey* (Ministry of Health, 2004).

8. Conclusion

A significant proportion of New Zealand's child population – 11 percent – are children with a disability. There are age, gender and ethnic specific variations in levels of prevalence which could provide the evidence base necessary for the planning and implementation of social policy and service provision for these children.

However, the anomalies and gaps identified in the data relating to children with a disability suggest that a concerted effort is still required to ensure that all available information on this specific population is exploited, if social policy reports and information are to reflect the needs of the New Zealand child population in its entirety.

As a way forward, I would suggest that the data from the *Disability Survey* be integrated into the data sets pertaining to identified social policy applications of wellbeing for children in New Zealand. Taking as an example education, early childhood and school attendance data are presented in both the *Children and Young People: Indicators of Wellbeing in New Zealand* (Ministry of Social Development, 2005a) and the *Living with Disability in New Zealand: Summary* (Ministry of Health, 2005a) reports. They could be integrated. The same is true for data on *Social Connectedness* - internet access. Finally, participation in sport and leisure activities, another aspect of *Social Connectedness* is available for the child population, including those with a disability from *New Zealand Sport and Physical Activities Surveys* (Sport and Recreation New Zealand, 2002). The *Children and Young People: Indicators of Wellbeing in New Zealand* report however, even though it draws on this source does not include information for children with a disability.

I would conclude for 11 percent of the child population to remain consistently absent in social policy data and represents a significant *gap* compounding attempts to improve knowledge building and to address wellbeing for children with a disability.

The gaps identified in this chapter will undoubtedly have an impact for the specific population which will affect their experience of wellbeing but also directly related to our inability as a society to move from a medical to a social discourse of disability.

Chapter 3. Discourses of disability: from medical to social

When my friends ask me what it's like to have a brother with Down Syndrome I can tell them all the things like about facial features, effects on his body and the extra chromosome and stuff. What I'd like to tell them is that way he has about him, that manner he has, that thing that is just him. How can I describe that, how do I tell them about that? (Sibling 13 years).

1. Introduction

The increasing availability of courses on disability studies and published articles could be argued to identify a growing knowledge in the academia of disability. This chapter is an overview of the dominant discourses of disability. It argues that the notion of wellbeing as a holistic approach to health, socialisation and wellness of children with a disability has remained consistently marginalised amid varying interpretations of *disability* prioritising various types of service provision. The persistent individualistic construct of disability has focused on pathology with little regard to children's voice in terms of identity, family, social institutions of either childhood or disability as an experience in their social world.

The implications of discourses of disability for children with a disability are that they can compound social interaction and skill development delays across the lifespan. The influence of the social construct of disability as interconnected with the daily experiences of children is represented by the social environment in which children are living, interacting and accessing social institutions.

1. Discourse analysis

Discourse analysis is founded in the sociological analysis of power relationships and the role of social institutions, for example medical power and health systems. The definition of discourse promoted by Illich (1975) and Foucault (1970) is as a way of knowing, of discussing issues, organising knowledge and categorising people, and in so doing, regulating people (Middleton, 1996; Rabinow, 1997).

Illich and Foucault critiqued the process of medicalisation and the dominance of the medical profession. Illich's critique identified institutions and expert knowledge as counter productive to the diversity of society (Illich, 1970) and social institutions as

disabling of individuals (Keller & Woodhead, 1995). Illich claimed the impact of institutions and professions dominated individual thinking around health and education due to the assertion that institutional prescriptions were superior to other forms of knowledge. He challenged the power process as dehumanising and diminishing human capability (Giddens, 2001; Illich, 1970).

Complementary to this work was the development of the theory of discourse by Michel Foucault in the early seventies (Giddens, 2001; Haralambos, Krieken, Smith, & Holbon, 1996). Foucault identified the advance of professional disciplines such as the medical profession and the modern institution (hospitals, schools, prisons, and asylums), linked to new forms of controlling and monitoring the social population as justified or rationalised within the dominant discourse. For Foucault, discourses seen as based on the premise of truth consequently legitimise practices as worldviews, impact on the actions of individuals and institutions (Fraser, 2004; Rabinow, 1997). Discourses are more powerful in their context, even when or if the context is capable of more than one meaning (Fraser, 2004).

2. The dominant discourses of disability

The four dominant discourses of disability were recognised by Fulcher (1989) as being medical, lay, charity and rights discourse (Fulcher, 1989; cited in Neilson, 2005). The first three discourses have themes that focus on individual needs and are linked in application to the *medical model of disability* due to the reliance on pathological definitions and descriptions of disability. The fourth discourse, the rights discourse, has themes of choice and consumer rights (Neilson, 2005). The rights discourse is linked in application to the *social model of disability*, acknowledging the social and physical constraints of a given environment or society as disabling²³.

1. Medical discourse

This is considerably the most powerful of the discourses. From the period of the Enlightenment, disability became represented as pathological, and consequently constructed as an individual medical problem rather than connected with the able-bodied population or the manner in which society functions (Barnes, 1992; Davis,

²³ A fuller discussion of the historical influence of disability discourse linked to legislation, policy and service provision for children with a disability in New Zealand is available (Kirk, 2005a).

1993; Foucault, 1977; Stone, 1984). Disability in this discourse is seen as a physical deficit, a health and personal problem where individuals need to be treated, cured or rehabilitated in order to be “normal” (Ballard, 1994).

Within this discourse of disability responsibility is placed on professionals or experts such as doctors, psychologists, rehabilitation counsellors and educationalists to utilise their specialist knowledge to fix or cure the individual’s deficit (Fraser et al., 2000; Fulcher, 1996). The relationship between the professional helper and the person with the disability who is seen as the client, patient or student requiring assistance, is viewed as the natural power - knowledge complex of the relationship. These roles have been accepted as an integral part of this discourse.

Of concern within the medical discourse is that the social science researcher has been added to this group of professionals assigned to identifying a cure for disability. The role of the researcher is debated by Cooney (2004) as contentious and supportive of the medical discourse of disability; a position that may well indicate a need for a broader debate so as not to limit research findings from discussions of social issues of disability awareness.

The medical discourse as the dominant discourse of disability still holds power and can significantly influence governmental legislation. One example is the 1992 New Zealand Government decision to place disability-related services under the authority of the Department of Health, despite strong lobbying from the disability sector and international examples of social sector applications of disability related service provisions (Beatson, 2004a; Kirk, 2005a). Additionally, as argued in the previous chapter of this thesis, New Zealand Government reports consistently separate data relating to people with a disability from inclusion in *mainstream* reports, for example *Children and young people: Indicators of wellbeing in New Zealand* (Ministry of Social Development, 2005a) and *Living with disability in New Zealand: Summary* (Ministry of Health, 2005a). The disability data are restricted to a generic profile of disability and not incorporated into social policy data other than on a pathological, medical basis (Kirk, 2004). However, from this perspective, in New Zealand disability is still regarded as a health problem and not a social issue.

2. Charity discourse

The charity discourse can be directly linked with the medical perspective and has influenced historical institutional and organisational foci (Kirk, 2005a). In this discourse, the individual with a disability is seen stereotypically as dependent, childlike, passive and needy (Neilson, 2005). The charity discourse originating from a historical perspective supports forms of institutionalisation, humanitarianism and benevolence encapsulated by the need to be in care or cared for. There is no recognition of the need for or right to privacy or choice for people with disabilities, and their judgements and preferences are regarded as inferior to those of the professionals (Fraser et al., 2000; Fulcher, 1996; Swain, French, Barnes, & Thomas, 2004).

In New Zealand this has presented a dilemma for charity groups such as the Crippled Children Society (CCS) and Intellectually Handicapped Children (IHC)²⁴ when they have attempted name changes to encourage attitudinal shift and contemporary positive imagery of the client group. It needs to be acknowledged that the charity dollar is a major source of income for these groups and rebranding can be potentially financially disastrous to the provision of staff and services these advocacy and disability groups provide (Fraser et al., 2000; IHC, 2003, 2004; Neilson, 2005).

3. Lay discourse

The lay discourse is aligned with the medical and charity discourses and has been seen to propagate negative myths and stereotypes about people with disabilities that have persisted through history, often reinforced by literature and media (Darke, 1999; Fulcher, 1996; Neilson, 2005). Similar to the stigma of the charity discourse, the lay discourse regards people with disabilities as inferior, dependent, asexual, marginalised and child-like. Consequently, for those with disabilities life is considered less worthwhile (Fulcher, 1996; Johnston, 2005; New Zealand Herald, 2004).

Ballard (1994) identified the negative attitudes of the majority of the community towards those with disabilities in New Zealand as contributing to inappropriate labels: the language of disability is often negative, refers to people by disability rather than

²⁴ CCS formerly referred to as the Crippled Children's Society and IHC was formerly the NZ Society for the Intellectually Handicapped now split into IHC parent advocacy and IDEA Services (Beatson, 2004b).

their name, and is reliant on stigmatised labels of impairment, notably handicapism (Ballard, 1994; Bogdan & Taylor, 1992). The attitudinal barriers to social inclusion are perpetuated by the labels of disability. They promote the perception of an individual constantly in need of help rather than capable of reciprocity in relationships, particularly for children with a disability, which intensifies marginalisation as the social response to diversity (MacArthur & Morton, 1999; Van der Klift & Kunc, 1994). Categorisation through labelling of children, argues Stanley (2005), limits professional practices and reinforces pedagogical hierarchies of power; for labelled children, this ultimately compromises skill development, particularly in areas of resilience (Stanley, 2005).

These three discourses of disability are predominantly focused on the individual with variant degrees of negativity, limited social role expectation and valorisation. The reliance on health determined pathology is fundamental to these discourses. The historical perspective of disability gives some understanding as to the origins of discourse, social inclusion, social role expectation and the experience of the person with a disability. This is particularly pertinent for children with a disability as evidenced by the influence of the power - knowledge complex and the role of professionals and institutions in the care and control of children with a disability in New Zealand. The development of identity, recognised as a crucial element of child development (Smith, 1998), is influenced by the discourse of disability, particularly by the experience of labelling. Many parents of children with a disability recognise this in their response “*Label jars, not people*” (Ballard, 1994:14).

Furthermore, the dominant discourses reflect the feeling that people with a disability do not really belong in our society; the birth of a child with a disability is still seen as a disaster and parents and communities are very pessimistic about that child’s future from the outset (Fraser et al., 2000; Johnston, 2005; New Zealand Down Syndrome, 2004). These dominant discourses of disability support ways of knowing or legitimising practices that lead to issues of social exclusion for children with a disability. This is evidenced in historical segregation of children with a disability into *Colonies* later re-named hospitals, institutions purpose built for lifelong care and containment such as in Templeton, Levin and Mangere (Beatson, 2004a; Kirk, 2005a). It was not until 1980 that “stay-over” facilities were provided at Levin’s Kimberly Hospital for parents to visit their children (Beatson, 2004a).

4. Rights discourse

The rights discourse has largely emerged since the 1960's civil rights movement, and is characterised by themes of self-reliance, independence, competency, capability, consumer rights and a socio-political approach to disability issues (Fraser et al., 2000; Fulcher, 1996; Oliver, 1996, 2004). This discourse is in opposition to the medical, charity and lay discourses due to a focus on equality and citizenship (Fraser et al., 2000; Fulcher, 1996; Oliver, 1996, 2004; Swain, French, Barnes, & Thomas, 2004; Wolfensberger, 1995) and because it challenges attitudinal discrimination and differentiation in the terminology of disability and impairment. American sociologists Goffman (1968) and Scott (1970) challenged the process of stigmatisation and social construction of dependence by rehabilitation professionals based on medical orthodoxy and discourse of individual impairment as the basis of disability. Young disabled Americans formed the *Movement for Independent Living* (ILM) where de Jong (1979) claimed that attitudinal and environmental barriers were as significant as impairment in the assessment of disability (Barnes, 1996). This early setting down of the context of disability led to what Oliver, in 1983, later termed the *social model of disability* (Barnes, 1996).

One key example of the rights discourse development is the *Union of the Physically Impaired Against Segregation* (UPIAS) when Hunt (1966) made the crucial distinction between physical impairment as a traditional bio-medical basis of functional ability, and disability as disadvantage or restriction of activity caused by contemporary social organisation (UPIAS, 1976 cited in Barnes, 1996). Hunt, through UPIAS, challenged this bias as the basis of social exclusion, hence discriminating against the rights of disabled citizens. This argument was later elaborated on and extended to accommodate all impairments – physical, sensory and intellectual – and was then adopted by the *British Council of Organisations of Disabled People* (BCODP) in the late 1970's (Barnes, 1996; Finkelstein, 2004).

Finkelstein (1980) challenged the historical origins of capitalist society linked with disability discrimination. Stone (1984) theorised society as a function of commodities distribution with a second tier of needs perception, using inability as the foundation of needs assessment (a core element of disability service provision) (Barnes, 1996). The work of these early academic advocates and activists slowly promoted the rights

discourse of disability and the evolution of the contemporary debate of the conflicting medical and social model of disability.

This shift in disability discourse was both less evident and historically later in New Zealand. The 1992 assignment of disability services to the management of the Ministry of Health as discussed earlier, clearly aligned disability as a health issue, identifying it with a medical rather than a rights discourse of disability. It was not until 1997 that the Human Rights Commission ran a series of workshops throughout New Zealand, training people with disabilities to advocate in the community to inform their specific disability groups about the Human Rights Act (1993). The training focused on the issues of discrimination and empowerment (Neilson, 2005). The *New Zealand Disability Strategy* (2001) and the establishment of the *Office of Disability Issues* have been heralded as an acknowledgment of the rights discourse of disability (Ministry of Social Development, 2004b).

Additionally, when considering a shift in the dominant discourse of disability the WHO definition of disability presented earlier remains contentious. Over more than two decades, people with disabilities have challenged this definition as based on a medical pathological approach. Oliver's 1990 definition suggests disability as:

The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities (Oliver, 1990:11).

This definition highlights a lack of collective response from society to support component populations which have been identified as disadvantaged or compromised. Neilson (2005) also champions this definition, which she believes removes blame on the individual with a disability when difficulties with communication, access or transportation occur in the community.

As outlined in Chapter Two, New Zealand recognises two definitions of disability; firstly a bio-medical definition based on the WHO definition used in the *New Zealand Disability Survey* (Statistics New Zealand, 1997, 2001) and census data reflecting the medical discourse of disability. The second definition is from the *New Zealand Disability Strategy* (Ministry of Health, 2001) and is reflective of the rights discourse and the social model of disability, where disability is identified as not an individual

impairment but a process which relates to the interaction between the person with the impairment and the environment (see Chapter Two: section 3).

Here, New Zealand's application of two definitions of disability for data collection purposes and the definition of disability endorsed to direct policy and Government provision clearly shows the conflict between the dominant discourse of disability and the adoption of definitions. How these definitions, interpretations and appreciation of the issues of disability are experienced in society continues to reflect the discriminatory basis of the dominant discourse of disability. This sentiment is echoed in the report by the Human Rights Commission (2004), consistently recognising disabled people as one of the most disadvantaged groups in New Zealand. The Commission stresses an urgency in implementing the *Disability Strategy*, indicative of the specific disadvantage for children with a disability in access to health and education services leading to poor health and education outcomes (Human Rights Commission, 2004).

It can therefore be argued that New Zealand remains entrenched within the medical discourse of disability although policy attempts to challenge this stronghold are evident. The Office of Disability Issues as part of the Ministry of Social Development is additional testament to this. An example of this is eligibility to education remains linked to pathological criteria and assessment. This is illustrated by Special Education funding schemes such as the *Ongoing Reviewable Resourcing Scheme* and the *High Health Needs* (Ministry of Education, 2004e) which are founded primarily on the medical discourse of disability rather than the rights discourse: the right to education for all.

Clearly, there is still a considerable tension between the dominant discourse of disability applied through legislation, policy directives, service provision and aspects of professional training and development.

3. Concepts of disability applied: the medical and social models of disability

The contemporary debate of disability discourse has focused on a comprehensive critique of mainstream academic theories and policy approaches to people with a disability. Over three decades the notion of the *social model of disability* has been advocated. The three discourses of disability: medical, lay and charity, are based on

the premise of bio-medical impairment. Issues within this approach are the individualistic locus of problem and responsibility, and the reliance on pathological foundations and solutions to disability issues. These discourses have led to policy, service provision and professional practice grouped evidenced as the *medical model of disability*. The fourth discourse, the rights discourse, is argued to reflect issues of social inclusion confronted by people with a disability and policy, service provision and professional practice reflective of the *social model of disability*.

Historically the International Year of the Disabled Person (IYDP) in 1981 challenged society to a change in attitudes about people with disabilities, from a focus on sickness to a focus on independence and equality (Barnes, 1996; Beatson, 2004b; Finkelstein, 2004; Morris, 1991; Neilson, 2005; Oliver, 1990; Woodill, 1994).

The 1980's saw the emergence of the debate of disability terminology and definitions as key factors in determining how disability is interpreted and socially constructed. However, today most Western countries employ the 1980 World Health Organisation (WHO) definition in the field of social policy (Barnes, 1996), and for the regulation of disability services and collation of disability data (Organisation for Economic Co-operation and Development, 2002) disability, according to this definition, remains based on a pathological and individualised medical model.

It was in the early 1980's that the medical and social models of disability were introduced as an alternative theoretical construct by Oliver (1983) as a binary distinction between the individual and society to promote understanding by professionals of the issues of disability. The model format conceptualised more graphically the medicalisation of disability and articulated society as disabling for individuals through its inability to provide services or take into account the needs and requirements of disabled people within social organisations (Oliver, 1990, 1996).

The medical model of disability is often referred to as an individualist, personal tragedy model and informed by medicine and medical science (Drake, 1996; Oliver, 1996; Taylor, 2004). It identifies *disabled* from individual physiological or cognitive impairments; medicine can cure, treat or rehabilitate disabled people (notably collectively referred to as a homogeneous group). Thus professional approaches, services and policy processes aim to return disabled people to "normal" and therefore able to be equal to their able-bodied peers. Finkelstein (2004) from the 1980's

proposed that people with a disability were rendered dependent by this approach, which governs all interactions between the helpers and the helped, thus enforcing *hegemony of care*. Barton (1996) has argued that the medical model of disability configures perceptions of disability held by the non-disabled. He argues further that the impact of the medical model of disability culminated in institutional management and legitimisation of control of this identified, labelled and therefore “deviant” section of the population.

It is not within the scope of this chapter to cover deviance theory other than to acknowledge that one way in which individuals are controlled and stigmatised is by labels, specifically deviant labels as shown in Goffman’s (1963 cited Anleu, 1999) work on sociological analysis of the body and social interaction. Stigmatisation involves casting an individual into the category of outsider, other than “normal” or not quite human. Goffman examines labels as stigmatising one group or type so as to confirm the normality of another group, thus dislocating social interaction. Attributes of the stigmatised deviant population are deemed irrelevant or secondary due to the stigma or label as overriding personality attributes, ability and social status (Anleu, 1999). Useful commentary around disability will clearly need to understand deviance theory and social interactionism. With relevance to the medical model of disability it is crucial to state that physical, sensory and intellectual disabilities are usually defined in terms of specific comparison with the “normal” human body. Anleu (1999) states that medical intervention and medical technology, which may have little therapeutic effect, can aid conformity with everyday social activities and enhance social inclusion, an argument strongly supported within the medical model of disability services provision. New Zealand examples of supporting disability labels as deviance identification are evident: for example, the *Mental Defectives Act 1911* categories for care and containment of *idiots*; *imbeciles* and the *feeble minded* (Beatson, 2004a); the 1945 opening of the Levin Mental Deficiency Colony for feeble minded and defective boys now known as the Kimberly Centre (Beatson, 2004a) but still remains “home” for institutionalised residents (Kirk, 2005a). The *1999 Intellectual Disability Compulsory Care Bill* allows for people with intellectual disability including children aged 10 - 17 years to be incarcerated in special facilities for up to three years at a time, with no automatic right to legal representation (Beatson, 2004a).

Historically legislation has attempted to challenge public response (lay discourse) to stigmatisation and disability as deviance. In New Zealand, the 1954 Mental Health Amendment Act introduced changes in terminology from *mental defect* to *intellectual handicap*; however this Act did not change the practice of institutionalisation of children with intellectual handicaps. The *Education Act 1989* granted children with a disability the same rights and entitlements to education in mainstream schools as non-disabled children. However this Act was not supported by adequate provision for these students in regular classrooms (Beatson, 2004a). The *Criminal Procedure Act* of 2003 introduced two companion Acts providing people with psychiatric and intellectual disability with more appropriate and humane treatment and endorsing detention after conviction, compared with detention for up to three years regardless of proof of conviction (Beatson, 2004a).

A consistent theme in New Zealand can be identification of legislation which views disability as deviance and the dominant perspective of disability as inferiority. For example the *Industrial Relations Act 1973* which allowed for people with a disability to be paid less than the minimum wage (Beatson, 2004a).

The medical model of disability can be argued to have depicted the dominant discourse of disability and hence directed professional practice and disability services, notably institutions and rehabilitation orientated therapy along with policy and legislative developments. The pattern of segregation begun in the 1900's was entrenched in New Zealand society by the eligibility criteria for access to the health and education institutions for children with a disability well into the 1970's. Indeed as a country we can still boast to have residents waiting transfer from residential institutions to community facilities thirty years after a policy of de-institutionalisation was endorsed. The medical model of disability has historically dominated disability services in New Zealand (Beatson, 2004b; Kirk, 2005a).

The development of the *New Zealand Disability Strategy* (Ministry of Health, 2001) is reflective of the shift to the social model of disability and a rights discourse. However, this policy has not yet obtained the support of a dominant discourse when compared within a historical perspective of disability discourse and identified service provision and professional practice.

The gap identified is that the medical model approach fails to regard effectively the social and environmental factors which may promote or inhibit independence (Ministry of Health, 1998) and compound issues of disability. In contrast, the social model focuses on the relationship between people with particular physical and mental capacities and their social environment (Marks, 1997). It acknowledges that environments limit access and opportunities for work, education and social participation, and that prejudice, discrimination, and stigma are not an inherent part of the social environment (Ministry of Health, 2001; Smart, 2001).

The social model of disability as already identified, is reflective of human rights and equality. The established critique is that it was not individuals that were disabled by their physical or mental impairments but organisation of society as designated by non-disabled people that was more significantly disabling. Within the social model the locus of the problem is not within the individual but within the oppressive aspects of social, political and economic environments in which disabled people live (Barnes, 1996; Drake, 1996; Fraser et al., 2000; Swain, French, Barnes, & Thomas, 2004).

Oliver (1990) identifies the central tenet of the social model of disability as a group problem solving process, enhanced by collective approaches; effective solutions cannot be imposed, and therefore power or knowledge sharing and partnerships are pivotal. This provides a link with the concept of solidarity through the emphasis on issues of collective social responsibility. Oliver (1990) suggests organisational and administrative processes will need to facilitate this process. Ultimately this is the challenge presented by the application of the social model of disability: a shift in the power or knowledge complex where people with a disability retain the locus of control and challenge the entrenched stigma of social relationships and social role valorisation of people with a disability within society. For children with a disability this would imply their participation in decision-making processes.

As noted previously, New Zealand policy in support of the social model is the *Disability Strategy*. However, research evidence suggests that for people with a disability there remain issues of exclusionary social interaction in their daily living. This is highlighted particularly for those with intellectual impairment as the *Ordinary Lives* report identifies (National Advisory Committee on Health & Disability, 2003) and is reiterated by the Human Rights Commission (2004).

Again, for children with a disability, there seems to be limited evidence that the rights discourse of disability and social model application is practiced. Recent research and reports of the experience of children with physical disability and intellectual disability in New Zealand challenge the application of a social model of disability or the adoption of the rights discourse of disability as evident in their exclusionary experience of the social institutions of health and education. In their qualitative research, MacArthur and Kelly (2004) identify teacher attitudes as a consistent barrier to social interaction and access to education for children with a disability. This finding is echoed through literature on children with a disability and issues of access to social institutions such as health and education, which is strongly influenced by professionals' attitudes and vocational knowledge and or personal value laden experience (MacArthur & Morton, 1999; Wylie, 2000).

4. Conclusion

The overview of the discourses of disability presented in this chapter suggests that the conceptual shift from the medical model of disability to the social model is increasingly being promoted, both in New Zealand and internationally. The social model of disability is often the model stressed in relation to children with a disability in the literature (Beatson, 2004b; Brynner, 2000; Taylor, 2004).

However, illustrated New Zealand operational definitions for children with a disability, policy and service provision tend to remain reliant on medical model definitions rather than the ecological, social model of disability.

I would argue that within New Zealand society disability rights remain a contentious health and social issue; regionally variant and often contingent on changing government policy and legislation. The lack of open public debate or nation wide application of the social model of disability would seem to identify that the tentative headway made by rights and disability activists' may not have the power to challenge the social construct of disability nor sway public opinion. This is escalated for children when issues of funding, resourcing and professional development remain unaddressed despite ongoing governmental reports, restructuring and policy initiatives. It seems a fair but poor testament to our society that disability remains a historically persistent social health issue.

Chapter 4. Theoretical perspectives and their policy relevance

To apply the whole child approach requires some understanding and knowledge about the conceptual frameworks and the evidence that underpins the approach (Ministry of Social Development, 2004e:16)

1. Introduction

This chapter first outlines three theoretical perspectives relevant to the theme of wellbeing for children with a disability: the conceptualisation and definition of wellbeing itself; the ecological theory of human development; social solidarity theory. With an emphasis on children with a disability, a second section of the chapter then examines the relevance of these perspectives in relation to current policy and research applications in the area of child wellbeing and the development of indicators of wellbeing.

2. Wellbeing

The notion of wellbeing has been identified as an over-arching goal of social policy internationally and in New Zealand (Drake, 2001; Ministry of Social Development, 2001a) but seems to have no established universal definition. The interpretations presented here of the concept and definition of wellbeing for children come from a review of international and New Zealand literature and focus in particular on their significance for children with a disability.

1. Theoretical basis of wellbeing

International interpretations

Drake's (2001) theory of the principles of social policy identifies individuals, societies and social policies as reflecting values and principles of a society which have been prioritised to define the parameters of wellbeing. He argues that justice, freedom and equality are the three over-arching objectives of wellbeing which are exercised through the development of social policy. Policies then endorse principles of wellbeing through the process of service provision based on concepts of fairness and equality. Drake argues that if this process fails, a need is created and the obligation of the state to meet that need is recognised as the rights of the citizen. Wellbeing

becomes defined in relation to the kind of vision of society a government holds. He suggests that the manner in which governments provide fair treatment through its policies and structures will reflect the mandate of the core prevailing norms and the collective notion of wellbeing.

Central to Drake's theory of wellbeing is the requirement to accommodate diversity within populations and to treat the norms and beliefs of different communities with equal recognition and respect. When certain groups in society fare less well than others in commanding opportunities and resources, this can be traced to social infrastructures, such as the organisation of public services or systems (Drake, 2001). Drake argues that the policy principles of freedom and liberty provide the foundations for the contemporary notion of "equality of opportunity". It follows therefore that respect for diversity and the acknowledgement of difference would be reflected in policy development. He defines diversity not only in terms of culture and ethnicity, but also in terms of gender, sexual orientation, physiological and cognitive differences between people (Drake, 2001:116).

Applying Drake's theory of wellbeing and social policy to children with a disability, it would imply equality of opportunity, supported by government structures and policies that recognise diversity and need; the policies would be carried out through processes based on principles of justice and fairness, with the recognition of children's rights. Rights for children with a disability would become manifest through policy driven by equality of opportunity and equality of access to services.

Doyal and Gough (1991) identify the theory of human need as the basis of wellbeing, arguing the notion of *need* should be redefined in contemporary society. Need is often described as denoting a drive or motivation, as in the analysis of Maslow (1954). Maslow identified physiological needs, safety and security, love and belonging, self esteem and self actualisation as a five tiered hierarchy ranking of how individual needs are prioritised. The successful way in which these needs are met was viewed as central to human development. Doyal and Gough (1991) rebuff Maslow's hierarchy on the basis that inter-relationship of needs is more usual, and propose a framework comprising only two levels of need: firstly, physical health and autonomy as basic needs and capabilities and secondly, intermediate needs that require satisfaction for successful human development. The intermediate needs are: nutritional, protective housing, non-hazardous environments, appropriate health care, security in childhood,

significant primary relationships, physical security, economic security, appropriate education, safe birth control and childbearing.

The authors' theory of human need and need satisfaction emphasises the importance of "constraints" which occur to promote or inhibit needs being met, such as rules, regulations or expressions of collectively held and enforced aims and beliefs (ibid: 77). These constraints act as rules of society and constitute our sense of self and others, and are the foundation of socialisation. They also enable individuals and groups to identify boundaries, which in some instances stipulate what is regarded as "normal" and acceptable by the majority.

Doyal and Gough (1991) distinguish the importance of individual competence - the capabilities required to participate fully in all structures of life - as a fundamental element of wellbeing. The authors recognise that disability in particular, can be linked to restricted opportunities to participate in social settings. This is because people with a disability are not provided with opportunities which help them acquire the necessary capabilities and basic skills to participate in society.

In relation to this thesis, the theory of human need is relevant because the ways in which the needs of children with a disability are recognised will depend upon a society's concept of what is considered "normal". The notion of being a "normal person" is consolidated through constraints (as rules of society and or policy) which promote or inhibit the choices and socialisation experiences of this specific population group. The theory of human need also recognises that individual autonomy is a basic human need, and this could be related to the wellbeing of children with a disability because it is linked to the principle of equality of opportunity to participate in society.

New Zealand interpretations

New Zealand writers Cheyne, O' Brien and Belgrave (2005) emphasise that the goals of social policy are founded on five fundamental principles of wellbeing: justice, need, equality, freedom and citizenship with an emphasis on dignity and individual rights. They assert that wellbeing is ensuring that people are treated fairly, with an emphasis on enhancing social cohesion and minimising inequalities. Similar to Drake (2001) and Doyal and Gough (1991), they identify the elements of wellbeing as those things valued in our society, and considered as rights, based on the theory of need. The authors suggest that public policy needs to respond to culturally specific values,

and argue that the concept of equality recognises that people should not be permanently disadvantaged by disability, gender or ethnicity (Cheyne, O'Brien & Belgrave, 2005).

The authors identify the role of the state in securing the structure of rights. The right of citizenship is generally understood in relation to two key aspects of wellbeing: access to publicly funded goods and services and participation in society. They have argued that access and participation would facilitate the notion of belonging in society and being free from discrimination. The importance placed on citizenship as an element of wellbeing would be illustrated in constitutional elements as a value that underpins the notion of distributive justice, human rights and equality (Cheyne, O'Brien & Belgrave, 2005).

Duncan (2004) states that contemporary definitions of social policy are largely based on the idea of wellbeing and that dimensions of wellbeing can be identified for the purposes of a theory of social policy. He defines wellbeing as relative to personal circumstances given that certain basics such as food, good health and social belonging would, in general terms, be universal requirements (Duncan, 2004:9). He identifies aspects of *subjective* wellbeing need to be recognised along with cultural variance within dimensions of wellbeing. Subjective wellbeing would relate to moods and feelings such as joy or elation. Life satisfaction would be in terms of personal wealth, family relationships, community participation, employment and goal achievement. Duncan recognises the relationship between factors of circumstantial life satisfaction and subjective aspects of wellbeing (ibid: 10) and identifies the government as responsible for maintaining law, safe environments, and access to education, health and systems of social support (ibid: 11). He recognises the objectives of social policy to support a general ideal of popular happiness and wellbeing based on specific concepts that underlie political thought: citizenship, equality, social justice, freedom and need. He argues that wellbeing as a contemporary term could traditionally have been equated with a feeling of happiness and life satisfaction. Human happiness he suggests, comprises three factors which can be measured: subjective wellbeing; life satisfaction; and absence of depression or anxiety (Duncan, 2004).

Duncan (2005) has endeavoured to examine the cross-cultural, ethical and political uses of the notion of happiness with reference to New Zealand social policy and

survey applications and challenges the age old idiom of happiness and the contemporary link with economic utility.

Drawing from the various strands of these different conceptual and theoretical perspectives to wellbeing, I suggest that a definition of wellbeing for children with a disability would support participation in all aspects of society; equality of opportunity and equality of access to services through the recognition of justice and citizenship rights; freedom from discrimination and the promotion of a sense of belonging in the community, underpinned by happiness. Here, the implication for the wellbeing of children with a disability would be the identification of circumstantial life satisfaction factors as relevant to the child's sense of subjective wellbeing and happiness.

Government policy would reflect the ability to support children with a disability by providing securities such as access to health resources, access to education, social support, personal safety, and community participation to promote equal opportunity for wellbeing and happiness.

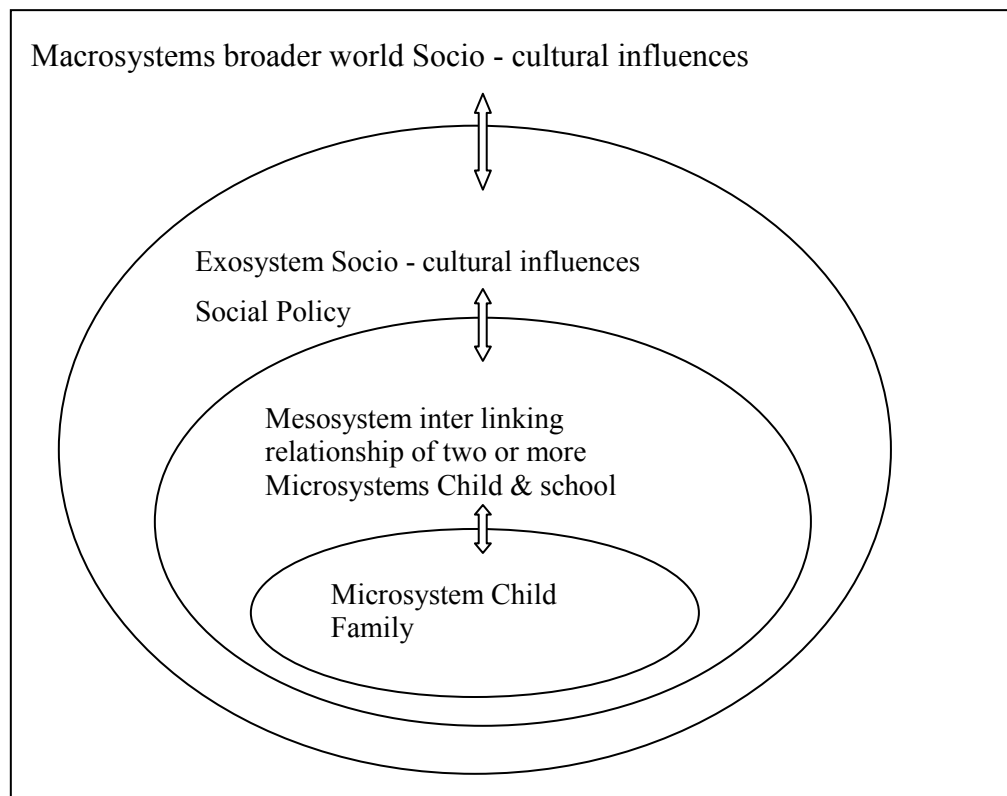
3. Ecological perspective

The ecological theory of human development is the paradigm evident in both social policy and educational policy in New Zealand. The *Key Settings Model* that underpins New Zealand social policy draws on the study of human development proposed by Urie Bronfenbrenner (1917 - 2005) in the late 1970's (Ministry of Social Development, 2002).

1. Theoretical basis of ecology of human development

Bronfenbrenner proposed that human development occurs in the course of a process of developing an understanding of the world through the interaction of the individual with their social environment. This occurs as a series of nested ecosystems in which the individual develops and interacts. Bronfenbrenner (1979) examined these nested systems on four levels: the microsystem, the mesosystem, the exosystem and the macrosystem.

Figure 2 Diagram of Ecological Model



Source: Author's diagram

At the level of the microsystem, direct and concrete interactions between the developing person and significant others occur (1979:22); for example earliest influences are the family, local neighbourhood or community institutions such as the school, and peer groups (Huitt, 1999). The mesosystem is defined by the interrelations of two or more microsystems, such as work and family; for example, in the case of children, the interrelations of social institutions of education or sports would represent a mesosystem. The influence of these systems and institutions interacts with, and is filtered through, microsystem institutions. The exosystem refers to systems that are not in direct interaction with the individual, but have an indirect effect on their micro or mesosystems; for example social policy and the elected government mandate to educational provision. Finally, the macrosystem provides the general cultural context in which the lower order systems are situated (Bronfenbrenner, 1979:26).

Bronfenbrenner's ecology of human development pioneered the notion of settings in which the life is experienced. This leads to mutual accommodations with self and

others, a process which influences individual development and interrelations. These distinctions of *nested*, concentric circles of environmental influences have become widely accepted in family theories and ecological appreciations of human development (Huitt, 1999; Stevens, Dickson, Poland, & Prasad, 2005; White & Klein, 2002).

The ecological paradigm, as an approach to child development, challenges traditional theories which propose that human development is primarily an individual process of orderly, chronological stages relating to developmental capability from infancy to adulthood. It emphasises the fact that children develop and learn within the context of social interactions and relationships as key players and within various social and cultural contexts of their environments.

4. Solidarity, social policy and social inclusion

The meaning of social solidarity as a construct provides an understanding of the sense of a collective commitment by community and state in ensuring service and resource provisions for specific population groups. As such, it embraces notions of social cohesion, social bonds or connectedness, unity and social commonality.

As a macro-level construct, its relevance to social policy in relation to children with a disability is that it reflects principles of social inclusion and participation. Llewellyn - Davis defines solidarity as:

A commitment to some kind of mutual aid or support, based upon perception, by those who are solidary, that they share certain characteristics, or that they are equal with respect to some social principle (Llewellyn - Davis, 1978:206, cited in Crow, 2002:6).

1. Theoretical basis of solidarity

The theory of solidarity is accredited to Emile Durkheim (1858 - 1917) as a key founder of social theory. Durkheim's theory of solidarity was centred on identifying the source of social order and disorder, and a central issue of his work concerned the individual self-interests of human beings which he argued can only be held in check by social forces that originate outside of the individual. Durkheim characterised this external force as a collective conscience, a common social bond that was expressed by the ideas, values, norms, beliefs and ideologies of the culture, institutionalised in the

social structure, and internalised by individual members of the culture. He elaborated the cause and effects of weakening group ties on the individual in his two works, *The Division of Labour in Society* (1893) and *Suicide* (1897) (Elwell, 2003).

Durkheim identified two forms of solidarity: *mechanical* and *organic*. Mechanical solidarity places emphasis on shared values amongst members of a group, in pre-industrial societies and traditional cultures where there is limited division of labour. In such societies, social behaviour and values are relatively standardised, where people take on similar tasks and daily activities and share similar experiences. Durkheim argued that for these societies, social institutions and practices would convey similar values and norms and thus mutually reinforce one another.

The norms, values and beliefs of the society, which Durkheim identified as the collective conscience, were all encompassing, so that the collective conscience and individual conscience became virtually identical, and consequentially most behaviour was governed by social norms.

Organic solidarity, Durkheim argued, developed as a result of the division of labour (Elwell, 2003; Lukes, 1973). As a given society becomes more complex, individuals play more specialised roles and therefore become increasingly dissimilar in their social experiences, material interests, values and beliefs. Individuals within such a socio-cultural system consequently have less in common, despite their increasing dependency upon each other for individual day-to-day existence. As a result of the increasing division of labour, individualism develops at the expense of common values, beliefs and normative rules of society, leading to a loss of sense of community or group identity, weakening social bonds and consequently diminished social cohesion (Elwell, 2003; Lukes, 1973).

Durkheim established *anomie* as a condition of normlessness either in a whole society or in one of its component groups, tracing it to two major causes: the division of labour, and rapid social change associated with modernity, where a variety of groups with different values and goals are not disciplined by consistent or strong group norms. The lack of sense of identification within the wider community weakened social constraints on human behaviour. These conditions led to social *dis-integration* - Durkheim believed that the functional needs of society necessitated the emergence of new forms of social integration.

Critics of Durkheim's theory argue that modern systems or institutions have a limited effect in transmitting shared values, promoting individual discipline or cementing social solidarity. Durkheim also assumed that the education system transmitted the norms and values of society rather than the ruling elite or ruling class, but gave little consideration to other cultural or value systems, nor aspects of individual competition (Haralambos, Krieken, Smith, & Holbon, 1996).

Determining the functions of social institutions and patterns of social facts – aspects of social life that shape our actions as individuals, such as the state of economy or the influence of religion - played a key role in Durkheim's theory. These patterns of "social facts" established that solidarity is maintained when individuals are successfully integrated into social groups and are regulated by a set of shared values and customs (Giddens, 2001).

5. Policy relevance

The following section now examines the relevance of these conceptual and theoretical perspectives in terms of current policy and research applications in the area of child wellbeing and the development of indicators of wellbeing and relevance to children with a disability.

1. Wellbeing

The complexity of theoretical perspectives and operational definitions of wellbeing have implications for social policy. At a fundamental level, objective wellbeing would identify aspects of the conditions of living in a given society; often resource orientated and supported by social infra-structures. Subjective aspects of wellbeing would identify the experience of living in society, the consideration of human happiness and general satisfaction. Often domain specific evaluations are considered to relate to general indicators of the subjective quality of life and wellbeing such as satisfaction with work, health or social relations (Duncan, 2005; Tesch-Romer, Kondratovitz, & Motel-Klingebiel, 2001). The conceptualisation of wellbeing in relation to policy therefore requires consideration of objective and subjective aspects of wellbeing: applied to children with a disability this suggests the need to consider not only the objective aspects of wellbeing, in access to resources for example, but also their subjective aspects, such as happiness.

Across education and social sectors there is recognition that the concept of wellbeing should be underpinned by capacity building (Ministry of Education, 1993, 1996b; Ministry of Social Development, 2004c:36). In terms of knowledge building there is recognition that both families and youth should be given the opportunity to participate in the elaboration of the concept of wellbeing (Pryor, Roberts, & Jose, 2004; Stevens, Dickson, Poland, & Prasad, 2005). However, there still does not seem to be a focus on youth with disabilities or families with a child with a disability.

Contemporary discussion supporting the principles of wellbeing for children with a disability in New Zealand can be identified in examples of current research in the area of education. This discussion is around the values that underpin inclusive education from the position of teachers' practice and the child's experience. Particular beliefs and values of social justice, fairness and human rights are identified as underpinning practises of teachers in early childhood settings in relation to attendance and participation of children with a disability (Gunn et al., 2004).

The work by MacArthur on inclusive education practise can also be equated with the notion that wellbeing is fundamental to education practice. Aspects of wellbeing that can be identified in this study are: values of fairness; rights based equity and social inclusion. These are seen as fundamental to the subjective happiness and skill development of students with a disability enrolled in New Zealand schools (MacArthur & Kelly, 2004; MacArthur, Purdue, & Ballard, 2003).

More specifically, the New Zealand wide consultation process *Let's Talk Special Education* (Ministry of Education, 2004b) undertaken to inform policy and service development for children with a disability in education in New Zealand in 2004 identified aspirations of wellbeing for children with special needs as a priority for parents and educators. The concept was reported by the parents and educators as what could be termed subjective notions of wellbeing: this included happiness, sense of belonging, acceptance, self - esteem confidence and respect, dignity and experiences of success. Additional aspects reported by parents were an expectation for their children to reach their potential emotionally, spiritually and physically; being valued in their schools, and by neighbourhood and community. Participation and learning were discussed separately and centred on social inclusion and competency in skill development (Ministry of Education, 2005a).

It would follow from this review that the application of wellbeing requires that the underpinning conceptual basis needs to be clearly established, and a definition set down before any comprehensive measurement indicator can be applied.

2. Ecological theory

New Zealand's social policy and education curriculum are underpinned by ecological theory. The ecological perspective emphasises that a child's development is affected by contexts of home, school or neighbourhood, and the contexts beyond them, which in turn influence how their caregivers and teachers act towards them (Smith, 1998).

There are at least two qualitative studies in New Zealand that have drawn on Bronfenbrenner's ecological theory. The first is Smith and Taylor's (1998) study families in transition and the involvement of families in Family Court proceedings. The changing nature of families (divorce, separation, remarriage) is argued to be due to changing social and cultural values, in turn altered by other social and economic conditions. The authors show the significance of ecological theory and Bronfenbrenner's notion of mutual accommodation in terms of environmental context and children's experience within it (Smith & Taylor, 1998).

In the second study, ecological theory has been applied to family resilience. This study shows that families' experience of the practices within early childhood centres (microsystem) are supportive and provide a connection within a community of others outside the immediate family. The link with the mesosystem was identified as the quality of the relationships that early childhood centre staff have with families, advisory agencies and social agencies (Duncan, Brown & Smith, 2005). This could be elaborated on and should also apply for children with a disability and school.

In Australia, Law (2005) developed an empirical investigation of ecological theory applied to youth, families, and aspects of mental health in relation to the youths' interconnectedness with their neighbourhoods. The influence of multiple environments on the developing child was examined in relation to children's sense of security and social connectedness. The child's family, peers, school and neighbourhood experiences were examined through a series of specifically designed questionnaires. The resulting conceptual model predicts the impact of predisposing influences of peer interactions; family relationships; school and community connectedness to outcomes of youth adjustment and social connectedness. The study

identifies the four worlds of youth: their family; their school; their peers and their inner world. The recognition of these four worlds is promoted to assist in aspects of mental health promotion and youth social connectedness. The implications of these findings are identified to inform school and school counsellor service provision issues of best practice to support positive social outcomes for youth in Australia (Law, 2005).

Finally, it can be argued ecological theory would clearly support the social model of disability as the paradigm to underscore service provision for children with a disability in New Zealand schools, because of its emphasis on the interdependent nature of environments in which children with a disability live

3. Social Solidarity

The theory of social solidarity²⁵ would suggest that contemporary issues of social policy in relation to children should be underpinned by the notion of the social contact and a sense of collective responsibility in ensuring the inclusion of society's component population groups.

Middleton (1999) and others (Ministry of Education, 2005a) have argued that a two-tiered education system for children reinforces marginalisation through social exclusion, practised on the basis of physical segregation. In New Zealand, this remains prominent in current debate. *Lets' Talk Special Education* 2004 identified that many parents want regular school options but report that for regular class placement to work well for more children and young people, attitudes and funding need to change (Ministry of Education, 2005a).

New Zealand policy documents promote social development as the framework of social inclusion, a process identified as coordinated social change that promotes the wellbeing of the population and of disadvantaged groups. Social inclusion is defined by the Ministry of Social Development in the vision statement of an inclusive New Zealand where all people participate in the social and economic life of their communities (Ministry of Social Development, 2005b, 2005c). In addition, social

²⁵ Other terms such as social cohesion, social connectedness, participation, inclusion and belonging are often equated with solidarity.

issues of inequities, rights, identity and social exclusion are identified in the New Zealand policy context (Ministry of Social Development, 2003).

This is expanded specifically for children and young people through outcome frameworks and elaborates on areas of behaviour and capability which are intrinsic to social inclusion:

Children and young people obtain the knowledge and skills to enable them to participate in society, feel secure with their identity, develop socially constructive behaviour and the capacity for economic independence (Ministry of Social Development, 2005a:11).

Social Connectedness is the term used in the *Social Report* and *Children and Young People: Indicators of Wellbeing in New Zealand* to identify measurable indicators of social inclusion. This term refers to social relationships and is recognised as integral to wellbeing (Ministry of Social Development, 2003, 2004c, 2005a). Here, the importance of social bonds and relationships are highlighted as beneficial to individual and collective society leading to better performance and economic outcomes as attributes of happiness, wellbeing and prosperity.

When children and young people achieve shared goals or contribute to a group performance, a sense of satisfaction and pride can be established with lasting benefits for social participation later in life (Ministry of Social Development, 2005a:114).

Brynner's (2000) OECD review of longitudinal data which includes the New Zealand Christchurch and Dunedin studies (*Church Report*, 2003) identifies life course patterns that lead to social exclusion. The author states that disability, when associated with special needs, has led to the rise in policy development concerned with inclusive education and addressing the restrictions on opportunity for children with a disability. Brynner (2000) argues that this has added to the debate on rights legislation in support of the obligation of the state to assume special needs initiatives in matching provisions with the needs of individual children.

Special needs have therefore become relevant to the social inclusion and exclusion of component population groups. I interpret this to mean that the obligation of the state in recognising children's rights would reflect macro level solidarity, though the

implementing of policy and provision of resources and services for children with a disability, and in so doing, enhancing solidarity at the micro level of daily living.

Brynner (2000) suggests that a holistic approach would encourage and encompass a focus on the broader issues of disability related to social exclusion. This idea is also supported by Sen (1993) who stresses lack of ‘capabilities’²⁶ as the key component of social exclusion (Sen, Nussbaum, & World Institute for Development Economics Research, 1993). Brynner (2000) concludes that when children are denied access to material, cultural and emotional resources that enable them to acquire capabilities, then cognitive development and educational success are compromised and further extended to broader areas of health and social participation. The life course processes to which children are exposed will mean they will either acquire or fail to acquire capability, which then becomes a defining factor in the importance of achieving adult identity and employment. Poor acquisition of basic literacy and numeracy, and poor educational attainment would therefore lead ultimately to social exclusion. Brynner (2000) highlights that longitudinal studies²⁷ show that individual disability can be viewed as a bench mark of other risk factors in the long term and that children with a disability are less likely to achieve and express *satisfaction* with life as adults.

In the United Kingdom context, Middleton (1999) identifies social exclusion for children with a disability by illustrating their marginalisation through the service provision of health, education and social services which are based on a conceptual differentiation of *children* and *children with a disability*. Middleton argues that children with a disability undergo a process of social exclusion as a result of their being viewed as a ‘group apart’.

Labelling some children as ‘disabled’ or ‘special’ sets them outside mainstream healthcare and disempowers both their parents, and the professional workers who may deal with them on a day-to-day basis... Disabled children grow up feeling different, stigmatised and afraid (Middleton, 1999: 37).

²⁶ Sen’s allied notion of human capabilities is described as the capability to participate in an activity (Doyal & Gough, 1991:167).

²⁷ For example: 1958 British Birth Cohort Study; 1965 Sweden Individual Development and Adaptation; 1972 New Zealand Dunedin Birth Cohort Study; 1979 USA National Longitudinal study of Youth; 1995 USA Kauai Longitudinal Study. For a full list see Brynner, 2000:10.

6. Conclusion

The theories reviewed in this chapter relate to the question of wellbeing for children with a disability because they help challenge and clarify the need for appropriate definitions, and because they outline the interrelatedness of collective and individual responses towards meeting the needs of children – and specifically the component population group, children with a disability.

The ecological framework which appears to accommodate well the social model of disability reminds us of the need to consider the needs of children with a disability in relation to their broader environments.

From the international and New Zealand research reviewed here it can be said that although the concepts such as social connectedness and inclusion are recognised as integral to wellbeing, in practice service provision appears to endorse the separation of children with a disability as a group apart.

Chapter 5. Wellbeing for children with a disability: research approach

This chapter outlines the research approach adopted in the thesis to explore the perception of wellbeing for children with a disability. The issues surrounding interviews with children, sampling and data collection process are outlined and the research method and interview process described. The development of the research analysis, ethical considerations and limitations of this study are briefly reviewed. The findings are reported in Chapter Six.

1. Children's voice: interviewing considerations

A pivotal aspect of this research study was to gain the perception of wellbeing from children with a disability, a perspective that is often forgotten, particularly amongst this group in the expanding research on children and youth (France, 2004:177; Gillman, Swain, & Heyman, 1997; Lewis & Kellett, 2004). Research with disabled children and young people presents many ethical and methodological challenges (Lewis & Kellett, 2004), and it is important to recognise that children with a disability are often grouped together by pathologies such as blind, deaf, cerebral palsy, autistic or Down Syndrome, suggesting that the individuals labelled together are all similar. However, it is recognised both internationally and in New Zealand that this homogeneous approach fails to allow new opportunities for disability research to examine biographical and lived experience as an empirical research method (Clark & Statham, 2005; Fraser, 2004; Lewis & Kellett, 2004; MacArthur & Kelly, 2004).

In the New Zealand context, the Children's Issues Centre advocates that research relating to the experience of children be conducted with children as participants (Smith, 1995; Smith, Taylor, & Gallop, 2000), a stance supported by other researchers working in the field of disability (Lyle, 2005; MacArthur & Kelly, 2004). New Zealand and international research on students' perspectives of the school experience has provided a critical starting point for teachers to reflect on their practice and consider how best to support the participation and learning of students with disabilities at school (Lewis & Kellett, 2004; Lyle, 2005; MacArthur & Gaffney, 2001; MacArthur & Kelly, 2004; MacArthur & Morton, 1999).

1. Photography and data collection

For the purpose of this Thesis, child participants were given a disposable camera and their photos were used to provide a visual record of what they considered represented aspects of wellbeing in their daily lives. The photos also aided in communication with the participant as a tool to support verbal expression, and for assisting articulation of abstract concepts. In addition, the use of photos and photo albums was aimed at assisting in the child participant's sense of ownership and engagement in the interview process.

The use of a camera by children as research participants is a relatively new technique and one aspect of the *Mosaic* approach endorsed as a research method to enable the voices of very young children and children with a disability to be heard (Morrow, 2001). This multi-method framework includes the use of photos and participatory activities such as guided tours or map-making so that children can highlight important people, places or events in their lives (Clark & Statham, 2005; Morrow, 2001).

This technique has been adopted as a research methodology for investigating young people's views on their social context and environments, with the intention of exploring subjective experiences of their neighbourhood and social networks (Morrow, 2001). Cameras have also been used in Australian health research to obtain the views of children relating to service provision in the hospital environment and has been described as photo voice (Darbyshire & Campbell, 2005).

Cameras have also been used in New Zealand as a research tool to obtain the voice of children with an intellectual disability, their siblings and parents in order to explore their perspectives on what comprises a good family and community life (Lyle, 2005).

2. Definitions in the research approach

1. Definition of children

There is variation in the age range designated to define children in New Zealand. The *Children and Young People: Indicators of Wellbeing* (2005) report relies on Statistics New Zealand data where children are defined as those between 0 - 18 years and young people are aged 18 - 24 years. The report also utilises the *New Zealand Disability Survey* which categorises children in the range of 0 - 14 years. The Ministry of Education's Special Education resourcing, the *Ongoing Reviewable Resourcing*

Scheme (ORRS) funds children in education to the age of 19 as the end of their nineteenth year (Ministry of Education, 2004e).

Given these variations, for this study children are identified as those in the 0 – 19 age range which is the range covered by the provision of special education services.

2. Definition of disability

The definitions of disability that informed the selection of the children in this research were drawn from the Ministry of Education Group Special Education and *New Zealand Disability Survey* documents (Ministry of Education, 2004d; Statistics New Zealand, 1997). The child participants were purposively selected on the basis that they met eligibility criterion for these services.

3. Definition of education and special education

Following the rationale of entitlement established in several significant policy statements (Ministry of Education, 1989, 2004d), a New Zealand definition of the *right to education* was drawn on to inform this study (see Appendix 3). The *Right to Education Framework: He Whare Tapapa Matauranga* (Human Rights Commission, 2004: 262) outlines four broad standards of education: availability, accessibility, acceptability and adaptability²⁸. This framework also promotes *key factors* of the Government as regulator, provider and funder of schools; the student's right to education and duty to comply with compulsory requirements and the child's parents as 'first educators' (Tomasevski & UNESCO Asia Pacific Regional Bureau for Education, 2004).

3. Purposive sample

The sampling strategy was non random and nine participants were purposively selected based on being either service users (children with a disability and parents), service providers (classroom teacher and special education service provider) or policy professionals (national policy planning and service development). The researcher used personal contacts as the starting point to recruit participants (McBurney, 2001; Rubin & Rubin, 1995; Strauss & Corbin, 1998) (see Table 1a).

²⁸ For a full definition of these terms refer to Human Rights Commission, 2004: 280.

1. Service Users

There were four service user participants in the study. Two children with a disability were selected based on age and developmental language skill. The child participants are members of a two parent family and each have at least one sibling. They attend secondary schools in their area and are known in their local community. The child participants are young people who have Down Syndrome, and are both covered by Group Special Education funding allocations through the ORRS. The two parent participants were parents of the two children selected for the research.

Table 1A. Research participant profile 2005

Research Status	Age in years	Gender	Ethnicity	Family Situation	Professional Position	Career
Service User	17 years	Male	European	2 parents; 3 siblings	Attends State secondary school	
	15 years	Female	European	2 parents; 1 sibling	Attends Integrated secondary school	
	45-50	Female	European	Married couple two children		
	50-55	Female	European	Married couple two children		
Service Provider	50-55	Female	European		Classroom teacher junior school	25 years
	50-55	Female	European		Class room teacher Deputy Principal SENCO	33 years
	45-50	Female	European		Group Special Education Service Co-ordinator	20 years
Policy Position	45-50	Female	European		National Service Development Advisor	20 years
	55-60	Female	European		national service development advisor	30 years

²⁹

There was one male research participant. This was not intentional but may be indicative of the gender ratio in the area of service provision in primary schools and / or in the area of disability policy and service provision.

²⁹ SENCO Special Education Needs Co-ordinator.

2. Service Providers

Three adult participants were selected based on having had over five years experience in providing services for children with a disability in the school environment. Two full-time primary classroom teachers were selected for their extensive experience in relation to teaching children with a disability; one is also the school Deputy Principal and the Special Education Needs Coordinator (SENCO) for the school.

The third service provider participant was selected due to experience in service provision coordination of Group Special Education (GSE) services in the geographical area of the research participants. GSE is the division of the New Zealand Ministry of Education that allocates, directs and delivers services for children with a disability.

3. Policy Professionals

The two participants selected for their Policy Professional role have extensive experience in service provision, service planning and service development for children with a disability.

4. Data collection: process and tools

For eight participants data were collected by means of face-to-face interviews; one adult interview was via phone conference because of the difficulty in arranging a meeting. The one-to-one interview was the method chosen to obtain an in-depth understanding and insight into the complexity of the notion of wellbeing. This approach enabled the researcher to ask for clarification and elaboration on the themes discussed. Data collection tools were designed to facilitate a semi-structured interview context, allowing the participants to answer in their own terms without being restricted by a standardised questionnaire (Crabtree & Miller, 1999; May, 2002; Smith & Taylor, 1998), but at the same time enabling the interviewer to keep the participants focused. This approach is recognised as a powerful research technique when not much is already known about the topic being researched, or where that topic is particularly complex (Davidson & Tolich, 2001; Strauss & Corbin, 1998)

All interviews were recorded by audio tape and notes taken throughout the interview. The tapes were transcribed and content checked with the participants for accuracy and clarification where necessary. This procedure was explained on the consent form.

1. Child participants

Four types of data collection tools were used with the children: a camera which was supplied by the interviewer; the *Ordinary Life* framework prepared as a laminated card; interview support material gathered by the child participant; and the interview guide.

The children were given a disposable camera three weeks prior to the interview and asked to photograph the people, places, events and things in their life they liked and considered would help show the researcher what wellbeing means for them. They were asked to take the camera to school. In addition, the children were asked to collect together other photos or things they would like to have at the interview that were important to their daily life (referred to as interview support material). The photos and interview support material were used in the interview and were important additional communication aides used in the research process. The photos remained the children's property and were documented in the field notes.

The children were shown an adapted version of the *Ordinary Life Information Gathering Model* taken from an existing research project that explored issues of community membership for adults with an intellectual disability (National Advisory Committee on Health & Disability, 2003). This model is endorsed as a research tool for gathering information and assisting communication for adults with communication difficulties and / or intellectual disability (Earle, Corner, & Roberts, 2004). The framework identified aspects of communication; independence in daily living; school; learning; relationships and participation in the community (see Appendix 3). This was used as an additional tool to explore the child participants' perceptions of wellbeing and day-to-day experiences.

The children's interview guide focused on obtaining data relating to their ideas and perception of wellbeing, what factors influenced it and how this related to the school environment. The interview themes were:

- Background of the child, their family and school
- The children's perception of school and description of what they liked and disliked about school
- The link to after school and things the children liked to do

- Ideas about wellbeing and what constitutes an “OK” life
- What aspects of school or other activities may be hard for the children participants
- Other comments

The *Ordinary Life Information Gathering Model* and interview guide for the child participants were pre-tested on three children aged between 11 - 14 years. The wording and clarity of the questions were checked. It was also adapted for size and a hand drawn model was used as this was considered more visually appealing than the original printed version.

2. Adult participants

Three types of data collection tools were used for the adult interviews: interview support material identified by the participant, three selected frameworks and the interview guide. The adults were asked to bring any support material they felt was relevant to the interview. This consisted of photos, certificates and academic records such as the IEP and report cards and role descriptions within the area of service provision for children with a disability at school. The frameworks included:

- *Children and Young People: Indicators of Wellbeing in New Zealand*. Outcome domains (Ministry of Social Development, 2005a:136).
- *The Key Settings Model* (Ministry of Social Development, 2002:14).
- *The Right to Education Framework* (Human Rights Commission, 2004:262).

These were introduced towards the end of the interview to ensure the participants had had plenty of opportunity to express their views and perceptions of wellbeing for children with a disability without being limited to the presented frameworks. The frameworks were presented to the adult participants as representing New Zealand’s current social policy perspectives on children, and their reactions sought on the relevance of these frameworks to children with a disability.

3. Content of the interview guide

The interview guide was developed to obtain data on the thesis’ three questions: perception of wellbeing; factors which influence wellbeing for children with a

disability at school, and the relevance of identified child social policy operational frameworks to the wellbeing of children with a disability.

The guide drew on the *Guide to Applying the Whole Child Approach*³⁰ which sets out six sets of questions to consider in relation to policy and service provision. These broadly cover:

- What will be the effects on children of this policy?
- Will there be differential effects?
- How can we involve children in work on this policy?
- What links need to be considered?
- What are the key settings to focus on?
- How will other settings influence this policy?

These questions were adapted with a particular emphasis on differential effects, links and the Key Settings. The interview guide was divided into themes with open-ended questions and prompts:

- Background of research participant
- Perception of wellbeing and description of wellbeing by the research participant
- Factors which influence wellbeing for children with a disability at school
- Any differences in working with children with a disability
- Links which need to be considered: other agencies; provisions; policy strategies
- Presentation and discussion of policy frameworks
- Other comments

³⁰ This guide provides a set of key questions to consider when developing policy and services for children (Ministry of Social Development, 2004e). These questions were adapted for this study. For a detailed list of questions see (ibid: 8-9) or <http://www.msd.govt.nz>.

4. Pre-testing the interview guide

The adult interview guides were pre-tested on four individuals who were not those interviewed for the research study and included: one parent of a child with a disability; two service providers - one classroom teacher and one family service provider of children with a disability; a person with a policy background.

The interview guide was first administered followed, by the three frameworks which were presented to the participants on laminated cards for comment (see Appendices 3 and 6).

5. The interview process

1. Making contact, setting the scene

Initial contact with the research participants was by phone, followed by a written explanation of the research process. The information sheet and interview consent form were emailed to the participants (see Appendix 4). This contact was followed by a personal visit from the researcher to the child and parent participants to explain the research procedure and the consent process. In addition this visit served as an initial interaction to establish rapport with the participants in recognition of the potential sensitivity of the subject and the personal nature of the research inquiry.

2. Interview camera and initial meetings: child participants

The child participants were given their disposable camera and photo album at the initial meeting and asked to think about what other material they could use to show what wellbeing meant for them in their day-to-day experience of school and home life (for example other photos, mementos of events, social stories compiled as books used in the curriculum or communication aides used in the classroom). This first meeting also helped to introduce the concept of wellbeing and an “*Ordinary life*” to the child participants. The participants were able to ask for clarification of the research study and the aim was to reduce issues of anxiety related to the research process. They were also asked to think about where and when they would hold their interview. The role of the interview advocate or interpreter was explained and the child participants were asked to think about who they would like this to be. The consent form and interview information sheet were explained.

This initial meeting was followed up with a phone call to establish the interview meeting at a time and place convenient to the participants. The choice of location of the interview was important in ensuring an environment where child participants were comfortable to discuss and share ideas and experiences. The importance of choice of location as a non-hostile environment has been identified: recognising that some environments are interpreted by child participants as threatening. For children with a disability this may be related to prior experiences, as for example, a health environment (France, 2004; Lewis & Kellett, 2004).

The children interviewed were given additional explanation and two consent forms; one for the child and one for parental consent for the child to be interviewed. Again, material gained from the interview was treated as confidential and was clarified with the participant prior to use in the final research document.

3. Establishing the research interview: adult participants

The adult participants were contacted by phone initially to establish interest in being involved in the research. This was followed up by sending them the information sheets and consent forms (see Appendix 4).

Four schools were contacted prior to establishing a school where teachers would agree to the research interview. The reasoning reported for declining to participate in the research was a general feeling of lack of knowledge on the research topic even though the schools contacted had experience of service provision for children with a disability or special needs.

The service providers requested a copy of the interview schedule prior to consenting to the interview process. As the interview schedule provided an indication of the themes the research was to explore, in order to gain confidence of the participants, this was not felt to prejudice the research process. The interview guide was emailed to the Service Provider and Policy Professional participants who then agreed to the research interview.

All the research interviews were held in the location and time selected by the participants.

The researcher has personal experience in the field of children with a disability and as such did know some of the participants. As the purpose of the research was to gain an understanding of what wellbeing means at the micro level amongst only a few people,

the researchers experience was seen to add to the ability to gain in-depth understanding on sensitive areas and / or some of the complexity of the topic.

4 The child participants' interviews

It was important to build a relationship for the interviews. The use of a disposable camera given to the participants enabled them to identify areas of their daily life that contributed to their sense of wellbeing. The photos were developed prior to the interview and used as a communication aide in the research interview. This aspect of the research assisted the child participant to verbalise thoughts and emotions related to an abstract concept from a more concrete tool, and were a constant reference point throughout the interviews. In addition the photos and album provided a sense of ownership of the interview process. The child participants also had some other materials selected to support the interview process, such as examples of school and technology work, a display of art work, a report and Individual Education Plan, a video of the school play, a Compact Disc of choice and a list of favourite activities.

The process of recording the interview was shown to the child participants and examples of recording and replaying the researcher and participant's voice started the interviews. The child participant interviews were conducted over a half day with shared refreshments and opportunity for breaks. The opportunity for regular breaks, and the child participants being able to refer to family members in the home while the interview was in progress, assisted the interview process.

5 The adult participants' interviews

The adult interviews included three interviews in private homes, three interviews in an interview area in the workplace and one interview by teleconference. All adult interviews were approximately two – two and a half hours long. Refreshments were provided and there were no interruptions.

6. Analysis of research findings

The field notes and audiotapes from the interviews were transcribed verbatim. The transcripts were analysed for themes, patterns and / or categories by the interviewer. In the initial analysis, a coding or text unit was defined to represent the expression of an idea relating to a particular theme of the interview guide.

1. The analysis process

A qualitative research analysis technique is the reading and re-reading of data for emerging themes, interpretations and typologies or classifications (Smith & Taylor, 1998; Strauss & Corbin, 1998). As anticipated, the coding categories were refined, defined and revised after the interview notes and audiotape transcripts had been re-read several times. This technique was the basis of the transcript analysis.

The categories for the transcript coding were identified with reference to the themes of the interview guide: for example Perceptions of wellbeing (POW) as sections of the transcripts relating to description, ideas and comments of participants perception of wellbeing. These were highlighted in the transcripts and compared for themes. The example below was categorised as “building capability” a dimension of wellbeing. Further analysis of this example identified “skill based learning” as a Factor which influences wellbeing (coded FIW) identified by this participant.

The idea of wellbeing for children with a disability I suppose, they have got more to contend with so I think that we need to make sure they have the skills to get on in life as much as they can. I would say that they need to read and write and be able to feel good about themselves (Service Provider 2).

A broader approach taken to content analysis, is when content analysis technique is extended to examining the context within which any written, visual or spoken form of communication occurred (Shuker, 2001; Strauss & Corbin, 1998). This approach was applied to the photos taken by the child participants and interview support material such as report cards and IEP examples. The initial analysis was developed further into comparative grids in which data were grouped into coded categories representing interview themes by participant research status. An example of this procedure is given in Table 2a in a table format

Table 2A. Child participant transcript analysis grid 2005

Interview theme	Child participant: John	Child participant: Mary
School work (SW)	<p>Interview quotes related to school work</p> <p>Photo content and verbal descriptions of photos related to school work</p> <p>Interview support material related to school work</p> <p><i>Ordinary Life Information Gathering Model</i> field notes</p>	<p>Interview quotes related to school work</p> <p>Photo content and verbal descriptions of photos related to school work</p> <p>Interview support material related to school work</p> <p><i>Ordinary Life Information Gathering Model</i> field notes</p>

Table 2a illustrates how data from two children, obtained from using the interview guide, photos, interview support material, and the *Ordinary Life Information Gathering Model* were analysed. The theme which emerged was “school work”. At a later stage this was reinterpreted as part of a concept of “building capability”.

7. Ethical considerations

The initial research proposal was subject to approval from the Human Research Ethics Committee, Faculty of Arts and Social Sciences of the University of Waikato.

Participants’ privacy was maintained as much as possible. No identifying data linking the respondent to the responses were reported in the findings. The names of the child participants have been changed to ensure confidentiality. Initials as pseudonyms have been used. However, given the specialist area of the topic under study it may be possible for the respondent to be identifiable so the fact that the interviews were the basis for a Master’s thesis was outlined. Additional measures were taken to ensure confidentiality; the time and place of the interview were selected by the participant, and the interviews were not time limited, so that participant’s could fully express and explore their ideas.

As outlined by Fraser et al (2004) every effort was made to ensure for the child participants that the potential risk of emotional harm was minimised when expressing

sensitive ideas or discussing of sensitive topics. This included consideration of the time and place of the interview, pre-interview contact meetings, the consent process, the child controlling the length of the interview, the use of the camera and communication aids and the presence of a supporting family member.

The participation in the research was voluntary. Verbal consent was sought before commencing the interview along with written consent and information sheets as outlined earlier. The information sheet provided contact details so that the participants could contact the researcher after the interview if they had any further queries or concerns.

The participants were informed of their right to withdraw from the research, without any consequence, during the introduction of the research, and before being asked for the consent to participate. The participants were informed that the audiotape, transcript of the interview, an analysis of the interview and the process of undertaking the interview were as part of assessment for a Master's thesis. The participants were informed of the right to be entitled to a copy of the transcript and to any data related to them. This information was also noted on the information sheet (for the Interview Guides, Information Sheets and Consent Forms see Appendices 6 – 8).

8. Limitations of the research

1. Issues of purposive sampling

Ideally the research would have involved interviews with a greater number of children, parents and a range of service providers, but due to the limitation of a Master's research study and time constraints, only a small number of participants were interviewed.

In a larger research project, I would suggest that the principal service groups would also include some of the range of specialist services such as speech language therapy, psychology, learning and behaviour initiative difficulties, developmental delay, health personal, teacher aides and behaviour support workers. However, for this thesis a limited scope of service users and services providers were selected to gain an insight into the *Key Setting* of the school.

Given the sensitivity of the research topic, recruitment of the participants (particularly the Service Provider and Policy Professional), was more difficult than initially

presumed. The initial interest was positive but there was apparent hesitation from potential participants to commit to “recording” their views on wellbeing for *children with a disability* in the school environment. In addition, for the Policy Professional, the timing of the research was acknowledged as “sensitive” due to it being the New Zealand election year as some of the potential participants were employed in a Government agency at that time.

2. Issues of the research procedure: child participants

The child participant interview procedure worked well. The pre-planning and the involvement with their camera proved beneficial, having established some rapport with the participants and their engagement with the research process through the photo record. The time frame of the interview process allowed for social interaction such as afternoon tea, being shown around the house and playing a game of cards which aided the child participants’ comfort with information sharing and the interview process.

The child participants did express some anxiety over some of the issues covered in the research and the presence of a family member in the proximity helped the participant either explain their point or clarify the issue. Notably, both child participants had their entire family at home when they were being interviewed. The child participants both referred to different family members for points of reassurance, confirmation or issues of clarity during the research. This was often on ideas such as dates of events and was not seen to detract from the interview content for this study. These aspects of the research procedure would require fuller consideration before expanding on this research topic.

3. Issues of the research procedure: adult participants

The interview schedule assisted with keeping the semi-structured interviews focused on the themes of the interview. This assisted with data collection and analysis of findings. Leaving the discussion of the frameworks to the last stage of the research inquiry was of benefit in two ways. Firstly, the interviews had already covered the participants’ perception of wellbeing and identified factors which influence wellbeing in their experience, so that the frameworks did not necessarily bias the research data. Secondly, because the participants had covered the perception of wellbeing, they were

open to discussion on their views on the relevance to of the frameworks and primed for a more in-depth discussion.

The selection of the three frameworks for discussion was probably too ambitious for the scope of this particular research study as a Master's thesis. The selection of the social policy frameworks was recognised as directly relevant to the research inquiry, but this resulted in an excess of data for transcribing and analysis. The selection of the *Right to Education Framework* in particular, introduced further complexity to the issues of wellbeing and tended to focus the discussion to broader education issues. This "wheel" was the last framework introduced and consequently, full discussion of the perceptions and implications of the framework were not fully explored. This would be more appropriate as part of a larger inquiry.

4. The research topic: findings and analysis

The data gathered provided a significant volume of material to be examined. As a result, I have prioritised the presentation of findings in terms of those which are the most illustrative and important in relation to the research aims: the perception of wellbeing and the factors which influence wellbeing for children with a disability.

The three selected frameworks used for discussion and interpretation at the final stage of the interviews provided a rich insight into the complexities between policy frameworks, interpretation and implementation by service providers *at the chalk board*³¹. The interview transcripts and the material collected have been analysed and a summary of the common themes across the participants' interviews is presented in section 4 of Chapter Six. I hope to expand on and use more of the data at a later stage, and this possibility was covered in the consent process with the research participants.

The interview transcripts were rich with anecdotes and the lived experiences of several children with a disability; I feel this is not given full justice in the presentation of a Master's thesis.

³¹ This is an expression coined in relation to the experience of classroom teachers and issues of inclusive education (Rietveld, 2003).

Chapter 6. Research Findings

The Whole Child Approach in the development of policy and services is about making sure the needs, rights and interests of children and young people are taken into account... and that policies contribute to healthy development and wellbeing of all children (Ministry of Social Development, 2004e: 5).

1. Introduction

The findings presented in this chapter and which address the thesis' questions are from nine semi-structured interviews with three groups of selected key informants: Service Users (child and parents); Service Providers (teachers and special education provider) and Policy Professionals. The three questions are:

- What does wellbeing mean for children with a disability?
- What factors influence wellbeing for children with a disability at school?
- Given their experience, are current policy frameworks relevant to the wellbeing of this specific population of children with a disability?

The participants were asked to describe their perceptions of wellbeing by answering questions on their personal experience related to children with a disability at school (Appendices 5 and 6). The concepts that have been subsequently developed emerged from the content analysis of the participants' transcripts and photo record (see Chapter Five: section 6 for an overview of methodological details).

Findings on the perception of wellbeing and the factors which influence it in the school environment were analysed and described as a series of seven dimensions. These are: building capability; identity; friendship; communication; participation; care and support and environments. However, given the volume of information, I have selected five dimensions to present in this thesis: building capability; identity; friendship; communication; participation (see Appendix 7 for the full list). Brief definitions of the concepts and terms which have emerged from the analysis of qualitative data are outlined. A summary table is presented at the start of each section. The left-hand column represents the dimension of wellbeing drawn from the content

analysis of the participants' interviews as responses to the research question: "What is your perception of wellbeing?" The next four columns are the identified *factors* which influence the specific dimension of wellbeing as articulated by the interview participants. This presentation format is used for each dimension of the findings, followed by a descriptive summary, illustrated with examples from the interview content.

The children were shown an adapted *Ordinary Life Information Gathering Model* in the last stage of their interviews. These findings were incorporated with the interview content analysis and represent the children's perception of wellbeing and the factors which influence it. The adult participants were shown selected social policy frameworks in the last stage of the interviews and asked to comment on their relevance for children with a disability (see Chapter Five: section 8). The themes that emerged from this discussion have been summarised in section 4.

2. Definitions of the concepts used

The concepts in Tables 1 – 5 presented in the following pages represent the various dimensions of wellbeing which have been developed by the researcher based on responses from the research participants.

1. Definitions of the dimensions of wellbeing

The concept *building capability* has been developed to identify all aspects of the child participants learning; it refers to working towards specific skills or learning tasks or skills that the participants have already acquired. Building capability was inspired by the interview content but also corresponds to the literature reviewed on aspects of wellbeing (see Chapter Four: section 2).

The concept *identity* as a dimension of wellbeing has been developed based on the child participants' photo record, and descriptions of themselves, as well as the content of the adult participants' interviews. This concept refers to aspects described as characteristics such as individuality or personality.

The dimension *friendships* was directly reported by participants to describe a reciprocal relationship characterised by mutual assistance, equal roles, social value, individuality, approval and support and corresponds with literature reviewed (Lyle, 2005; MacArthur & Morton, 1999; Meyer, 2001).

The concept of *communication* has been used to refer to a system of exchange of information between people by means of speaking, writing or using a common system of signs or behaviour.

The concept *participation* was directly reported by participants as involvement and inclusion in activities and events experienced in all environments. This is a definition that could be considered synonymous with definitions of social inclusion, social connectedness and solidarity (Ministry of Social Development, 2005a, 2005b; Rustemier, 2002; Tesch-Romer, Kondratovitz, & Motel-Klingebiel, 2001).

2 Definitions of the factors which influence wellbeing

These concepts reflect findings on the thesis's second question: "What factors do you consider influence wellbeing for children with a disability at school?" The meaning participants attributed to these factors are summarised for each dimension of wellbeing, and are presented in the tables at the start of each section. The majority of keywords used to define factors are self explanatory, but where appropriate, a brief context explanation of the terms used is given in the following section.

Wellbeing Dimension: Building Capability

The concept *meaningful work* as a factor influencing building capability describes activities and responsibilities identified by adult and the child participants to denote pursuits that were goal directed, or were identified as having meaning or purpose by the participant and / or described as work.

Meaningful work can be aligned with the objective and subjective aspects of wellbeing. The objective aspects of meaningful work are task orientated or *skill based*: curriculum based school work; class tasks; and home tasks. The term *supported* in the context of meaningful work is defined as material support such as assistance from an individual, and material resources such as educational resources or adapted curriculum material. This is also linked to issues of *skill based professional development*.

The subjective aspects of meaningful work are related to skill acquisition: achievement; goal of competency. *Achievement* is used here to define an event or task the participants described as something they had succeeded in doing, or the act or process of finishing something. The concept *goal of competency* is defined as an

ability to do something measured against a standard, acquired through experience or training.

Wellbeing Dimension: Identity

The concept *ability to learn* as a factor which influences identity was developed to define the attitude towards or perception of a natural tendency to do something successfully or well. In this context this includes steps towards, or partial contribution to aspects of the specific learning task or activity.

Wellbeing Dimension: Participation

The concept *school culture* was developed to define aspects of peer interactions, the child participants' identification of peer groups and codes of behaviour in the playground and at breaks, and was associated with issues of a valued social role at school.

3. Perceptions of wellbeing

1. Introduction

The key setting focus for this study was the school environment. To determine how the nine selected key informants perceived wellbeing they were asked to describe their ideas and views of wellbeing for children with a disability at school. The child participants were asked to describe what kind of things they liked doing best at school and to show the photos they had taken of what makes life good for them.

Participants were also asked to explore further what factors they thought influenced wellbeing for children with a disability at school and how this influence was experienced in the classroom or school setting. The adult participants were asked whether there were any differences in parenting or working with children with a disability as compared to working with a typically developing child and what they saw as their role in influencing wellbeing for children with a disability. They were also asked if they had any involvement with other agencies or links to other settings.

1. Building Capability

Table 1: Building Capability and the factors which influence wellbeing

Dimension of Wellbeing	Factors which influence wellbeing			
	Service User Child	Service User Parent	Service Provider	Policy Professional
Building Capability	Meaningful work	Meaningful work	Meaningful work	
	Skill based	Skill based	Skill based	Skill based
	school work	adapted curriculum	adapted curriculum	adapted curriculum
	class tasks	class role	class tasks	
	home tasks	home tasks		
	Supported	Supported	Supported	Supported
		Resourced	Resourced	Resourced
		Age appropriate	Age Appropriate	Age appropriate
		Planned	Planned	Planned
	Achievement	Achievement	Participation	
	Goal of competency	Goal of competency	Goal of independence	Goal of competency
	Safety	Safety	Safety	Safety

In Table 1 the concept of *building capability* as a dimension of wellbeing is shown. This concept has been identified to represent a consistent theme of the child and adult participants' interview content and photo record when comments focused on working towards specific skills or learning tasks such as maths, literacy, computer skills, cooking, woodwork, school music and drama and extra curricula gym and swimming lessons. Children and parents also acknowledged aspects of independence in skills of daily living such as transport and self-care and extra curricula skills such as sports. The factors influencing building capability identified by adults and child participants are now described.

1. Meaningful work: skill based

The concept of meaningful work encompasses three areas of work which are task orientated or skill based: school work; class tasks and home tasks. Child and parent participants also identified tasks as responsibilities.

The child participants' description and photo record showed academic participation in class (school work) such as their seating arrangements, involvement in specialist

subject rooms such as the computer, music and technology rooms (cooking and woodwork). The description of meaningful work focussed on curriculum based school work.

Here's me at school [photo] doing cutting for my project [social studies]. The things I like at school are cooking things like muffins, cutting and doing my work. My work is English, maths, science and social studies, it is good. Mary

There's me doing my work-that's in maths [photo] ...That's in the classroom at school. I'm doing maths with S. She's my teacher aide. [...] There's me again, doing my work. School work. That's my timetable on those cards. I like doing work, that's my favourite, work. And here is me doing my reading [photo]. John

Parents acknowledged their children's motivation to attend to curriculum areas such as literacy, numeracy, social studies and science. The core curriculum subjects required aspects of learning to be adapted for the child.

Mary likes to go to school with other kids that she has always been at school with and keep on learning with them, make things with them, do some drama and singing and hang out at lunchtime. Do maths and English with them, and the social studies projects, she likes that, it's important to her. Parent 2

The area of meaningful work included class tasks such as taking the role to the office as a daily responsibility or being responsible for keeping work areas clean and tidy such as the woodwork room. Transcripts from the child interviews suggest that this gave them a sense of identity and role within the classroom.

My job is collecting the role, it means every time it's up... before school and after school, collect the names and if they're sick, [write] go home. I take it in my class, my group. I like doing those things at school. Mary

That's me taking the wood out to the wood furnace [photo]. You pull the wood out. That's at woodwork. I just help my mates, I pick it up and give it to X and he stacks it up...it's my job at school. And here's me doing it again [photo] cos I like doing it. It is quite dangerous because if you put your hands too close, it will get cut off. Yes, I like woodwork. I took a picture. John

School work included participation in technology curriculum subjects of cooking and woodwork. The child and parent participants had selected examples of school work to show as interview support material: the parent examples included an Individual Education Plan (IEP) and progress report, a report card and a display set up of the child's art work. The child participants had prepared baking for the interview and displayed an item of completed work: a photo frame, a wooden titanic model and a CD rack.

There's Mr B [photo]. He works in the workshop and works with us. We do cabinets and stools. That's woodwork. I made a stool and a Titanic model. There's the Titanic right there [points to model on the bookshelf]. I made that for (Mum) [points to CD rack]. John

The Service Provider interviews also identified skill based tasks as fundamental to building capability. These participants mentioned a limited range of skills but did emphasise skills required for adult life.

But as for kids that I've taught, they need to learn what they can but what they do learn isn't necessarily what they have to. But it is important. If they can only read to survive when they're adults, then that's important. Service Provider 1

A third dimension to the concept of skill based activities were those completed at home and identified by the children and parents as involving roles of responsibility and opportunities to test skills and develop independence. This included independence in self-care of hygiene and grooming, looking after siblings, being ready for school and being involved in household chores such as cooking, care of the pets and gardening.

My bedroom is up there and I've got a Hulk bed. It's wicked... I heard (mother) say to me that I hope your room is tidy, or something. And I said 'ok Mum', I like to do that. I always keep it looking tidy and clean. John

2 Supported: resourced; age appropriate and planned

All participants recognised support as a key influencing factor of building capability. The child participants' references to their teacher aides and their role in supporting curriculum skill development and capability were central to their descriptions of classroom experience.

There's me doing my work [photo] – that's in maths, that's in the classroom at school. I'm doing maths with S. She's my teacher aide. John

The adult participants talked of support in this context when referring to teacher aide assistance for such things as access to the curriculum including areas of curriculum adaptation, teacher aide hours, eligibility criteria, and educational resources such as reading texts, computer access and visual learning aids. They also recognised teacher or teacher aide skills, issues of professional development and the expertise of the educator as factors of support and resources which influenced building capability.

[...] But then it is also important that you look at the staffing and the personnel because well, you know that some teachers are less able to be flexible [...] it might be just a bit of an ask because of their inexperience so that wouldn't be a good placement. So skill base and experience probably are high up there when we look at how to support this child. [...] professional development courses plus the ongoing school development [...] the outside agencies that come in and support you so you develop your skills and your understanding and practice through their expertise. Service Provider 2

The Service Provider and Policy Professional recognised that their capacity to support children could be compromised if their access to material support was inadequate.

You do need to take their disabilities into account and to try and ensure that they can access the curriculum as best as they can and as best as the school can, and of course very often, that comes down to resourcing. Usually with children who have got already identified needs, ORRS or high health needs, then some of the resourcing is in place. But more recently we have had difficulty supporting children [listed various disabilities] because their needs are not so easily identifiable and don't always meet the current criteria from the Ministry. Service Provider 2

The Policy Professional participants' mentioned broader implications of support for children to access opportunities and environments beyond the school.

I think the responsibility of support agencies is to work with parents and the child and obviously as the child gets older; their participation in the decision making gets more. But it is the support then, if there is an issue of not being able to access the environment or have the opportunities that they need, so it is

the role of agencies to make sure that those are available. Policy Professional

2

The Service Provider participants noted that the requirement for resources for building capability needed to be age appropriate and linked to age appropriate learning environments. Examples to illustrate this were such things as developmentally appropriate reading texts or curriculum material where the text content was inappropriate for the chronological age of the children. This factor was reiterated by the Policy Professional participants' and expanded to environments that are child appropriate as well as age and developmental stage appropriate in areas of service provision such as when specialist services were needed which however, have to be accessed through adult service provision.

I think there is probably a bit of work to be done to achieve good age, stage developmental services across the sectors [...] The areas like health could probably improve [...] I think that they [education] do understand the nature of age, stage development. [...] They are children first; before they are disabled really [...] you have to have services that were child and youth specific for them. Policy Professional 1

The parent and Service Provider interviews identified that aspects of building capability needed to be planned, which they remarked is not always the case, pointing to a lack of curriculum adaptation and professional skill development to support skill based learning.

You can't really do valid learning unless planned and provision is made so it requires curriculum based planning by professional teachers. I think this has been lacking in Mary's programme, probably in big chunks for years, maybe not totally. A huge amount is lacking. Parent 2

3 Achievement

Linked to the concept of meaningful work was the notion of *achievement*. A sense of achievement seemed to provide a strong motivating factor for the children to carry on aspects of skill development.

That's our cooking teacher [photo]. Cos we cook with him. He gives us the recipes and you write down your recipes and you cook the recipes on there [points to oven in photo] He tests us how good our cooking is. And he thinks

about your cooking. He thinks that it is great going and it is quite good...and so I like going to cooking. John

Achievement was also linked to an acknowledgement that the children's ability to learn had been taken seriously, and competency acquired³². This is illustrated for example, by the importance of certificates of achievement as opposed to participation certificates. In contrast to the parents and children, Service Provider emphasis was on participation rather than an expectation of achievement as an outcome.

These are some of my certificates- freestyle breathing, Argos gym, Super swimming. My report is good [support material shown in interview], me in the school play [photo]. School is fun. Sport is quite good. Mary

For Mary, recognition used to be certificates and statements, now recognition is particularly... it is something that gets tested. Mary is so excited that she is going to get a test. I don't know how many children would get excited to bring home a maths test, but for her it really validates what she is doing. Parent 2

4 Goal of competency

A further dimension of building capability identified was associated with achievement but related to educational experiences with a *goal of competency*. The children and parents identified that tasks and learning were validated when children were expected to achieve and become competent, according to criteria used for typically developing children. This application was often lacking, hence a goal of competency was an important influencing factor for building capability.

I do have my IEP. I think my Mum was there as well and we were talking about my behaviour at school has been good actually... I am learning my writing, my computer and I like doing the drums and woodwork and the teacher aides are happy they like working with me. John

³² The interview support material examples included the participants' latest school report and a copy of an Individual Education Plan (IEP), woodwork, artwork and baking used to illustrate the children's steps toward skill capability.

He enjoys school. He is reading, he is writing...they are the skills that we feel are really important for John to get on in life. I have right from the word go. I want this child to read. I need him to write. Parent 1

5 Safety

Children acknowledged aspects of safety in regard to learning skills in the cooking and woodwork areas. Parent and Service Providers recognised broader issues of safety in skill acquisition and within the school environment such as the student's awareness of personal safety, school boundaries and road safety. Their responses indicate that it cannot be assumed that normal safety precautions are appropriate or adequate for children with a disability.

Even now I won't allow J to walk long distances on his own and things like that...like he's probably very, very capable of it...but I just don't have the confidence that J wouldn't just go off with someone, you know, jump in their car. A real safety thing. Parent 1

So a youngster like that may need less Teacher aide support but if you factor in, ok, they are at a school that is on State Highway 1 and it is not fenced and there have been three occasions when that child has left the classroom and headed towards the road. Those are the ones who are very difficult. Service Provider 3

2. Identity

Table 2 Identity and factors which influence wellbeing

Dimension of Wellbeing	Factors which influence wellbeing			
	Service User Child	Service User Parent	Service Provider	Policy Professional
Identity	Sense of belonging	Sense of belonging	Sense of belonging	Sense of belonging
	Happiness	Happiness	Happiness	Confidence
	Social role	Social role	Social role	Social role
	Ability to learn	Ability to learn		
	Disability	Disability	Disability	Disability
		Self esteem		

The concept of identity as a dimension of wellbeing has been developed from the child participants' photos and their description of themselves. The children associated a sense of self to the photo record with items such as "my locker", "my friend", "my uniform". The photo record content and description included the participant in school uniform, the children's family and friends, their school locker and desk, their teacher aides by subject of aid support, classroom setting and social settings (birthday party or social events). The child participants' *Ordinary Life Information Gathering Model* interview content analysis was incorporated into this dimension of wellbeing as the findings were of most relevant to the participants' sense of identity (Appendix 3).

1. Factors which influence identity

The concept was further explored by asking the participants what factors they considered to influence the activities/images shown in the photo record and / or as described by the participant. These factors were identified as influencing the child's sense of identity: sense of belonging; happiness; confidence; social role; ability to learn; disability identity and self esteem (see Table 2).

Children and parents described the importance of children's sense of self, belonging and happiness.

My life is being with my parents, and my parents like to be with me, and I like to be with them John

And my Dad, when he's at the Mount – I go with him. He looks after me... cos he likes to be with me. So that's why he wants me for the weekend. John

The Service Provider interviews recognised that being happy and having a sense of belonging were factors that contributed to identity and the child's social role in the classroom.

I suppose that I would say that they are able to feel good about themselves and feel positive about themselves by being in an environment and with people, staff and children who support them positively and also in a way of treating them as an individual and a human being, rather than an object of curiosity [...] Service Provider 2

Policy Professionals linked identity with confidence as it is experienced in the home and school environments.

If the child is feeling confident within their family environment and feeling confident about the peer group they've got, they can relate to all of their whanau and their local community. [...] all of those are times of confidence and so they are getting the chance to understand and express themselves uniquely within that. Policy Professional1

2. Identity: recognition of ability to learn

Both the child and the parent participants noted the importance of recognition of ability to learn, as central to the children's sense of identity and confidence.

Here is J's report; he's doing OK in these areas and we are working on computer basics. He does well when he's confident with what he's doing. Parent 1

However for the Service Providers the notion of ability to learn was linked to the availability of resources, such as teacher aide support

They are often lost if they don't have Teacher aides. Service Provider 1
You do everything you can as a school but that child still has to function in a mainstream room without aid for the whole of the day. And that obviously makes her, at times, unable to deal with what is going on. Service Provider 1

3. Disability as part of the child's sense of identity

The parent participants described aspects of socially appropriate behaviours related to their child's behaviour, linked with issues of disability and identity.

He needs to be socially accepted within the community. So we don't want him out there doing inappropriate behaviours. I have always been very strong on that. I am really upfront with John...He went through a stage where he would continue to be talking away to himself. That is fine to a point. But when a boy gets to 17 years of age, it is no longer appropriate. And I say 'John, hey it's not good. You don't talk to yourself. You've got to have someone around or you can have a conversation with somebody, but you don't just...' and he'll go 'Oh OK Mum' Parent 1

Children and parents identified areas related to identity and aspects of disability such as the child participants' examples of the support they required to remember the daily timetable at school or to communicate as a unique aspect of themselves.

I do have my own things for my work at school. Like looking at these [photo] cue cards so I know which one I'm doing. I put it on [timetable for the day schedule shown in the photo] and I like to know morning, after lunch and that's today I like doing those ones and it is part of who I am. I like doing my work John

The parent interview content recognised their child's identity and issues of disability identity

I have taken him to Special Olympics and he didn't enjoy it. I know it sounds a little bit hypocritical, especially with John, but he doesn't enjoy other disabled children. [...] It's a bit of a battle ground between him being able to socialise with so called "normal" kids and yet is probably more accepted the other side of the spectrum, if you know what I mean. He doesn't feel comfortable there.

Parent 1

The child participant photo record was of the classroom and technology rooms of the school. There was no photo record of segregated teaching or learning rooms which the parent interviews stated the child participants attend this may be reflective of the child's sense of identity.

John is brought out of his normal class setting to do his correspondence work. But he is brought into another class setting, so he is with normal children. But children who are behind, that need extra tuition as well. He is still within a classroom setting but there are about 10 boys. He is the only child with a known disability. The rest of the children are so called, normal kids who have fallen behind. Parent 1

The parent participant acknowledged self esteem and confidence as influencing disability identity.

[...] And John left Primary School with a very, very high self esteem and I think that that would be one of the most important things for children with a disability to have. They have got to really respect themselves and know that they're just like everyone else and hey, I don't need to be spoken to like this.

Parent 1

The Service Provider participants described examples of issues related to disability identity.

You know, I see it with some of the children; it is that feeling that you are a retard that you are not like everybody else. [...] Kids do feel that, especially as they get older. They think they are different. Service Provider 1

The policy participants noted that the concept of disability identity for children was generally not well understood in New Zealand.

The thing still in New Zealand, we don't talk about disability identity equivalent to any other type of identity or culture. Normally I would talk about the culture of disability but I'm not sure that that is a general term that is accepted or understood really. For children this needs to be more emphasised. Policy Professional 1

3. Friendship

Table 3 Friendships and factors which influence wellbeing

Dimension of Wellbeing	Factors which influence wellbeing			
	Service User Child	Service User Parent	Service Provider	Policy Professional
Friendships	All environments	All environments	School	All environments
	Facilitated	Facilitated		Facilitated
		Age Appropriate		Age Appropriate

The role of friendships was highlighted as vital to the concept of wellbeing for child participants in their interviews and in their photo record. The parent, Service Provider and Policy Professional participants all also recognised the role of friendships as a dimension of wellbeing, although from different perspectives.

1. Friendships: all environments

The children described and included friendships in their photo record and illustrated the importance of their interactions with friends at school.

That's me C and J...and these ones [photo]. They are my friends. They are in the same class as me at school... And they were last year. Yes I do have nice friends and... [photo]. John

Parents and Service Providers highlighted the importance of friendships at school as a source of children's identity and happiness.

I think yes, those with a disability are included very well here. I think they are respected by the other children a lot more easily than in some schools. You see them being friends. If they are friends, then they are not seen as somebody who is different, they are friends – that makes a big difference. Service Provider 1

Parents identified the need for friendships to extend beyond the school environment and children mentioned and photographed friendships in social or sporting environments, although these seemed to be connected with family members and support people.

These are my friends at a birthday party for M [photo]. M is my friend and we play basket ball and shoot hoops, she is also my cousin. Here is S [photo] we like to go to swimming. S is my friend and my swimming coach too. Mary

The parent and policy participants indicated that friendships and social interaction often needed to be facilitated.

There are natural friendships of people that are around but for a million reasons there are not so many natural friendships [...] we had a programme at the Intermediate school and there are genuine friendships that have continued from that [...] but I think they all need to be facilitated. Parent 2

One of the things that it seems to me that is different in gaining good outcomes for youngsters with disabilities is that we need to be more intentional about it. [...] even things as fundamental as friendships; you need to think quite strategically about that. Policy participant 2

The Policy Professional and parent participants identified age appropriate friends as an influencing factor of friendships. This finding was linked to concerns regarding the child participant age / stage child development issues and social interaction.

4. Communication

Table 4 Communication and factors which influence wellbeing

Dimension of Wellbeing	Factors which influence wellbeing			
	Service User Child	Service User Parent	Service Provider	Policy Professional
Communication	Social	Social	Social	
	Language skills	Language skills	Language skills	Language skills
		Resources	Resources	Decision making

The dimension of communication was highlighted by the adult participants. The child participants appeared confident to utilise a variety of communication skills in environments in which they felt comfortable or secure. This included a range of visual cues or signing to support spoken language as identified in the earlier example. The children's interviews also highlighted how communication was interconnected with identity and social interaction, and this has been interpreted as social communication.

1. Communication: social communication; language skills

Adult participants identified acquisition of speech and language as a vital skill for building capability. Skills of communication were identified by the child and parent participants and Service Providers as an element of wellbeing.

Communication is a big one...it needs to be put under the microscope more often than it might be for a child who is developing normally. Because many, as you well know, these children can't actually, or don't actually communicate their emotional state. Service Provider 3

2. Communication: language skills; decision making and resources

Policy Professionals identified language skill development as a factor influencing communication that may create a barrier to understanding issues of the child's wellbeing and their participation in decision making.

[...] particularly for children with a disability where there is a language barrier. I think we need to continually reinforce and develop language skills at whatever level that child or young person can communicate so they can let us know what their needs are and be involved in the decisions that are made.

Policy Professional 1

Language skill development was identified by parents along with the need for specific speech language services. This took the form of a privately funded speech language programme due to no service provision in this area.

We had Johansson but that's not available now and of course GSE hasn't offered any speech language programme for Mary for years. They just presume we will take care of it but it is such a specialised area. Parent 2

5. Participation

Table 5 Participation and factors which influence wellbeing

Dimension of Wellbeing	Factors which influence wellbeing			
	Service User Child	Service User Parent	Service Provider	Policy Professional
Participation	All environments	All environments	All environments	All environments
		Age appropriate	Conditions	Conditions
	School Culture	School Culture		
	Sense of belonging	Sense of belonging	Sense of belonging	Sense of belonging
	Planned	Planned	Planned	Planned

Participation in all environments such as school, sports and social occasions was identified as a dimension of wellbeing by all participants. Children and parents described participation in events, activities, sports and social outings; this was also evident in the photo record. The Service Provider and Policy professionals described their perception of the importance of experiences of participation for children with a disability such as inclusion in activities and events ranging from the school play ground through to local community activities.

The key thing for them to learn is to be independent and to be able to take a full part in the life of the school really, isn't it? Not just in the curriculum but in all activities in the school and the community. Service Provider 2

1. Participation: conditions of participation

Service Providers and Policy Professionals noted that opportunities for participation were linked with the skill of the family unit such as the families' ability to advocate for their child, the family networks within the community and the families' ability to address resourcing issues.

I think there is no question that it [participation] can actually vary according to the family experience. [...] For the child to be in a family, where they are accepted as just a child of the family, where they are part of the daily experiences of that family, where they have the same expectations, that they

will grow and contribute and take responsibility and be the human being that they are and that that family is connected. Policy Professional 1

Participation for children with a disability seemed conditional upon various factors such as the availability of resources and / or the ability of the school to either access or provide adequate resources for children with a disability to attend school activities beyond the classroom, unlike typically developing children.

I think it varies from school to school...they have a student who uses a wheelchair for mobility but can't self-propel it...they rang to work out going to the snow so that he went. That school's philosophy is around enhancing the well being of that little person, including him and full participation. And then you will get the other extreme where the whole class were off on school camp and our little person couldn't go because she had a toileting problem. Not a major toileting problem, something that can be managed. But...No school camp because of your toileting problems... I just have this picture of this little person watching all of her classmates hop on the bus. Service Provider 3

Service Providers and parents saw age appropriate participation as relevant to several dimensions of wellbeing. This was illustrated by examples from areas of formal instruction such as swimming lessons where older children were grouped with the much younger children or new entrants, because of developmental skill, creating tension around developmental ability versus chronological age. However, age appropriateness was considered in conjunction with class placement in the school setting.

With class placement we do consider maturity,[...] But the special needs child we put into the year 2 class because we felt that socially she would cope with that and the work she wouldn't have coped with, no matter where she was.

Service Provider 1

2. Participation: school culture

The child and parent participants identified two separate aspects of participation at school as educational participation (building capability) and participation or interaction within the school. I have interpreted this as school culture, identifying this as aspects of peer interactions, the child participants' descriptions of recreational periods, recess and codes of behaviour with issues of a valued social role at school.

It's that social interactive stuff with the other kids. He's easily led so you don't want him just doing anything some of the kids say to him, like the smoking incident. But on the whole he seems to know who to steer clear of and what areas are ok. He loves music, so he will go to the music room and play the drums and a couple of the kids might be there and they might do a bit of jamming together, you know and things like that. Parent 1

Some of the things you don't do at school are like dancing. I like dancing at home but because at school I don't like people teasing me and pulling the fingers at someone and so I actually don't like dancing. Yes, at school either. John

At school then one period, or two more and then lunch. At lunch, probably sit by S Block now we are in room 6. The canteen is scary. Too much people so who sits with me is my friends, we stay together at lunch. Mary

The significance of social interaction and the role of school culture, as a social environment, were fundamental to wellbeing, but this influencing factor was not readily identified by the Service Provider participants.

3. Participation: sense of belonging; planning and organisation

All adult interviewees recognised that a sense of belonging and inclusion influenced the degree of participation of children with a disability.

Mary enjoys being with other kids and doing the things other kids do. If she is part of the group and feels she belongs it's not a problem, she'll join in and really get involved. Parent 2

I just know that if they feel comfortable and are staying happy, they will learn I think. Just feeling included, that they feel they belong... I think that that feeling of exclusion is the hardest thing. Service Provider 1

They also made reference to the importance of planning and the organisation of participation for the children in school and out of school environments. The Service Provider and Policy Professional referred to the need to plan participation within the class and for the school to ensure children with a disability were involved in activities. The child and parent participants' referred to participation that was planned,

particularly in areas of sport and social events to ensure social inclusion. The influence of organisation and planned social inclusion and participation were identified in all interviews.

I like sports. I like swimming and basketball and golf. I play the sports mum can get me into. She tells me when and I go to sport with mum or who she can get to drive me. Sometimes I like to go in the taxi but its dad and sometimes its nana. John

He loved basketball when he was at primary school but there's nothing offered for him at secondary school at all. We have gone through [sports agency] to get John into a sport and they are organising it now with a support person so we'll aim to get him involved with golf. Parent 1

8. Summary of findings

These findings are briefly summarised here but are discussed in Chapter Seven. The participants' perception of wellbeing for children with a disability at school focused on building capability, and how it could be influenced by the factor meaningful work. This has subsections: skill based school work and the school curriculum, class and home tasks. The requirement for building capability for children with a disability was the need for support identified by factors of planned, age appropriate and resourced support. In addition this was often described as support for skill based tasks associated with subjective aspects of the goal of competency and achievement as influencing factors of meaningful work that led to building capability for children with a disability. The adult participants also identified broader aspects of safety and the child participants identified issues of safety in learning skills at school. Adult interviewees recognised that supported skill development, and capability could be linked to later life outcomes of adult capability and independence.

The interview participants recognised factors of a sense of belonging, happiness and recognition of ability as influencing the dimension of identity and social role for children with a disability. Parent and Policy Professional participants described disability identity as a poorly understood factor influencing wellbeing for children.

All participants recognised friendships as a dimension of wellbeing, and with the exception of Service Providers, that facilitating them enhanced opportunities for friendship development and social interaction.

The dimension of wellbeing described and interpreted as communication encompassed factors of social communication and language acquisition, interconnected with identity and social interaction. The adult participants recognised communication as vital to building capability and the Policy Professional highlighted the role of communication for children with a disability as a factor influencing their ability to participate in decision making.

All interviewees highlighted the importance of participation for children with a disability, in all environments. Children and parents differentiated the factors of participation at school and the less overt influence of school culture in relation to wellbeing. There were recognised *conditions* related to participation for children with a disability which were identified as factors of age appropriateness, resourcing, support and the skill base of the family unit. Participation was planned and the adult participant interview content recognised participation in social environments and social interaction as fundamental to wellbeing for children with a disability.

4. Social policy frameworks for children

In the final stage of the interview, the adults were asked to consider operational frameworks from current New Zealand social policy, in order to extend the discussion on conceptual issues, and to draw on the experiences of the participants. This section covers the adult participants' views on two selected social policy frameworks (see Chapter Five section 4.3 and Appendix 3).

1. Domains of wellbeing for children and young people in New Zealand (Ministry of Social Development, 2005a: 136).
2. The Key Settings Model (Ministry of Social Development, 2004e:25).

Participants were asked to consider three points: the relevance of the frameworks to wellbeing for children with a disability; areas of the frameworks requiring emphasis; what aspects would need to be included in the frameworks to reflect factors which influence wellbeing for children with a disability.

1. Framework: Domains of wellbeing for children and young people in New Zealand

Table 6 Ten outcome domains of wellbeing for children and young people in New Zealand 2005

Health	Civil rights
Care and support	Justice
Economic security	Culture and identity
Safety	Social connectedness
Education	Environments

Adapted from Ministry of Social Development, 2005a:136.

1. The relevance of the domains of wellbeing framework

The adult participants all agreed that the *Children and Young People: Indicators of Wellbeing in New Zealand* (2005) ten outcome domains and outcome statements of wellbeing in social policy for children were of critical relevance to children with a disability.

2. The domains of wellbeing that would require emphasis

All participants however, emphasised four domains as having specific importance for children with a disability: care and support, education, social connectedness and safety. Without these it was considered that the other domains would not be achieved. Parents noted in particular that their impact on wellbeing would be different when applied for children with a disability and acknowledgment of this difference would need to be reflected in indicators of wellbeing for their children.

Care and Support; I think that has been the most important. The idea of relationships with respect, and being valued as part of care and support [outcome domain statement] I would say very much so. To me, that is the basis of everything because I think a lot of things come from that [...] Social connectedness; this is the area that I almost feel is lacking. It is not through the children [with a disability] not trying... Although he is happy at school, the link perhaps isn't there between the school and outside of school. There is not that friendship thing continuing. Parent 1

Service Providers echoed the need for emphasis on the domains of safety, education and social connectedness.

The social connectedness – the friends. I think the need for very supported social connectedness is often overlooked [...] that leaps out at me in my experience and in the work that I do. Not enough attention is given to participation and being part of the local neighbourhood, the child first kind of stuff gets lost with disability. Service Provider 3

The Service Providers noted that the education domain outcome statement which states that all children should obtain knowledge and skills to enable them to be full participants in society was not emphasised or applied equally for children with a disability. These participants acknowledged that issues of resourcing, professional development and the Ministry of Education funding criteria were influential factors that would need to be considered as integral to the education outcome domain. The issues of resourcing seemed pivotal:

[...] Just looking at the education one [outcome statement] which is obviously my one. You know, it says obtain the knowledge and skills to enable them to be full participants in society. I'm just thinking about the resourcing there Maree.[...] So you think, well if our school hadn't gone out of our way with that other pupil who I have identified who has got severe learning delay and hadn't given Teacher Aide time, well that child would be just doing what? Learning what? Service Provider 2

The Policy Professionals emphasised the need for additional approaches and support within the ten outcome domains to reflect the needs of children with a disability and issues of inclusion.

[...] What we do tend to do, however, is in fact with our interventions, remove some of these for kids (outcome domains of wellbeing). Like the physical environment - that gets denied kids. The social connection – that gets denied kids. Even their cultural identity often gets denied them. Certainly civil rights, certainly good education. We are actually stripping through our intervention, access to a lot of these things away from the kids. Policy Professional 2

3. Aspects that would need to be included to reflect factors which influence wellbeing for children with a disability

Parents highlighted the importance of including “support person” and resources within a framework of wellbeing, and the need to clarify the unique issues of the role of support for children with a disability, as compared with typically developing children.

Care and Support: The issue of understanding care and support really needs to be included more. The interesting thing about caregivers is most people just don't seem to understand what the role is – a lot of the public ask us if we are Mary's caregiver – no I am her Mum! Or am I her teacher aide – no, I'm her Mum! Parent 2

They also recognised that the domain of education would need to include and emphasize professional development, and the skill base of the teacher. This was expanded on in terms of the teachers' ability to adapt the curriculum, provide learning tasks and steps towards competency and to adequately monitor, evaluate, plan and report on aspects of their child's learning and achievements:

It is harder for our children to gain knowledge and skills. I think that while they may get dollars for resources, there is a deficit in professional input. There is a pretty poor return in professional capacity for the dollars. I don't expect to achieve the same but I would like to see programmes for her. We have managed to get schools to agree to report on what she has been learning and what she has achieved. Parent 2

Policy Professional participants indicated these domains would need to emphasise family context and the role of the family in supporting children with a disability, suggesting that wellbeing for children with a disability requires a more holistic approach.

How I would see it is that our work is to help the family become that family that includes disability and they change whatever their functioning is so that they include disabilities. [...]. You have to think how the family has to be supported to change in that way. Once that happens, I believe that the significant number of other needs will work, because there will be a common

understanding of needs and what to look for and how to get that determined.

Policy Professional 1

They also identified the need to include an overall emphasis on human rights which would significantly influence the outcome domains of wellbeing for children with a disability, noting that this perspective would enhance the likelihood for children with a disability to have equal access to the same opportunities as other children, with a particular emphasis on access to the curriculum and participation in the community.

[...] We have a whole system of education that in fact is set up to deny kids' with a disability access to the level and nature of education that that we would see as appropriate to valued citizens [...]. If you look at the experiences of disabled people, they get abandoned, they get segregated, they get congregated, they are materially poor, and they are denied access to a higher order of opportunities in life. They are poorly educated, they tend to be unemployed, they tend to be denied opportunity for intimate and long term relationships with other people, they hold no socially valued roles, or very, very few socially valued roles and yet these are all of the things that we are saying are indicators of well being. I think they are increasingly being seen as a menace, treated as menaces. Policy Professional 2

The key finding from this part of the study was that while all domains of wellbeing were considered relevant for children with a disability, there was a need to prioritise certain aspects of the domains for children with a disability. The seven adult participants also mentioned discrepancy in terms of how these domains would be addressed for children with a disability, as compared to typically developing children, and pointed to issues such as funding, limited resources, professional development in the school environment and family support within the broader community. The participants also emphasised the need to identify issues of access, opportunity and application of services to meet these outcome domains for children with a disability.

2 Framework: Key Settings Model

The *Key Settings Model* illustrates the application of the ecological approach in New Zealand social policy and is central to the *Whole Child Approach* (Ministry of Social Development, 2002; 2004e; Appendix 3). However, when interviewed, parents and Service Provider said they were not aware of this model.

The adult participants acknowledged that the *Key Settings Model* would be a very relevant approach to issues relating to the wellbeing of children with a disability. Parents considered the model as depicted the way they themselves approached issues of participation and service provision for their children because it identified their central role in negotiating and advocacy across *Key Setting*. They emphasised the links across *Key Settings* that they had established, such as relationships with key personnel in the *Key Settings* of community and institutional settings from an early stage of their child's development, including health services and relationships with the paediatrician or health centre staff. The link with the school was illustrated by personal relationships with the teacher and the teacher aides, and through formalised communication such as daily notebook entries and email contact. Parents considered these relationships as having a strong influence on the wellbeing of their children.

I think that some of the best support for Mary has come from the open dialogue that you build up from home to school and vice versa. It has to go wider than that too, like swimming club and the gym and church group. You know you put a lot of time in; especially over the years [...] it's not all grace and favour. Parent 2

Parents' emphasis was on the interconnectedness of settings for wellbeing of their children.

[...] the strong influence is as a family unit and your extended family, in this model by the inner circle. I think it is perfect actually. It actually works really well. Ultimately you kind of step from your family environment out to your friends and probably amongst this wider kinship groups would be your support people if you had support people involved (respite care),[...] But his (Johns) teacher aide, for example, would sit probably into the community and institutions – schools, workplaces, etc. Parent 1

In response to being shown the *Key Settings Model*, the Service Providers found it visually appealing and suggested it should be a key instrument for development of service provision to support wellbeing for children with a disability, noting that it was of particular relevance for children with a disability because of the importance of the link between home and school.

Your home is your basis and then you move out. ... And then obviously, as you move out, you need the support of your wider family if you have got a child with a disability and then of course you need the support of the wider community. What is happening here in the school impacts both ways. Because if kids haven't learnt what they need at school, like it affects their life in the community. It certainly affects the community because they just have to carry them. This is the model I would look at and want to use. Service Provider 1

The Service Providers identified the central role of the school as a *Key Setting* and as having a significant impact on the wellbeing of children with a disability. They recognised the example that the school was central in facilitating factors influencing participation, relationships, and building capability and that it could encourage broader relationships linking the child to out of school activities. They also emphasised the need for a commitment to resourcing to match this *Key Setting* in the role of education and wellbeing for children with a disability.

On this one (the Key Settings Model) it has got the friendship groups first but I really think it is the schools first because this is how I see it. It is the schools having the ethos and the welcoming and you know. That's what I would say really because the school has got to put all of that underlying stuff in place to allow the kinship, the group thing and peers to be really positive and have healthy relationships. Service Provider 2

The Policy Professionals also endorsed the *Key Settings Model* as an appropriate model for identifying factors which would influence the wellbeing of children with a disability, and suggested it would need to include the disability community, the role of parents and "parent's voice" in service provision and decision-making processes.

I think that the model is applicable. I just think there needs to be an emphasis on [...] the role of the disability community to support that family and whanau. And what must be clear about that is that their role is to support. It is not to overtake the right of parents to be parents and to do their function. Their role is to help parents understand the experience of the child and so that they can do their parenting. Policy Professional 1

If we want healthy children, then we say in our society that we believe that this is where they come from. So therefore, if you take one lot of children out of this [framework], then you are saying 'these children don't belong some way or another'. Policy Professional 2

What the study has therefore shown in terms of the *Key Settings Model* is that it was considered very relevant to service provision for children with a disability. All adult participants were able to identify aspects of the model relevant to their experience with children with a disability as well as the need to develop links across settings as a way of influencing factors which enhance wellbeing for children with a disability. The experience of individual families or parents in building relationships across Key Settings was also recognised as supporting the wellbeing of children with a disability at school, and facilitating their inclusion in community activities such as involvement in clubs and sport. However, their experience also suggested that there was not a systematic application of this model to service provision for children with a disability.

The wider application of this model would therefore be an area they would see would need emphasis including for further development of services for children with a disability at school.

Chapter 7. Discussion

In this chapter the findings of the research interviews are discussed and presented in relation to selected New Zealand research on issues of inclusive education, children, wellbeing and disability. The limited scale of this study means that these findings can only be drawn on as a starting point for discussion.

1. What is wellbeing for children with a disability?

What the thesis has found in relation to the question “What does wellbeing mean for children with a disability?” is that all dimensions of wellbeing that apply to typically developing children also apply to children with a disability. The seven dimensions of wellbeing identified in this research are: building capability; identity; friendships; communication; participation; care and support and environments. These broadly relate to five of the ten outcome domains and outcome statements of the *Children and Young People: Indicators of Wellbeing in New Zealand* report which are: care and support, education, culture and identity, social connectedness and physical environment (Ministry of Social Development, 2005a).

However, a further key finding is that although the concept of wellbeing may be perceived as similar for all children, the factors influencing it for children with a disability are quite different.

The study has highlighted that for children with a disability; the concept of wellbeing is not necessarily applied as a fundamental principle guiding service provision, and therefore has limited meaning in their daily life experiences, particularly in the school environment. The essential elements of wellbeing identified by participants (building capability and achieving skill development; identity; friendships; communication; participation; care and support and environments) were seen as very strongly interconnected across different environments (such as the school, classroom, family, community settings), and were considered as essential to the child’s happiness and social inclusion.

In addition, having considered the meaning of the concept of wellbeing, participants found it to be congruent with their long term goal of achieving independence for children with a disability.

The question raised by the study is therefore whether, contrary to the aims of the *Whole Child Approach*, the effects of social and educational policies and services on the wellbeing of children with a disability are actually being compromised, so that on a day-to-day basis, the development of their wellbeing is not necessarily being enhanced or adequately supported.

2. What factors influence the wellbeing of children with a disability?

The research participants' responses clearly indicate that when exploring the possible application of the *Whole Child Approach* to policy and service provision for children with a disability, there are significant differential effects that must be taken into consideration and which can broadly be described as factors influencing wellbeing. To be addressed they require concerted efforts to ensure and provide for additional planning and structuring of *all aspects* of daily and family life, carried through from the family to the school environment, so that opportunities to enhance social participation for this specific population is on a par with other children.

Both Service Provider and Policy Professionals recognised the necessity to provide daily structure in education and a commitment to additional planning. This planning was identified as heavily reliant on resources and seen as pivotal in achieving what was considered normal daily experiences for children in areas such as participation in the curriculum, sport, extra curricula activities and development of friendships. Whilst recognising that these findings reflect only nine interviews, they do suggest that when planning, structure and resources are in place for children with a disability, they will achieve in both family and school environments.

A further aspect to the issue of resourcing mentioned by parent, Service Providers and Policy Professionals in relation to the building capability dimension of wellbeing was the impact of policy decisions on issues of service provision such as resource allocation (such as teacher aide hours, access to specialist services, curriculum adapted material), eligibility criteria and investment in professional development. The interviews highlighted for example, perceptions that there was a consistent compromise in the application of a child first approach – putting the needs of children with a disability first. What this suggests is that policy criteria governing service

provision and resource allocation can take precedence over the actual day-to-day needs of providing a supporting environment for children in the classroom.

Unlike typically developing children where the expectation is of academic achievement, the findings suggest that this is not the case for children with a disability. This suggests that another differential effect is that the right to learn (identified in the study as achievement, goal of competency and ability to learn) must consistently be negotiated and advocated for children with a disability.

Any advance made towards ensuring the education and wellbeing of children with a disability was seen by participants as contingent upon good luck or individual effort and family resourcefulness on the part of parents or Service Providers as opposed to the result of a systematic approach to service provision or education for children with a disability.

3. Building capability – a central aspect to wellbeing for children with a disability

Building capability emerged as a central theme of the interviews. This may have been due to the research focus on the school as the *Key Setting*. However, this key finding can be linked with the theory of human need as discussed in Chapter Four, which identifies capability as a basic human need and an essential element of wellbeing. I will therefore outline what the relevance of this theory to building capability and to New Zealand current social policy initiatives could be.

The fundamental assumption of the theory of human need is that physical health and autonomy are the preconditions for human action and interaction, and are the foundations of wellbeing and social participation. Autonomy in this context is defined as the ability to acquire basic skills and capabilities needed to participate in society, and is achieved through opportunity to access societies' institutions. In practice, individual autonomy is demonstrated in terms of maximising competency and building capability in many basic skills common to all cultures and societies such as literacy, numeracy and communication. These basic skills need to be achieved according to recognised culturally specific standards or principles such as basic measures of literacy and numeracy (Doyal & Gough, 1991).

The findings from this thesis can also be linked to the broader principles outlined by Doyal and Gough (1991) as common to all cultures: social roles are a universal

human attribute and central to individual identity; individual autonomy stems from the opportunity to participate in some form of socially meaningful activity: to be denied these capabilities is to be fundamentally disabled. The importance of social roles and general social goals are that they represent the minimal requirements for ensuring an individual's social participation. As noted by the authors, social goals can also refer to the goal of achievement of capabilities that must be planned for and sustained over time (Doyal & Gough, 1991).

The link between building capability and its theoretical significance also finds resonance in the New Zealand social policy initiatives examined in this thesis in terms of the domains of social wellbeing, knowledge and skills documented in the *Social Report*.

Knowledge and skills enhance people's ability to meet their basic needs, widen their range of options open to them in every sphere of life, and enable them to influence the direction their lives take. The skills people possess can also enhance people's sense of self-worth, security and belonging (Ministry of Social Development, 2005b: 34).

Underpinning this statement are principles of basic human need – autonomy, basic skills, social roles and meaningful activities.

These principles are also evident in social policy indicators of wellbeing for children which reflect education as a key outcome domain. Education is seen to provide children and young people with the skills and knowledge they require to pursue opportunities and participate meaningfully in economic and social life. The ability to develop key literacies (reading, writing, numeracy and science) for example, is identified as essential, if New Zealand is to be an inclusive and just society (Ministry of Social Development, 2005a: 78). This is an established expectation for children – but the interviews highlight shortcomings in the area of building capability which should or could be addressed for children with a disability (goal of competence). The published data for children with a disability is quantified attendance data: there are no published data relating to school achievement for children with a disability.

In addition the principles of the theory of human need and social roles as avenues for the development of autonomy are also identified in the policy application of wellbeing for children in New Zealand.

Critical social knowledge and skills are also gained as young people learn to “grow up”. Merely by participating in education, they are required to take action, interact with peers and others, learn responsibilities, exercise choice, form judgements and make decisions (Ministry of Social Development, 2005a:78).

A key finding however, is that the application of these principles in New Zealand to children with a disability seems to be inconsistent and therefore requires further exploration. This inconsistency is illustrated for example, by factors which inhibit building capability such as the range of issues around the support required to build skills, including material resources, teacher training, and criteria of eligibility for additional support.

A further issue raised by all adult participants in relation to building capability was the use of individual eligibility criteria applied to children with a disability, criteria not relevant to typically developing children: in other words access to resources for typically developing children reflects the principle of education as a right, yet for children with a disability this right is negotiated. The difference in application of this principle is illustrated by Service Providers who acknowledge that the model of individualistic eligibility criteria has led to inadequate child and school wide resources and service provision, which in turn compromises access to education and social participation of children with a disability at school. Service Providers also indicated that the requirements of professional skill experience and knowledge, compounded with a lack of resources could predispose schools to resist inclusion of children with a disability at their local school.

These findings on the differences in factors which influence building capability are echoed in broader research relating to the educational experiences of children with a disability or special needs in New Zealand. Since the instigation of *Special Education 2000* (SE2000) policy in 1996 for example, it can be argued that factors of resource allocation, teacher aide hours, eligibility criteria, educational resources, curriculum adaptation and professional skill development and expertise have become of central concern. This is evidenced as early as the first three stage, extensive Massey review and evaluation of SE2000 policy, by the recently established research programme on effective services for students with physical disabilities, by the nation-wide consultation process *Let's Talk Special Education* and service provision report, and

the currently launched research project *Enhancing Effective Practice in Special Education* (Bourke et al., 2001; Ministry of Education, 2004a, 2004b, 2005a, 2006; Wylie, 2000).

These findings on difference in influencing factors also extend to research related to children's voice and their participation in the contexts of secondary schools and their experiences of transition to the workforce. The low expectation of educators for children with a disability, prescriptive options, lack of support networks, lack of skills learned, limited funding and resourcing were found to have an impact on meeting the needs of children with a disability when planning for the transition from school to work (Cleland et al., 2005).

However, contrary to this body of research are findings from the *Ministry of Education Annual Report 2004/05* which records a funding reduction to students verified within the *Ongoing Reviewable Resourcing Scheme* (ORRS) for 2004 and 2005 (Ministry of Education, 2005b). This seems to be in contradiction with the day-to-day experiences of the needs of both Service Providers and users who participated in this research.

4. The interconnectedness of factors influencing wellbeing: their impacts on the social experience and participation of children with a disability

A key finding of this research is that the degree to which the interconnectedness of factors influencing wellbeing for children with a disability are recognised and facilitated will enhance or inhibit the child's social experiences, and therefore have an impact upon their experience of social inclusion and participation. Social experience in the context of this research is defined as the interconnectedness of factors influencing the dimensions of wellbeing - building capability, identity, friendship, communication and participation.

As an example, for the dimension of wellbeing *communication*, the relative interconnectedness of language skill development and social communication factors will depend upon service provision of speech language therapy focused on communication skills training. This in turn will influence a further dimension of wellbeing for children with a disability, *participation*. The outcome of the lack of communication skills was highlighted with examples of language difficulty when the

children were anxious, or unfamiliar with people, places or activities, or when they were unsupported in such social interactions. In the key setting of the school, language difficulty was more manifest and was identified as having an impact on peer group interactions.

When the interconnectedness of factors influencing the dimensions of wellbeing were not recognised, parents acknowledged that their children's identity suffered, that there was a lack of curriculum adaptation, segregated learning and that their children became less involved in extra curricula activities. In sum, the dimensions of wellbeing building capability, identity, friendship, communication and participation were compromised.

These findings are again consistent with international and New Zealand research (Christchurch and Dunedin longitudinal studies) on social exclusion. Brynner's (2000) review of longitudinal studies discussed earlier (Chapter Four: section 5.4) highlights that failure to acquire basic skills and capabilities is a key component of the exclusion process, and is linked to the achievement of basic skills, identity and social participation in adulthood.

1. Wellbeing dimension: identity

A further example of the interconnectedness of factors influencing social experience and participation was related to the wellbeing dimension of identity. The findings suggest that the identity of children with a disability is often not well understood and compromised by tensions between factors of a sense of belonging, happiness and recognition of ability, acceptance of diversity and social role. Parent and Policy Professionals saw disability identity as a poorly understood factor, describing it as a multi dimensional concept involving self, peer group and family identities. The fact that the children chose to take photos of themselves in a mainstream class context for example, may be indicative of the association they make between self identity and their place with their peers at school. Although not presented here, some interview content suggests that when these aspects of identity are not considered, the children's communication skills and anxiety behaviours will be compromised, in turn influencing their social interactions and their increased vulnerability to bullying.

This finding relates to New Zealand ethnographic research on the experience of self and group identity for children with an intellectual disability. The research considers

the experiences of children with disabilities and matched non disabled peers as they move through primary school. It explores children's voice and issues of the context of identity for children with a disability, along with schools' capacity to emphasise children's similarities and inclusive teaching practice to support participation.

MacArthur and colleagues' research highlights how participation and children's identity will be influenced by varying teacher approaches, areas of additional help children felt they needed but that were unavailable, and children with a disability not wanting to be treated as a homogenous group (MacArthur, Kelly, Sharp, & Gaffney, 2005).

The thesis's findings are also consistent with research on children with a disability and their sibling and parent experiences on disability identity in New Zealand schools. Disability as a factor pre-disposing children to bullying and differences in social experiences of exclusion or marginalisation are identified in this study (MacArthur, 2005; MacArthur & Gaffney, 2001). The research concludes with implications for schools to develop school wide programmes for safe and supportive environments, friendship development and playground social interaction.

Finally, Kelly's (2005) research on impairment, disability and childhood identities also discusses perceptions and experiences of disability from the perspective of children with learning disabilities, their parents and their social workers. The study concludes that children with learning disabilities are able to develop an understanding of impairment and disability in the context of their own lives, and can articulate their own experiences, despite the absence of discussion with their parents or professionals. Kelly urges adoption of a more holistic approach to children, disability and social experience in order to better inform the fields of the sociology of childhood and disability theory (MacArthur & Kelly, 2004).

2. Wellbeing dimensions: friendship and communication

The study suggests that when adults involved in the lives of children with a disability do recognise the interconnectedness of factors influencing wellbeing and are prepared to facilitate them, then there does appear to be a link with participation and inclusion of children with a disability. This finding can be further explored specifically in relation to wellbeing through the growing research on issues of inclusion for children with a disability or those identified as having special needs in New Zealand. For

example, Gunn and colleagues (2004) argue that when teacher practice reflects a different way of thinking and talking about children with a disability, children's inclusion and full participation in their local early childhood setting is enhanced. Their research showed that modifications to the curriculum, adaptations to the environment and adapted teaching approaches were measures identified by teachers as necessary for ensuring the children's learning needs. In addition, the study showed that teachers who actively promoted practices of inclusion and challenged the values that did not support full participation, were able to bring about a change in the broader community of the local early childhood environment (Gunn et al., 2004).

This is also consistent with international recommendations and research regarding issues of inclusive education. The United Nations for example promotes the classroom teacher as serving a crucial role in the necessary shift to an inclusive pedagogy (United Nations, 2004). The Barnardos organisation and United Kingdom research on children, disability and social exclusion have shown that classroom practice and forms of school organisation directly impact on the social experience of children with a disability or children identified as special needs as influencing socially inclusive or exclusive school experiences (Middleton, 1999; Sebba & Sachdev, 1997).

The importance of friendship as an essential dimension of wellbeing has been highlighted in this thesis. However, the role of the adult in recognising and facilitating it appears crucial in ensuring a successful outcome for children with a disability. Surprisingly, unlike Service Providers, both parent and Policy Professionals in recognising the importance of friendships also noted the need for assistance in facilitating and maintaining these relationships for children with a disability.

There is an increasing body of New Zealand and international evidence suggesting that friendships and social skill development need to be supported and learned in the same way as other skills. When service providers recognise the need for adult facilitation and support for the maintenance of friendships there is a stronger link to social participation for children with a disability particularly through school lunch breaks, class placement, sport and social activities (Lyle, 2005; MacArthur & Gaffney, 2001; Meyer, 2001; Roffey, Tarrant, & Majors, 1994; Smith, 1998; Woolley, Armitage, Bishop, Curtis, & Ginsborg, 2006). Parents and family have a primary influence in social development, but children spend a lot of time in the school

environment and this key setting becomes a critical social context for the development of friendships.

Secondly, communication was recognised as a dimension of wellbeing by the research participants with an emphasis on factors of language skill development and social communication. The lack of speech language service provision was also identified by the parents and Service Providers. In the broader literature, communication development, and more specifically speech development for children stem from an interaction between innate prerequisites and environmental factors. For children with specific developmental language problems, difficulties extend well beyond language and often include substantial problems in social relationships (Johansson, 1994; Rutter, Mawhood, & Howlin, 1992). For many children and young people with learning and communication problems, the lack of competence in language skills can compound dimensions of wellbeing such as identity, social role and participation. Roffey (1994) outlines four interconnected factors which influence communication, identity and social participation. These are limited verbal response which cause people to reduce interaction, communication skills which are central to social success, children often communicating better with their peers, and society's frequently negative attitudes and responses towards people with learning and language problems (Roffey, Tarrant, & Majors, 1994).

Communication as an essential dimension of wellbeing for children with a disability identifies the unique requirement to address factors which influence communication through issues of specific service provision highlighting a fundamental problem in addressing the needs of this specific population group. A further identified service anomaly is the service provision issues of speech language therapy acknowledged as a persistent and ongoing national service gap consistently raised as a concern by families (Bay of Plenty District Health Board Disability Advisory Committee, 2005; Hawkins, 2005)

Linking back to theory, language is considered a basic capability essential to autonomy and human need (Doyal & Gough, 1991). At a fundamental level therefore, this suggests that children with a disability may be being denied access to this basic skill.

5. Are current social policy frameworks relevant to the wellbeing of children with a disability?

1. The relevance of current of social policy frameworks

The following section focuses specifically on relating the study's findings to the policy framework of the *Key Settings Model*. Extending the discussion to include the policy framework *Domains of wellbeing for children and young people in New Zealand* would take this thesis well beyond its scope.

The *Key Settings Model* provides a visual depiction of the principles underpinning ecological theory as applied to policy and service development for children in New Zealand, situating them in interacting Key Settings of family; wider kinship groups and friends and peers; community and its institutions (schools, workplace) and set within broader social, cultural and economic environments (see Appendix 3).

The relevance of the *Key Settings Model* to the theme of wellbeing for children with a disability was emphasised by parents, Service Providers and Policy Professionals alike. For example, they identified the importance of collaborative relationships between families and professionals as a way of developing family skills to support children with a disability, and in ensuring effective access to resources and opportunities.

Parents in particular, were aware that their child's ability to develop and participate in daily life would be significantly enhanced depending upon a family's level of involvement across key settings. This was illustrated by their efforts to enable their children to enrol in community groups and to maintain participation. Parents achieved this themselves by making key contacts within various settings a skill that they recognised would not necessarily be required of most parents. This finding is supported in international research where it has been found that the ability to utilise or seek support for children with a disability can be taught to families. When collaborative relationships are formed, the mutual exchange of support and knowledge is a key element in working with families and in the development of successful education programmes for children with a disability (Fraser, 2005; Rietveld, 2003; Summers et al., 2005). However, central to the success of this process is the skill base and experience of the professional workers involved (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004; Summers et al., 2005).

As identified earlier when collaborative relationships are established between parents and the family, the school and professionals, there is often a more facilitated process of service provision. However, the finding from the study would further endorse the need to establish an “enabling model of disability” as an approach to service provision for children with a disability, a model already promoted by Rietveld (2003). This approach stems from a professional disability discourse of social justice and rights, and implies that the type of relationship parents’ form with professionals and the school is not unilateral. The focus across these relationships would be on ensuring an adequate knowledge-base for teachers and other professionals to ensure that decisions are well informed and adequately relate to the specific needs of children with a disability (Rietveld, 2003).

Finally, interviews illustrated the limited links across key settings. The predominant approach to service provision seemed to rely on an “osmosis” pattern, generally typical of developing children, but did not appear to consistently reflect efforts to ensure the enhancement of inter-agency support. Interviews illustrated the lack of a consistent approach across all settings when dealing with the needs of children with a disability. At another level, findings suggest the difficulty in applying the *Key Settings Model* when faced with differences in individual, family and institutional capabilities.

2. Implications for policy and service provision

In terms of service provision some key themes were of concern to all the adult participants. These were factors such as: the relationship of parents with the school; lack of professional skill development specifically in areas of curriculum adaptation; lack of resources to adequately support the needs of children with a disability at school; set criteria which limit inclusion of children with a disability or special learning needs as eligible for the range of support they need at school. These comments notwithstanding, the adult interviewees all identified a general notion of commitment from Service Providers “*to do the best we can*”.

These findings have several implications for policy and service provision. First, the quality of the relationship between Service Providers with the parent or family is crucial and needs to be supported. The parent and Service Provider interviews highlighted that when the parent and teacher had formed a pattern of open

communication, this process facilitated service provision for the child with a disability.

Secondly, it can be argued that the type or appropriateness of service provision will in part be reliant on the individual Service Provider's personal attitudes and professional skill base. The Service Providers and Policy Professionals in this research all had many years of service provision experience in working with children with a disability. The general point that they all made was that the attributes of the classroom teacher and the skill base or experience of the teacher or teacher aide were significant factors influencing access to the curriculum and class participation for children with a disability. In addition the ethos established in the classroom by the classroom teacher influenced the social experience of children with a disability in the broader school context. The implication is therefore that service providers require ongoing support and training if they are to enhance their specialised knowledge base to meet the needs of children with a disability and thus enhance their wellbeing.

Thirdly, in New Zealand the general inference drawn by research on inclusive education is that when the dominant disability discourse is rights based and teaching practice is considered from a social model of disability, then the social experience for the child is supported and inclusive (MacArthur & Kelly, 2004; MacArthur, Purdue, & Ballard, 2003; Meyer, 2001; Moltzen, 2001; Rietveld, 2003). What flows from this is the need to increasingly formalise service provision along the lines of a more holistic perspective which includes both the social and medical models of disability. More specifically, the social model clearly sits with the *Whole Child Approach* as applied through the *Key Settings Model*.

Finally, the thesis has highlighted the fact that the level of service provision can be significantly influenced by the limits of eligibility criteria set by policy directives. The Service Providers identified issues of inadequate support and inability to provide the range of resources required for children with a disability at school. The tension identified through the experience of these research participants was reflected in the disjunction between the needs of children with a disability and the schools' ability to support these needs when they were not covered by current policy and eligibility criteria. This finding is consistent with research related to the ongoing debate of inadequate funding and restrictive eligibility criteria for children with a disability to access the curriculum in New Zealand schools (Beatson, 2004b; Quality Public

Education Coalition, 2004; Wylie, 2000). Unlike educational funding for children in general, this suggests that the issue of funding for special education services cannot be taken for granted because of its volatility as a policy priority.

Chapter 8. Conclusion

This thesis has explored the meaning of wellbeing for children with a disability and has emphasised the need to encourage children's voice as part of this research. This specific population group it should be remembered represents 11 percent of New Zealand's total child population. The overarching conclusion drawn is that although the concept of wellbeing in principle and in practice should be the same for all children, the reality of this is questionable for children with a disability. The key findings of this research are the difference in the factors influencing wellbeing, the need for recognition of the interconnectedness of these factors, and the appropriateness of ensuring a holistic approach to service provision for this group of children. These findings have implications for data gathering techniques and how the information collected is used to inform policy and service provision.

Although the findings are based on only nine interviews, their relevance to the broader New Zealand and international literature on disability, inclusive education and policy means that they can be drawn upon as a starting point to further examine the meaning of wellbeing for children with a disability in New Zealand

One of the first conclusions that can be drawn from this thesis is that there is a clear need to critically review specific aspects of the survey questionnaire for children used in the *New Zealand Disability Survey*. The synthesis of secondary published data highlighted a range of gaps in information available on children with a disability – definitional inconsistencies of the age ranges representing children as a specific policy target group; a shortcoming which has implications for cohorts of children currently aged 14 – 21 years whose needs may include planning for the transition to work.

Further gaps relating to data on children with a disability included fragmentation of data sources across agencies; difficulty of access to data sets for research purposes; recording anomalies of the incidence and type of disability; and limited possibilities for inter-group comparisons, between ethnic groups for example, and limited possibilities to study the social determinants of disability for families and their children. In short, these gaps compound the difficulties facing policy makers and researchers involved in the development of policy and service provision outcomes for this specific population group.

The second conclusion drawn from this thesis is that current approaches to data collection on disability are still strongly grounded in a medical as opposed to social model approach, a situation which runs contrary to the holistic nature of the different dimensions of wellbeing for children set out in New Zealand's policy frameworks. This is an approach consistent with the medical, lay and charity discourses which historically in New Zealand have perpetuated a separatist approach to service provision for those with a disability. By implication, the conceptual basis underscoring these data collection tools needs reviewing. As a starting point, further consideration could be given in New Zealand to the ICF definition of disability and the United Nations (2001) recommendations for disability data. Similarly, a further avenue for improving data collection could be provided by the Ministry of Education's *July Returns* which already serves as a source of information regarding this population group.

A third conclusion, inspired by the different theoretical perspectives examined in this thesis, is that there are aspects of New Zealand's social contract for children which are inconsistently applied when considering the needs of children with a disability. The theory of social solidarity advanced by Durkheim for example, suggests that if social arrangements are not underpinned by principles of solidarity, then there is a risk of social fragmentation and exclusion. Linked to this and as pointed out by Doyal and Gough (1991), policy needs to recognise building capability as a fundamental requirement if a range of life chances are to be guaranteed to all citizens. This thesis has questioned whether children with a disability are in fact being granted the right to learn and to achieve academically – one key dimension of wellbeing which is intended to promote the social inclusion of New Zealand's children and young people. By implication, the right to education cannot be assumed to be one of the principles underpinning the wellbeing of children with a disability.

The fourth conclusion, which must be tentative because it is based upon a small scale research undertaking, is that the policy application of the *Whole Child Approach* and the *Key Settings Model* do not currently meet the objectives of providing a holistic and inclusive approach to addressing children's wellbeing because the daily experiences of meeting the needs of children with a disability are constantly compromised or re-prioritised. The research findings presented here suggest that this

occurs because we still see children with a disability and their families as a *group apart*.

Finally, it can be argued that the discrepancy between identified need, and the actual criteria of Governmental resource allocation are reflective of the principles underlying Doyal and Gough's (1991) theory of human need. If a society values people, their autonomy and their social roles, then policy and eligibility criteria for services should reflect this. Arguably, this interpretation of the ramifications of the theory of human need require further development in the New Zealand context and specifically for the population of children with a disability.

All these conclusions point to the tenuous foundation of service provision to children with a disability. It would seem that the meaning of wellbeing for children with a disability requires further exploration if the needs of this specific child population are to be equally situated in relation to all children, and openly debated on the agenda for New Zealand children.

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Appendix 1. ICF

1. International Classification of Functioning, Disability and Health - ICF

International Classification of Functioning, Disability and Health - ICF

Definitions of the International Classification of Functioning, Disability and Health - ICF (<i>United Nations, 2001</i>).
Body Functions are the physiological functions of body systems (including psychological functions). Body Structures are anatomical parts of the body such as organs, limbs and their components. Impairments are problems in body function or structure such as a significant deviation or loss
Activity is the execution of a task or action by an individual. Participation is involvement in a life situation. Activity limitations are difficulties an individual may have executing activities. Participation restrictions are problems an individual may experience in involvement in life situations.
Environmental Factors make up the physical, social and attitudinal environment in which people live and conduct their lives.

Source:

United Nations. (2001). *Guidelines and principles for the development of disability statistics* New York: United Nations.

Appendix 2. Indicators of wellbeing for children

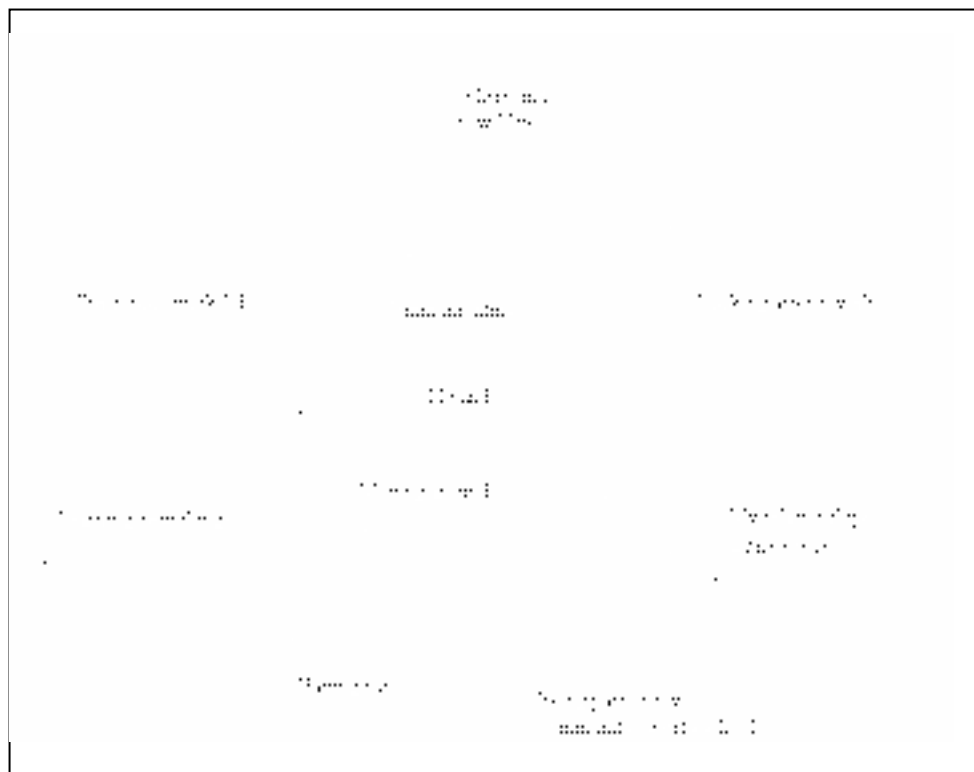
1 Indicators of wellbeing for children and young people

Health	Low birth weight births Infant mortality rate Hearing failure at school entry Prevalence of obesity Prevalence of smoking at 14-15 years Under 18 birth rate Youth suicide rate Immunisation coverage at two years Oral health at school entry Prevalence of regular marijuana use Quantity of alcohol consumed on a typical occasion Prevalence of significant symptoms of depression
Care and support	Youth positive relationships with parents Child abuse and neglect
Economic Security	Children living in low-income families Children and young people with low living standards Food security Youth unemployment rate Hourly earnings from wage and salary jobs Youth activity rate
Safety	Unintentional injury mortality rate Intentional injury mortality rate Intimidation at school Youth criminal victimisation Youth perceptions of safety Youth road casualties
Education	Early childhood education attendance at ages 3-4 years Reading achievement at Year 5 Reading literacy of 15year olds Mathematical literacy of 15year olds Scientific literacy of 15year olds School truancy rate School leavers with no qualifications Tertiary qualification completion rate
Civil Rights	Young people voting in national elections
Justice	Police apprehension of 14-16 year olds Cases proved in Youth Court
Culture and identity	Young Maori who can speak te reo Māori
Social Connectedness	Internet access in the home Participation in sport and active leisure
Environment	Household crowding

Ministry of Social Development. (2005a). *Children and Young People: Indicators of Wellbeing in New Zealand* (pp.139). Wellington: Ministry of Social Development.

Appendix 3. Frameworks presented in the research interviews

1. Ordinary Life Information Gathering Model



Source:

National Advisory Committee on Health & Disability, 2003. This model has been adapted by M.Kirk for the interviews with the child participants

National Advisory Committee on Health & Disability. (2003). *To have an 'ordinary' life Kia whai oranga 'noa'* Wellington: Ministry of Health and Office for Disability Issues.

2. Children and Young People: Indicators of Wellbeing in New Zealand. Outcome domains

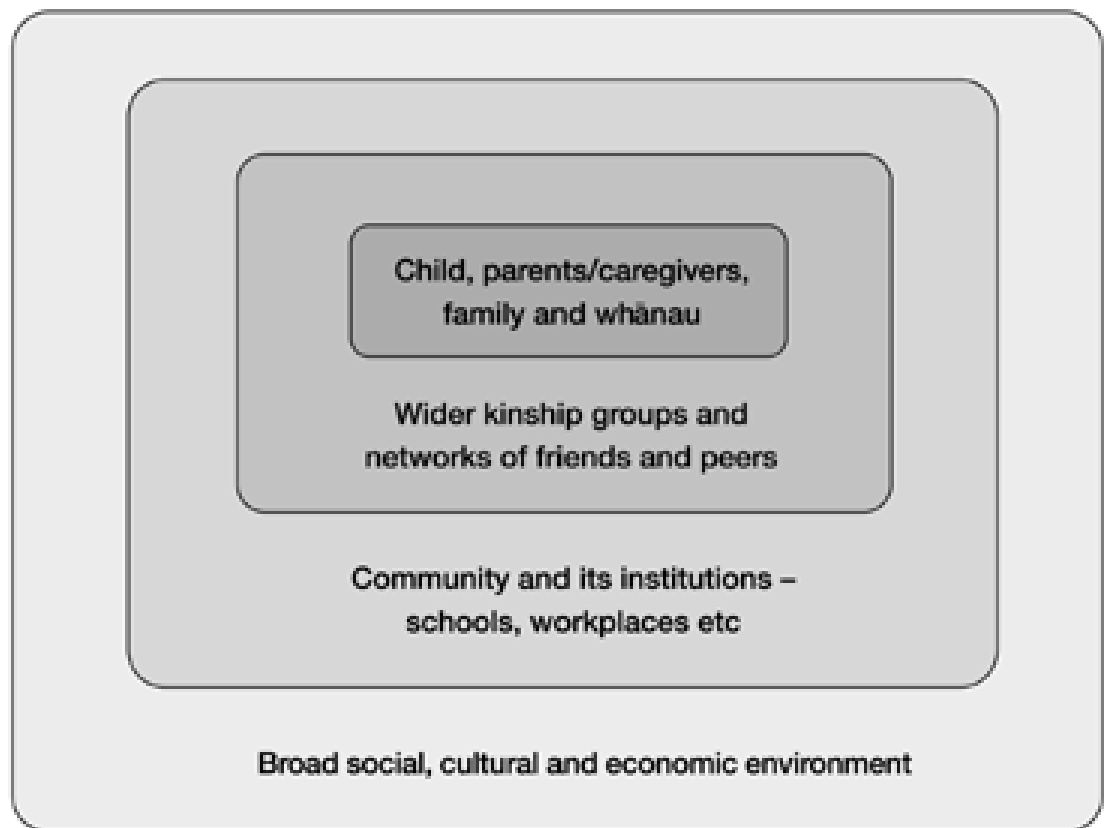
Ten outcome domains have been selected for inclusion in an indicators framework of wellbeing of children and young people. These are listed below.

Health	All children and young people enjoy good physical and mental health with access to good - quality health care.
Care and support	All children and young people enjoy secure attachment to parents and caregivers in a nurturing relationship where they are valued, respected and supported.
Economic security	All children and young people enjoy a secure standard of living that means they can fully participate in society. All young people achieve the transition to economic independence
Safety	All children and young people enjoy personal safety, and are free from abuse, victimisation, violence, and avoidable injury and death.
Education	All children and young people obtain the knowledge and skills to enable them to be full participants in society.
Civil rights	All children and young people enjoy fundamental human, civil and political rights, free from discrimination and exploitation. Children and young people are given the opportunity to participate in decisions that affect them.
Justice	All children and young people take growing responsibility for their actions, and have access to fair and equitable treatment within the justice system.
Culture and identity	All children and young people are able to participate in the culture and values important to them and their families and to feel secure with their identity.
Social connectedness	All children and young people enjoy friendships and social, cultural and recreational activities that build confidence and security, promote healthy relationships, and encourage civic and social responsibility.
Physical environment	All children and young people live in, and have access to, healthy natural and built environments.

Source:

Ministry of Social Development. (2005a). *Children and Young People: Indicators of Wellbeing in New Zealand* (pp. 136). Wellington: Ministry of Social Development.

3. The Key Settings Model



The Key Settings Model

These settings are seen as influencing children's health and wellbeing in New Zealand. So an individual child's wellbeing is seen as developing in relation to a number of interlinking settings which are;

Parents or caregivers, family and whanau.

Wider kinship groups and networks of friends and peers.

The community and its institutions which includes schools, workplaces etc.

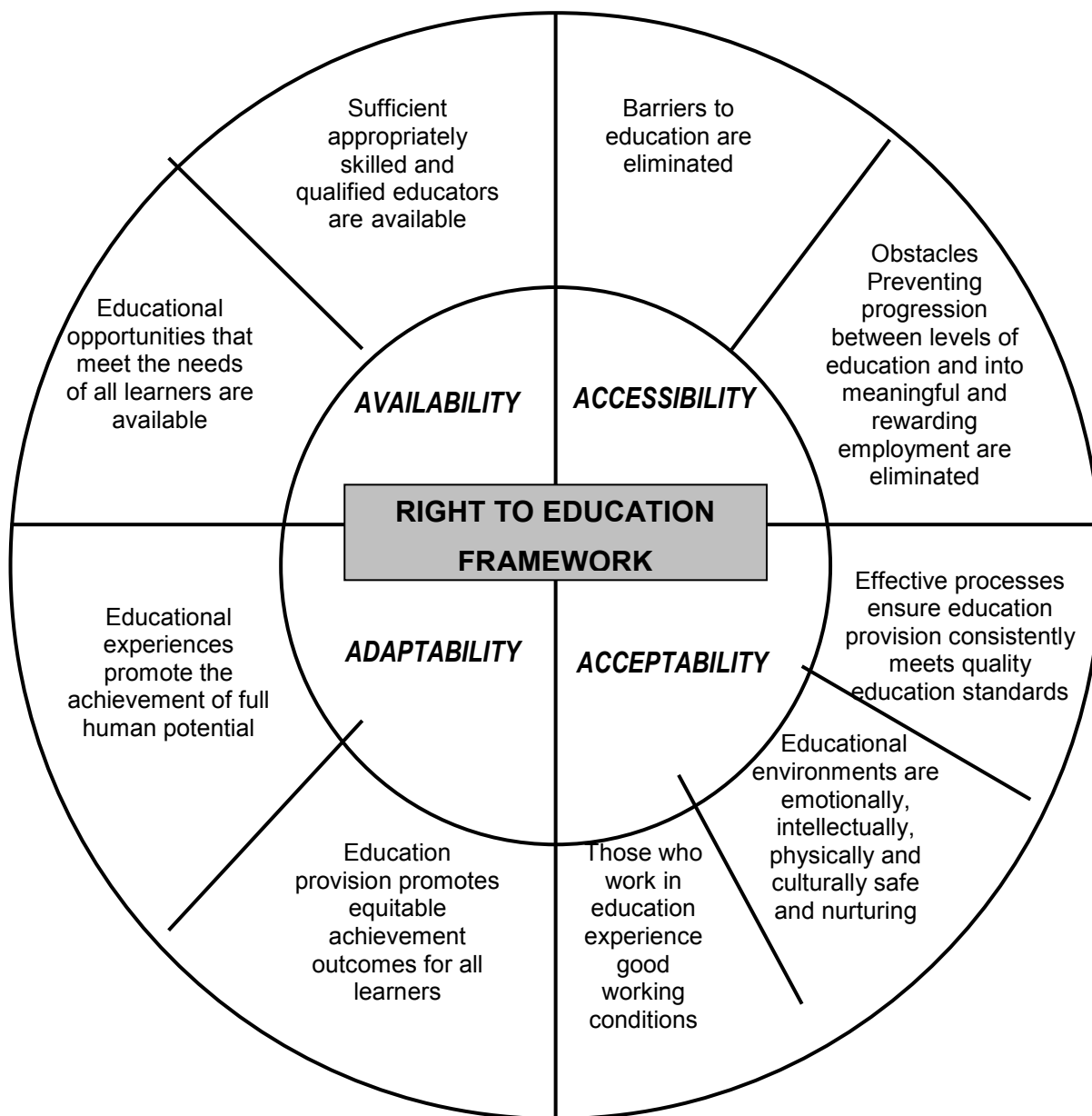
The broad social, cultural and economic environment.

Source:

Ministry of Social Development. (2004e). *Whole child approach: a guide to applying the whole child approach* (pp.25). Wellington: Ministry of Social Development.

4 The Right to Education Framework

Human Rights Commission. (2004). *Human rights in New Zealand today. Nga tika tangata o te motu. New Zealand human rights action plan for human rights. Mana kit e tangata* (pp. 262). Auckland: Human Rights Commission



The *Right to Education Framework* has been designed to be applicable to education in Aotearoa New Zealand. The human rights standards and considerations are interdependent, that is, the achievement of one is not necessarily evidence for the full achievement of the right to education. The *Right to Education Framework* can be used for education evaluation, review and strategic planning purposes. For more detailed information about this framework and about the right to education refer to the *Right to Education He Tāpapa Mātauranga* discussion document (Human Rights Commission, Te Kāhui Tika Tangata, November 2003).

Appendix 4. Information sheet and consent form child and adult participants

1. Information sheet child participant

Wellbeing for children with a disability in New Zealand (layout condensed)

Dear

This information sheet is to help you decide whether you would like to take part in a study for my University work.

What it's about

I am doing a study about what wellbeing means for children with a disability. Because children spend a lot of time at school I have chosen it as the place to talk about. Not many people know much about what life is like for children with a disability at school. So if you agree I would like you to tell me what you think about some of these things. I am also going to talk to some adults who work with children with a disability. Then I am going to write a report for my University teacher called a Master's thesis.

What you would have to do

You and your Mum or Dad will sign a special form, called a Consent Form, which tells me that you understand about my study and you want to be in it. I will ask you about the things you do. You can use the disposable camera to take photos of you doing everyday stuff, especially at school. I will have a tape with me when I talk with you so I can remember what I need to write down. We will talk about the photos and what you think. I will come to your place or somewhere that you would like to do the talking. Your mum or dad or your brother/sister can be with you at the interview to help me so that I am sure of the things you say. This is to make sure I have got your ideas right.

You can change your mind, even if you sign the form. You can change your mind later if you don't want to be in the study any more and if you don't want to talk to me sometimes. That's all OK

What happens with the study?

After I have talked to you, other children with a disability and some adults I will use the tapes and my notes to write my report. I might have to check some of things I write down from our talk with you and your mum or dad or brother/sister if that is OK with you - just to make sure I have got it right. Your real name will not be used so you can be kept private but your ideas will help me understand and help me write about wellbeing for children with a disability.

If you want to know more about the study If you, or Mum or Dad, want to know more about the study or think of questions you can ask me or my teacher. Our names are:

Maree Kirk

Phone 07 5776972

Dr. Sarah Hillcoat-Nallétamby

Phone 07 8384523

2. Consent form child participants

What Wellbeing means to me

CONSENT FORM FOR CHILDREN

I have read the information sheet (or someone has read it to me and talked about it) for the "Wellbeing for children with a disability in New Zealand" project and I understand it.

I know that.....

I don't have to be in the project unless I want to be.

Mum and Dad have agreed that I can be in the project.

Mum or dad or my brother/sister can be with me at the interview to help Maree make sure she has got my ideas right. This is called being an advocate or interpreter. They can help when we check what Maree writes from the interview called the transcript.

Later on I can change my mind if I don't want to be in the project anymore.

I don't have to answer any of the questions if I don't want to.

I can change my mind or ask for the tape to be turned off anytime I want.

If I ever have any questions I can ask Maree about them or get Mum or Dad to phone Maree's teacher, Sarah, to ask her.

No bad things will happen to me if I change my mind about anything to do with the project.

I would like to be part of the project.

.....

My signature (name)

.....

The date

3. Parent of student participant information sheet

Wellbeing for children with a disability in New Zealand:

A search for meaning

Researcher Maree Kirk

As part of my Master's thesis I am undertaking a research project on the topic *Wellbeing for children with a disability in New Zealand: a search for meaning*.

I am interested in establishing some of the dimensions of wellbeing as identified by children, parents and service providers for children with a disability in the community context of the school. The study will explore the notion of wellbeing for children with a disability at three levels as an individual, in the community and the broad social, cultural and economic environment such as policy that directly impact on the child. Drawing from a child's experience and understanding is invited to take part in an interview the aim of which is to explore his/her perceptions of the notion of wellbeing for children with a disability.

The interview will be taped and transcribed to assist in analysis and you may be asked to clarify parts of the transcript once this stage of the research is complete.may withdraw any information from the interview during the interview or at the final stage of the transcript. The findings of the interview, analysis and final report will be used as the basis for my Master's thesis. You are welcome to review the findings once I have completed the thesis. A copy of the final thesis will be made available on request.

The anonymity of the interview will be assured as far as no identifying information will be contained in the data. Confidentiality as a participant will be respected and maintained in all aspects of data collection and collation.

.....is free to withdraw from this study at the research stage.

For any queries or further information you can contact me or my supervisor.

Declaration to participants:

Iftakes part in the study, he/she has the right to:

Refuse to answer any particular question, and to withdraw from the study at any time.

Ask any further questions about this study that occurs to you orduring participation.

Be given access to a summary of the findings from the study when it is concluded.

You are able to contact me or my supervisor with queries or for further information

Maree Kirk

Dr. Sarah Hillcoat-Nallétamby

Phone 07 5776972

Phone 07 8384523

Email kirkgrey@ihug.co.nz

Email alletam@waikato.ac.nz

Thank you for.....and your assistance.

4. Parent of child / student participant consent form

Wellbeing for children with a disability in New Zealand: A search for meaning

Parent of Child /Student Participant Consent Form

In signing this consent form you are agreeing that the purpose of the research and the conduct of the interview and data collection process have been clearly explained to you. You are acknowledging that that you have read the information sheet and agree that.....can take part in this project.

You do not give up your legal rights by signing this consent form.

This project will be guided by the principles in the University's "Handbook on Ethical Conduct in Research 2001"

(See <http://www.waikato.ac.nz/uow/research.shtml#internal>)

You are able to withdraw..... at any stage or to retract information that may be given in the interview.

You may be asked for explanation of the transcript from the interview with for further clarification with the researcher. This will be discussed withThe photos used in the interview will not be published as part of this study.

You will be given a copy of this letter for your reference.

A copy of the executive summary will be made available to you.

Thank you again for your assistance with my research project

.....

Maree Kirk

Researcher

Date

.....

Participant's Parent (Name)

.....

Signature

Date

Supervisor: Dr Sarah Hillcoat-Nallétamby

Department of Societies and Cultures

University of Waikato

Private Bag 3105

Telephone 07 838 4523

5. Adult participant information sheet

Wellbeing for children with a disability in New Zealand:

A search for meaning

Researcher Maree Kirk

As part of my Master's thesis I am undertaking a research project on the topic *Wellbeing for children with a disability in New Zealand: a search for meaning*.

I am interested in establishing some of the dimensions of wellbeing as identified by children, parents and service providers for children with a disability in the community context of the school. The study will explore the notion of wellbeing for children with a disability at three levels as an individual, in the community and the broad social cultural and economic environment such as policy that directly impacts on the child. Drawing from your experience and field of expertise you are invited to take part in an interview the aim of which is to explore your perceptions of the notion of wellbeing for children with a disability.

The interview will be taped and transcribed to assist in analysis and you will be asked to check the transcript once this stage of the research is complete. You may withdraw any information from the interview during the interview or at the final stage of the transcript. The findings of the interview, analysis and final report will be used as the basis for my Master's thesis. A copy of the executive summary will be made available to you. A copy of the final thesis will be held in the Waikato University library.

The anonymity of the interview will be assured as far as no identifying information will be contained in the data. Your confidentiality as a participant will be respected and maintained in all aspects of data collection and collation.

You are free to withdraw from this study at any stage.

For any queries or further information you can contact me or my supervisor.

Declaration to participants:

If you take part in the study, you have the right to:

Refuse to answer any particular question, and to withdraw from the study at any time.

Ask any further questions about this study that occur to you during your participation.

Be given access to a summary of the findings from the study when it is concluded.

You are able to contact me or my supervisor with queries or for further information

Maree Kirk

Phone 07 5776972

Email kirkgrey@ihug.co.nz

Dr. Sarah Hillcoat-Nallétamby

Phone 07 8384523

Email nalletam@waikato.ac.nz

Thank you for your assistance.

6. Adult participant consent form

Wellbeing for children with a disability in New Zealand: A search for meaning

Adult Participant Consent Form

In signing this consent form you are agreeing that the purpose of the research and the conduct of the interview and data collection process have been clearly explained to you. You are acknowledging that that you have read the information sheet and agree to take part in this project.

You do not give up your legal rights by signing this consent form.

This project will be guided by the principles in the University's "Handbook on Ethical Conduct in Research 2001"

(See <http://www.waikato.ac.nz/uow/research.shtml#internal>)

You are able to withdraw at any stage or to retract information that you have given in the interview.

You will be shown a copy of the transcript for further clarification with the researcher.

You will be given a copy of this letter for your reference.

A copy of the executive summary will be made available to you.

Thank you again for your assistance with my research project

.....

Maree Kirk

Researcher

Date

.....

Participant (Name)

.....

Signature

Date

Supervisor: Dr Sarah Hillcoat-Nallétamby

Department of Societies and Cultures

University of Waikato

Private Bag 3105

Telephone 07 838 4523

Appendix 5.

1. Interview guide for child participants

1. Background and establish rapport

- Can you tell me about your family?
- Have you got any brothers or sisters?
- Have you always gone to this school?

2. Participant perception of school.

- What kind of things do you like doing at school?
- What do you like best about school?
- What don't you like about school?
- Tell me about playtime and lunch time at school?

Prompts; photos, social story books, school diary

3. Link to after school or social activities.

- Tell me about the things you like to do after school?
- Are you always able to do the things you like doing after school?

Prompts; photos, social story books, school diary

4. Ideas about wellbeing

- Can you tell me what being well or having an OK life means for you?
- What would you put on your list?
- What does having a happy life mean to you?
- Do you have all these things?
- What are some of the things that can make it hard for you?

Prompts; photos, social story books, school diary

5. Ordinary Life Model

This model shows what some people think having an Ordinary Life means. Can we go through this and you tell me what you think of each section for your life?

Is there anything else you want to tell me about?

Thank you for your help with my project.

Appendix 6.

2. Interview guide Service Provider & Policy Professional

Note the interview guides for the service provider and policy position interviews are presented here together to reduce unnecessary duplication and the layout is condensed.

1. Background of ‘service provider’ participant: ‘policy provider’

Can you tell me about yourself and your current position?

Can you tell a bit about your career as a?

- Teacher
- Group Special Education Service Coordinator
- Policy Advisor

How long have you worked with/ in relation to children with disabilities?

- Have you worked in other service areas with children with disabilities?
- Have you had any special training to prepare you for working with children with a disability?
- Is there any degree of difference in working with children with a disability compared to working with children in general?

Prompt: areas of additional support/professional training or development/resources/networks/coping strategies/ career affects/ attitude/values/personal experience)

Teacher: How did a child with a disability come to be in your class this year?

(Did you “volunteer” or did s/he get assigned in the same way as other children?)

2. Participant perception of wellbeing for children with a disability

- How would you describe the idea of wellbeing for children with a disability at school?
- What factors do you think influence wellbeing for children with a disability at school?
- How is this influence applied in the classroom setting?
- What is your view of the provision of services for children with a disability at school?
- Do you consider it to be part of your role as
 - Teacher
 - Group Special Education Service Coordinator
 - Policy Advisor

to encourage and actively support wellbeing for children with a disability in the educational setting?

If Yes - in what ways do you do this?

If No - who, if anyone, do you think should do this?

- What other agencies are working / involved with children with a disability?
- How do they work with the school?
- Are children with a disability benefiting from the school environment in the same ways as all students in the school?
- Do you identify any negative effects for (child with a disability) in the school environment?

Prompt; bullying or teasing

(Note: Whole Child Approach Guide benefits /risks as consumers or clients of services)

- Are there any special provisions made for children with a disability at school?

Prompt; support person with child /additional planning/resources

- If Yes What are these?
- Are there things that need to happen which would encourage or support the development or maintenance of wellbeing for children with a disability?

If yes What are these?

3. Operational Frameworks: Show adult participant – service provider and parent participant the frameworks

1. Domains of wellbeing for children and young people in New Zealand

Children and Young People: Indicators of Wellbeing in New Zealand (Ministry of Social Development, 2005: 136).

2. The Key Settings Model

Guide to Applying the Whole Child Approach (Ministry of Social Development, 2004:25).

3. The Right to Education Framework

Human Rights in New Zealand Today (Human Rights Commission, 2004:262)

3.1 Show Model Dimensions of wellbeing for children and young people

In your view how relevant are these dimensions of wellbeing to children with a disability?

Are there other dimensions that would need to be emphasised and / or included when we are thinking about children with a disability?

3.2. The Key Settings Model

- In your view which key settings are the most important to wellbeing of children with a disability?
- Are there any key settings that would need to be included or emphasized for children with a disability? Prompt; support person, additional planning

For example The Community and its institutions school setting

- Is any consideration taken of aspects of the key settings model when class placement is being decided?
- If yes. In your view does this influence broader relationships?

Prompt: friends, sports, interests, family

- Does educational policy affect children with a disability's lives across more than one key setting?
- If so in what ways?
- In your view how do other settings influence this policy?
- What broad policy, funding or regulatory frameworks affect your current work with children with a disability?

Prompt: health funding, carer support, respite care.

3.3 The Right to Education Model

- In your view does this model relate to your experience with (child with disability) or working with children with a disability?
- Are there other sections that would need to be included or emphasized when we are thinking about children with a disability?

4. Policy relevant to wellbeing for children with a disability.

- Since the 1990's do you recall any significant factors, policy or experiences that have led to a change in relation to wellbeing for children with a disability?
- How would you describe attitudes to inclusion and the concept of wellbeing for children with a disability in policy directives

Service provision

In your current experience

- With your experience, how would you describe the current trends in service provision?
- What insights can you share with me about how you see the concept of wellbeing for children with a disability being expressed?

Researched?

Promoted?

Do you have any further comments?

Thank you for your assistance.

3. Interview guide for parent participant

1. Background Parent Participant

- Can you tell me a bit about your family and (child with a disability)?
- How many children are in your family?
- What are the ages of the children in the family?
- What are some of the things you have experienced with (child with a disability)?
- Is there any degree of difference in parenting (child with a disability) compared to parenting your other children?
- Can you describe this for me?

Prompt: areas of additional support/training/resources/networks/coping strategies/ career affects/ attitude/values/personal experience.

2. Participant perception of wellbeing for children with a disability

- How would you describe the idea of wellbeing for children with a disability at school?
- What factors do you think influence wellbeing for children with a disability at school?
- How is this influence applied in the classroom setting?
- What is your view of the provision of services for (child with a disability) in the educational setting?
- Do you consider it to be part of your role as (child with a disability) parent to encourage and actively support wellbeing for *your child* in the educational setting?

If Yes - in what ways do you do this?

If No - who, if anyone, do you think should do this?

- What other agencies are working / involved with (child with a disability)?
- How do they work with the school?
- Is (child with a disability) benefiting from the school environment in the same ways as all students in the school?
- Do you identify any negative effects for (child with a disability) in the school environment?

Prompt; bullying or teasing

(Note: Whole Child Approach Guide benefits /risks as consumers or clients of services)

- Are there any special provisions made for (child with a disability) at school?

Prompt; support person with child /additional planning

- If Yes What are these?
- Are there things that need to happen which would encourage or support the development or maintenance of wellbeing for (child with a disability)?
- If yes. What are these?

3. Operational Frameworks

Show parent participant the frameworks

1. Domains of wellbeing for children and young people in New Zealand

Children and Young People: Indicators of Wellbeing in New Zealand (Ministry of Social Development, 2005: 136).

2. The Key Settings Model

Guide to Applying the Whole Child Approach (Ministry of Social Development, 2004:25).

3. The Right to Education Framework

Human Rights in New Zealand Today (Human Rights Commission, 2004:262)

3.1 Show Model Dimensions of wellbeing for children and young people

- In your view how relevant are these dimensions of wellbeing to children with a disability?
- Are there other dimensions that would need to be included when we are thinking about children with a disability?

3.2. Show the Key Settings Model

- In your view which key settings are the most important to wellbeing of children with a disability?
- Are there any key settings that would need to be included or emphasized for children with a disability? Prompt; support person, additional planning

For example The Community and its institutions school setting

- Is any consideration taken of aspects of the key settings model when class placement is being decided?
- If yes. In your view does this influence broader relationships?

Prompt: friends, sports, interests, family

- Does educational policy affect children with a disability's lives across more than one key setting?
- If so in what ways?
- In your view how do other settings influence this policy?
- What broad policy, funding or regulatory frameworks affect your child with a disability? **Parent**

Prompt: health funding, carer support, respite care.

3.3 Show the Right to Education Model

- In your view does this model relate to your experience with (child with disability) or working with children with a disability?
- Are there other sections that would need to be included or emphasized when we are thinking about children with a disability?

4. Policy relevant to wellbeing for children with a disability.

- Since the 1990's do you recall any significant factors, policy or experiences that have led to a change in relation to wellbeing for children with a disability?
- How would you describe attitudes to inclusion and the concept of wellbeing for children with a disability in policy directives

Service provision

In your current experience

- With your experience, how would you describe the current trends in service provision?
- What insights can you share with me about how you see the concept of wellbeing for children with a disability being expressed?

Researched?

Promoted?

Do you have any further comments?

Thank you for your assistance.

Appendix 7.

1. Interpretative grid: dimensions of wellbeing

Dimensions of Wellbeing	Factors which influence wellbeing			
	Service User Child	Service User Parent	Service Provider	Policy Position
Building Capability	Meaningful work	Meaningful work	Meaningful work	Meaningful work
	Skill based	Skill based	Skill based	Skill based
	School work	Adapted curriculum	Adapted curriculum	Adapted curriculum
	Class task	Class role	Class task	
	Home tasks	Home tasks		
	Supported	Supported	Supported	Supported
		Resourced	Resourced	Resourced
		Age appropriate	Age appropriate	Age appropriate
		Planned	Planned	Planned
	Goal of competency	Goal of competency	Goal of independence	Goal of competency
	Achievement	Achievement	Participation	
	Safety	Safety	Safety	Safety
Identity	Sense of belonging	Sense of belonging	Sense of belonging	Sense of belonging
	Happy	Happy	Happy	Happy
	Social role	Social role	Social role	Social role
	Ability to learn	Ability to learn		
	Disability	Disability	Disability	Disability
		Self esteem		
Friendships	All environments	All environments	School	All environments
	Facilitated	Facilitated		Facilitated
		Age appropriate		Age appropriate
Communication	Social	Social	Social	Social
	Language skills	Language skills	Language skills	Language skills
				Decision making
Participation	All environments	All environments	All environments	All environments
		Age appropriate	Conditions	Conditions
	School Culture	School Culture		
	Sense of belonging	Sense of belonging	Sense of belonging	Sense of belonging
	Planned	Planned	Planned	Planned
Care and Support	Family/home	Family/home	Family/home	Family/home
	Planned	Planned	Planned	Planned
		Resourced	Resourced	Resourced
	Role of support	Role of support	Role of support	Role of support
		Advocacy	Advocacy	Advocacy
Environments	Home	Home	Home	Home
	Secure/Happy	Secure/Happy	Secure/Happy	Secure/Happy
	Local	Local	Local	Local
	Acceptance of diversity	Acceptance of diversity	Acceptance of diversity	Acceptance of diversity
	Interconnected with other dimensions	Interconnected with other dimensions	Interconnected with other dimensions	Interconnected with other dimensions

