Acceptance, Recognition, and Supported Independence: Wellbeing for Children and Young People with a Disability in New Zealand

The Voice of Youth with Down Syndrome

A thesis

submitted in fulfilment of the requirements for the degree

of

Doctor of Philosophy in Sociology and Social Policy

at

The University of Waikato

by

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THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

2019

Abstract

The aim of this thesis is to identify what wellbeing means for children and young people with a disability and the factors that influence wellbeing in the home, school, and the community. The research was carried out through consecutive interviews that captured children's voice through the methods of visual sociology. Grounded theory was the basis for the analysis which produced rich data to describe the lives of these young people with Down syndrome.

In addition, interviews were undertaken with parents and service providers at a local and national level to gain an insight into the celebrations and challenges of the everyday lives that were experienced by the young people and their families. Service provision was examined from the perspective of all three groups of participants.

Wellbeing is a complex phenomenon and although there has been increasing interest in this field, particularly for children, there is a dearth of research about wellbeing for children and young people with a disability. The findings of the research pointed to three key principles of wellbeing: acceptance, recognition, and supported independence.

These three key principles form the basis of three models in the findings. The first model is an ecological perspective; it illustrates how the level at which policy is introduced and implemented intersects and works to benefit or hinder the service provision in schools and for the children and their families.

The second model—the dimensions of wellbeing for children and young people—emerged from the data and was used in conjunction with the ecological perspective model to develop the supporting teaching practice for students with Down syndrome and learning disability programme. The third model is, therefore, a capability model for schools.

The result of the research is the creation of practical tools that can be used to review policy and service provision with the aim of ensuring that children and young people with a disability enjoy entitlements equal to those of all children in New Zealand.

Acknowledgements

I am grateful to my supervisors, Dr. Jo Barnes and Dr. Patrick Barrett, for their advice and whose expertise was invaluable. Throughout the writing of this thesis I have received a great deal of support and assistance from their insightful comments and encouragement. Thank you Jo for your hospitality and friendship while we worked through the final draft and thank you Patrick for your steady hand, counsel and quiet humour.

I would like to thank the University of Waikato for the Doctoral Scholarship. I am also grateful to Associate Professor Kristine Moffat and the members of the post graduate studies office for their guidance and support throughout my doctoral thesis.

I was privileged to do this research and am extremely appreciative of the generosity of the young people with Down syndrome and their families who shared their thoughts, ideas, and hopes for the future with me. I would like to thank the service providers, the schools and Down syndrome associations that have taken part in my research and through the seminar programmes.

The thesis is dedicated to Jordan, Georgina, Fraser and Spencer whose constant presence and support throughout the research has meant so much to me and who continue to inspire me in all aspects of my life. They are the epitome of my aim of this research which was to champion complete inclusion for young people with a disability.

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Chapter 1:
Introduction

Children and young people make up a significant proportion of New Zealand's population (Office of the Children's Commissioner, 2016), and children and young people with disability have consistently been measured as making up 11% of that group (Statistics New Zealand, 2013a; Kirk, 2007). There are persistent concerns, however, about the adequacy of government and societal responses to the needs of children and young people with disability (Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities, 2016; Smith, 2013; Starr & Janah, 2016; Wynd, 2015; Moran, 2014; Office for Disability Issues, 2016). The aim of this thesis is to explore what wellbeing means for this group in New Zealand. It pursues this goal with a particular focus on the lived experience of children and young people with disabilities in regular New Zealand schools, as this context is central to their development and their experience of wellbeing. The focus is on children and young people with intellectual disability, in particular Down syndrome, as there is increasing awareness that young people in this group are more likely to experience social and educational exclusion by comparison with other children and young people including those with physical disabilities alone (Michailakis & Reich 2009; UNESCO, 2015; Banks, McCoy, & Shevlin, 2013; Tipton, Christensen, & Blacher, 2013). The focus of this study is on understanding wellbeing from the child's and young person's perspective, in order to develop a conceptual framework that will help schools, parents, communities, and public sector agencies to understand and promote the wellbeing of children and young people with disability in New Zealand.

Background Context of the Thesis

My interest with this topic of children with disability stems from my personal experience as a mother of four children, the youngest of whom has Down syndrome. Many years of challenging and stimulating interaction with government, social service agencies, health and educational institutions has led me down the path of working closely with the Down syndrome Associations and

other disability entities. I had long been concerned with the lack of acknowledgement of the capabilities of children and young people with a disability. My experience has been that this group of children often attend regular school and are ever present in our community but do not experience the same attention as their peers. It seemed to me that it was best to take time to hear from the young people themselves about their lives and what they thought the adults around them could be doing to improve their wellbeing.

The focus of this study, therefore, is on children and young people with Down syndrome. "Children and young people" are defined as those who fall within the 0-24 age range inclusive. The study's purpose is to understand wellbeing from the perspective of this group, in order to inform the principles and practices by which schools, parents, communities, and the wider services sector support their needs. The analysis of the experience of this group will provide insights into the wider experience of children and young people with a disability. There is a particular focus in this study on the school sector, given that the majority of children and young people with disabilities attend schools and that schools are a key social institution with the potential to profoundly impact their wellbeing, especially in terms of social participation and inclusion.

The choice of the 0-24 age range was guided first, by the Ministry of Education's eligibility criteria for special education support, as this support is available for children and young people aged 0-21 years (Education Review Office, 2010; Education Act 1989) and secondly, by Statistics New Zealand which defines a dependent young person as a "child in a family nucleus" aged 18-24 years and not employed full time (Statistics New Zealand, 2014, p. 24). The reference to disability refers to those children and young people with a physical, intellectual, psychiatric/psychological or sensory impairment which limits them from actively participating in society due to either physical or social barriers in their environment.

While the age range that defines children and young people with a disability varies across government agencies, so too does the definition of disability or the level of "special need" as a basis for eligibility with regard to accessing public services. For instance, in the Disability Survey 2013, children

with a disability were defined as those aged from 0-14 years with a physical, intellectual, psychiatric/psychological, agility, speaking, developmental delay, learning disability or sensory impairment which limited them from actively carrying out day-to day-activities or which meant a restriction or lack of ability to perform (Statistics New Zealand, 2013a).

Perspectives on Disability

The way in which the children and young people who are the subject of this research are considered is, therefore, informed by theoretical perspectives and related models of disability that influence both the practices and the environments of the children and young people who make up this group.[1] The medical model of disability, which is based on a biophysical perspective and which views disability as the outcome of physical or mental impairment, continues to dominate approaches to practices and policies in this field. The model can be seen as emerging from the expansion of scientific knowledge and the development of the position of the doctor and scientist as the custodian of societal values and curing processes (Neilson, 2005; Humpage, 2007). The medical model frames disability as an individual impairment to be "cured" or contained, a goal thought best achieved by placing people with disabilities under the direction and authority of the medical profession (Oliver, 1990).

The medical model assumes that the impairment arises from symptoms due to a disorder, syndrome, disease or condition that is subsequently categorised

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[1] It is important to acknowledge the difference between theory and model, as identified by Campbell and Beckett (2015). A theory provides understanding and explanation, whereas a model provides a representation (description) of significant structural and/or functional features, properties, or characteristics of another object or process, as in the social model of disability. In this view, the social model's explanatory capacity provides explanation for the disablement process as it describes this process (see Campbell & Beckett (2015). The social model of disability as oppositional device. *Disability and Society, 30*(2), 270-283.). Altman (2001) explains that a model is a set of relationships and that these then develop to form different outcomes around numerous scenarios which do not affect real communities until they are put into practice. Models of disability have generally been used to illuminate the experiences and goals of disabled adults (as noted above). These experiences and goals may be quite different from those which parents of children with disabilities envisioned for their children (Bricout, Porterfield, Fisher, & Howard, 2004, p. 47). In fact, they may be quite different than those envisioned by children and young people with a disability themselves (Meloni, Federici, & Dennis, 2015). Therefore, it is important to briefly consider the various disability models Such as Altman, B. (2001). Disability definitions, models, classification schemes, and applications. In G. L. Albredht, K. D. Seelman, & M. Bury, *Handbook of disability studies*, (pp. 97-122). Thousand Oaks, CA: Sage Publications,

and classified. The goal is the prevention, treatment, and management of disease processes and traumas in service. This goal is to be achieved by reducing or eliminating the pathology associated with disability, as well as secondary conditions (Drake, 1999). As a result, the needs of people with disability will be resolved by individual provision (Jackson, 2018). This approach medicalises the consequences associated with the impairment of an individual and leads to diagnoses or labels and to corresponding treatments, interventions, therapies or rehabilitative services. Critical perspectives of the medical model emphasise that it has been the medical profession that, predominately, has created the disability "industry" and has in important ways contributed to the marginalisation of people with disabilities (Shakespeare, 2010). Scholars such as Oliver (1990, 1996), Campbell and Oliver (1996), Barnes, Mercer, and Shakespeare (1999), Striker (1997), Davis (1997), Mitchell and Snyder (1997), Linton (1998), and Shapiro (1993) all identify the role of the medical profession and medical systems in shaping the development of notions of disability.

The model can be seen as having both positive and negative outcomes for children and young people with a disability. Generally, it is the medical profession that classifies or diagnoses impairment and doing so has potential to assist with the development of positive life span trajectories from a child development approach, although this is contingent on the accompanying disability discourse. The process of diagnosis may also allow access to social services or institutions such as health and education. Once again, however, this access is contingent on the theoretical perspective of disability. For example, to gain access to social services, ongoing medical certification that confirms the disability diagnosis is required.

The social approach to disability, i.e., the social model (Oliver, 1990; Barton, 1996; Drake, 1999), is a response to the standard "individualist and deficit views of disability" (Barton, 1993, p. 235). The social model of disability posits that disability is a social construction, which is to say that society creates "disability" by imposing hindrances that affect the ability of persons with different abilities to participate fully in society (Swain & French, 2000). Central to this approach is a distinction between impairment and disability. Oliver's (1990) influential definition of disability identified it 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" (p. 11).

The distinction between disability and impairment is also clearly identified by Barnes, Mercer, and Shakespeare (1999). For them, "Impairment … refers to some bodily defect, usually constituting 'a medically classified condition'" (p. 7). The social model emerged from the intellectual and political arguments of the Union of Physically Impaired Against Segregation (UPIAS). The core argument was that society disables physically impaired people through unnecessary social isolation and exclusion from full participation in society. Thus, disabled people are an oppressed group in society (UPIAS, 1975). According to Shakespeare (2010) and the later development of UPIAS thinking, the key elements of the social model are the distinction between disability (social exclusion) and impairment (physical limitation) and the claim that disabled people are an oppressed group. Disability is defined not in functional terms, but as "… the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities" (UPIAS, 1975, p. 20).

Shakespeare (2010) states this redefinition of disability (broadened from physical impairment) itself is what sets the British social model apart from other sociopolitical approaches to disability and is what, paradoxically, gives the social model both its strengths and its weaknesses. While the strength of the medical model is that it provides diagnosis and service, the flaw occurs when this model is extended to a functional deficit approach to service provision. Similarly, the strength of the social model is that impairment is considered in sociopolitical terms, so that the diversity and inclusion of all children and young people is considered across environments. The weakness is that the social model downplays the health needs related to the impairment, whether it be physical or intellectual. For children and young people with intellectual disability their impairment is generally considered within the medical model with consequences evident in the social model. Thomas (2004) argued that the limitations of impairment or disability identified in the medical model and the barriers to social access of the

social model both fell short of identifying the social relational influences that illuminate the real divide in disabled people's lives associated with systemic social exclusion. The medical model is evident when disablist social barriers of accepted body and cognitive standards in society such as intellectual ability are imposed (Thomas, 2004). When children and young people with intellectual disability health needs are met and the diversity of childhood populations is respected in terms of their inclusion in all opportunities, the social model allows for an ongoing interaction of enabling or disabling environments. Thus, paying attention to the framing of the medical and social models of disability is important to a conceptual framework of wellbeing for children with a disability as regards their human development, social participation, and inclusion in the many social, health, educational, and family environments.

Scholars working within the social model identify exclusionary societal practices such as negative attitudes, physical impediments, and institutional and social barriers that isolate and stigmatise individuals with disability (Bricout, Porterfield, Fisher, & Howard, 2004, p. 50). These authors draw on the social systems model of Llewllyn and Hogan (2000) which maps out the relationships between disability and disability services for children and their parents. They draw attention to the medical-educational gap and the parent and professional relationship. From this perspective, the focus is on the vital transactional context, relationships, and processes within the ecological interactions for children and young people with a disability.

Bronfenbrenner's (1992) ecological systems theory views health and development as occurring within these kinds of complex networks of interaction. Bronfenbrenner's approach draws attention to the ecological context of children and young people with disability as a rich, thick, multidimensional construct. His approach identified the interaction of many processes such as heritability and the interaction between biological characteristics and environmental systems across time and space that determine how an individual will develop. Bronfenbrenner's theory which emphasises the idea of interaction, which suggests that similar environmental conditions and contexts will lead to different outcomes for different people, particularly children (Bronfenbrenner, 1992). This insight is critical to understanding the impact of disability on various aspects of child

development and offers a model that suggests the possibility that there may be many points of entry when looking to improve the life situation and developmental wellbeing of an individual with a disability (Rosenbaum, 2010).

From the ecological systems perspective, disability can be seen, therefore, as a consequence of individual, social, political, and economic conditions which support or restrict the life opportunities of those with an impairment. This viewpoint accommodates both a medical and social explanation of the nature of disability. It is typically through a medical diagnosis that a child with an impairment is identified and a basis for support and intervention, often across the child's life course, is established. It is often, however, the physical and social environments of childhood that inhibit inclusion or restrict the life opportunities of children and young people with an impairment. Therefore, the early contact with health and education service providers and the disability discourse within professional practice are important influences for the child and family. Next, in considering the research question, it is essential to situate the study population.

Approaches to "Profiling" Children And Young People With Disability

The demographic profile of children with a disability has remained relatively consistent since New Zealand's first Household Disability Survey in 1996. This observation is, however, based on the extremely limited published data pertaining to the study population (Starr & Janah, 2016; Wynd, 2015). What is available comes in the form of secondary published reports which focus on a specific type of disability and medical diagnosis. This information is spread across different government departments and so makes comprehensive analysis very challenging (Starr & Janah, 2016). Data is typically gathered with a view towards understanding the fiscal costs of disability. Examples are: The Cost of Disability, a report cofunded by the Ministry of Social Development and the Health Research Council (Disability Resource Centre, 2010); the annual Health and Independence reports published by the Ministry of Health, which focus on the public funds allocated to improving care and support for people living with long-term conditions and disability (Ministry of Health, 2018); and, the Demographic Report on Clients Allocated Ministry of Health's Disability Support Services (Ministry of

Health, 2017). The Ministry research, however, is focused on adults with disability.

The ORS involves a stringent verification process for a student to be designated one of two levels of 'very high needs' for school and beyond and 'high needs' only for school life (5-21 years). The ORS criteria are for learning disability, hearing impairment, vision impairment, physical disability, difficulty with language use and social communication that significantly impact the student's ability to access the curriculum. The ORS provides additional or specialist support such as speech language therapist or behavioural psychologist and teacher aide support along with additional curriculum supports, technology and consumables (Ministry of Education, 2020).

The number of students receiving ORS has increased from 6,664 in 2005 to 9,718 in 2019. A national budget and policy change in 2010 identified a corresponding increase in the number of children and young people counted in the ORS data. The Ministry of Education adopts the use of census data for funding and service provision for children across education services for other social groups such as achievement programmes funded according to ethnicity or socioeconomic status. For children with a disability however this is not the case. The Ministry of Education approach is not consistent with the use of census based data for funding for children with a disability. The Ministry fiscal approach varies across the two child population groups: children without a disability and children with a disability.

The Ministry of Education also has a fiscal focus on the data relating to children and young people with a disability. The Ongoing Resourcing Scheme (ORS) "is for students who have the highest ongoing levels of need for specialist support at school. Only a small number of students (about 1% of the school population) will have this highest level of need" (Ministry of Education, 2020). In addition, the students receiving ORS funding for additional support in school are eligible for longer and identified as those aged up to 21 years of age who require the highest level of need for special education (Education Counts, 2018). The data approach used for the whole student population of 1% of students with ongoing levels of need identifies a significantly lower percentage than the disability data

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would suggest. To illustrate this anomaly, the 2013 Disability Survey records that 11% of children aged 0-14 years have a disability and of those 52% have learning disability and 16% of youth aged 16-24 years have a disability (Statistics New Zealand, 2020a). The disability data pointedly suggests the ORS percentage is an under calculated population based service allocation.

In order to fund population based service allocation equally in all areas of education we need to consider the approach to disability data collection. The World Health Organization's (WHO) Global Disability Action Plan 2014-2021 and the Convention on the Rights of Persons with Disabilities (CRPD) require member states to collect relevant and internationally comparable data on disability and to support research on disability and related services (WHO, 2015; World Bank Report on Disability Data, 2011; Human Rights Commission, 2014). New Zealand relies on the WHO's International Classification of Impairments, Disabilities and Handicaps' (ICIDH) 1980 definition in its New Zealand Disability Surveys (Statistics New Zealand, 1996, 2001, 2007). This ICIDH definition used a functional limitation concept of disability for adults, where disability was defined as any limitation in activity resulting from a long-term (6 months or longer) condition or health problem. The use of this standard initially ensured that a country's results were comparable with those of other countries (Statistics New Zealand, 2001) and New Zealand was in line with an international standard for data collection on disability. Crucially, however, the ICIDH definition was updated in 2001, and the more recent International Classification of Functioning Disability and Health (ICF) was not used by Statistics New Zealand in 2013 to ensure that the data would continue to be comparable (Statistics New Zealand, 2013b).

For the first time with the 2018 Census in New Zealand the intention was "data on disability will be output directly from the census. It will allow cross tabulations with other census data. However, it is not comparable with the previous information on disability" (Statistics New Zealand, 2018b, p. 40). The intention was for disability data to be collected through health questions relating to limitations in basic activities as an indicator of disability status for those aged five years and over. The levels of participation "by disabled people in aspects of life covered by the census (such as employment and education) with those of non-

disabled people to see if disabled people are achieving social inclusion" (Statistics New Zealand, 2018b, p. 40). The topics covered information on the experience of difficulty with vision, hearing, mobility, remembering, self-care, and communications. The questions for the survey and the definitions were drawn from the Washington Group on Disability Statistics (Statistics New Zealand, 2018b, p.39). Worthy of note in the planning process was the lack of reliance on historical New Zealand survey design, cultural context, and success of child disability data survey design in preference to the adult centric Washington Group survey design. The intended outcome was comparisons to be made between average outcomes for disabled and non-disabled populations but the Census 2018 questions "were not designed to identify the disabled population" (Statistics New Zealand, 2020b, p. 12). The result was the lack of disability data, particularly child disability data 0-14 years, from the 2018 Census.

The New Zealand Household Disability Surveys (NZHDS) (1996, 2001, 2006, 2013a) define a child as a "usual resident of New Zealand aged less than 15 years". This age range of 0-14 years is in line with some international disability surveys but not others; for instance, it was used in early disability surveys in Australia and Canada (Harper, 2010; MacKenzie, 2008; personal communication, Statistics New Zealand, 2010), but not in Scotland (2016) where the age range is 0-17 years. Having these differing age ranges does lead to some problems when comparing profiles of children and young people with disability across countries. The definition of disability for children aged less than 15 years relies on a broader definition than that used for adults, as discussed above. The definition for children includes not only activity limitation, but also specific chronic conditions or health problems, use of special education services, use of specific types of equipment, and support needs (Ministry of Health, 2005; Statistics New Zealand, 1997, 2007). For comparison, it is important to note the United Nations Convention on the Rights of the Child (1989, p.1) definition of "a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier."

New Zealand relies on the World Health Organisation (WHO) International Classification of Impairments, Disabilities and Handicaps, (ICIDH) 1980 definition for the New Zealand Disability Surveys (Statistics New Zealand,

1996; 1997; 2001; 2006; 2013). These surveys used a functional[2] concept of disability for adults where disability was defined as any limitation in activity resulting from a long-term condition or health problem. This focus on functional limitation resulting from a condition is congruent with the 'disability' component of the ICIDH definition of disability (World Health Organisation, 1980). New Zealand asserts that a functional definition has been recommended as an international standard for data collection on disability; the use of this standard ensuring that the results are comparable with other countries (Statistics New Zealand, 2001). The ICIDH definition was updated in 2001. The more recent International Classification of Functioning Disability and Health (ICF) was not used in 2006 or 2013 so that the data from the surveys would be comparable.

The NZHDS definition of children with a disability is delineated into classification by disability types; these classifications include children with the following special needs: sensory; hearing; seeing; use of technical aids; chronic condition or health problem; intellectual; psychiatric or psychological; children requiring Ministry of Education Special Education; attention deficit disorder; and, speaking disability (identified as both difficulty speaking and/or being understood (Statistics New Zealand, 1997, 2007, 2013a). Notably, these definitions of disability for children and young people, which typically rely on self-reporting by parents on functional limitation and the use of special education services, are broader than the definition created by the Ministry of Health that determines eligibility for government-funded disability support services.

The NZHDS divides children with a disability into three categories: special education (46%); chronic conditions or health problems (severe asthma, cerebral palsy, diabetes or other chronic conditions) (39%); and, psychiatric or psychological disabilities (21%) (Statistics New Zealand, 2007, p. 4). Learning difficulty was the most common impairment type, as it affects 6% of all children; in contrast, 52% of disabled children have difficulty learning (Statistics New Zealand, 2014, p. 4). Children with Down syndrome would come under the category intellectual disability and learning disability. A significant proportion of

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[2] Function in terms of physical or psychological ability being limited by health status and requiring some form of assistance to perform tasks (authors own definition).

school-age children with an impairment reported high levels of unmet needs, while 32% of disabled children aged 5-14 recorded an unmet need for equipment or support services to help with their education (Statistics New Zealand, 2008, p. 15). The proportion of unmet need points to notable service gaps for this specific child population.

The definition of disability as regards support services remains medically driven and contested, as this definition is founded on pathologies which, when applied to children, fail to recognise that the early diagnosis of aetiologies is often unclear. The "diagnosis" of developmental delay, for example, occurs over a long-term period and is largely observational. Diagnosis can, therefore, be arbitrary and regional variance is common (Middleton, 1999). The definition also focuses on being able to "function independently"; this definition is, however, very subjective for a child population, as a child's ability to do a task independently also varies with the child's age and stage of development and, for example, parental skill within families.

The earlier New Zealand Disability Strategy (Ministry of Health, 2001), on the other hand, defined disability from a social and ecological (rather than a medical) perspective. From this perspective, disability is not only a physical, sensory, neurological, psychiatric, intellectual or other impairment, but a process which relates to the interaction between the person with the impairment and the environment (Ministry of Health, 2008). It is a much more child-friendly definition, but it has not been used for either data collection or service development in New Zealand.

For over two decades there has been a clear recognition that at least 11% of New Zealand children and young people have a disability. For children in the 0-14 age range, the data is based on households and residential facilities. Table 1 shows that the proportion of children in New Zealand with a disability has remained consistent over the last 20 years. In the 1996, 2001, and 2013 censuses the figure for children 0-14 was 11%; the 2006 census, however, showed an increase of 3% to 14% because the published data included children in residential facilities. The data relating to people over 14 with a disability is given in the age

ranges 15 to 44, 45 to 64, and 65 plus. Thus, it is impossible to identify the number of young people with a disability between 15 and 25.

Table 1

Percentage of Young People with Disability, 1996, 2001, 2006, and 2013

	Age group (years range provided)		
Year	0-14 years	15-44 years	Total population across all age groups
1996	11%	12%	20%
2001	11%	13%	20%
2006	14%	9%	19%
2013	11%	16%	24%

Adapted from Statistics New Zealand, 2007, p. 3, 2013a, p. 3.

Table 1 shows a consistent assessment that 11% of New Zealand's children and young people have a disability. This general figure is reinforced by the Ministry of Education assessment that 15% of the student population has additional or special learning needs (Tomorrow's Schools Independent Taskforce, 2018), although the Ministry of Education data does not identify children with special needs, learning support needs or disability type consistently in published data (Starr & Janah, 2016).

Children and young people with Down syndrome

As noted, the focus of this study is on the experiences of children and young people with Down syndrome, an impairment with recognised characteristics which is confirmed by medical diagnosis shortly after birth (Selikowitz, 1997). Down syndrome, which is caused by an extra copy of all or part of chromosome 21, is the most common naturally occurring chromosomal manifestation. Down syndrome can have a range of effects on an individual's health and development; it is one of the most common causes of learning disability and is recognised worldwide (DownsEd, 2007; Zimpel, 2016). In New Zealand, we do not know the

exact number of people with Down syndrome; however, it is estimated that one baby in around 1000 is born with the condition, an estimation of one baby every week (New Zealand Down Syndrome Association Inc., 2007).

Children with Down syndrome are a part of the wider group of children and young people with disability. As noted above, approximately 11% of all children born each year have a disability, and of this group, 17-32% were consistently found to need some kind of additional health service (Statistics New Zealand, 2001, 2008).

Gaps in Government Services And Initiatives

Children and young people with disabilities do, for the most part, participate in the education system, although often in a discontinuous way. In New Zealand, there is a dual school system where state and integrated schools provide mainstream, regular education; in addition, there are 37 special schools or satellite units with programmes for children and young people with disability which form part of the schooling network (Education Counts, 2018). Around 20% of this group have their schooling interrupted for a long period; a smaller proportion often have to change schools (11%), and an even smaller proportion have to live away from home to attend a school (3%) (Statistics New Zealand, Disability Survey, 2013; Customised Report, 2016, as cited Starr & Jannah, 2016[3]). As with most other children, school is a critical experience in the lives of children and young people with disabilities. That experience, however, is typically characterised by unmet need in areas such as help with schoolwork in class, access to special equipment, and adapted classroom materials to help with learning (Statistics New Zealand, 2007; Starr & Janah, 2016). The Education Review Office (2015) identified gaps in terms of achievement and progress measures and reporting for students with special education needs when compared with achievement and progress reporting for all students. These gaps include

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[3] Statistics New Zealand NZHDS child disability data was presented in a series of topic reports following each survey. From 1996-2006, the child disability data was published and presented as a population group. The NZHDS data from 2013 presented the child and adult data in a combined Disability Survey Report 2013. In order to obtain further detailed information, the process is to request customised reports. Depending on the detail of the data request, this process will incur a cost – unlike the earlier practice of publicly available disability data that related to type of disability, education, health, and unmet needs for children with a disability in New Zealand.

limitations in terms of access to specialist services and professional development for those teaching students with special education needs and for Boards of Trustees.

It is, therefore, clear that there are important gaps in government services and initiatives for children and young people with disabilities. A starting point for this research, therefore, is the observation that fragmented policy development and service provision across government and community agencies undermine a cohesive approach to supporting the wellbeing of children with a disability in New Zealand. As Starr and Janah (2016) report, funding support is fragmented and unnecessarily complicated; there is inadequate data and reporting on student achievement and progress; there is little coordination and cooperation between government agencies; and, there is no enforceable right to education in New Zealand for children and young people with disabilities. The current enforcement mechanisms are ineffective, difficult to access, and do not have the power to direct that either the school or the Ministry of Education takes action (Starr & Janah, 2016).

These problems remain despite Ministry of Education references to a commitment to inclusive education, which it defines as learning contexts "where all children and young people are engaged and achieve through *being present*, *participating, learning* and *belonging*" (Ministry of Education, 2014). Moreover, the Ministry states that New Zealand schools should be inclusive:

All students are welcome and are able to take part in all aspects of school life. Diversity is respected and upheld … all students are confident, connected, actively involved, lifelong learners and work towards this within the New Zealand Curriculum. Students' identities, languages, abilities, and talents are recognised and affirmed and their learning needs are addressed (Ministry of Education, 2013, online).

The Education Review Office (2015) report on inclusion in New Zealand schools translated what inclusion means for children and young people with disabilities, stating: "In fully inclusive schools, children and young people with special education needs have a sense of belonging as they participate as much as possible in all the same activities as their peers" (Education Review Office, 2015, p. 7).

This is a clear statement that education, if it is to be inclusive, involves a commitment to supporting participation by children and young people with disabilities in the same activities as their peers. While this may be the stated goal of the Ministry of Education, the investigation by Starr and Janah (2016) concluded that the New Zealand education system is characterised by a narrow or limited view of education as it applies to students with disabilities, and that this view has significant implications for the ability of this group to thrive.

There is a substantial body of research that identifies the crucial role of early intervention, particularly within the school context, in supporting the development and wellbeing of children with disabilities (see, for example, Bargagna, Bozza, Purpura, & Luongo, 2012; Burgoyne et al., 2012; Colozzo, Mckeil, Petersen, & Szabo, 2016; Guralnick, 2010, 2011; Mahoney, Perales, Wiggers, & Herman, 2006; Karaaslan & Mahoney, 2013; Nawi, Ismail, & Abdullah, 2013). Importantly, children, particularly those with Down syndrome, appear to experience better social inclusion if their ability to develop their capacity for communication is supported by early intervention (Burgoyne et al., 2012; Fricke, Bowyer-Crane, Haley, Hulme, & Snowling, 2013; Jackson, Cavenagh, & Clibbens, 2014). Although early intervention and the need for communication support are recognised, nationally consistent government support for children under 6 from the Ministry of Health, and for those over 6 years of age from the Ministry of Education, is insufficient to meet the needs of children and young people with a disability.

Additionally, there are examples of poor links across the Ministry of Health-funded disability support services, poor data, and a lack of accessible information that specifies possible services (Van Eden, 2013; Wynd, 2015). Service reviews point to the absences of a cohesive child-centred service and life course approach for this specific child population (Van Eden, 2013). This situation, in part, is caused by the fact that, while children and young people with a disability constitute a specific population subgroup, there is no widely used definition of the group. Recognition of problems within this sector are also evident in the admission by the then Associate Health and Disability Issues Minister in 2017 that the disability support system was not working well, and the undertaking that a review was being carried out in line with the Government's

new social investment approach to welfare to improve services with the goal of "enabling good lives" (Wagner, 2017).

Despite the fragmented nature of central government policy for support of the development and wellbeing of children and young people with a disability, individual government agencies have at times, albeit in an uncoordinated way, sought to respond to this need. For example, there are several Ministry of Education initiatives that identify the need for families and professionals to be more informed in relation to children and young people with a disability and special education needs. Between 2004 and 2010, the Ministry held a series of consultative forums under the banner of *Let's Talk Special Education, Success for All* (Ministry of Education, 2004, 2005, 2010). The Ministry does emphasise the importance of achieving positive outcomes for children with special education needs (Ministry of Education, 2006, 2010, 2015). There is impetus to shift from the deficit label of "special education" to the more inclusive label of "learning support" and to restructure special education service provision. The work programmes and consultations carried out as part of *Success for All* resulted in a review of funding frameworks, regional restructure, and a pilot project for a new model for the lead practitioner and service provision approach to schools from 2017 (Office of the Minister of Education, 2016). This practice framework was rolled out nationally in 2018 along with a renewed review of special education services; as a result, special education was rebranded as learning support. This review of curriculum replaced the previous focus on National Standards.

Notwithstanding such initiatives, the gaps identified in the *Ordinary Life Report* on services for people with disabilities in New Zealand, particularly those with intellectual disabilities, remain (National Advisory Committee on Health & Disability, 2003). A follow-up IHC report in 2016 identified that, despite the range of pilots, trials, and demonstration projects aimed at increasing choice and control for people with disabilities since 2003, many people with intellectual disabilities are still not able to live valued and "good" lives and do not have equal access to opportunities and citizenship (IHC, 2016).

These gaps affect not only the individuals with the disability, but also families supporting a member with a disability. This is particularly the case for

families in low income households who are more likely to experience failures in terms of inadequate special education support; behavioural and social support at school; teacher aide hours; and, support with exams to achieve tertiary qualifications. Importantly, within the school context, there is a recognised need for greater professional development in relation to disability (Families Commission, 2007; Office of the Children's Commissioner, 2012; Human Rights Commission, 2010; Wynd, 2015). Such conclusions were evident in the 2001 NZHDS, and the issues raised have yet to be resolved. Adults with a disability are more than twice as likely to be unemployed as nondisabled adults, and those who are employed work fewer hours per week (Ministry of Health, 2005; Statistics New Zealand, 2017).

The report that resulted from the Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities (IMM, 2014) outlined education in New Zealand as fragmented and inequitable. Criticisms included the lack of an enforceable right to education for students, housing affordability, accessibility (physical environment, transportation, information and communication), and social exclusion and poverty particularly among disabled Māori and Pacific children (IMM, 2014).

The final deficiency in government services referred to here was identified by the Child Poverty Action Group. It drew attention to the lack of uptake of the Child Disability Allowance for families with a child with a disability, a lack of data on the actual number within this category, and the whereabouts and socioeconomic status of disabled children and their families (Wynd, 2015). The IMM report also referred to a lack of information about parents as "caregivers", and the significant number of grandparents or other family members, adoptive or foster family members, caring for disabled children and young people. The needs of this group are usually overlooked during the formation and implementation of social assistance policies (Wynd, 2015). There are longstanding gaps in data collection, quality information, policy implementation, and variable parent-professional relationships. In addition, there are a range of concerns with fragmented services and the lack of access to service provision for children and young people with a disability.

As regards the Ministry of Education's reporting programme, 14 years has elapsed since the Let's Talk Special Education (2004) initiative, a period of time which encompasses almost all of a student's time at school. The Tomorrow's School review (2018) identified the main issues for children and young people with a disability. The issues relating to the provision of learning support included: students and their parents' feeling unwelcome in their local school; fragmented support; support not always being available; and, support taking a long time to arrive (Tomorrow's Schools Independent Taskforce, 2018)

The Research

The enduring concerns with the inadequacy of child disability data, the lack of accessibility to information, education, communication, person-centred disability social services, and a lack of understanding of family and disability perspectives raise many questions about the adequacy of our response to children and young people with disability. More importantly, the current situation suggests that government policies and practices are not informed by an awareness of what is required to achieve wellbeing for this group.

The research focuses on the experience of those with Down syndrome specifically and on the factors influencing wellbeing in the home, school, and community environments.

The overall goal of this research is to understand what wellbeing means for children and young people with a disability and to use this understanding to inform government policy and practice, particularly in the area of education. In order to achieve this aim, this thesis aims:

1.   To explore wellbeing from the perspective of children and young people with Down syndrome, with a particular focus on their school experiences.

2.   To understand, from the perspective of the parents and family members of children and young people with Down syndrome, what they perceive as wellbeing for this group.

3.   To understand the factors that influence wellbeing for children and young people with Down syndrome within the school sector.

4. To understand, from the perspective of the parents of children and young people with Down syndrome, what they perceive as the influence of education and social development policies and three selected New Zealand policy frameworks) on wellbeing for this group.

5. To understand, from the perspective of service providers (teachers and national policy developers) of children and young people with disabilities, what they perceive as the influence of education and social development policies and three selected New Zealand policy frameworks on the wellbeing of children and young people with a disability.

Additionally, drawing on these findings, the objective is to develop and evaluate a conceptual framework of wellbeing of children and young people with Down syndrome and to use this framework as a basis for making recommendations for policy and practice for both this group and the wider group of children and young people with disabilities.

The intention is to detail what constitutes wellbeing for children and young people with a disability in a way that is informed by the perspectives of children and young people themselves, and those in their world. There is a lack of research that draws directly on the experience of children and young people from this group (MacArthur & Kelly, 2004; Shakespeare, 2009; Thomas, Swain, Barnes, & French, 2004; Rees & Main, 2016; Boggis, 2011). I adopt a grounded theory approach (Charmaz, 2006; Glaser, 1978, 1992, 1998; Glaser & Strauss, 1967, 2009; Strauss & Corbin, 1990, 1997) and seek to include children as active participants in the research.

Chapter 2 presents an outline of the theoretical perspectives of wellbeing that inform this research. The concepts of wellbeing are reviewed in relation to adults and children and then, specifically, for children and young people with a disability. Additionally, these theories are examined for their relevance to this research. The broad concepts of hedonic and eudaimonic traditions, human rights, capability, and wellbeing across environments are considered in terms of their appropriateness for a framework of wellbeing among children and young people with a disability.

Chapter 3 introduces the methodological rationale and specific methods used to collect data on the wellbeing of children and young people with Down syndrome. The research approach is described. Three New Zealand selected policy frameworks that came out of the grounded theory approach will be discussed. The frameworks were used in the adult research enquiry and were an ecological approach to wellbeing, an objective concept through an indicator list for children and young people, and a human rights perspective. The chapter addresses the use of grounded theory and methods to record children's voice through the use of visual sociology. In the first phase of the research, interviews with the young people, their parents, and service providers were undertaken. The results of these interviews then informed the next stage which involved testing and validating the dimensions of the wellbeing theoretical framework.

Chapter 4 presents the first substantive findings of this research. It argues that a central principle that informs the wellbeing of children and young people with Down syndrome is acceptance. Acceptance is understood as a sense of belonging and is evident in social role valorisation, discourses of disability, self-esteem, and a social disability identity.

Chapter 5 describes the second key principle of wellbeing that emerged from the research—recognition. Recognition involves respect in a way that values difference and leads to access to opportunities for the development of capability. Recognition is interpreted as informing access to learning and other support services and is a part of debates about equal entitlements.

Chapter 6 reports on the observation that wellbeing amongst this group was linked with the idea of supported independence and involved the kinds of supports and living environments that promoted an ordinary life—doing everyday things in everyday places. Wellbeing involved supports within the home, school, and community for the development of those capabilities that enable individuals to live a valued life.

Chapter 7 considers the three principles of acceptance, recognition, and supported independence from the perspective of Bronfenbrenner's (1979) ecological systems and develops a model of practice to inform policy and service provision. The chapter reports on how this model was tested and validated with

parents and teachers who have worked with children and young people with Down syndrome.

Chapter 8 concludes the research with a summary of the key findings and reflections on the significance of the study. It also suggests areas where the research could be extended. All of these suggestions relate to the goal of improving policies and practices to enhance the wellbeing of children and young people with a disability.

In this thesis, I have attempted to capture the nature of the challenges that children and young people with a disability encounter daily. The young people with Down syndrome and their families acted together to ensure that their futures and aspirations were as secure as those for all other New Zealand children. The parents and young people openly shared their life stories with me and the descriptions of what they experienced to ensure their children's wellbeing was optimised. Wellbeing is a complex and multifaceted phenomenon, and the framework I have developed is an attempt to improve the lives of all children and young people with a disability.

Chapter 2:
Conceptualising Wellbeing for Children and Young People with Disabilities

Introduction

The focus of this research is on the meaning of wellbeing for children and young people with a disability in New Zealand, an area of social policy that remains largely unexamined. Wellbeing is an overarching focus in the study of social policy (Drake, 2001). It has been described as "a complex, multifaceted construct that has continued to elude researchers' attempts to define and measure it" (Pollard & Lee, 2003, p. 60). This chapter focuses on identifying concepts of wellbeing applicable to the study of wellbeing in children with a disability with a view to informing a conceptual analytical framework.

The purpose of this chapter is to establish how we might approach the theorisation of wellbeing, and how this theorisation might inform the assessment of what wellbeing for children and young people with a disability means. Defining wellbeing for children and young people with a disability is an essential first step in building links between policy development, resource allocation, and service provision in order to promote wellbeing for this population. The first section of this chapter reviews established conceptualisations of wellbeing as they apply in the adult world. As the focus of this thesis is children and young people, a separate section on the conceptualisation of wellbeing and disability for adults has not been included. This overview is followed by a review of key themes that can be applied to the study of wellbeing in children and young people with a disability. These themes inform the analytical framework that is used in this research and which is detailed in the third and final sections.

Concepts of Wellbeing

Broadly, wellbeing can be understood as a socially dependent, culturally anchored construct that changes over time in response to both changes across an individual's life course and the broader sociocultural context (Crivello, Camfield, & Woodhead, 2009). While there have been calls for the integration of differing

perspectives into an overarching definition of wellbeing in what is a rapidly
increasing body of literature (Diener & Suh, 2000; Bourke & Geldens, 2007;
Dodge, Daly, Huyton, & Sanders, 2012; Lambert, Passmore, & Holder, 2015), as
yet there is no universally accepted explanation for how wellbeing—for adults or
children—should be defined or measured (Minkkinen, 2013; Raghavan &
Alexandrova 2,015; Pollard & Lee, 2003; O'Hare & Gutierrez, 2012; Drake,
2001; Ministry of Social Development, 2001; Statistics New Zealand, 2014, Ben-
Arieh, Casas, Frønes, & Korbin, 2014; Kosher, Ben-Arieh, & Hendelsen, 2017;
Cummins, Lau, Davey, & McGillivray, 2010; Diener, 2006).

Analyses of wellbeing typically focus on adults and take place within
cross-disciplinary research focusing on quality of life, happiness, life satisfaction,
economic security, and psychological wellbeing. A simple way of conceptualising
this multifaceted concept is as the answer to the question "how are people doing?"
Responses to this question are likely to encompass all aspects of human
experience and the way it is shaped by social contexts, expectations,
socioeconomic conditions, and societal values (Ben-Arieh, Casas, & Korbin,
2014; Camfield, Streuli, & Woodhead, 2009; Crivello et al., 2009; Fattore,
Mason, & Watson, 2007; Gillet-Swan & Sargeant, 2015; Pollard & Lee, 2003;
Michalos, 2008; Ryan & Deci, 2001; Diener & Suh, 2000).

However, as the inquiry into wellbeing is conducted across a number of
disciplines, definitions and measures of it vary markedly. Psychological
perspectives, for example, emphasise subjective wellbeing and tend to focus on an
individual's experiences, their perceptions, evaluations of these experiences, and
what constitutes being essentially fully human (Diener, 1984; Dodge et al., 2012;
Ryff, 2018). Wellbeing is assessed using positive measures (social relationships,
interest in daily activities), the absence of negative affect, and overall evaluations
of life or life satisfaction (Jarden, 2011). Economic perspectives on wellbeing are
more likely to focus on material measures such as household disposable income—
the maximum a household can afford to consume without having to reduce its
assets or increase its liabilities (factoring in social transfers that households
receive from governments such as education and health services) (Organisation
for Economic Co-operation and Development (OECD), 2013). The limitations of
gross domestic product (GDP) as a sole measure of wellbeing are recognised

through measuring the social and environmental costs and benefits that GDP ignores (Anielski, 2007; Ayuso-Mateos, Salvador-Carulla, Chisholm, 2006; Salvador-Carulla, Lucas, Ayuso-Mateos, & Miret, 2014). Other conceptualisations focus on wellbeing at the societal rather than the individual level (Taylor, 2015). The point is that definitions of wellbeing are shaped in an important way by the disciplinary foundations from which the topic is approached.

Hedonic and Eudaimonic Theory

There are two distinct but related philosophical traditions that currently underpin the theories, literature, and research on wellbeing: hedonia and eudaimonia. The hedonic conceptualisation of wellbeing emphasises a positive affective state focused on pleasure, happiness, the absence of pain, subjective wellbeing, and satisfaction with life (Deci & Ryan, 2001; Cooke, Timothy, & Melchert Connor, 2016). Hedonic notions of wellbeing accentuate cognitive evaluations as people act in the pursuit of the greatest balance of pleasure over pain (Kahneman, Diener, & Schwarz, 1999; Taylor, 2015; Crisp, 2013). In assessing wellbeing, the hedonic approach focuses on the appraisal of the conditions of one's life, an approach that has led to contemporary understandings of psychological wellbeing (Deci & Ryan, 2008).

The eudaimonic tradition conceptualises wellbeing in terms of positive psychological functioning, the development of personal strengths, and contribution to the greater good. Eudaimonic ethics draw on Aristotle (translation 1985), according to whom the goal of human functioning was to live in a way consistent with one's true self, with one's development, values, realisation of potential, and inherent nature, thus, giving purpose and meaning to life (Waterman, 1993; Waterman, Seth, & Conti, 2008; Ryff & Keyes, 1995; Ryff, 1989). Ryff (1989) identified six eudaimonic dimensions that remain in use in current research. The six dimensions are environmental mastery; purpose in life; positive relationships; autonomy; personal growth and self-acceptance and are referred to as the model of psychological wellbeing (Ryff, 1989;2018). The research where Ryff's model is used were grouped into areas such as demography, epidemiology, sociology, health, disadvantaged groups, and parents

of children with a disability (Ryff, 2018). The model offers opportunities to probe how core experiences of adult life impact people's perceptions of themselves as living by their own convictions (autonomy), being capable (environmental mastery), being meaningfully engaged (having purpose in life), being connected to others (positive relations), realising their potential (personal growth), and experiencing positive self-regard (self-acceptance) (Ryff, 2018, p.244).

The eudaimonic understanding of wellbeing has informed many different concepts, including humanistic theories of psychology like those of Abraham Maslow (Lambert et al., 2015). Maslow's hierarchy of needs, which emphasises self-actualisation (or the achievement of one's full potential), systematically examined the scope of human potential (Maslow, 1954, 1968). Generally speaking, humanistic theories are based on the individual's needs, health, goals, values, and qualities that are required to achieve meaning across a life span and thus wellbeing (Lambert et al., 2015).

Subjective wellbeing

Subjective wellbeing has its origins in the hedonic traditions (Kahneman et al., 1999; Diener, Scollon, & Lucas 2009). Subjective wellbeing is multifaceted. It has been defined in terms of three interrelated components: the presence of positive affect or happiness; the absence of negative affect or unhappiness; and, life satisfaction or contentment (the cognitive sense of satisfaction with life) (Diener & Suh, 1997; Diener, Suh, Lucas, & Smith, 1999; Ryff, Singer, & Love, 2004; Ryan & Deci, 2001; Kashdan, 2004). Subjective wellbeing looks beyond education, income, marital status, and job morale and offers greater recognition of the role of the individual's goals, coping efforts, and dispositions (Diener et al., 1999; Diener, Scollon, & Lucas, 2009). The key to subjective wellbeing is acquiring social information and observing differences and similarities between oneself and others (Diener et al., 1999). For example, in Diener's (1984) study, social comparison is recognised as influencing subjective wellbeing. Upward comparisons, where others are perceived as being better off, are understood to decrease happiness, while downward comparisons, conversely, may increase happiness (Diener et al., 1999). Further aspects of the influences of social information and experiences are linked to subjective wellbeing.

Subjective wellbeing is also influenced by an individual's expectations and hopes, with the process of moving towards achievable aspirations being at least as important to wellbeing as is the end state of goal attainment. Importantly, individuals may be satisfied as long as they are making adequate progress toward their goals (Diener et al., 1999; Thorsteinsen & Vitterson, 2018; Wiese, 2019). Distinct personal goals that are valued and autonomously chosen and which are facilitated in daily life contexts can contribute positively to subjective wellbeing; whereas, a lack of these kinds of attainable goals can have a negative impact (Diener et al., 1999; Thorsteinsen & Vitterson, 2018).

Happiness and wellbeing

Happiness is also considered within the hedonic tradition where it has been associated with wellbeing dating back to translations of Aristotle (Diener et al., 2009; Taylor, 2015; Ryff, 2018). The quality of one's personal relationships with family members, friends and colleagues, situational factors, and social conditions are considered vital to an individual's happiness (Bok, 2010). Bok discusses how people who participate in social groups and organisations and who are in close relationships and have a network of friends are happier. While he does not refer to acceptance, the implication is that one has to be accepted or order to participate in these relationships (Bok, 2010 p.19-20). Happiness is valued by some proponents of objective theories of wellbeing (Kraut, 2009; Fletcher, 2013). Kraut's developmentalist approach includes happiness in cognitive, social, affective, and physical dimensions of life in a way that is appropriate to individuals' stage of development, including that of children (Raghavan & Alexandrova, 2015). Bok (2010) describes wellbeing 'comes from being connected and engaged, from being enmeshed in a web of relationships and interests' which are maintained without interference from outside pressures such as over stress or health needs, giving the individual a sense of ongoing acceptance.

Given these insights, research into wellbeing should encompass ideas of subjective wellbeing, autonomy, social comparison, social acceptance, the importance of the pursuit of valued goals, and happiness. There are further

hedonic considerations relevant to answering the question of "how are people doing?".

Wellbeing and life satisfaction

The self-reported component of "having a good life" in subjective terms aligns life satisfaction within the hedonic tradition (Diener et al., 2009). Life satisfaction as a concept suggests that wellbeing is subject to conditions such as authenticity and autonomy (Taylor, 2015). Judgements of standards for, or contributors to, a satisfying life are important, so that subjective and objective concepts can be applied on an individual level and/or on a broader social level.

Various elements of culture (such as beliefs, values, cultural practices) and the way individuals define themselves within a particular culture play a crucial role in divergent life satisfaction judgment styles found cross-culturally and, therefore, judgments about life satisfaction (Suh, Diener, & Updegraff, 2008). This finding implies that research into wellbeing should incorporate judgements about elements of a satisfying life. For marginalised groups, this judgement would include measures of social acceptance, given the importance of this for a satisfying life. The traditions of hedonic and eudaimonic approaches are, therefore, related to wellbeing and, although coming from different philosophical origins, both perspectives can be evident in some approaches to wellbeing such as quality of life.

Quality of Life

The term "quality of life" (QOL) conceptualised in hedonic and eudaimonic theory encompasses physical, psychological, and social aspects of functioning and is used by a wide range of disciplines including medicine, psychology, sociology, and education. QOL is often used interchangeably with subjective wellbeing and life satisfaction (Cooke, Melchert, & Connor, 2016). QOL is used as the basis of measurement in frameworks where wellbeing is the broader concept.

QOL and wellbeing are seen as closely interconnected in the health sciences. This perspective is informed by the WHO definition of health as "a state of complete physical, mental and social *wellbeing* and not merely the absence of

disease or infirmity" (WHO, 1948). From a QOL perspective, wellbeing has specific domains such as work life, social life, family life, spiritual life, financial life, community life, and marital life and life satisfaction is assessed in relation to these (Sirgy, 2012). The notion of quality of life is understood as an indicator of subjective aspects of wellbeing (Salvador-Carulla, Lucas, Ayuso-Mateor, & Miret, 2014). Notably, human rights and QOL concepts are often integrated in the development of indicators and reviews of outcomes of service provision (Maeyer, 2017; De Negri Filho, 2013). QOL indicators can be used to identify the promotion or reduction of human rights for population groups such as social determinants of health, poverty and or public health.

QOL information is a useful indicator of people's subjective wellbeing and that data can be aggregated to represent the views of specific demographic groups (for example, children, women, the disabled, the elderly, and the poor) and of people in specific geographic areas (such as communities, state/provinces, and countries). The QOL indicators, therefore, have potential to provide information on the degree of equality or inequality experienced by disadvantaged groups at a societal level beyond that of the individual or household (Estes & Sirgy, 2017). The notion of QOL, then, offers an integrative concept that includes human rights and implies that research into wellbeing should be self-reported, should encompass multidimensional domains, and should have a focus on indicators, across individuals, groups, and society.

Human Rights and Wellbeing

The notion of human rights also has implications for understandings of wellbeing. The Universal Declaration of Human Rights (UDHR) (1948) was considered the foundation for the promotion of the wellbeing of humanity, noting that the core idea of the Universal Declaration is human dignity and respect (Task Force Human Rights, 2015). The importance of this approach, as exemplified in the UDHR, is that it provides a basis upon which to identify and address inequalities in wellbeing for population groups (Gooda, 2011).

The notion of human rights refers to the legal, social, ethical, and/or moral principles of freedom and entitlements in society. They are seen as

acknowledgement of basic human needs, the importance of opportunities to acquire capabilities in education and employment, and the importance of human relationships. For these reasons, human rights are considered as essential to wellbeing. The philosophical underpinnings of human rights are much debated and not within the scope of this thesis (see Talbott, 2010; Nickel, & Reidy, 2009; Tasioulas, 2015). Major advances in the recognition of human rights occurred after World War II and, according to Sieghart (1990), the core principles can be summed up thus: "every human being has certain rights by virtue of his [sic] humanity alone; the principle of inalienability; no human being can be deprived of those rights; the rule of law" (p. 8).

In Human Rights, the growing commitment to children's wellbeing and children's rights and the intercorrelation between them is evident and shown in empirical research. The commitment has been defined as the realisation of the child's rights and the fulfillment of the opportunity for the child to be all he or she can be in light of the child's abilities, potential, and skills (Bradshaw, Hoelscher & Richardson, 2007). The rationale is to ensure that the broad, rights-based vision of wellbeing in the two human rights frameworks are considered. As has been cautioned when undertaking research, when children's rights are considered, children with disabilities are often unaccounted for and when the rights of people with disabilities are considered, children with disabilities tend to be forgotten. "Except in cases where expressly mentioned in the CRC, such as in areas of education, training, health, and rehabilitation services, rights for children with disabilities were disregarded" (Sabatello, Schulze, & Schulze, 2014, p.97). To ensure equal respect of all people's rights, it is regarded as imperative that the CRC extended to children with a disability obligation on the government remains visible.

The CRPD (2006) elaborates on the rights given to children by the CRC. The position of disabled children has been further enhanced by CRPD, in particular Article 7 which incorporates "the best interests, and the rights to be heard and have views taken into account, found in Articles 3(1) and 12(1) CRC, as Articles 7(2) and (3) respectively" (Sandland, 2017 p.94). Article 7 acts as a bridge between the CRC and the 50 Articles of the CRPD (2006)

The CRPD (2006) builds on previous human rights conventions, and drew together the work of disabled people, disability organisations and governments to negotiate the contents of the convention, including New Zealand's input with Robert Martin, a man with intellectual disability (Inclusion International, 2016). CRPD provides an instrument to refocus human rights within the experience of disability and for people with a disability to be represented as active holders of human rights on an equal basis to non- disabled people. The CRPD provides a new framework to challenge actions, securing state resources, public spending on social programmes and service provision and the contribution to wellbeing in relation to disability issues (Iriarte, McConkey & Gilligan, 2015). It is important to note, however, human rights are values and principles which are not enforceable or accountable through service provision. In this thesis they are discussed to the extent that children's rights informs the wellbeing framework which provides the option of measurable priorities which are implemented through service provision and therefore have the option of being enforced through government policies and procedures for child outcomes. For these reasons the United Nations Convention on the Rights of Children (UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) are the human rights frameworks primarily used in this thesis.

The Capabilities Approach

The capabilities approach brings together other perspectives on wellbeing in a way that emphasises that wellbeing is achieved when people have the opportunity to "be and do"—to be who they want to be and do what they want to do. Sen's capability approach is concerned with the nature of "being"; he posits that, ultimately, humans want to live well and achieve the highest good or happiest state within what constitutes a good society (Clarke, 2006; Ryan & Deci, 2008; Gillet-Swan & Sargeant, 2015). The capabilities approach has emerged as a leading alternative to the economic framing of wellbeing in measures of poverty, inequality, and human development (Clarke, 2006; Gillet-Swan & Sargeant, 2015). It encompasses social, economic, and ethical examinations of a framework of human capability, life, and freedom. For Sen (1999), wellbeing is related to opportunity, the capacity to use and access distinct opportunities, and the freedom

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to do so in relation to personal preferences. As such, commodities are a means by which an individual can achieve utility. In this sense, capability is related to both opportunity structures and the agency of the individual (Sen, 1999).

The capability approach is a flexible framework, and when evaluating wellbeing, Sen argues, the most important thing is to consider what people are actually capable of being and doing, that is, their functionings. Functionings are valuable activities and states that make up people's wellbeing; they include areas such as health, being safe, work, and so on (Sen, 1999). The capability approach involves "concentration on freedoms to achieve in general and the capabilities to function in particular" (Sen, 1995, p. 266). Sen draws a clear distinction between capabilities and functionings: "A functioning is an achievement, whereas a capability is the ability to achieve … what real opportunities you have regarding the life you may lead" (Sen, 1987, p. 36).

Functionings are the "beings and doings" of a person. Sen emphasises that capabilities reflect an individual's real opportunities or positive freedom of choice between possible lifestyles (Sen, 1999; Clarke, 2006; Ben-Arieh et al., 2014; Robeyns, 2003). His framework is flexible and can be applied across a range of environments, spaces or settings (Clark, 2006).

Various researchers have sought to augment Sen's approach, the most notable being feminist philosopher Martha Nussbaum. Nussbaum's (2003) approach to wellbeing proposes a set of basic human capabilities as the goal of social policy. She outlined 10 capabilities that should be provided within each society as an entitlement and "opportunity for functioning" (Clark, 2006; Gillet-Swan & Sargeant, 2014; Robeyns, 2003, p.15). These are: life, bodily health, bodily integrity, senses, thought and imagination, emotions, practical reason, affiliation, care of other species, and control over one's environment (Alkire, 2002, p. 203; Nussbaum, 1992, p. 222; Hamilton & Redmond, 2010; Gillet-Swan & Sargeant, 2015).

Nussbaum advances "threshold levels" for each of the capabilities, and states that "the social goal should be understood in terms of getting citizens above this capability threshold" (2000, p. 6). Nussbaum identifies these capabilities as ''equally fundamental" and necessary for establishing what is good (2000, p. 5).

They should, she suggests, be treated as both interdependent and independent, acknowledging both that achieving one capability can be independent of achieving others, and that each can augment the others. These objective capabilities should inform rights formation and political intervention, as they relate to wellbeing (Nussbaum, 2000; Anand, Hunter, & Smith, 2005; Hamilton & Redmond, 2010).

White (2008) also developed a multidimensional capability approach to wellbeing; she incorporates subjective, material, and relational dimensions. In her dynamic interactive process individuals become who and what they are in and through their relatedness to others. Overall, wellbeing is seen as a process influenced by relationships in social contexts. The capability approach to understanding wellbeing, thus, implies that research into wellbeing should focus on levels of opportunities and on interdependent and independent capabilities related to opportunity structures (including social institutions). There is an affinity between these ideas and the assumptions that inform ecological theory.

Wellbeing across Environments: Ecological Systems Theory

Originally proposed by Bronfenbrenner (1977, 1979), ecological systems theory has been widely adopted by developmental psychologists interested in understanding individuals in context. Bronfenbrenner's (1979, 1995) approach to human development informs an ecological approach to the understanding of wellbeing and draws attention to the interrelatedness of individuals, their social contexts, and their environments. Bronfenbrenner highlights the impacts of the social environments or systems of childhood. The ecological model depicts concentric circles of influence, with the inner most circles representing the most immediate influences (such as the family) and the outer circles representing broader social influences (Wise, 2003). Ecological systems theory has been used to focus on wellbeing in rest homes and health care and residential facilities (Pittenger, Huit, & Hansen, 2016; Manning, 2017). Bronfenbrenner recognised that external influences on the family, even those with which the individual may never directly interact, might have a large impact.

Summary

In summary, the notion of wellbeing can be seen as a multidimensional concept with potential to guide a systematic approach towards answering the question "how are people doing?". It recognises wellbeing in terms of positive affect and happiness, life satisfaction, and people's perceptions of autonomy, capability or environmental mastery, having purpose, connection to others, personal growth, and self-acceptance. These concepts are recognised and arguably interchangeable within constructs of wellbeing across disciplines. A further finding, across the review, is that the importance of the pursuit of and progress towards goals is significant. The QOL framework takes a different approach in that it provides the basis for measuring a range of indicators and for the analysis of the quality of service provision. QOL concepts assist in identifying the experiences of specific demographic groups.

In comparison to the hedonic and eudaimonic based concepts of wellbeing the human rights foundation of wellbeing acknowledges the legal, social, ethical, and moral entitlements in society. Various human rights conventions have historically been used to address issues of wellbeing for specific groups. On the other hand, the capabilities approach draws attention to the conditions and opportunities to live well and achieve the highest good, and it reflects an individual's real opportunities to truly function and achieve the positive life of his/her choice. These opportunity structures are shaped by the environments and contexts that inform human development. Finally, the ecological systems approach recognises the interrelatedness of individuals, their social contexts, and their environments and the impact these have on wellbeing cannot be under estimated.

The six fundamental principles of wellbeing that emerged from the review outlined above are, therefore, worth considering in the pursuit of a framework for the analysis of wellbeing in children and young people with a disability. These six principles stress that:

- wellbeing is a life process at a fundamental level based on human needs;

- wellbeing involves an individual's having the ability to reach his/her potential through capability and the opportunity to take on valued social roles;

- subjective wellbeing and happiness are considered in relation to others (given the importance of social acceptance and social comparisons);

- wellbeing involves self-actualisation and autonomy;

- wellbeing recognises the significance of the role of individual goals and pursuit of aspirations; and, finally,

- wellbeing encompasses a sense of satisfaction across socioeconomic life domains.

Wellbeing and Children

Having reviewed theories of wellbeing for adults, the purpose now is to examine conceptualisations of wellbeing in relation to children and young people. The study of children as a population group has led to the recognition of new concerns about the early stages of life. These concerns are reflected in scholarship on the wellbeing of children from economists, medical researchers, psychologists, and sociologists (Pollard & Lee, 2003; Bornstein, Davidson, Keyes, Moore, & the Centre for Child Well-Being, 2003). In some of these studies, terms such as life satisfaction and quality of life are used interchangeably with wellbeing (UNICEF, 2014; Knies, 2011; Pollard & Lee, 2003; Veenhoven, 2000), while others stress differences between the terms (Gasper, 2004; Diener, 1984). Child wellbeing research has, therefore, been approached in a variety of ways (Pollard & Lee, 2003, Hanafin & Brooks, 2005).

Despite increasing interest, wellbeing has not been well theorised for children and young people (Diener, 1984; Ryff, 1989; Ben-Arieh, 2005; Raghaven & Alexandrova, 2015). The view of children as adults in deficit, unable to experience wellbeing until adulthood as a consequence of maturity and socialisation, has framed much thought on the nature of childhood. Philosophers as early as Aristotle viewed childhood as a stage in which one was unable to experience a complete life (eudaimonia). This view comes through in Maslow's

hierarchy (1987) in which children are said to lack the necessary potential for self-actualisation. This view essentially denies the possibility of wellbeing for children in their present lives (Fattore, Mason & Watson, 2016). Such a view is particularly significant for children and young people with a disability.

Adult measures of economic progress (through national economic indicators or household incomes) continue to be a default measure of child wellbeing, but these measures are increasingly being challenged by the need to take into account other life dimensions (Fattore et al., 2016; Gore, Emerson, & Brady, 2015). Economists have traditionally equated wellbeing with an individual's material conditions such as income and wealth (Gasper, 2004), and in relation to children, this link is evident in research into child poverty and wellbeing (Camfield et al., 2009; Wynd, 2015; Dale, St John, Asher, & Adam, 2010; OECD, 2016; UNICEF, 2013; Hodgson & O'Brien, 2010). Economic perspectives on wellbeing for children also look at the overall impact of state welfare (through child benefits) on measures of education and access to health services. Child wellbeing is clearly influenced by parental income and access to housing, health, and education (Qu & Weston, 2012; Boston & McIntosh, 2012); however, material conditions alone cannot be relied upon to account for a child's wellbeing (McGregor, & Pouw, 2017; Gasper, 2004). Nevertheless, there is an enduring assumption that if income increases, then the wellbeing of children will move in the same direction (Easterlin, 2003; Milligan & Staple, 2011). This is an inadequate measure on its own. It is, therefore, important to consider the other concepts of wellbeing and how these would inform an analysis of wellbeing for children and young people with a disability.

Wellbeing for Children: Conceptual Shifts

Ben-Arieh (2000, 2005, 2008, 2010) identifies four major conceptual shifts that have led to our current perspective on the wellbeing for children: 1) a shift from a focus on survival to a focus on wellbeing; 2) a new emphasis to promote positive outcomes for children; 3) a shift from "well-becoming" to "wellbeing" involving a recognition of children's life experience in the present rather than a focus on their future development as they become adults; and, 4) a major shift from traditional to new domains of wellbeing for children. This change is evident in a

number of international "state of the child" reports since the 1980s and in the emerging and consistent interest in the childhood social indicators movement (Casas, 2011; Kamerman, 2010; Kosher et al., 2017).

These shifts have cumulatively led to the development of a consensus about the conditions that shape child wellbeing. These include the status of the families with which children live, their income and wealth, jobs and earnings, and the quality of housing conditions and environment. Furthermore, wellbeing indicators for children are accepted as including health status, education and skills, opportunities for social inclusion, the family environment, personal security, and their subjective sense of wellbeing (OECD, 2015, p. 146).

Wellbeing and well-becoming: The developmentalist approach

As noted above, a key change in the conceptualisation of wellbeing for children has been the shift from seeing children as "becomings" to "beings", a shift from seeing a child as a work in progress—or earlier as an adult in deficit—to a child as a "being", present and accountable in his/her own life experience here and now. These concepts refer to life as it is experienced in the present and life as it develops toward adulthood (Ben-Arieh et al., 2014).

Assessments of needs within the earliest years of the individual's life span have typically been approached through the developmentalist concept of wellbeing for children (OECD, 2009). In this conceptualisation of child wellbeing, the child is viewed "as a work in progress" (Conti & Heckman, 2014, p. 364). The developmentalist conceptualisation of child wellbeing "envisions a core set of capabilities as capacities to function, including cognition, personality, and biology" (Conti & Heckman, 2014, p. 365). This perspective emphasises that childhood wellbeing includes "the accumulation of human capital and social skills for tomorrow" (OECD, 2009, p.25). In this approach, wellbeing involves the achievement of developmental milestones and the successful negotiation of childhood institutions such as the school environment (OECD, 2009). The developmentalist perspective is more likely to be associated with a greater focus on poor child outcomes and can be associated with assessments of wellbeing in

terms of physical health (see Australian Institute of Health and Welfare (AIHW), 2003, Ministry of Health, 2016, Ministry of Education, 2017a).

Through a developmentalist lens, then, children have been viewed as "in need" if their health or development is not in line with the normative standard developmental milestones or if a physical health need or impairment is present (a deficit orientation). This approach has, however, been changing as, increasingly, conceptualisations of the child that homogenise and decontextualise children and their lives are being viewed as problematic (Brady, Lowe, & Olin Lauritzen, 2015). Newer approaches acknowledge the diversity and variation of children's lives and, thus, take into account age, gender, ethnicity, and capacity as well wider socioeconomic contexts. The fact is children live in different national and cultural contexts, are subject to a range of different normative standards, and have access to different institutions (including bodily, social, and material resources) (Prout, 2005; Punch & Tisdall, 2012).

Wellbeing, human rights and the right to agency

Wellbeing is considered a guiding principle of the United Nations Convention on the Rights of the Child (UNCRC) despite the fact that the word wellbeing, itself, is rarely mentioned in the main text (Bradshaw, Hoelscher, & Richardson, 2007; Cassells, McNamara, & Wicks, 2011; Doek, 2014; Ben-Arieh & Frønes, 2011; Lundy, 2014). As Lundy points out "the phrase 'children's rights and well-being' has become something of a mantra in the literature on childhood, a recurrent pairing which suggests that the concepts are inextricably related yet nonetheless distinct" (2014, p.2439). As Camfield et al. stress "monitoring, promoting and protecting well-being is central to the realisation of children's rights" (Camfield et al., 2009 p.65) and the language of rights lends moral and legal force to claims toward improving conditions for children (Lundy, 2014).

 The rights identified in the UNCRC (1989) are understood as contributing to the conditions for wellbeing and, therefore, have the potential to contribute to a framework for the study of wellbeing among children and young people (Ben-Arieh & Frønes, 2011; Australian Research Alliance for Children and Youth (ARACY), 2010).

The UNCRC (1989) offers a normative framework that contains four general principles on how to conceptualise child wellbeing. The principle of non-discrimination (Article 2) refers to the need to recognise the life situations and wellbeing of excluded groups of children, including children with disabilities. The principle of the best interest of the child (Article 3) implies that there should be a child focus in all that is done with and for children in order to strengthen children's roles as citizens in their own right. The complexity of children's lives is reflected in the principle of survival and development (Article 6). The principle of respect for the view of the child (Article 12) acknowledges children's right to be heard, to have an opinion, and to have that opinion taken into account in decision-making about their lives (Bradshaw et al., 2007; Doek, 2014; Kosher & Ben-Arieh, 2017).

Furthermore, the new sociology of childhood underlines the rights of children as citizens of the present and acknowledges them as actors with their own individual agency and not simply as beings on their way to adulthood. Children are conceptualised as competent social actors who are capable of making sense of and affecting their social environments, i.e., as "experts themselves". This conceptualisation recognises children as individuals rather than simply as part of a homogenous group or family unit, and, thus, qualifies them to speak on their own behalf. The sociology of childhood also stresses the need to consider the significance of power relations as they relate to children (Ben-Arieh et al., 2014, Fergter & Richter, 2014, Matthews, 2007).

In these conceptualisations children and young people are acknowledged as "social actors" both living within a structured life stage (childhood) and playing a role in structuring that stage (Mason & Hood, 2011). With specific reference to children and young people, much of the wellbeing debate identifies young people's competency as experts in their own lives (Statham & Chase, 2010) and their potential future outcomes (Raghavan & Alexandrova 2015; Fergter & Richter, 2014; Matthews, 2007; Redmond et al. 2016). The value placed on the authentic voice of children is evident in the principle in the UNCRC (1989) that children's voices should be heard in decision-making about their welfare (Fattore et al., 2016). Critically, children and young people are vital social actors in defining their own wellbeing and in research related to this.

Environments for capabilities

Child wellbeing, therefore, is embedded within a complex network of social and economic relationships (Crivello, Camfield & Woodhead, 2009). Recognising the interrelatedness of different dimensions of wellbeing that are situated in a social context is consistent with a "whole child" or holistic approach to wellbeing (Hamilton & Redmond, 2010). This approach, therefore, links social and affective states of wellbeing with other dimensions of wellbeing such as material wellbeing, physical health, agency, and the capacity to be reflexive and critical (AIHW, 2012). Understandably, therefore, a whole of child or holistic approach is critical in any conceptualisation of wellbeing for children. For children, therefore, wellbeing is observable through two interdependent domains:

- The individual dimension—consisting of internal (intrapersonal) and relational (social/interpersonal) characteristics; and

- The environmental dimension—consisting of influences from three spheres: family and home, early education settings and school, and community. The extent and nature of the effect of these spheres changes according to the age of the child. (AIHW, 2012, p. 9)

Bronfenbrenner's ecological model of wellbeing recognises not only these interactions between multiple environments, but also the individual and relational characteristics of the child (AIHW, 2012). This consideration is echoed in both New Zealand's child policy approach and its service provision for children (Ministry of Social Development, 2002a, 2002b, 2003). New Zealand's early childhood curriculum—Te Whariki—is underpinned by Bronfenbrenner's ecological model, not only in terms of pedagogical approaches, but also in policy decisions (Clarkin-Phillips, 2012).

A whole child approach, therefore, seeks to take account of the environments in which children live and socially interact. The capabilities of children and young people are formed through social interaction within the home and broader environments, and they play a major role in the foundation of human development (Biggeri, Ballet, & Comim, 2011). Sen's and Nussbaum's capability approach is also, therefore, applicable in the context of child wellbeing. The

capabilities approach establishes the preconditions for a good life for children and young people as shapers of their own social reality. It emphasises acting, freedom to do things, functionings, and being and points to the fundamental preconditions society must provide so that children and young people may flourish (Biggeri et al., 2011; Fegter & Richter, 2014). This approach has historically been applied with a focus on deficit when addressing children's issues. An example of this focus is the Human Development Index and the two dimensions (health and knowledge) which directly affect children as regards its data on morbidity, disease, and impairment. The development of capabilities is a process, and this is especially relevant during childhood when the potential for developing key capabilities may be missed, in some cases irreversibly, in later life (Biggeri et al., 2011; UNICEF, 2007; Fegter & Richter, 2014).

Assessing child wellbeing

The ideas noted above are reflected in a number of reviews that have identified distinct domains for considering child wellbeing (Pollard & Lee, 2003; Child Trends & Halle, 2003; Reidy & Winje, 2002; Ben-Arieh, 2002; Hanafin & Brooks, 2005; Australian Research Alliance for Children and Youth (ARACY), 2010; Rosanbalm et al., 2016; Goswami, Fox, & Pollock, 2016). Mickelwright and Stewart (1999) suggest that there are four key domains which indicate the potential for a child to lead a "good life": material well-being, health and survival, education and personal development, and social inclusion/participation. According to the Annie Casey Foundation (2013), the key domains are economic well-being, education, health, and family and community. The five areas of focus in the comprehensive wellbeing review undertaken by Hanafin and Brooks (2005) are: physical and mental health, achieving full potential in learning and development, safety and protection, economic security and opportunity, and being connected, respected (free from discrimination), and able to contribute (Minister for Children and Youth Affairs, 2017). Notably, children with a disability are included within these five outcomes as a population group (Kirk, 2006; Llewellyn & Leonard, 2010).

This approach to understanding wellbeing for children, therefore, implies that research into wellbeing should have a holistic approach that takes account of

the different environments within which children live and socially interact. Furthermore, this approach implies that research with children needs to pay attention to several unique factors including the family, schools and communities, culture, and developmental pathways (Hamilton & Redmond, 2010; AI Health Welfare, 2012). It implies the need to pay particular attention to the need to hear the authentic voice of the child within the context of her/his daily life experiences and to the power relations associated with allowing children to speak about their own experience of childhood. The themes outlined here from the Australian research are also reflected in the work of other international researchers of child wellbeing.

The figure below encapsulates a holistic approach and the different environments of children's lives. This approach to understanding wellbeing for children reflects an adapted quality of life approach for children that includes domains of specific emphasis related to relationships, participation, where they spend their day, health, education, family, material/economic considerations, affective states, and personal autonomy. In terms of the concepts and approaches discussed, the hedonic or eudaimonic basis is not as distinct in the literature on child wellbeing as it is in the literature for adults, something which is well described in the model by Rees (2013).
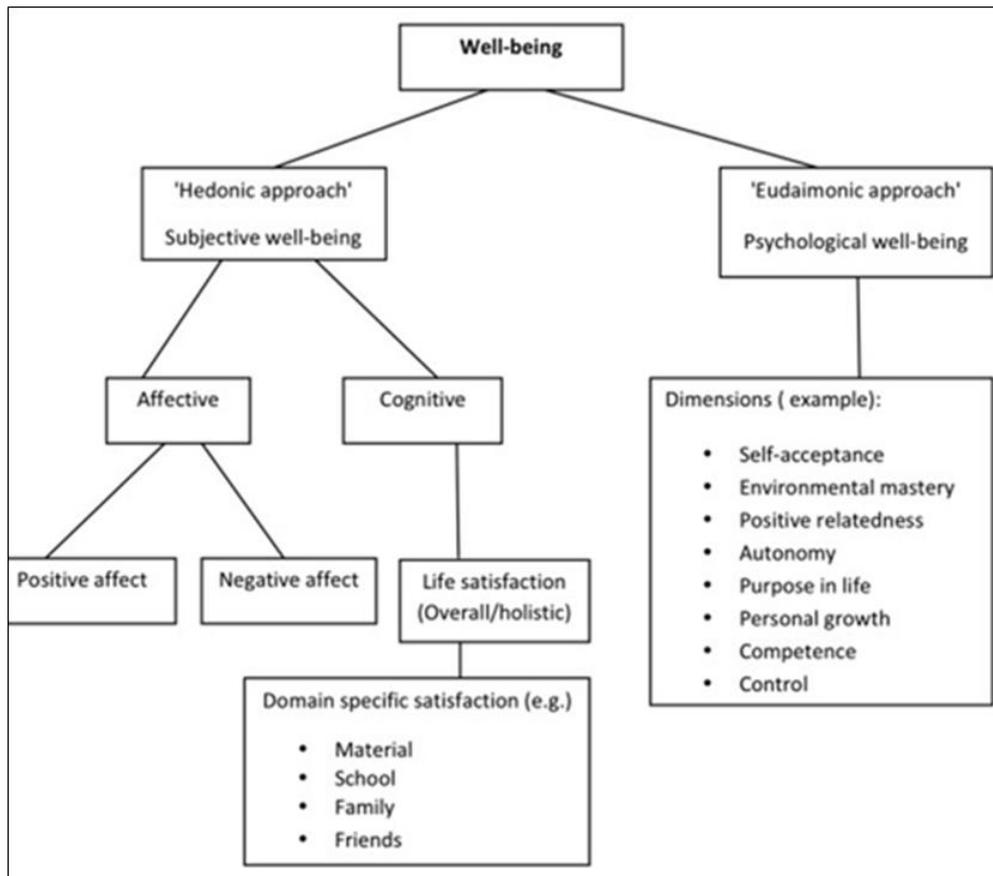
Figure 1. Approaches to defining wellbeing.
Source: Rees et al., (2013, p. 8) with modifications by MYWEB (2016, p. 4)

Figure 1 was developed by the Measuring Youth Wellbeing (MYWEB) European review and it incorporates the Children's Society model 2013-2018[4]. MYWEB adapted the Children's Society model with dimensions similar to the Ryff scale. The model incorporates hedonic and eudaimonic wellbeing and shows how these are assessed for children and young people. This is an example of a domain-specific satisfaction list for children and youth where these traditions could be measured or considered as indicators (Measuring Youth Wellbeing, 2016) and so shows the multifaceted approach to wellbeing for children and young people. This model is considered to be appropriate for research into children with a disability.

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[4] In G. Rees et al., The Good Childhood Report, 2013, p. 9, with adaptions taken from Goswami et al.'s (2016) "Measuring Youth Wellbeing Model".

The principle differences between wellbeing for children and adult wellbeing research would be the focus on the whole child perspective and of the child on a trajectory into the future.

Summary

The study of children as a population group has led to the recognition of new concerns regarding the early stages of life. Despite increasing interest in the concept, wellbeing has not been well theorised for children and young people. The view of children as adults in deficit denies the significance of wellbeing for children in their present lives. Economists have traditionally equated wellbeing with an individual's material conditions; this link is evident in research into child poverty and wellbeing. Economic perspectives on wellbeing for children also look at the overall impact of state welfare. It is clear, however, that child wellbeing is also significantly influenced by health, education, parental status, and social relationships.

A foundational approach to assessing needs within the earliest years of the life span is the developmentalist concept which views the child as well-becoming i.e., as developing a core set of capabilities through the achievement of developmental milestones and the successful negotiation of child institutions such as the school environment. These "normalised" standards of cognition, biology, and social skills, however, have often focused on poor child outcomes and can be associated with assessments of health and wellbeing. This approach has been challenged by ideas acknowledging the diversity and variation of children's lives.

Developments within the sociology of childhood have led to an acknowledgment of the diversity and variation of children's lives, taking into account age, gender, ethnicity, and capacity, as well as wider socioeconomic contexts. This perspective not only emphasises children as agents, but also children's rights and opportunities. There is an increasing emphasis on the use of the human rights framework to acknowledge both children as social actors in their own world and children's capability to make sense of and affect their social environments.

Ben-Arieh et al. (2000, 2010, 2014) have consistently argued for the need for research and policy focused on the promotion of wellbeing of children as a population group. This argument is in line with the UNCRC (1989) rights framework. The capabilities of children and young people are formed through social interaction within the home and broader environments, both of which can help establish the preconditions for a good life. Children and young people depend on and are vulnerable to relationships and social institutions. When applied to children, the capability approach requires specific acknowledgement of the influence of care and power relationships and of social institutions. Wellbeing for children encompasses the whole child and incorporates both ecological systems and developmentalist insight.

Wellbeing for Children with a Disability

Despite growing interest in the concept of wellbeing and improvements in definitions of wellbeing as it relates to children, constructions of disability have hindered progress in developing clearer conceptions of wellbeing for children and young people with a disability (O'Hare & Bramstedt, 2003; Childhoods, 2005; European Committee for Social Cohesion, 2004; Fawcett, 2016; OECD, 2002). In fact, traditional wellbeing frameworks have used childhood disability as a marker of poor health status (and, consequently, poor wellbeing) or have omitted considerations of disability, rather than considering children with disability as a group for whom a distinct consideration of wellbeing is merited (ARACY, 2010). Research that examines the views and opinions of children and young people with disabilities is largely nonexistent, highlighting a significant gap in the current literature (Foley et al., 2012; Crivello et al., 2009; Maher, Olds, Williams, & Lane, 2008).

A challenge associated with conceptualising wellbeing in this area is the need to take into account the type of disability, age, and level of functioning of any potential research population (Hanafin & Brooks 2009; Australian Institute of Health and Welfare, 2009; Foley et al., 2012). These dimensions all influence daily experiences of independence, mobility, access to education, social inclusion and participation, and access to social services (Barnoy, Biton, & Itzhaki, 2017; Porcelli, Ungar, Liebenberg, & Trépanier, 2014; Kearney, 2014; Foley et al.,

2013). These factors are all recognised as important dimensions in the emergent concepts of wellbeing for this group.

Wellbeing, disability, and Quality of Life

QOL studies for children and young people with a disability have the potential to provide insights into the conceptualisation of wellbeing. QOL studies to evaluate the performance status of persons with disabilities have, for instance, led to the development of the Karnofsky index for the measurement of functional impairment. This index was updated in the 2000s to become the WHOQOL disability model (WHOQOL-DIS) for persons with physical and intellectual disabilities. The WHOQOL-DIS model identifies health-related wellbeing classifications of disability[5] as practical concepts of health and disability (Salvador-Carulla et al., 2014).

QOL frameworks are broadly used in the area of intellectual disability. One that is widely used in social and education settings is the eight-domain model proposed by Schalock and Verdugo (2002, 2012). In this model, the eight interrelated domains are personal development, self-determination, rights, interpersonal relationships, social inclusion, material wellbeing, physical wellbeing, and emotional wellbeing (Morisse, Vandemaele, Claes, Claes, & Vandevelde, 2013; Gomez, Verdugo, & Arias, 2015; Gomez et al., 2016). The model acknowledges desired states and mental states (affect). It encompasses universal and cultural dimensions, objective and subjective components and seeks to account for individual and environmental factors such as social inclusion and participation (Gomez et al., 2016). There is obvious overlap with the QOL concepts used for the assessment of adult and child wellbeing more generally.

Conceptualisations of wellbeing for children and young people with a disability share common themes with conceptualisations of wellbeing for youth more generally in terms of the need for attention to functional wellbeing, capability, domain-specific wellbeing (objective list approach), alongside considerations of affect and quality of life (Maher et al., 2008; Porcelli et al., 2014). The importance of opportunity-related wellbeing and self-determination

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[5] International Classification of Functioning, Disability and Health (ICF)

through the pursuit of goals, and progress towards achievement, is often overlooked in children and young people with disability (Kaftan & Freund, 2018). Findings from research with young people with a disability have highlighted their views on service provision and the limitations on opportunities for participation (The Children's Society, 2013).

Capabilities for children with a disability: To be and do

According to the capabilities approach to wellbeing, most children are expected to grow, develop, become increasingly autonomous, benefit from educational and social experiences, and extend their prospects or capabilities. The capabilities approach is used by Ben-Arieh and Frønes (2011) for children, because of its flexibility in representing different individuals, groups, and contexts and its ability to recognise the impact of the structure of the environment and the strategies and goals of the group.

While, the capabilities approach has informed research involving adults with a disability, there is limited research that uses this approach with children and young people with a disability (Broderick, 2018; De Beco, 2017). As noted by Biggeri et al. (2011) and De Beco (2017), the capability approach has not yet adequately engaged with children's issues; the focus has remained generally on the perspective of education, with limited exploration of the significance and relevance for theory, policy, UNCRPD, inclusive education, and development practices regarding children.

Sen has stated that people with a disability may need different types of capability inputs (policies, resources, social norms, and infrastructures) to reach the same level of wellbeing as the nondisabled (Mitra, 2006; Sen, 1999, 2009). The capability approach may have limitations when considering specific conditions or extremely vulnerable groups (such as severe disabilities and intellectual impairment) and so to overcome this problem Trani, Bakhshi, Bellanca, Biggeri, and Marchetta (2011) suggest instruments to measure effective functionings, potential functionings, valued beings and doings, barriers to choices and resources. Employment (or work as a capability) is a crucial opportunity

through which young people with disability can experience material wellbeing and social participation (Honey, Kariuki, Emerson, & Llewellyn, 2014).

Fawcett (2016) notes that, while significant changes have occurred, expectations relating to children with a disability still differ markedly from those applied to children generally. Examples include limited expectations, restricted social and educational opportunities, their childhood status being significantly prolonged, and questions continually being posed about the capability of children and young people with disability (Cologon, 2013; Thomas, 2013; Fawcett, 2016). It is a consistent trend that 15-24-year-olds with a disability are less likely to be part of the labour market (Honey et al., 2014; Statistics New Zealand, 2017). This fact would suggest the capabilities approach to wellbeing is applied differently for this group.

An analytical framework for the study of wellbeing among children and young people with a disability, therefore, implies the adoption of a holistic perspective that takes account of the types and amounts of capability inputs, the barriers to choices, and access to resources. Creating such a framework presents the challenge of considering the aspirations and expectations of children and young people with disability, whether these are supported individually and/or systemically, and an examination of the potential for self-actualisation. The ecological approach to wellbeing has been used in studies where external life circumstances are identified as having a significant role across the life span. Porcelli et al. (2014) claim that an ecological and strength-based approach to wellbeing is needed to highlight the resources of physical disabled youth and the opportunities offered by their environments (2014). Disabled youth are identified as having circumstantial disparities beyond impairment such as differential access to material and social resources and exposure to discrimination (Porcelli et al., 2014).

Children and young people with disabilities face greater risk from lower socioeconomic conditions and lower subjective wellbeing (Emerson & Hatton, 2007; Honey, Emerson, & Llewellyn, 2011; Wynd, 2015; Murray, 2018). Emerson et al. (2012) claim that poor socioeconomic circumstances explain up to 2050% of the risk of poorer mental and physical wellbeing outcomes for children

with intellectual disability in high-income countries (Emerson et al., 2012; Savage, Mcconnell, Emerson, & Llewellyn, 2014). This risk is evident in New Zealand in terms of poor mental health and employment outcomes, low socioeconomic status, and the fact that at least 15% of disabled children live in households with incomes under $30,000 (Statistics New Zealand, 2014). Savage et al. (2014) describe this situation as disability-based disparity

The social exclusion of children and young people with a disability presents threats to wellbeing. Studies on peer relationships and experiences in schools for children and young people with a disability identify a lower rate of social participation as impacting on the developing of social problem-solving and/or emotional regulation (capabilities), as well as the ability to maintain these skills and capacities (Chamberlain, Kasari, & Rotheram-Fuller, 2007; Guralnick, Neville, Hammond, & Connor, 2007; Koster, Pijl, Nakken, & Van Houten, 2010; Engel-Yeger, Jarus, Anaby, & Law, 2009; King et al., 2009; Vignes et al., 2009; MacArthur & Gaffney, 2001; MacArthur, Sharp, Gaffney, & Kelly, 2007; MacArthur, 2013). At the community and societal level, stigma and poor accommodation of individual needs cultivate and compound the social exclusion of disabled youth (Savage et al., 2014).

Conclusion

The focus of this chapter has been on identifying concepts of wellbeing that might be applied to the study of the meaning of wellbeing for children and young people with a disability. As this review makes evident, the concepts of wellbeing that relate to children are pertinent for children and young people with a disability.

Wellbeing has been identified as a multidimensional, holistic concept that needs to be seen within the context of the whole child or young person. The review emphasises the need to identify the ecological systems the child and young person inhabits and the role of family, community, and other institutions that have a bearing on that person's wellbeing. This approach includes consideration of sociopolitical influences on the family such as family and professional relationships, social inclusion, and community participation. QOL indicators

emphasise subjective wellbeing including happiness, assessments of satisfaction, the inclusion of the pursuit of goals, and expectations.

A human rights lens emphasises the human needs (health, education, and social participation) of children and young people with disabilities, and the capabilities approach draws attention to the way expectations, skills, and competencies are met. The review has emphasised that any assessments of wellbeing among children and young people with a disability need to be based on hearing the authentic voices of individuals who are a part of this group. An approach to understanding wellbeing for children with a disability, therefore, should include opportunities for self-reporting on the many different environments within which the child lives and socially interacts.

The chapter outlined key dimensions of wellbeing among children and young people with disabilities; the next chapter will detail the research approach.

Chapter 3:

Assessing Wellbeing in Children and Young People with a Disability: A Research Approach

In exploring the meaning of wellbeing for children and young people with disabilities, this research draws on a grounded theory approach. As noted in the previous chapter, the current wellbeing literature accentuates the need for a research approach that prioritises the rights and authentic voices of children and young people with a disability in the context of their everyday lives. The aim of this thesis is, therefore, to understand the lived experiences of children and young people in this group to enable the identification of factors that influence wellbeing. The methods were designed to capture the perspectives of children and young people with Down syndrome, particularly the young person's voice. This process involved the adoption of innovative research methods that are used in visual sociology and involved the production of a photo record and photo voice, along with interviews. The study also aimed to hear from parents and service providers on what they perceived as wellbeing in this group. This chapter, therefore, describes the research approach and the specific considerations associated with researching children and young people with intellectual and speech disabilities. It covers issues of sampling, data collection, the interview process, and ethical considerations.

The research objectives were:

1. To explore the meaning of wellbeing and the factors that influence it from the perspective of children and young people with Down syndrome.

2. To understand wellbeing and the factors that influence it from the perspective of the parents/whānau of children and young people with Down syndrome.

3. To investigate wellbeing and the factors that influence it from the perspective of the service providers/policy makers that work with children and young people with a disability and/or Down syndrome.

4. To assess the relevance of three selected New Zealand policy frameworks in relation to the wellbeing of children and young people with a disability.

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The research, therefore, focused on collecting data on the perspectives on wellbeing of children and young people with Down syndrome, their parents, and a selection of service providers. This process involved face-to-face interviews with 38 participants from across the central North Island of New Zealand. The analysis of this data provided the basis for conceptualising wellbeing for children and young people with a disability

I developed an implementation model of the conceptual framework of wellbeing for children and young people with a disability to support building capability within the schooling context entitled "Supporting Teaching Practice for Students with Down Syndrome and Learning Disability" (STPDS) (see Figure 2). Phase two of the research then involved applying this model across three regions involving 42 primary schools that were teaching students with Down syndrome. The implementation process was analysed and an action research programme was used to investigate its effectiveness.

Research rationale

Grounded theory is an approach that has been used in research with people with chronic illness and people with a disability (including intellectual disabilities), and it accommodates the use of visual research tools to gather data (Charmaz, 1990; Rashid, Hodgetts, & Nicholas, 2017; Saffer, 2017; Hultman, Forinder, & Pergert, 2016; Vaccaro, Kimball, Moore, Newman, & Troiano, 2018; Griffiths, 2013; Hollins, 2012; Konecki, 2011). Glaser and Strauss developed this approach in the 1960s as a research process that focused on developing theory from the data, rather than on experimenting with data to support an existing theory (Glaser, 1978, 1992, 1998; Glaser & Strauss, 1967: Strauss & Corbin, 1990, 1994).

In grounded theory, data collection and theory generation are considered synonymous, as "two parts of the same process" (Glaser 1978; Glaser & Strauss 1967). The research process involves the constant comparative analysis of the qualitative data in a process of hypothesis development and, ultimately, theory generation (Bourke, 1999; Glaser & Strauss, 1999; Glaser, 2014). In this study, there is a progressive and ongoing interplay between the development of the research intention and the comparative and ongoing literature review, which

contributed to the accumulation of knowledge and theory. As Strauss and Corbin have argued, "Grounded theory methodology and methods (procedures) are now among the most influential and widely used modes of carrying out qualitative research when generating theory is the researcher's principal aim" (1997, p. vii).

An in-depth qualitative approach was adopted as is appropriate for grounded theory research into topics where there is limited knowledge (Aldridge, 2014; Clark & Morriss, 2017; Powell, Graham, & Truscott, 2016; Powell, Graham, Taylor, Newell, & Fitzgerald, 2011).

The principal purpose of grounded theory is to develop an explanation of an observable fact, phenomenon or experience by identifying the key elements of that experience, and then categorising the interactions and relationships of those elements in a way that is sensitive to the context of the experience. This process involves systematic data analysis, verification, and theory development. Crucially, in grounded theory concepts are the key elements of analysis of the study findings, since theory is developed from the conceptualisation of data, rather than the actual data (Glaser & Strauss, 1967; Glaser, 1992; Strauss & Corbin, 1990; Charmaz, 2006).

Grounded theory approaches are primarily concerned with improving the quality of emergent theory. Strauss and Corbin (1990) state that there are four primary requirements for judging a good grounded theory:

- It should fit the phenomenon, provided it has been carefully derived from diverse data and is adherent to the common reality of the area;

- It should provide understanding and be understandable;

- Because the data is comprehensive, it should provide generality, in that the theory includes extensive variation and is abstract enough to be applicable to a wide variety of contexts; and,

- It should provide control, clearly stating the conditions under which the theory applies, and should describe a reasonable basis for action (interpreted as recommendations).

In this research, these four requirements can be interpreted in the following way:

- The phenomenon that is the focus of the research is the notion of wellbeing and the common reality of this phenomenon among children and young people with disability and specifically children and young people with Down syndrome;

- The research seeks to provide understanding of the lived experiences of this group in a way that is clear and accessible;

- This understanding will be based on data that is comprehensive, collected through careful purposive sampling techniques and from a variety of contexts;

- Insights and conclusions will be compared with other research and specify the conditions within which they can be seen as a reasonable basis for action and recommendations.

The research procedure was, therefore, designed to ensure a flexible and comprehensive investigation of the research topic—the phenomenon of wellbeing among children and young people with disability, specifically Down syndrome.

Typically, grounded theory development is based on case study research. Case study research is an empirical inquiry that closely examines a contemporary phenomenon (the case) within its real-world context. The case study provides an up-close and in-depth inquiry into a specific, complex, and real-world phenomenon. Creating the case study may include interviews, documentary sources, and actions that, over an extended period of time, build a comprehensive study. The case can refer to multiple people or a single person, organisation, community, programme, policy, practice, decision, or event, i.e., a concrete entity, within a specific place and time, taking account of context (Yin & Campbell 2018). Case study research has been critiqued for a lack of both credibility and generalisability due to working with small case numbers (Yin, 2014; Zainal, 2007). Nonetheless, the benefits of case study lie in its ability to increase our understanding of specific contemporary phenomenon in a variety of contexts, often generating large amounts of data, from specific case study groups (Molteni & Maggiolini, 2015; Yin & Campbell, 2018). Case study research can be used to

build on theory and, in this research, it was used to build knowledge in an area where there is limited research.

An important aspect of Glaser's (2005) grounded theory approach to case study was the incorporation of the sociological perspective of symbolic interactionism, acknowledging the meanings of events and of social interactions to people in natural settings. Blumer describes symbolic interactionism as follows: "People act toward things based on the meaning those things have for them; and these meanings are derived from social interaction and modified through interpretation" (Blumer, 1966, p. 541). The merit of case studies informed my decision to encompass the parents and family setting of the children and young people. Yin describes aspects of quality control in research as maximising four crucial elements of case study design: construct validity, internal validity, external validity, and reliability (Yin, 2014).The addition of the parent and whānau allowed the ability for additional background context that could assist with the research process and credibility throughout the process.

The case studies did not extend to the service providers of the children and young people and their family unit. The risk of case study selection bias or information bias was considered, meaning that the child, young person or their family may or may not give the same quality or reliable research information if the service provider from the school or community service or social service organisation was also directly involved in their case study. The involvement of a service provider may have had the potential to inhibit or prompt the participant response in the research process and thus create a bias to the case study and impact the quality of the case study design.

The service providers were separate schools and not providers to the children and young people and their families. The national service providers were not providers to the children and young people and their families. The identity of the case study participants' were anonymous.

Grounded theory focuses on understanding the context of the research phenomenon, which more readily leads to new emergent issues and concepts. Therefore, it is crucial when integrating two or more methods, such as the case studies with the children and young people and their parents and the qualitative

interviews with the service provider groups to ensure that the philosophical assumptions behind the methods are the same: examining the phenomenon of wellbeing for children with a disability.

Case study research involves the systematic application of procedures to guide sampling, data collection, the focus of analysis, and theory formulation (Strauss, 1987). The notion of children's voice was a central concern and informed the selection of research tools such as visual aids to support the data collection process (Young, Dagnan, & Jahoda, 2016).

Grounded Theory Approaches and Data Collection

In order to advance the case study strategy within the research, there was a need to consider two important factors for approaching data collection. First, the grounded theory approach implies the need to select a natural setting appropriate to investigation of the topic. Second, the use of a case study methodology implies the need to ensure the method of data collection allows for the researcher's being able to capture the participants' experience of their social world.

In approaching the selection of a natural setting for children and young people with disabilities, I drew on the concepts of wellbeing examined in chapter 2 which identified the importance of the ecological systems the child or young person inhabits and the role of family, community, and other institutions. Bronfenbrenner (1979) identified the natural environments as being home, school, community, and social institutions, and pinpointed the attitudes and ideological culture as the individual and interrelational experiences within microsystems, mesosystems, the exosystem, and macro systems. On this theoretical basis, the school was selected as an easy, natural child context for the research. School is a childhood social institution setting and is, therefore, a microsystem identified within the ecological system theory. This is an everyday context where children spend 30 hours a week and so it was selected as a starting point for the research.

The second consideration of "best fit" methods led to the selection of a variety of data collection approaches. The need to carefully assess methods is recognised by Charmaz (2006), who argued that: "Grounded theories may be built with diverse kinds of data-field notes, interviews, and information in records and reports. The

kind of data the researcher pursues depends on the topic and access…and may invoke varied data gathering strategies" (p. 14).

This point is particularly relevant to the attempt of the current research to gain access to the perspectives of children and young people with a disability. As mentioned above, the goal of hearing the voices of children and young people required appropriate methods of data collection. This goal led to the selection of visual research tools including pictorial aids and diagrams and the use of cameras as a research tool. These tools are outlined below.

Research procedure

The second primary requirement of grounded theory noted earlier was to provide an understanding of the lived experiences of the young people and research group in a way that is clear and accessible. Using a case study approach, this research aimed to base itself in natural settings in the participants' social worlds. The appropriate method selected to achieve this end in each case is explained below.

In grounded theory approaches to research, data collection is guided by theoretical or purposive sampling—that is, sampling based on theoretically relevant constructs.

Theoretical sampling:

> *[is]* data gathering derived from the evolving theory and based on the concept of "making comparisons", whose purpose is to go to places, people or events that will maximise opportunities to discover variations among concepts and to densify categories in terms of their properties and dimensions. (Strauss & Corbin, 1998, p. 201)

At the outset of the research, open sampling methods for identifying individuals, objects or documents are recommended to identify the data's relevance to the research question. The next phase is systematic relational or variational sampling, with the objective of locating data that either confirms the relationships between categories or limits their applicability. The final phase generally involves discriminate sampling, which consists of the deliberate and directed selection of individuals, objects or documents to verify the core category and the theory as a whole and to compensate for other less developed

categories (Strauss & Corbin, 1998). Purposive sampling employs different nonprobability sampling techniques in order to focus on the particular characteristics of a population or experience. A purposive sample is not representative of the general population and so this technique is often used for qualitative and/or mixed methods research (Patton, 1990, 2002; Suri, 2011).

For this research, using a population sample of all children and young people with a disability would have been too broad, as the range of variables such as context, type of disability and impairment, and eligibility criteria for services would have required extensive quantitative and qualitative investigation. As a result, the population sample was narrowed to a specific disability and child-centred site—children and young people with Down syndrome attending regular school.

The choice of this population prompted further consideration of the range of documents (policy outlining the criteria for receiving services, assessment protocols or records) and of other participants who would be able to make a significant contribution to the study. As a result, the parents of the children and young people with Down syndrome were included in the sample population, as were those who provided services to this group—teachers, special education providers, national education providers, disability organisation providers, family service providers, and social development providers (disability support services and welfare services).

The sampling strategy for the research was non-random and a total of 38 participants were purposively selected: 12 children and young people with Down syndrome, their parents, and seven individuals from service provider organisations. I used the New Zealand Down Syndrome Association, the Bay of Plenty Down Syndrome Association, the Ministry of Education Special Education team managers, and personal contacts as starting points to recruit participants (McBurney, 2001; Rubin & Rubin, 1995; Strauss & Corbin, 1998).

Research participants: students and parents and their families

Students with Down syndrome were selected as an appropriate group to examine the meaning of wellbeing for children and young people with an intellectual disability. Having identified the sample as children and young people aged 12 to 24 years old by the completion of the study, I will refer throughout this chapter to the study population as students and/or young people. In later chapters, the study population is referred to as young people.

Down syndrome is a diagnosed chromosomal disorder and it is recognised that people with Down syndrome have a mild to moderate intellectual disability. Typically, students with Down syndrome are now included in mainstream education. Therefore regular schools were selected for the study. For students with Down syndrome, language articulation is often difficult; articulation of abstract concepts can be challenging; and, all aspects of the curriculum usually need to be adapted (Faragher & Clarke, 2013).

The students who were selected ranged in age from 12 and 18 years and by the completion of the research process were aged up to 24 years. There were eight female and four male students with Down syndrome. At the start of the research, two of the male students were aged 17 years and two were aged 15 years. Two of the female students were aged 17 years; two were aged 15 years and the youngest female student who was aged 12 years; and, the final three were aged 18, 16, and 14 respectively. Students came from a range of family types, as described below, and all but one had at least one sibling. All of the students received Ministry of Education special education funding allocations through the Ongoing Reviewable Scheme (ORS). At the time of the first interviews, all were in regular, mainstream education attending either intermediate or secondary schools in their local area, and all were known in their local community.

There was some hesitation on the part of the parents of the male students with Down syndrome concerning issues of speech delay. For students with Down syndrome, language difficulties are common. Some parents were onscious of this issue, given their child's life stage and, given that speech articulation difficulty can be more evident for male students, a number of the families contacted were not keen for their sons to formally participate in the research group.

Table 2.

Research *Group Children and young people with Down syndrome -at the start of the research*

Student	Age	Gender	Ethnicity	Family	School
Reid	17	M	E	Two parents 3 siblings	Secondary
Sean	17	M	Māori	Two parents 2 siblings	Secondary
Nelson	15	M	E	Sole parent o sibling	Secondary
Scott	16	M	E	Two parents 1 sibling	Secondary
Mandy	17	F	E	Two parents 4 siblings	Secondary
Mary	17	F	E	Two parents 2 siblings	Integrated secondary
Amanda	16	F	E	Two parents 1 sibling	Secondary
Reina	17	F	E	Sole parent 1 sibling	Secondary
Adele	18	F	E	Two parents 3 siblings	School/Tertiary
Alice	16	F	E	Two parents 3 sibling	Secondary
Elizabeth	14	F	E	Sole parent 1 sibling	Secondary
Kristie	12	F	E	Two parents 2 siblings	Full primary

The research sample included 11 families broken down into 12 students, 13 mothers, and 10 fathers, not all of whom were interviewed. A total of 31 students and parents participated in the interview process; both parents attended the interview process in six of the interview cases. The majority of the sample was composed of couples where the child with Down syndrome had siblings. There were three families with two children, five families with three children, and three families with four children. There was one sole parent and one sole child family in the sample group. All households had a parent who was working either full time or part time. In the partnered households, parents shared full-time work and full-time care responsibilities. Of the parent participants, all but three had tertiary qualifications, with six obtaining further qualifications after having a child with Down syndrome.

The demographics of each family unit were relevant and varied; one family had one child; the child with Down syndrome was the eldest in two families and the youngest in 8 families; and, two students with Down syndrome were middle children and were adopted. The families were all New Zealand European except for two, one of which was Māori and the other Pasifika.

Research participants: service providers

The service providers were selected on the basis of their experience in service provision or policy development for children and/or education provision in the disability sector. The service providers can be classified as belonging to two groups; education providers and national service providers. Two of the education providers were employed as classroom teachers and one was a school deputy principal. Another education provider held a shared special education coordinator role (SENCOs) and there was a mix of primary and secondary school teachers. The service education-related providers were in roles in regional special education provision. As for the service providers, two worked in national policy and service development roles; one worked in a government department; one was employed in a nongovernment organisation; one was a former government minister for national service development; and, one was a policy advisor. Those who had a policy focus worked in the areas of statistics, disability, education, and child and family services. The seven service providers were New Zealand European; six were female and one was male. All the service provider participants had over 15 years' experience (the minimum requirement for selection was 5 years).

Research instruments

Two considerations guided the selection of research tools: 1) how best to capture the perspectives of children and young people with Down syndrome and 2) how to do so in terms of recognising the need for diverse and appropriate methods of data collection for this specific research group. The first consideration led to recognition of the work on children's voice in research accessing children and young people's perspectives. The second consideration led to the use of methods used in visual sociology; a camera, photo record, and photo voice were all used as

research tools and interview support material within a mixed method approach to data collection.

Changing social attitudes and views of children and young people over several decades have led to the acknowledgement of the importance of including children's perspectives in a range of areas (Burton & Phipps, 2010; Christensen & James, 2008; Kellet, 2010; Mukherji & Albon, 2010; Ainscow & Messiou, 2018; Berman & MacArthur, 2018; Browne & Millar, 2016; Shogren et al. , 2015). This shift in attitudes has led to greater recognition of the "student voice" in educational research and has been described in terms such as student empowerment, student rights, and student participation in decision-making (Manefield, Collins, Moore, Mahar, & Warne, 2007; National Behaviour Support Service, 2014; Robinson, 2014). The importance of involving young people with a disability in decision-making in social services has also been recognised (Franklin & Sloper, 2009). This recognition reflects the insight that children's perspectives provide a potential avenue for improving student outcomes, facilitating school change, facilitating reflective teaching practice, and considering how best to support the participation and learning of students at school. In the broader literature, the perspective of children is recognised as contributing to service design in education, health or economic conditions in ways that enhance wellbeing and are in line with the United Nations Convention on the Rights of the Child (1989, Article 12) (Eriksson, Asplund, & Sellstrom, 2010; Mitra, 2004; National Behaviour Support Service, 2014; Graham & Fitzgerald, 2011; Sixsmith, Gabhainn, Fleming, & O'Higgins, 2007; Gillet-Swan, 2014).

A critical concern is to ensure that the voice of the child and young person is heard in more than a token way, given that genuine student engagement has been seen to raise self-esteem and increase research efficacy (Mitra, 2004; Fielding & Rudduck, 2002; Fielding, 2004; Flutter, 2007).

Mosaic method and visual sociology/approach

A multimethod framework, described as a mosaic approach, has been promoted as an alternative to interviews by Clark and Moss (2011) and by Clark (2005) as an effective way of eliciting a more comprehensive expression of the views of

children. The types of methods that are recommended are 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; Clark & Moss, 2011; Morrow, 2001; Kirk, 2006; Blaisdell, 2012; Pascal & Bertram, 2009). Morrow (2001) has effectively adopted this technique in investigating young people's views on their environments. She used it to explore subjective experiences of neighbourhoods, including the home and the school and the social networks within these. The mosaic approach is adopted here as an approach to support communication not only of views, but also of abstract concepts that may require variable and comprehensive forms of expression. In this approach, options were also made available through which the participants could communicate these ideas to me.

The use of a camera by children as research participants is recognised as enabling the voices of very young children, children with chronic illness, young people with communication difficulties, and children with a disability to be heard (Morrow, 2001; Clark, & Morriss, 2017; Darbyshire & Campbell, 2005; Lyle, 2005). The photovoice process is, thus, valued for its ability to uncover rich descriptive information. As a research tool, it is almost exclusively used to answer descriptive research questions, as, for example, in Booth and Booth's (2003) examination of the collective and individual experiences of mothers with learning disabilities (Catalani & Minkler, 2010). The best results are found when studies demonstrate high levels of participant involvement with the process and where the cameras and basic training are used to document and engage in dialogue with others about the photographs and their meanings—a core part of photovoice methodology (Catalani & Minkler, 2010).

Visual method

These research methods applied in this study were first established in the 2006 pilot[6], and so there is substantiated evidence for this approach. Pauwels (2013, p. 5) describes the use of dual typology as the use of "pre-existing visual" materials and the use of "researcher-instigated" visuals. In this research, the pre-existing

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[6] The pilot was undertaken as part of my master's thesis.

visual materials are described as interview support material. I requested that the participants select pre-existing materials as described below. The researcher-instigated visuals are those "provoked or prompted" (Pauwels, 2013, p. 5) by the researcher, either as researcher-produced or participant-produced visual material. The participant-generated photos are described below.

Student participants were given an easy to use disposable camera and two photo albums along with a local store gift voucher to have the photos developed. I requested that the students carry the camera with them to school and on their daily activities. In this way, the students were encouraged to take photos to provide a visual record of what they considered represented aspects of wellbeing in their daily lives. The photos aided communication with the participants and were used to support verbal expression and for assisting in the articulation of abstract concepts. The use of the camera provided a means for the students to acknowledge the role of significant people in their daily lives without reliance on descriptive language. The subject matter of the photos and the number of photos was left up to the students. The use of photos and photo albums was aimed at helping the participant's engagement in the interviews. The camera was also used by the students as a social tool when requesting that others, selected by the student, be part of their explanation of elements of wellbeing.

In grounded theory, the discriminate sampling method of identifying objects or documents is recommended to identify the data's relevance to the research question, and that approach was followed in this research. Thus, in addition to taking their own photos, students were asked to select other photos or items to show me what they considered would illustrate aspects of wellbeing. The students 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, after 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, after school or at home, these are pre-existing visuals. The pre-existing data was referred to as interview support material. These materials included photos of significant places, events or people, a range of memorabilia that

indicated the students' interests, certificates, media articles, daily charts, technology items, reports and selected schoolwork.

All of the adults (parents and service provider participants) were also encouraged to provide interview support material, documentation or objects to identify the participants' perspective on the data's relevance to the research inquiry. Examples of these materials were photos, certificates, media articles, and academic records such as the independent education plan (IEP), report cards or literature.

The Research: Phase One

The research involved interviews and other forms of data collection with 31 children and young people with a disability and their parents. The child and parent interview guides were informed by concepts drawn from the wellbeing review (ecological systems theory and whole child approach). Interviews were also held with seven key informants in areas of service provision and policy development. These interviews explored their perspectives on the meaning of wellbeing for children with a disability, the importance given to children's voices, and the relevance of policy and service provision as it was applied to this specific child population.

Data collection: process and tools

One-to-one semistructured interviews were conducted to obtain an in-depth understanding of the complexity of the notion of wellbeing. Face-to-face interviews are recognised as a powerful research technique when not much is already known about the topic being researched, or where that topic is particularly complex or potentially sensitive in nature (Davidson & Tolich, 2001; Strauss & Corbin, 1998). For 37 of the participants, data was collected by means of face-to-face interviews; one adult interview was via phone conference because of the difficulty of arranging a meeting. Prior to the interviews, I met with students and their parents to provide them with an opportunity to ask for clarification and elaboration on the themes discussed.

A semi structured interview guide was used to ensure interviews were focused, but space was made for participants to answer in their own terms and to share their experiences and perspectives without being restricted by a standardised questionnaire (Crabtree & Miller, 1999; May, 2002; Smith & Taylor, 1998). All interviews were recorded and notes were taken throughout the interview. These field notes and the interview data were transcribed and analysed. Some additional photos of the participants' surroundings were taken during the interviews. For example, these included photos of the students at home doing the interview with me, sitting in their chair in their homework area and requesting a photo taken while working or while undertaking a specific task in the house to show me. These photos were either requested by the student, used as part of the interview or the follow up interview and were part of the students' visual record. All visual material was with consent.

Three weeks prior to the interviews, students were contacted and asked to photograph the people, places, events, and things in their life that they liked and thought would show what wellbeing meant for them. They were asked specifically to take the camera to school. As mentioned previously, the students were given a gift card to develop hard copies of the photos and two photo albums (one album for the student and a duplicate album for me). The students were also asked to collect together other photos or things important to their daily life. The photos and interview support material were important communication aides.

The student interview guide focused on obtaining data relating to the students' experiences and perceptions of wellbeing, their ideas around the factors that influenced wellbeing, and how these related to the school environment or educational setting. Five broad areas were covered: the students' background, perceptions of school, links to out-of-school activities, good experiences, and difficult experiences. The student interviews ended with discussion of the students' perspectives related to an adaptation of the Ordinary Life Information Gathering model (OLIGM) (National Advisory Committee on Health and Disability, 2003). This communication aid was taken from a New Zealand study with adults with intellectual disability. In this research, however, it was adapted as a dual communication diagram and a representation of the ecological systems model for the students. There was also an opportunity for further discussion of

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this model at the end of the student interviews and in the successive interviews. For a copy of the student interview guides, see Appendix 1. For further information on the Ordinary Life Information Gathering model see Appendix 2. For a copy of the plain language information sheet for student consent, see Appendix 3.

The interview guide for the parents was designed to obtain data on their perceptions of wellbeing and on factors that influenced wellbeing for their child and for children with a disability at school. The parents and family members were asked to bring any support material they felt was relevant to the interview (discriminate sampling). The parent interview guide was structured thematically, with open-ended questions and prompts.

In the review of wellbeing in chapter 2, the need to adopt a whole child approach was identified. The parent and service provider semistructured interview guide drew on the *Guide to Applying the Whole Child Approach* (Ministry of Social Development, 2004), which is a New Zealand social policy development guide for child services. This guide sets out six sets of questions to consider in relation to policy and service provision for children (see Appendix 4). These broadly cover the effects on children of policy and, particularly, the differential effects of policy and links that need to be considered in policy development. The guide also identifies how children can be involved in work on policy. Questions were, therefore, developed which asked parents about policy, service provision for their child and for children with a disability more generally, and the links between home, family, school, and agencies. For a copy of the parent and service provider interview guide, see Appendix 1.

At the end of the interviews, all of the adult participants were asked to consider the relevance of three selected child policy frameworks. The purpose here was to gain insight into their experience of service provision as it was applied to this specific child population.

The three policy frameworks used were:

- The *Key Settings Model* (Ministry of Social Development, 2002b, pp. 14-15).

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

- The *Right to Education Framework* (Human Rights Commission, 2004, p. 262).[7]

In New Zealand, the key settings model, adapted from Bronfenbrenner's (1979) ecological approach, has been used in policy literature for children (Ministry of Social Development, 2002b). The ecological theory of human development was an important component of this research approach.

New Zealand has also established an indicator framework to guide investigation into contributors to wellbeing in children and young people, and this set of indicators was utilised in this research (Appendix 2.3).

Given the need to take account of the rights of children and young people, the framework from the New Zealand Human Rights Commission research (2004b) was also used in the development of these research tools. For a copy of the frameworks, see Appendix 2.

The interview process

It was essential that a strong level of trust and empathy be established with the students and their parents when approaching these interviews. Initial contact with all participants was by phone. Written explanations of the research process, a plain language information sheet, and separate interview consent forms for the student and parent participants were hand-delivered. As adult participants reporting on their own lived experience of their child's wellbeing, the parents were also given further information and consent forms in order to ensure that the complexity of the topic was clearly explained and understood (Graham, Powell, Taylor, Anderson, & Fitzgerald, 2013).

Further meetings followed and the students were given research packs that contained the research tools (a camera, two photo albums, and a gift card to develop two copies of the photos), a consent form, an information form with my

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[7] This framework involves four broad standards (the 4-A standards) as a basis for assessing the realisation of the right to education developed by Katrina Tomasevski, UN Special Rapporteur.

contact details, and a USB for electronic storage. The aim of this pack was to establish the students' independence as the key persons in the research process and their control over the information to be shared with me. This was an important aspect of the research not only in view of the students' range of communication abilities and possible need for support during the interview process, but also in recognition of the potential sensitivity of the subject and the personal nature of the research. The option of having an interview advocate or interpreter was explained and the students were asked to think about who they might like this person to be. The students' understanding of the study and what was required of them was checked prior to signing the consent forms. All interview materials were treated as confidential.

The student interviews were held after the parent interviews so that the students could observe the interview process to see it role modelled and have a final meeting with me to aid familiarity before their interview. The process of recording was practised with the students and two dictaphones were used in all interviews. Having the students hold one of these assisted with the interview process, as the student could control the interview process. This procedure acknowledged the skill of the young people with Down syndrome as part of the research process, as it created a flexible approach to communication while respecting the young people's views. I also allowed a flexible timeframe for the interview recording process and acknowledgement of my respect for the young people's developed skills across the research process and number of interviews. It is important to take this approach, as it enables young people to feel that they are equal partners in the participation process, and which is particularly important for students with learning difficulties and communication needs (Murray, 2012). The students were empowered through the use of the dictaphone, as was appropriate as an interviewee, to ensure they understood the process and were in control of the interview and recording process.

The parent interviews took place in private homes (with the exception of one conducted via teleconference and email messages). Six of the parents submitted additional material via email before and after their interviews. Six parents were interviewed a second time and at this time provided interview support material such as home planning schedules, flatting routines or an updated

IEP. Several of the parents (a different five) maintained contact with the research process via email.

The service provider interviews were undertaken at venues of their own choosing including their place of work and my home. The length of the interviews varied, but none took less than 2 hours; some were as long as 3 hours and 30 minutes. The service providers provided support material such as IEPs and policy documents. There were follow-up interviews with three of this group of service providers, which provided even more in-depth information.

Successive student interviews

For three students, there was one follow-up interview. The same method was used as in the earlier stage, with a second phase of photo gathering and questions that built on the data offered by the students. For another three students, there were two follow-up interviews. I accompanied these students on the last day at college, to a day at polytech, and at the completion of a job interview, respectively. Follow-up data was sent to me via email by another group of three students, along with additional photos of special occasions or big life changes. The remaining students were not available due to changing circumstances.

Data Analysis: Phase One

The field notes, transcripts, and recordings were read and listened to repeatedly to identify patterns and categories, which were then organised into designated codes and themes. All other forms of data obtained using the interview guide, photos, interview support material, field notes, and the OLIGM were analysed and compared. As an example of the relationship between the various codes and themes, the code "schoolwork" was reinterpreted as part of a theme labelled "building capability".

In the initial analysis, a coding or text unit was defined to represent the expression of an idea initially relating to a particular theme of the interview guide, something which Strauss (1987) refers to as a coding paradigm.

Open coding

In grounded theory, open coding analysis relates to identifying, naming, categorising, and describing phenomena found in the text. The initial, broad categories related to the interview guide, for example, to questions relating to perceptions of wellbeing. Ideas of and comments on perception of wellbeing were later compared for themes. The second broad category from the interview guide related to factors which influence wellbeing (FIW), and these were coded and highlighted differently. This coding technique was continued with all the interviews, field notes, visual tools, photo record, and interview support material. The codes were developed as the coding progressed. This process was recorded as coding notes and is a technique referred to as memos in grounded theory (Glaser, 1998; Glaser, 2000; Strauss & Corbin, 1997; Corbin & Strauss, 2007; Corbin & Strauss, 2014; Holton, 2010; Charmaz, 2014, 2015, 2017; Charmaz & Belgrave, 2012)

Table 2 illustrates how the coding progressed—how data from all the students' transcripts, photos, interview support material, and the OLIGM were analysed and compared. The theme illustrated in Table 2 is "schoolwork", which was reinterpreted and later conceptualised as part of the "building capability" concept and the factors influencing this. This method of data analysis was established in the pilot study and refined for this study.

Table 3

Initial Wellbeing Concept Analysis Grid

Interview theme	Students	Parents and Service Providers
Schoolwork Meaningful work Skill-based tasks	Interview quotes related to: schoolwork or work experiences Photos of schoolwork, curriculum subject, technical work areas, and sport Verbal descriptions of schoolwork, when showing the photos Interview support material related to curriculum work: documents such as IEP/reports/articles OLIGM: comments related to schoolwork	Interview support material related to schoolwork: IEP, timetables, examples of schoolwork in books and copies of materials Field notes related to schoolwork such as school timetable/diary or rosters Field note observations of home environment related to: schoolwork such as visual supports, timetables or aids for planning

Axial coding

Axial coding relates codes (categories and properties) to each other via a combination of inductive and deductive thinking. To simplify this process, the underlying or causal relationships are prioritised and the generic relationships identified as a start to grounded theory (Glaser & Strauss, 1967, 1999; Strauss & Corbin, 1990). For this study, this coding was done through the creation of a variety of analytical grids with an axial coding framework, as suggested by Borgatti (n.d.) (see Appendix 5). Table 3 below shows how the axial grid concept of the "schoolwork" phenomenon theme was developed into a framework first,

from the student interviews and then through the addition of the parent and
service provider data. This axial coding is described in the grid below. The factors
that influence the phenomenon theme "schoolwork" and the generic relationships
taken from the study are placed into the description to illustrate the analysis
process.

Table 4

Axial Coding Analysis for Wellbeing

Element	Description
Phenomenon: Schoolwork	Schema is schoolwork Photos, interview reference, support material such as IEP, report cards, project work, student text book examples
Causal conditions	These are the variables: teacher aide, classroom teacher, subject, enjoyment of subject material, ability to access subject material at appropriate level etc. that lead to the occurrence or development of the student's reference or photo of schoolwork.
Context	School environment. Classroom: main class or special unit as structural spaces (Active variables): teacher or teacher aide/assistant.
Intervening conditions	Similar to context: delineated to identify context with *moderating* variables: main class or segregation *Mediating* variables (intervening) adapted curriculum: teacher aide/correspondence work by qualified teacher Levels of access to curriculum
Action strategies	The role of teacher aide Role of school; classroom teacher; SENCO; teacher aide: Ministry learning support or special staff Role of family in supporting student to do schoolwork Resource provision, adaptation to curriculum, access to curriculum
Consequences	Intended: learning outcomes, *enjoyment* of schoolwork/school. Unintended: dislike of learning new things (learning aversion)

Selected coding

Selected coding is the process of choosing one category to be the core category
and relating other categories to that core category. In this study, the initial code of
schoolwork developed through the analysis process and selected coding became
the starting point for the theoretical framework. For example, schoolwork, skill-

based tasks, and planning became part of the selected coding for the category "building capability" and this was designated as a dimension of wellbeing. These related categories were coded as a FIW, as identified by the participants, and their responses were compared.

As the factors that influenced the phenomenon became clear throughout the analysis, the overarching themes emerged and the selected coded process began.

A broader approach to content analysis is when analysis is extended to examining the context within which any written, visual or spoken form of communication occurred (Shuker, 2001; Strauss & Corbin, 1998). This content analysis was applied to the student photos and to interview support material such as report cards, project work, student dairies and timetable charts, schoolwork examples, and IEP examples given to me as interview support material. The initial analysis was developed further into comparative grids in which data was grouped into coded categories representing interview themes. Categories were developed for identified phenomena or common perspectives on common experiences. An example of this procedure is given in Table 4.

Table 5

Selected Coding Analysis Grid of the Wellbeing Concepts

Element	Description
Phenomenon Building capability	Schema expanded to include: schoolwork, jobs at home, sports tasks, hobby tasks, independent tasks of daily living Photos, interview reference, support material examples: IEP, report cards, project work, text book
Causal conditions	Events or variables: school day, involvement in class, sports or family event Variables: (personnel) teacher aide, class room teacher, assistant, family, sports coach

	Subject, enjoyment of subject material, ability to access subject material at appropriate level etc. that leads to the occurrence or development of the student's reference or photo of schoolwork/home/sport/description of activity
Context	School environment; classroom: main class or special unit Home environment, community settings.
Intervening conditions	*Moderating* variables: main class or segregation. *Mediating* variables: levels of assistance, access or adaptation of what and by whom such as support provided
Action strategies	Mediating variables: by whom, e.g., teacher aide, swimming coach Of what: curriculum activity, sport or hobby activity, daily living tasks Supported learning Resource provision
Consequences	Intended: learning outcomes, enjoyment of task, independence in doing task Unintended consequence: learning aversion, link with identity

Tables 3 and 4 formed the basis of the selected coding that formed analysis grids that were then developed into the overarching themes of wellbeing presented in the study's findings. These themes are used in chapter 7 to discuss the dimensions of wellbeing for children with a disability and the factors which influence wellbeing.

Charmaz (2006) suggests another guide to developing grounded theory which uses diagrams:

Diagrams can offer concrete images of our ideas. The advantage of diagrams is that they provide a visual representation of categories and their relationships. Many grounded theorists … treat creating visual images of emerging theories as an intrinsic part of grounded theory methods … to tease out relationships while constructing their analysis and to demonstrate these relationships in their completed works. (p. 117)

This process was an integral part of the development of the analytical grids and identifying the interrelationships of the factors that influence wellbeing. This technique was also used in relation to the student interviews with the adaption of the OLG model and again in the analysis of key settings model, then in phase two with developing a model. The outcome of an adaptation of these models relevant to wellbeing for children with a disability is discussed in chapter 7 of the findings.

Conceptual ordering: On the way to a framework

Description is also basic to what we call conceptual ordering…refers to organization of the data into discrete categories …according to their properties and dimensions and then using description to elucidate those categories…the chief reason to discuss conceptual ordering …is because this type of analysis is a precursor to theorizing. (Strauss & Corbin, 1998, p. 19-22)

The early draft of the conceptual framework of wellbeing for children with a disability was used as a theoretical framework to extend the literature review and selectively search for related research studies to refute or to substantiate the general concepts drawn from the findings (Charmaz, 2006). The draft framework is identified as a precursor to a concept indicator model, where these concepts may eventually be grounded in empirical data.

Ethical Considerations

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

No information that could identify the participants' research material was kept and initials and pseudonyms have been used throughout the thesis in order to mask and protect their identities. The use of photographs and other digital items from the interview support material is confined to the hard copy of this thesis as a separate appendix and is submitted for examination, Appendix 7. (The photo record is Appendix 7 and can be viewed with the permission of the researcher). These visual materials will not available in the digital copy of the thesis due to privacy concerns and the inability of the researcher to control the electronic footprint created therein.

Morrow and Boyden (2014) identity four steps in ethical approaches to research with children and these were applied in this study. First, my access to the student participants was negotiated via their parents, who are responsible for their care, as part of the process of informed consent. Second, I designed research tools in consideration of the study expectations for the students and the contexts in which they may have wished to use the research tools. I was aware of the power relations between adults and children and considered this issue throughout the study process so that the students were autonomous in their own data collection.

Third, given the potential vulnerability of the student group, I considered this factor in all interactions with the students and their families. I was attentive to all obligations in this regard. Finally, in consideration of the differential power relationship between (adult) researchers and (child) participants in data collection, data interpretation, and presentation of research findings, grounded theory was selected as the research approach to uphold and preserve the students' perspective (Morrow & Boyden, 2014; Powell et al., 2011; Powell et al., 2016).

Participants' involvement in the study was voluntary. The consent process and information sheets were provided to the parent and adult participants and in easier language to the student participants. Time was allowed for clarification of the research process as part of consent throughout the study. All participants, with emphasis on the student participants, were given contact details for follow-up information or additional meetings and every effort was made throughout the study to ensure that the risk of the student participants' experiencing emotional harm was minimal, given the potentially sensitive nature of the topic (Fraser, Lewis, Ding, Kellett, & Robinson, 2004; Foley & Timonen, 2015; Powell et al., 2011; Powell et al., 2016; Morrow & Boyden, 2014).

For information sheets and consent forms, see Appendix 3.

As stated above, grounded theory approaches are primarily concerned with improving the quality of emergent theory. Insights and conclusions from my research were, therefore, compared with other research where the theory applies and as far as the conditions can be seen as a reasonable basis for action and recommendations.

In the first research phase, a model of supportive teaching practice (Figure 2) was developed and this was tested in the second phase of the research. The focus of this model was on building capability. Building capability was one of the dimensions of wellbeing that came from the findings from phase one of the research. The research emphasised skill-based learning, a supported learning environment, appropriate resourcing, the need for skilled teachers, the value of valued activities within the school context including class responsibilities, and the importance of meaningful work.
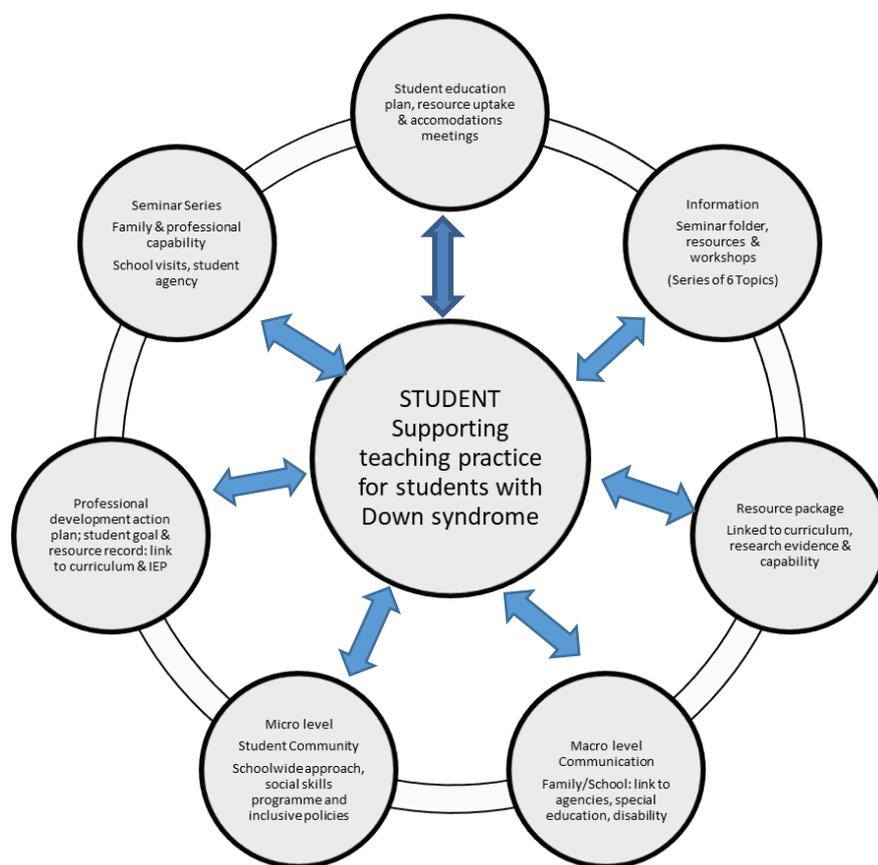
Figure 2. Supporting teaching practice for students with Down syndrome and learning disability in New Zealand. (STPDS model), Kirk, 2019.

The Research: Phase Two

Within the grounded theory process the categorising of the data was then conceptualised into broader themes. These broader themes, in turn, became the dimensions of the wellbeing framework. The grounded theory process includes a need to validate the data, and in order to do so the wellbeing framework was developed into a practical model. This model entitled *Supporting Teaching Practice for Students with Down Syndrome and Learning Disability* (STPDS) was then used in a pilot programme during the course of the research.

The STPDS programme was designed to link the theory and practical application of developmental and educational approaches with an emphasis on early intervention that support the specific learning profile of students with Down syndrome and learning disability in the classroom, in the school-wide environment, and within the home-school partnership.

The sampling strategy for the research of phase two was consistent with phase one of a non-random sample. Schools selected for the STPDS programme were selected on the basis of having students identified as ORS funded with Down syndrome and students identified as having learning disability receiving Ministry of Education Special Education services. I used the New Zealand Down Syndrome Association, the Bay of Plenty Down Syndrome Association, the Canterbury Down Syndrome Association, the Wellington Down Syndrome Association and the Ministry of Education (both national and regional) and drawing on personal contacts within these networks.

Overall, the model was tested in 42 regular primary and composite schools and 156 parents, grandparents, teachers, and service providers were engaged in the programme over the course of up to 9 months. Of these 119 were interviewed either individually or through focus groups, all of the programme participants (156) were given the opportunity to complete an online survey at the end of each day and at the completion of the programme. Forty-four children with Down syndrome enrolled in the schools participated in the programme.

The aim was to encourage an inclusive approach to school practice, and the programme provided teachers, schools, and parents with a comprehensive resource pack that could be used with both children with Down syndrome and the wider student group. The programme was tested in primary and composite schools as an approach to support early intervention, the school team and family supporting the student with Down syndrome may not have had access to full learning and social support services. The composite school will often provide a learning environment for students with Down syndrome up to the age of 14 years.

The programme was divided into five seminar days over a period of six to nine months and included interactive workshops on curriculum areas and inclusive teaching practice. The seminars included supported discussion of current practice, resources and access to assistance. The programme provided an opportunity to work with other schools as part of a professional learning community. Teacher release was included for the programme in one region which allowed whole school participation such as a team of six teachers and teacher aide attending. The provision of the education resource pack to each school in the programme provided school specific resources and access to ongoing information. The teaching team and the parents from each school attended each of the five seminars across the timeframe of the programme. In each of the three regions, 12-16 schools attended the professional development seminars together. The researcher facilitated the implementation of the programme which included school visits, and the teaching staff shared the results on the use of the programme and shared their views and further ideas with the researcher, each other, the parents, and the regional group.

Student participants of phase two

The second phase of the research involved working with 42 primary and composite schools, each of which had over 300 students. The schools were located in three regions of New Zealand: Bay of Plenty, Christchurch, and Wellington. The sample also included one composite primary and secondary school with students that taught children in levels 1-13, so, the student age range

varied from the outset. The students were aged between 6 and 9 years old and two students were 12 and 15-years-old and all were receiving ORS funding. The students were mostly of New Zealand European descent; 25% were Māori, and other ethnicities were also represented. There were 44 students with Down syndrome in the sample: half were female and half were male. The schools all had students with a range of other disabilities.

Parent participants of phase two

Seventy-five per cent of the parent participants were mothers and 25% were fathers; a high proportion of these participants were under 40 years of age. Additionally, four grandparents attended, as they were the full-time careers of the student.

Service providers: Schoolteachers and education providers

The final participant group included teachers, special education needs coordinators, principals, deputy principals, a teacher aide, specialist teachers, Board of Trustee members (also parents), specialist teachers from outreach services, and private speech language therapists. Ministry of Education specialist staff also attended; their roles included those of educational psychologist, occupational therapist, and speech language therapist.

Research instruments

The goal of this second phase of the research was to gain an understanding of the experience of the programme that was based on the STPDS model. The qualitative approach was designed to gauge the experience of the programme as described by the adults (parents, service providers, teachers, and the teacher aide). This understanding was achieved through semistructured interviews, semistructured focus groups, the use of cameras, and school visits. These methods were supplemented by observing the teachers and teacher aide in the natural setting of the classroom and school environments in the daily activities of teaching and working with the students.

Data Collection: Process and Tools: Phase Two

Four data collection tools were used: a semistructured interview guide with the option of completing a computer generated evaluation, a photo record, school visits, and focus group interviews. Data from the semistructured informal interviews, photo records in the form of programme support material gathered by me, and participant focus group interviews is presented in the findings.

An optional online survey was provided after each programme day to give participants an opportunity to give feedback of the merit or worth of the programme. The evaluation sought to explore the perception to which indicators of student learning or progress were 'supported' against the learning goals as a result of their teachers and support team participation in the programme and what change in pedagogical practices had contributed to any gains. In the survey participants were asked to rate the use of resources, access to information, and their perception of their own experience in areas such as confidence or knowledge in their area of work or responsibility as a result of attending the programme.

Fieldwork observation was undertaken at the school. Interviews were conducted with 119 of the 156 participants on the school visits. These were either semi structured, face-to-face interviews with individual service providers or sessions with small groups with two or more service providers. A focus group meeting was held to gather information on teacher, service provider, parent and grandparent perspectives on the programme. The service providers and school focus groups ranged from three to six participants in the 42 schools. Six focus groups of 4-7 parent and grandparent participants were held.

A photo record of student-teacher interactions was collected on the school visits, as was evidence of strategies in the classroom and examples of the student/s' schoolwork. Some video recording of student/s reading was also taken.

Data Analysis: Phase Two

The field notes, transcripts, and photo record were reviewed several times to identify patterns and categories; these were then organised into designated codes and themes. All forms of data obtained using the interview guide and the optional

computer generated evaluation, photos, interview support material, and field notes was analysed and compared. The detailed coding analysis process described earlier was applied to this data.

Summary

The research adopts a grounded theory approach to the conceptualisation of wellbeing for children and young people with Down syndrome from their perspective. In terms of selecting the research instruments, photo voice and visual sociology were employed to capture student voices in a mixed method, mosaic, two-phased qualitative study. The aim of the qualitative inquiry was to conceptualise wellbeing and its determinants and to inform the development of a framework to guide practice. Phase two of the research was undertaken as part of a grounded theory approach to the measurement and verification of the theory and the STPDS model.

The findings of the mosaic approach of interviews, various research documents, photo records, and a phase two programme summary of ground theory are presented in the following chapters.

Chapter 4:
Wellbeing as Acceptance

The next three chapters present the findings from 38 interviews; these included interviews with 12 students with Down syndrome and their parents, service providers (such as senior teachers and specialist education providers), and national providers (such as senior policy analyst in social development, family services, statistics, and disability, and an ex-minister). The analysis is presented under three headings which represent the key components of wellbeing for children and young people with disabilities that emerged; these are: acceptance, recognition, and supported independence. These ideas form the basis of a conceptual framework of wellbeing for children and young people with disabilities that will help to identify how policy and practice could be constructively developed.

As the first findings chapter, chapter 4 presents the first key element of wellbeing for children and young people with a disability that emerged from the research: acceptance. Acceptance is first broken down into its key component parts, before being refined into broadly applicable concepts. The conceptual framework for wellbeing for children and young people with a disability is then based on these concepts and designed to inform policy and practice.

Bronfenbrenner's (1979) ecological theory was used as a conceptual approach to guide the evaluation of the experiences of the young people in a way that takes account of the complex interactions between influences in the home, school, and community environments. The approach proposes that the environment can be understood through a model of nested concentric circles depicting micro and macro social systems (Ministry of Social Development, 2002a). These concentric circles of micro and macro environmental influences have become widely accepted in theories of human development. The ecological approach offers a broader understanding of the experiences of disadvantaged groups such as people with a disability (Lindsay et al., 2018).

This chapter focuses on the concept of acceptance, which is taken here to refer to the formal or informal admittance of a young person with Down

syndrome into a group and the absence of social disapproval. The desire for positive and lasting relationships is amongst the most pervasive and fundamental of human needs. The need to belong is deeply embedded within our social understanding and has important consequences for a broad range of psychological processes that have an impact on cognitive, emotional, behavioural, and health outcomes (Baumeister, DeWall, Ciarocco, & Twenge, 2005; Buckley, Winkel, & Leary, 2004; Cacioppo, Hawkley, & Berndtson, 2003; Twenge, Baumeister, Tice, & Stucke, 2001). The need to belong is, therefore, a crucial part of any discussion of wellbeing. Research also suggests that the threat of social exclusion can activate physiological response mechanisms designed to detect and regulate physical pain (DeWall & Baumeister, 2006; Eisenberger, Lieberman, & Williams, 2003; MacDonald & Leary, 2005). Learned responses to being accepted or excluded in childhood are significant across a life span and were evidenced in the interviews.

Acceptance for young people is influenced by a number of factors such as peer interactions and relationships, academic achievement, acknowledgement of skill, and the example of positive role models and support from parents and teachers or paraprofessionals or support people. Each of these factors emerged as an influence on acceptance in the interviews, and each is particularly salient for people with disability (specifically learning and intellectual disabilities) (DeWall, & Bushman 2011; Edworthy & Cole, 2012; Fiasse & Nader-Grosbois, 2012; Majorano, Brondino, Morelli, & Maes, 2017; Schwab, Huber, & Gebhardt, 2016). The impact of these factors grows exponentially from preschool through to tertiary education for students with a disability and for marginalised groups, increasingly influencing peer interactions and the formation of status hierarchies. In addition, an increasing emphasis is placed on the roles of peers and teachers in the development of a concept of self among students with a disability, where additional status hierarchies (in relation to ability) can also be experienced for those with physical, sensory, and intellectual disability (Guralnick, Connor, & Johnson, 2011; Majorano et al., 2017; Schwab et al., 2016).

In chapter 2, acceptance is noted as a component of eudaimonic wellbeing, encompassing positive self-acceptance, self-esteem, and positive appreciation by others. Acceptance is identified as an indicator and a measure of wellbeing in the

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Ryff scale of psychological wellbeing (Ryff, 1989; Ryff & Keyes, 1995; Schrank, Riches, Coggins, Tylees, & Slade, 2013; Seifert, 2005). Happiness is not considered an essential element of wellbeing within either Maslow's hierarchy of needs nor Ryff's approach. However, it is an essential consideration in a life stage development approach to wellbeing in childhood (Raghavan & Alexandrova, 2015) and is vital to the perspectives shared by the young people and their families. Kraut (2009) identifies happiness as a cognitive, affective state. For children, acceptance is an affective state (with the rudiments of happiness, quality of life, and social comparison in daily life experiences of wellbeing), and so it is important to consider it in relation to subjective wellbeing (Fletcher, 2013; Taylor, 2015; Cantor & Sanderson, 1999).

The interviews highlight the participant's self-assessments of acceptance and happiness; these encompass assessments of themselves, their own talents, capabilities or general sense of worth, and life satisfaction, and each of these can be seen as an influence on participation across environments. For the young people with Down syndrome, acceptance was often expressed and interdependently connected through a sense of belonging at home, within a group or school environment.

The Importance of a Sense of Belonging (Family, Home, School)

Feeling accepted within the family or school-based group and having a sense of belonging was found to be a fundamental component of the wellbeing of the young people who were interviewed, and this sense of belonging was an important factor in the development of a positive identity. According to Woodhead and Brooker (2008), a sense of belonging lays the foundation for a strong and resilient sense of identity that can sustain the young person through transitions and subsequent experiences that might otherwise have been less affirming and inclusive. Within the educational environment, a sense of belonging was a significant consideration, given the participants' transitions through classes and across schools.

Acceptance and a sense of belonging had their foundation within the family context and were a two-way process. First, it involved recognising and

meeting the child's needs and right to protection and providing for and caring for the child. The second part of this process involved allowing the child opportunities to express personal agency and creativity, to contribute, to care for others, to take on responsibilities, and to share in collective contribution and celebration (Woodhead & Brooker, 2008).

The participants, including parents, all attested to the significance of an awareness of acceptance and a sense of belonging. One example of this is described below:

I often feel Adele knows … at an intuitive level she can understand where she's included and where she's not included. She knows who's accepting of her and who's not - and whether she operates at a different level to other people. She just knows that's who she is - she wants to be involved, included like anyone else […] I think the peers can have a huge influence.   (Parent, Adele)

In the school context, acceptance involved a sense of belonging that was created by the young people's perceived social support which began at primary school and continued through to secondary school, a feeling of connectedness, feeling cared about, accepted, respected, and important to the wider school community (peers, teachers, and other staff). This is a cognitive evaluation that typically leads to affective behaviour in students (Strayhorn, 2012, 2018) such as prosocial behaviour and productive educational outcomes.

Strayhorn (2012, 2018) found that being deprived of a sense of belonging prevented individuals from coping with academic tasks, and learning generally, and impeded personal development. He drew on Maslow's (1954) hierarchy of needs in his description of the importance of the need for a sense of belonging in the school context, noting physiological and safety needs (security), and a need for esteem and self-actualisation. These needs were evident in the comments from the young people, as were the implications for their sense of belonging and ability to learn and thrive.

The experiences of the young people consistently demonstrated the negative implications that resulted from being denied a sense of belonging in the school context and was evident in the various social spaces associated with school life such as the classroom, subject department, club, or extracurricular group. The

experience of Amanda illustrates this connection between not having a sense of belonging and her capacity to learn. In discussing her art and maths classes, where she does not engage, where she begins to stutter or become nonverbal with her peer group, she said the following:

I didn't like art. They don't like me. I can't keep up. Just get over it. [the lesson] […]. Maths is bad, don't like me. She doesn't like me so won't teach it (teacher) […]. Have to do something else. Don't talk. (Amanda)

Amanda's feeling that she did not belong, that she was not liked, triggered her to withdraw, had an impact on her speech, engagement in learning, and, thus, on her development. Her parents responded by changing schools, after which Amanda established an art-based microbusiness. She was clearly interested in art, and it was evident that her lack of engagement within the school context was largely a product of her feelings of exclusion. The common response among the young people in this research when faced with feelings that they were not being accepted was an increased difficulty with speech and a tendency to begin to stutter, difficulty with articulation, mumbling, agitated talking, or becoming nonverbal. A sense of belonging within the school environment, therefore, was powerfully linked to the potential for personal development and learning (Strayhorn, 2012).

Within the same school a young person may experience feelings of isolation in one social setting or learning context and a sense of acceptance, belonging, and validation in another. The sense of belonging, then, was situational, given that interactions with members of the school community happened in a variety of places (Strayhorn, 2012). To minimise disconnectedness, students tended to seek out structured situations or learning contexts that aligned with their personal values and expectations (Strayhorn, 2012, 2018). This process was particularly crucial for the students with a learning disability, as their need for belonging was heightened by their typically less frequent interactions with familiar and supportive individuals (Ribera, Miller, & Dumford, 2017; Strayhorn, 2012:20). Structured settings were described as classrooms, student support services, academic units, student clubs and organisations, and informal social spaces (see also Ribera et al., 2017). The significance of these settings is dealt

with in the two sections below: first, spatial indicators and structured spaces and, secondly through acceptance as positive self-esteem and social acceptance.

Spatial indicators provide a sense of belonging

The young people interviewed as part of this research reinforced that feeling part of the school and a peer group was important (Ribera et al., 2017; The Children's Society, 2018). Among the various structured settings and social spaces that had the potential to either promote or decrease a sense of belonging, as described by the young people in this study, were their regular classrooms, technology rooms, cultural rooms (library, music), the spaces where they spent school breaks (such as morning recess and lunch) and spaces where they spent time on wet days, travel to and from school, and sports areas. The participants were highly attuned to spatial and situational senses of belonging. There were clear divisions between the home and school environments, social settings, travel, and learning contexts. Each space offered different opportunities to express personal agency, to contribute, and to take on responsibilities, all of which were related to a sense of belonging.

Spaces were described in concrete terms, often with notable personal "markers" that conveyed a sense of belonging. In the home context (a structured space), these included markers of ownership and control—having one's own room, having control over musical instruments and/or electronic or other devices, and having control over a work space in the home context. Nelson described home as "where I love to be". He showed me through his room and pointed out markers of his various interests and achievements, each of which helped to provide a sense of belonging at home:

My room, I have my desk, my computer, CDs, videos, and my chart, and my certificates, my work bag, my work. (Nelson)

This process of identifying concrete markers was repeated across the interviews, which was interesting, as each of the young people initiated their desire to show me the spaces and possessions that were important to them. This sense of ownership was also evident in their photo record of items such as those listed by Nelson in the above quote. The consistent use of the language markers of ownership, belonging or being part of a group were also consistent; for example,

"my" was applied to material objects and broader markers of belonging with people , for instance, "my family who love me" or "my teacher aide who thinks I'm good fun" and " my soccer team". In the school context, structured settings represented a sense of belonging through ownership markers such as having one's own locker; own desk; own workspace; own uniform; own badge/s; own school. This sense of personal ownership is well illustrated by Amanda, who identified her own space in a large coeducational secondary college as follows:

It's my locker and it's at school. 223 is my code. In my locker it's my stuff, and some of my books. All of us, and mine too. My own things. (Amanda)

Having been moved out of a school environment where she did not have a sense of belonging, Amanda described how in her new school she was confident about being able to navigate the school environment to get to familiar spaces such as her locker where she kept her belongings alongside her peer group. Her reference to "all of us" was a language marker which indicated a sense of inclusion with her peer group and was an affirmation of her sense of acceptance and belonging. The sense of personal "ownership" of a space within structured settings provided tangible evidence of belonging for the participants, particularly within the school environment. This sense of ownership also applied to wider social settings such as "the soccer field where I play soccer with my friends" or "my youth club".

The sense of acceptance and belonging within structured learning contexts was impacted by teacher and teacher aide-teacher relationships. These were critical relationships that had a significant bearing on feelings of happiness, enjoyment, and security; they influenced the desire to attend and participate in the life of the school. The following quote from Nelson captured this idea, in his terms:

That is D, she help me doing my work and stuff. Done helping me doing work, help with maths and handwriting in class. … I can do this (schoolwork). At school I'm happy, so I'm so happy with all this (schoolwork). I'm so happy to see my friends. (Nelson)

In this extract Nelson reflects on his feelings of happiness about being in the classroom with his peers and his teacher aide. In his case, he identified his social interaction with friends, his sense of achievement at school, and feelings of

happiness within this inclusive structured setting, all of which contributed to his sense of wellbeing. The link between a sense of belonging and wellbeing emerged from the interviews with all of the participants.

The sense of belonging was promoted by inclusion in age and peer-appropriate activities such as being included in the regular classroom environment. This type of inclusion was evident in the following comment by Scott in which he explained how he worked on a number of curriculum subjects either independently, with an adapted curriculum, or within a small peer group learning context.

There's me again doing my work, schoolwork. Like looking at these cue cards. I like doing my work in my class […] sometimes the big stuff gets a bit hard. Mrs D says, 'Come on Scott, we will work with our group'. I like that too. I don't like going to the learning unit, I told them that. (Scott)

He clarified that he preferred the mainstream learning settings rather than the special learning centre of the secondary school. Notably, he did not take any photos of the learning centre. In fact, none of the young people included photos of these spaces. Their omission was taken to imply that they did not convey a sense of belonging and inclusion. Instead, they conveyed a sense of separation and difference, and this was accentuated within the context of negative discourses of disability. Scott's clear preference for being with his peers indicated that he did not feel excluded, and that he felt he was learning. His comment also points to the developmental importance of peer relationships within adolescence; this point is borne out in research across populations of young people with and without a disability (Mann, Moni, & Cuskelly, 2016; Solish, Perry, & Minnes, 2010).

The participants all attended secondary schools that had a special education room, learning centre or designated structured setting where students with a learning disability could go for additional support. These spaces were not seen as contributing to feelings of belonging, and comments about them revealed negative attitudes towards disability. This idea was expressed in the comment from Adele's mother:

She was in the unit and the unit was so isolated. You get there and think, 'Oh my gosh, so many disabled children together'. Adele was shocked. (Parent, Adele)

The student and adult (parents and staff) school population often substituted the formal names for these settings using slang terms or colloquialisms such as "the retard centre". The young people knew these terms for the learning rooms they attended. Because these colloquialisms were considered as being used in jest as part of the daily culture of the school population and were not intended to be offensive, some of the parents noted this was a difficult practice to stop.

The negative portrayal of students with special education needs or specific disabilities in regular school is ongoing. The medical paradigm of disability and its associated negative language is regularly repeated in the media when there are references to disability (Convention Coalition Monitoring Group, 2013). The paradigm reflects an entrenched discourse where disability is a tragedy, a burden, and deficit needing pity and charity. Typically, the family is responsible if the person with a disability requires special treatment, and special services or special schools are required because people with a disability are different (Blindenmission & Pruisken, 2010; Selvaraj, 2016). Given this wider discursive context, it is unsurprising that the interview findings revealed values that were consistent with this paradigm where different standards of acceptance, the language of "they", and discrimination towards the young people with Down syndrome persist.

Three of the young people had changed schools due to challenges arising from negative attitudes; one had moved to a new region for this purpose, and two had moved to other secondary schools. In all cases, the moves were precipitated by an insistence by the school that students with a learning disability spend a large part of school day in separate special education classrooms. A fourth student had not been able to start school at the local primary with his siblings, so the whole family had moved schools. In each case, the young persons with Down syndrome thrived when moved to a school environment which included them in the regular school. These processes were evident in Nelson's case. In the quote below, Nelson's mother explained how she moved areas so that her son could have an inclusive education and how this decision had made a major difference to his sense of belonging and learning.

The school Nelson is at now is really good. […]. In Auckland, Nelson was in a satellite class, but they never mixed with the other kids. He couldn't count to 10. When he came here – his learning took off, he was happy, he had a brilliant teacher aide, things changed so much, and he's learning everything and mixing with all the other kids. Brilliant. (Parent, Nelson)

While Nelson still received additional learning support in an adapted educational programme, this support took place in a larger, inclusive peer group.

These findings are summarised in Figure 3 which outlines key factors that emerged as influencing a sense of belonging and acceptance. These are important to consider in a practical conceptual framework of wellbeing.
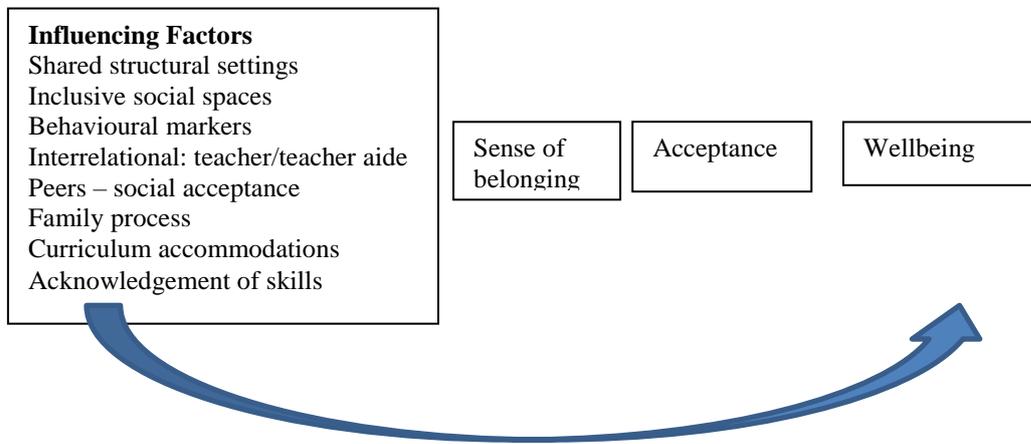
Figure 3. Acceptance: The influencing factors for a sense of belonging: Conceptualising wellbeing for children and young people with a disability.

Social roles are valued

The relevance of social role valorisation (SRV) was a theme that emerged from the interviews and was framed as an important dimension of acceptance. SRV is the term devised by Wolfensberger (1983) to identify the ways that people with disabilities are perceived, stigmatised, and offered or denied the opportunity to experience the "good things in life" and "an ordinary life" in the community. The term draws attention to the value placed on social roles in society (Osburn, 2006;

Mathews, 2017; Wolfensberger, 2003, Towell, 2012). The notion of SRV was developed out of the theory of normalisation (Wolfensberger, 2003) and it has made a major contribution to the policies of de-institutionalisation and the introduction of personalised social services for people with disabilities (Mathews, 2017). In SRV, when service providers, educators, or health professionals create or support socially valued roles, they will improve and increase the opportunities to achieve capabilities (Osburn, 2006; Sen, 1999). Social role valorisation established an approach to recognise the impact of expected roles and behaviours of people considered "different", marginalised or of less value (Osburn, 2006; Wolfensberger, 2000, 2011). From its early foundations, normalisation, reconceptualised as SRV, has played a central role in influencing theories, policies, and practice relating to learning disabilities (Yates, Dyson, & Hiles, 2008). The SRV framework has influenced how and what people (parents and professionals) perceive is possible for people with a disability. SRV models are drawn on by disability organisations in the United Kingdom, New Zealand, and Australia, among other countries. (Wolfensberger, 1998, 2000; Lemay, 2006; Osburn, 2006; Race & Race, 2003; Yates et al., 2008).

Within the SRV framework, three concepts are central: the power of mindsets (attitudes) and expectations; the elements of personal social integration and valued social participation; and, the experience of wounding, which relates to damaging or hurtful experiences associated with disability (Mann et al., 2016). Mann et al. (2016) found that the interplay of these three concepts had a strong impact on children with a disability at school. A key issue was the interplay between low expectations and segregated settings for children with a disability, particularly from an early age. Another crucial factor they identified was the negatively-oriented mindset of professionals such as teachers and health professionals, which caused damage by limiting social integration and which reinforced negative disability expressions and experiences in the mindsets of families.

The insights from SRV illuminated the comments made by the research participants on the importance of having valued roles within their home and school settings and the contribution of these roles to their sense of belonging. The opportunity to experience SRV within the family and home was a vital element in

the sense of belonging. First, SRV was illustrated through the recognition of the contribution to family life and the independence that was built through taking on responsibilities and household chores. Examples of these included maintaining the bedroom, emptying and stacking the dishwasher, folding and sorting the family laundry, feeding and walking the family dog, care of farm animals and farm work more generally, meal preparation, supervision of younger siblings, social interactions with whānau or family friends, and so on. The level of responsibility given to the participants, the number of home chores, the age when commencing these chores, and the complexity of the tasks varied within each family. What was significant, however, was the value attached to the role within the family and the expectation that the young person would perform the role in the same manner as other family members. The participants also identified the activities of daily living, for example personal hygiene, school preparation, school projects or homework tasks, that gave them an equal sense of belonging and these extended to sport or extracurricular activities.

Both the parents and the young people acknowledged that home tasks and responsibilities reinforced the position of the son or daughter as part of the family and promoted independence and personal dignity, highlighting the importance of family involvement in supporting the sense of belonging. Stokes, Turnball, and Wyn's (2013) review of the personal and social factors that impact on opportunities for independence among young people with disabilities found that there are typically fewer opportunities to negotiate social interactions for this population, despite the fact that there is little overall difference between young people with and without a disability in terms of their aspirations or hopes for education and training, work, relationships, money, sport, hobbies, and so on.

The interviewees identified the home environment as the most significant source of SRV, practice for independence, and working towards their aspirations. This idea is explained by Scott:

This is my guitar. I can get quite noisy on that. I put the song on and just smash it out. R and R (parents) they love it. […]. In the week the minute R and R gets home, they hear the big smash up of music going off […] they say have you cooked dinner already! Then I quieten down and go watch the news with them. Not if I am babysitting my sister, or my jobs night, but my music nights. I'll be ready for my flat. It's some of the things I love doing at home. (Scott)

Here, Scott refers to some of his responsibilities at home—he prepares a family meal one night a week and does some child care for his younger sibling—and some of what he enjoys about home life (his music). Throughout the interview, Scott referred to his parents by their names rather than as mum and dad; I interpreted this device as Scott's way of ensuring I understood his level of independence and aspiration to go flatting. The importance of home life and a sense of independence seen here in the case of Scott were exhibited consistently throughout all of the interviews.

The interviews, therefore, identified student wellbeing as being defined by a sense of belonging and acceptance through the performance of activities that were valued and respected. The ability to learn and having opportunities to express agency, to be creative, and to contribute were expressly linked to being happy and comfortable, to a strong sense of self-esteem and identity, and to being (and feeling) well supported.

Social role valorisation at school

Social role valorisation does not happen in isolation. Mann et al. (2016) have drawn attention to the role of education professionals as key contributors to SRV for children and young people with a disability and their families. This role was affirmed in the interviews, where relationships with teaching staff were talked about as a crucial element in the wellbeing of the young people with Down syndrome.

Positive affirmations by staff gave the young people a sense of belonging in their day-to-day experience of school. The participants' photos identified key people such as teacher aide, some subject teachers, deans, coaches, and support workers (service providers) in the daily contexts of their lives as people who contributed positively to their wellbeing. These "encouragers" were staff who were identified with phrases such as "they like me", "they tell jokes", "they keep me going", and "they know I can do it". These encouragers were found across the school community from office staff to the subject teacher or teacher aide.

The teacher is called Mr W. He tells the behaviour rules, called set the behaviour, and is social behaviour. He's happy about it. He's says Scott is a bit

of a joker. I know it for all of us (he listed the rules). He keeps me going. (Scott)

In this quote, Scott identifies his positive relationship with the college dean who provides positive affirmations, behavioural guidelines, and encouragement for Scott to "keep going". Scott was aware that the dean had affirmed that the school rules apply to all the students, that he was being included in "all the students", and this practice affirmed his sense of belonging. While this dean had not taught Scott, he was a key support in terms of behaviour queries and social interactions. For some of the young people, this role was filled by a member of the office staff, a librarian or caretaker; the common link was the genuine response and affirming nature of the interactions.

Parents highlighted, however, that the presence of key people who positively reinforced acceptance and a sense of belonging was tenuous and primarily just based on being lucky, rather than its being a routine aspect of school organisation and culture.

In summary, Figure 4 outlines the key factors that influenced SRV and their links with belonging and acceptance.

| **Influencing Factors** |
| *Opportunities to express agency* |
| Inclusive structural & social spaces |
| *Autonomy – taking on responsibility* |
| Social behavioural markers |
| Interrelational: teacher/teacher aide |
| *Key interrelational contributors (encouragers)* |
| Peers – interactions, *tasks/roles* social acceptance |
| Family process |
| Curriculum accommodations |
| Acknowledgement of skills |
| *Disability discourse* |

Sense of belonging

Social role validation

Acceptance

Wellbeing

Figure 4. Acceptance: The influencing factors for a sense of belonging and valued roles Conceptualising wellbeing for children and young people with a disability.

As can been seen in the diagram, where relationships are identified as central to acceptance within the school environment, these factors are interdependent. When there is no such interdependence, parents became more involved with the school.

The struggle for acceptance

When it became clear to parents that their son or daughter did not have a sense of belonging within his/her school environment, in all cases they adopted an advocacy role and, as was noted above, its adoption led to a change of school. Parents spoke of working hard to address practices that led to the exclusion of their children within schools, including challenging the negative ideas and attitudes about disability.

A key part of this challenge is addressing the deficit discourse of disability. The discourse of deficit operates through systems of measurement, classification, profiling, and moral power or value judgements on the types of deficit. Cognitive deficits, in particular, can be destructively and unfairly linked with ideas of "moral defect". This construction can have devastatingly negative impacts in areas such as education, immigration, and sterilisation laws (IHC, 2017; Paul, Stenhouse, & Spencer, 2018; Starr & Janah, 2016).

The role of the parent as advocate was well established in each family that was interviewed, with the role generally being taken up by the mother, but with sibling involvement in some families. Service providers also anticipated that the parents would take on the advocate role and intercede for education, broader service provision (health and benefit support), and provision of additional resources for their son or daughter. Other researchers have found that this type of intercession is common for children and young people with intellectual disability and is a response to poor levels of service for this group (Scior et al., 2016).

Read (2000) states that often these advocate roles are undertaken by the mother who will act as "mediator" between her child and the rest of society; she may act as a "buffer" for the child in an attempt to protect her child from becoming aware of harmful discriminatory attitudes in service provision. Within this pattern of advocacy, the parent/s will strive for opportunities for the child to

belong and have access to resources to learn, communicate, and participate; this effort often involves tiring (and sometimes challenging) activities such as interpreting policies and negotiating to get the information needed to make decisions (Bell, Fitzgerald, & Legge, 2013).

A recurring family experience, thus, was the need for constant advocacy. It is described here in the case of Adele whose mother referred to "2 years of meetings" with school officials, Ministry of Education officials, and a special education needs coordinator to try to address problems at school:

I just wasn't happy with XX. […] she was always integrated into the whole school before that. […] She's so capable. She was just sitting around, there was no engagement. […] My other girls said, "Mum, you don't want to have her there (in the special unit)". We tried for a couple of years. […] I talked with the headmaster, he wasn't interested, or the SENCO, the Ministry didn't seem to want to do anything … We moved her across town. […] At ZZ she's learning, accountable, there's no unit. She has a plan and is organised, in class, and it has worked out really well. […] She loves school and we hear all about it. We're all back on track again! No more "can't do this". What a change!   (Parent, Adele)

Adele had experienced a negative transition from an integrated, inclusive primary and intermediate school to a secondary school where, without consultation with the parents or family or the earlier schools, she was placed into a special unit. This situation had led to negative outcomes for Adele and the whole family. Adele was not engaged, her learning suffered, and this state of affairs led to unhappiness and inactivity at home. Adele's mother spent 2 years involved in IEP planning meetings with the school teaching staff, the principal, and the SENCO, and she met with the special education section of the Ministry of Education. As a part of this process, she made a formal complaint to the Board of Trustees and the Ministry of Education about the lack of educational provision and curriculum accommodation, but with no result.

Despite her advocacy, she was unable to bring about any change for Adele within the school. Adele was not moved from the special learning unit into regular classroom contexts. After an extended period of intense advocacy for change, they moved Adele across town to another school away from her local community and family, a move which required the added logistics of transport. As mentioned above, however, Adele was accepted into the new school, and as the quote

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indicates, she was included and began to make progress again. She became engaged in after-school activities once more, and her overall health improved. The impact of not belonging in the environment was remarkable.

Adele had been viewed by the school as the problem, not the approach to the inclusion of children and young people with disabilities in the school. This experience is not unique, and the wider issue has been the subject of disability studies and research into inclusive education (Slee, 2018). Common stories within schools and the wider community reinforce the notion that the "problem" of meeting the needs of children and young people with the school systems is located within the child. These responses reflect deficit discourses that are based on the medical model of disability and have a significant impact on the development, social inclusion, and participation of children with a disability (Skelton & Rosenbaum, 2010; Slee, 2018).

Discourse is an important marker of the social relations of disablement and enablement. "Special" is not a signifier of inclusion. It has always been a term applied to children seen as defective or abnormal. It represents a descending hierarchy of human value. (Slee, 2018, p. 18)

For the young people and their families, their values of belonging were challenged in the day-to-day experience of the school and impact of the disability discourse.

The recommendation from a number of the national service provider interviewees was to try and shift the discourse in schools to promote what was going well within the school context. These interviewees are involved in promoting a social model of rights-based disability discourse. The rights-based discourse focuses on the fulfilment of human rights, the right to equal opportunities, and participation in education and society (Blindenmission & Pruisken, 2010; Manago, Davis, & Goar, 2017). In the extract below, the service provider recommends a shift from a deficit discourse to a rights-based discourse:

Often in the media you tend to hear the negative things. We had a meeting the other day with professionals and I could see it sort of spiralling downwards into doom and gloom. People trying to throw in their real hard luck stories, well my stories are worse than yours. I was telling all of these good stories deliberately because, yes, there are plenty of them happening. But you tend when you ask someone to comment, the one that leaps to mind is "Oh my gosh,

guess what happened to so and so the other day". Rather than the fantastic, positive events that have occurred […]. We need to hear the good stories. (Service provider – education)

In the meeting referred to in the above quote, teachers and special education providers were overwhelmingly sharing "stories" of students with a disability through a negative lens, a deficit discourse, which indicates that within the professional community deficit discourses of disability continue to be influential in shaping the service culture. These ways of framing the issues faced by children and young people in the education system are difficult to shift, as indicated by this participant who reported attempting to counter these ideas with rights-based stories of students with disabilities involved within their school communities.

Children and young people with disability as the *"other"*

The education provider interviews revealed entrenched beliefs that proved to be limiting for children and young people with disability in terms of their potential to jeopardise these young people's sense of belonging in the classroom and school community. Typically, these beliefs led to the stigmatising of children and young people with a disability as the "other". These beliefs were revealed in the preconceived assessments of the learning capability of the child that were evident in discussions about their placement in classes or in references to their limited potential to learn. This discourse is taken here as reflecting a process of "othering" of people with disabilities in a way that emphasises their differences and limitations. The othering of people with intellectual disabilities has a long history, along with the use of functional assessment terms such as idiocy, retard, and moron within the medical and educational discourse (Simpson, 2011). Processes of othering lead to the establishment of norms within the social sphere and allow dominant groups to impose their perceptions upon those who are dominated, in this case children and young people with intellectual disability (Mathews, 2017; Simpson, 2011; Wolfensberger, 1972, 1996, 2003).

This othering approach was illustrated in the following scenarios: through class placement, where only one child with a disability or an "issue" would be "allocated" to a class so as not "to burden the teacher"; where a school would

"make provisions as much as it can"; and, where the belief was held that "it's up to families to instigate what the child needs"; in a mindset that "families need to push for it" (education); and, that "they need to provide the resources for reading and things". The education service provider interviews revealed inhibiting, entrenched beliefs through use of the phrase "the other students" and through emphasis on the parental advocate role and different ideas around structural placement and resource provision.

The educators' perception of parenting a child with a disability was that it was a burden on the family and that there was a need for the parents to have space away from their child with a disability (respite). This viewpoint is reflected in comments such as: "they do need respite from these ones though"; "it must be so hard to be the mother; they are special parents". This tragedy discourse identifies disability within the individual (the medical model of disability) alongside othering as observed as a generic issue of identity (those kids/those people/those parents).

Well there are two of us (teachers) and like we had two children last year, we had one each just to share the load. So that is another reason why you get them is to even it out a bit [...]. To have a break (the teacher), she (the student) will be in here to play for the afternoon 2 days a week, there's not much else you can do really, you are supposed to do all that planning but, well, you know. (Senior teacher)

In this quote, the teacher explained how the school made decisions about the placement of children with a disability in classes using language such as "share the load" which framed the process as a burden or "load". There was, however, a difference between the rhetoric of planning for a child or young person with a disability and the practice. For students with an intellectual disability, implementing the curriculum and planning for learning or engagement is not seen as something credible and, the "well, you know", betrays the generally held lower social yet unspoken expectation of those with an intellectual disability.

An example of how limited the awareness of disability discourse within professional practice, school culture, and education provision is can be found in the way the Ministry of Education has drawn on advice from the Central Region Special Schools to provide a framework for "Level One Learners" (Ministry of Education, 2001), but has failed to clarify who this student population group is

and how the education status of the "below level one learner" is diagnosed, assessed or categorised.

> What got me was Sean has gone all through school then the SENCO said he is a below level one – what! I thought, he has some NCEA Level 1 and NZQA credits at different levels anyway. Then I found out what she was talking about, I couldn't believe it!! The other teachers said nothing […] she was senior. He already had credits from other subjects – just out of control. He got polytech credits in his transition work – what are they doing? (Parent, Sean)

Here, Sean's mother explains her confusion and alarm at her son's "re-categorisation" late in secondary school. This recategorisation was not based on educational achievement, so the motivation for doing so was unclear, i.e., was it to exclude him from some curriculum subjects he had been attending or a misguided understanding of the Ministry of Education material. The situation was stressful for Sean and his parents, who sought additional learning opportunities for Sean to obtain further credits.

Below level one learners continue to be an unspecified population group, and there are no established criteria set by a professional body (David Wales, March 21st, 2018, personal communication) that needs to be applied when providing this label, yet it remains a term widely used within the Ministry of Education. Furthermore, when examining the factors that drive discrimination towards children with intellectual disabilities in school, how nondisabled children identify and misunderstand differences has been found to be the key driver (Nowicki, Brown, & Stepien, 2014). Perceptions of ability, physical characteristics, and differences in behaviours and learning abilities that were seen as less than "ideal" and thus "other" were key drivers of exclusion (Nowicki et al., 2014). These factors reflect the notions of the ideal and the role of othering in driving exclusion (Appleton-Dyer & Field, 2014).

Bersani (2008) stipulates the history of life experience for persons with intellectual and developmental disabilities is expressed predominantly through the voices of others – the voices of professionals or family members or policymakers who have not experienced the reality of life with a stigmatising label. He describes this reality of two worlds as the world of persons who are defined by disability and the world of those doing the defining (2008, p. 400). Bersani (2008) emphasises the divide through examining the negative power of a label. "A label

creates narrow lives by people defined by it – lives devoid of any of the facets that we find lend our lives dignity, afford us respect, and make our lives comfortable" (2008,p. 400). Bersani is referring to the changing terminology of mental retardation however it would appear that even when the language is changed, for example in relation to below level one learners as happened in New Zealand, the prejudices have not. Bersani determines, "The fact of stigma is that the status of the lives of these individuals transfers in society to the label" (Bersani 2008, 403).

In summary, Figure 5 outlines several key ways discourses about disability have influenced acceptance and wellbeing.

Influencing Factors
Opportunities to express agency
Inclusive structural & social spaces
Autonomy – taking on
responsibility
Social behavioural markers
Interrelational: teacher/teacher aide
Key interrelational contributors
(encouragers)
*Professional practice and
knowledge*
Peers – interactions, tasks/roles,
social acceptance
Family process – *parental
advocacy and family agency*
Family economic sustainability
Curriculum accommodations
Acknowledgement of skills
Disability discourse

Sense of belonging

Social role valorisation

Acceptance

Wellbeing

Disability discourse

Figure 5. Acceptance: The influencing factors of the impact disability discourse on service provision for a sense of belonging and valued roles.

Acceptance as Positive Self-Esteem

Self-esteem refers to an individual's sense of self-worth and is broadly considered to take into account behavioural, cognitive, and emotional aspects of the self and includes an individual's understanding of how he or she is valued by other people. Self-esteem is recognised as being critical to an individual's academic achievement, learning motivation, social adjustment, and wellbeing. Furthermore, self-esteem has been specifically identified as important in the limited number of studies of particular significance for students with learning disability (Edworthy & Cole, 2012; Goleniowska, 2014; Jemta, Fugl-Meyer, Oberg, & Dahl, 2009; Kumar & Raja 2009; Sati & Vig 2017).

A major contributor to wellbeing expressed through the young people's interviews was their experience of acceptance of diversity. The young people's perspectives on the "role of self" came across as a mantra of "do the same as, when you can, and different as is okay", especially "when you are liked". A significant contributor was a sense that what you are doing is meaningful and is equally valued within both structured settings and by the peer group. This feeling of being valued was reinforced by the teacher and the teacher aide. A key example of when this valuing was done well was when different schoolwork was set, but was in the same subject class as other students. This type of inclusion resulted in positive self-affirmations:

I like at school, I am good at it, learning at class. Most time my classroom, cool stuff. A lot of friends and my maths work and class. Happy. (Reina)

Have fun, feel happy. Better than last time. In class, do my work. I am learning. I'm happy all the time. (Lists subjects.) (Nelson)

In these two examples, Reina and Nelson identify the importance of the location of the classroom, being with their peer group, and the resulting sense of positive self-identity. The reference to "my work" was an acknowledgement of the differentiated curriculum, which was consistent across all the young people interviewed, along with many examples of differentiated curriculum within the interview support material.

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The parent interviewees were well aware of the complexity of self-esteem, SRV, stigma, and acceptance, and this understanding came through repeatedly throughout the interviews. Reid's mother, for example, said the following:

He probably achieved more a sense of himself and self-worth, because I think intellectually and scholastically he is so different to perhaps normal children, or even other children with a similar disability – he's not up there, but he has a huge sense of self-worth and self-pride, and his sense of community, and that stood him right the way through, like there is just something about being able to go into town or anywhere and feel that you belong. (Parent, Reid)

In this quote, Reid's mother identified acceptance, inclusion, personal agency, and a sense of belonging in the local community as being tied to self-esteem. The interviews offered other influencing factors which were examples of positive role models; student experiences of being valued by their peers; parents' experiences of their son or daughter being valued within group activities (such as sports clubs or choir) and by other adults; professionals, teacher aides and teachers responding to the young people's and parents' needs, suggestions, and requests; being encouraged to be involved; having new experiences (young people and parents); and, finally, of having opportunities to develop through sport, music, and other extracurricular activities. The following quote from a SENCO explains the important role of the teacher in setting the tone:

The thing that influences wellbeing for children with a disability is the atmosphere of the classroom. And that comes from the teacher. But it is also spread through the children right from junior school. So, it has to be modelled etc.: you know, the way the teacher reacts to that child and that affects the other parents and the inclusion of them and their support. … other parents were not happy with that child being in that class […] you have to work through it. You just have to include them (the parents) and let them see there are positives in having this child there. (Service provider - education)

Teachers, therefore, play a key role in ensuring students with a disability are welcomed and feel part of each class. In this instance, the teacher did so by acknowledging that, in this school, education is for all children. There were also attempts to include resistant parents in school open days, in order to reduce negative influences, identify education provision, and illustrate the benefits of inclusion. The ability to "feel you belong" is the foundation of positive self-esteem and comes from the input from the adults in the home, school, and macro system of state institutions.

There was, however, equal evidence of situations where this attempt to ensure a sense of belonging was not common practice within a school culture. The young people's interviews identified situations where wellbeing was not supported; they demonstrated this lack of support through increased levels of anxious behaviours (anxious vocalisations, tapping, jiggling leg, rubbing hands, getting up and walking around, speaking from the doorway) when discussing negative things at school, for example, a lack of independence and self-expression and a lack of friendships. The young people's sense of acceptance and belonging (or lack thereof) was expressed as a strong awareness of limited SRV and of not fitting in. In one interview, I asked Amanda whether there were any negative experiences at school she could tell me about. Amanda left the room and spoke with her mother (stuttering in her speech); her mother then gave this example:

My guess is that sometimes they say "hello" and then are a bit mean behind her back. And then adults look on and say "why doesn't Amanda answer people"; "isn't she rude". Well actually if people just walk by you all day long and say "hello", no one ever stops to talk to you […] wouldn't you get tired of it? […] She's having lunch on the stairwell, on her own each day. She's so anxious about the canteen. The teacher said, "they like that, don't they?" – they certainly accept significant differences. (Parent, Amanda)

Amanda re-entered from the edge of the room to nod agreement.

In attempting to relay the negative experience, Amanda became anxious and had her mother describe the context and social interactions that caused her to disengage within the school. Amanda's experience was not unique and was common across the interviews where positive encouragers and distractors or barriers to positive self-esteem were identified and, therefore, reinforced the point that the everyday lives of students with an intellectual disability are not well understood and evaluations often rely predominantly on parental reporting. The key identified factors were the interdependence of interpersonal relationships, modifications to the environment (interpreted as curriculum differentiation), and social and attitudinal factors as facilitators of or barriers to a sense of belonging and wellbeing; these findings are substantiated in the literature (Lyons, Brennan, & Carroll, 2016).

When this experience of a lack of acceptance associated with school was more acute for the students, they discussed the use of strategies such as self-talk

and/or phrases to reduce anxiety, the role of fantasy, the need to seek support, the role of parents as advocates, the need for support from home, the role of a support person who also likes the student, and seeking spatial locations that provide a sense of belonging and acceptance. The strategies engaged in by the students actually represent a complex sociological understanding of their situation. In the following example, Kirstie becomes less verbal. However, she still wants to answer the question. As outlined below, Kirstie withdraws from the situation and takes time out:

Researcher: What don't you like at school? Kirstie starts grinding sounds and leaves the room, returns with school timetable and points to a curriculum lesson. Kirstie shows me a DVD and lunch box, this is interpreted as the student going to a quiet space to have a snack break and to watch a favourite DVD when she is anxious in the specific situational lesson at school. (Kirstie)

In the interviews with the national service providers, positive identity was seen as an essential aspect of wellbeing for children and young people with a disability. This understanding was expressed through recognition of disability as part of the student's identity and as a necessary part of society's culture.

I don't think that wellbeing for children with disabilities is any different for wellbeing in general. Kids need to be in environments where their capacity to grow and develop is recognised…. I think that you start getting very confounded when we see disability as some sort of abhorrent actually. Disability is just an ordinary state of human existence and what tends to happen around the wellbeing of disabled people in my view is disability starts to take precedence. So, people try to ameliorate what is an ordinary state of childhood for the child, forgetting about what is fundamentally human. (National service provider)

Acceptance was a significant theme of the national service provider interviews. There was a focus on the human need for a sense of belonging and social inclusion (for both the student and the family) as being intrinsic to wellbeing from as early on as possible.

Social acceptance, relationships, and behaviour

Positive peer relationships and friendships throughout one's childhood and adolescence have been shown to predict better outcomes in adulthood by increasing self-worth, happiness, and interpersonal competence. Both the student and parent dialogues identified that young people with Down syndrome were well

attuned to the importance of acceptance within social spaces by the peer group. Below, Sean explains his experience in sports science, where he enjoys the peer group he has been at school with from primary school.

I like sport science because I have my friends from SS school. We do the sports together and have laughs and I do the work with them. I am good in the team and Mr. L knows I can do it too. (Sean)

Sean has a strong sense of belonging with this peer group and that has translated into participation and achievement in a secondary school environment. A number of participants had maintained a peer group from primary school and this ongoing bond had enhanced their sense of belonging at school. In addition, maintaining a peer group from early school years perpetuated a momentum in that the young person with Down syndrome (with familiar peers) was viewed in a positive manner, which resulted in experiences of encouraging teacher engagement for a number of the young people interviewed.

The parent participants described aspects of a sense of belonging and their role in developing social behaviour. For some parents, developing their child's social behaviour was a consideration from the early parenting years and was linked to full community participation. For these parents, the discussion was about acceptance of social behaviour that may come as a child grows (developmentally) through required practice and routines for their son or daughter such as social cues and social behaviour. This socialisation was considered to be the struggle with socially appropriate behaviours and was 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 Scott ... 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 "Scott, hey it's not good …" and he'll go 'Oh, OKAY Mum.' (Parent, Scott)

In this extract, Scott's mother describes the intention of teaching socially acceptable behaviour so that he is socially included as he progresses through school and grows up. She identified that she is respectful, uses clear language and instructions to Scott to describe what behaviour should be stopped and what the alternative behaviour is, in order to model what is expected in a social situation.

This was a consistent practice for a number of families, particularly where there were siblings. This type of behavioural modification was also reliant on parental skill or experience. For example, some of the parents were more socially active than others and so they ensured that their son or daughter was aware of social skills and social behaviour from an early age. Within these families, the young people were able to practise and repeat social behaviour from a very young age in a range of environments. For three of the parents who were less socially active in the community, their son or daughter was also less socially active, so had less opportunity to practise behaviour, and it appeared that less focus was placed on this aspect of the child's development.

The importance of peer and sibling modelling and scaffolding behaviour as natural childhood experiences for learning social skills was also identified within the young people, parent, and service provider interviews and is well described by this parent:

The measuring of the power of the role models, I just don't think we can emphasise that enough [...]. For me personally ... he needs to be in a regular setting surrounded by typically developing children. (Parent, Sean)

Appropriate behaviour and expectations were often set out before the social event or activity. This presocial participation preparation was identified by parents and young people as clarifying expectation (what would be happening, order of activities etc.) and/or as reducing anxiety for the young people. Such preparation included a range of strategies such as a photo of the venue or the use of sign language to supplement verbal language where needed for social participation at an event (anticipating that the young people's language could become compromised by anxiety and, therefore, become harder to understand). Pre-event situational role play, photos or visual aids to familiarise the young person with the expectations of participation were also discussed. A number of the young people had prepared phrases that they had been taught by parents or siblings to repeat when teased or to use to respond to comments from unfamiliar peer groups or in an unfamiliar situation (protective factors).

We use visual rules and routines, and expect a bit more from Elizabeth but she is clear what behaviour is OK and what is not at home, school, and when we are out. You know so she can learn, encounter different experiences and be part of the group. (Parent, Elizabeth)

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With Kirstie, there was the advantage of having sisters who could role model behaviour:

it's an advantage to copy … Have charts, home and for school, T.A. who knows her and teacher who wants her in the class ... get the balance with some sport and rewards so can be at school with friends or people she knows. Balance it all out and make all the rules clear …. (Parent, Kirstie)

Both these examples were typical across the interviews and show the extent of the protective factors and prosocial behaviours the families engaged in. The parents went to great lengths to encourage these strategies (generally well researched by the parents) at school.

Social Acceptance and bullying

A heightened awareness of expectations of social behaviour and participation was evident in the young people's perspectives on participation in school and the role of school culture in wellbeing. This understanding of group dynamics and the social culture (school culture) was expressed at various levels by all the young people within the study. The parent interviews also identified knowledge of the young people's awareness of the school culture, school experiences, and of being highly socially attuned. There is increasing evidence that people with Down syndrome do have a specific learning profile and strengths in the area of social skills, social understanding, and relating to others, right from birth (All Party Parliamentary Group on Down Syndrome, 2012). For example, in this interview the young person identifies a change in the class group and a student group dynamic and selects behaviour to deal with this situation.

Don't like P.E here on Friday OK. P.E good, Friday NOT. No P.E. Friday I say I will do health, tell her (teacher). I do running, soccer team, and soccer good with friends I like. Good. Second Friday, new ones, tell her I am good at sport, running, swimming, rugby, all, netball with friends but NO second Friday OK. Friday one, NOT second. Just best outside. (Reina)

The interviews examined participation and the young people's role in school culture, for example, in terms of their participation in activities at breaks, and at different locations within the school where participation was accepted. They were all very aware of the spatial context in terms of the social spaces within the school. Experiences of verbal and physical bullying were identified

with a high degree of clarity about who, when, where, and how this bullying occurred that indicated it was a key concern for the participants. This was revealed in comments by both the young people and their parents. Scott commented,

These are the boys in same class last year. They take me out to places like they go out to places. Like they go out and play rugby, cricket and that. I like going over there and playing with them. But (pause) if X is with them, if X there, is with me, he tries and gives me the fist. And I don't like fists being turned in my face ... that happens it turns into a fight. It means that I have to go and see the deans. Don't go when X there. (Scott)

Various bullying experiences were revealed ranging from peer-to-peer bullying, teacher-to-student bullying, and bullying on school buses. Bullying was also revealed in comments by parents who described difficult interactions within school environments. A variety of verbal and behavioural strategies to deal with these situations at school or on the journey to and from school were used. These strategies included phrases taught by parents and social skills programmes at school such as "don't bully me" or "don't shout at me, I don't like that". The behavioural strategies included withdrawing. The effects of bullying included the development of physical symptoms of sickness and behavioural outbursts at home. Outbursts included things like running away, negative self-talk, agitation, and so forth. The young people did not always immediately report what happened in terms of teasing and bullying at school and parents said it was important to know the cues. When it was not recognised and dealt with, the young people held on to the emotion from the bullying at school and expressed it at home, at a later time, where or when they could.

For most, bullying was generally unresolved or not addressed. A productive strategy was when the young people identified a specific teacher or senior staff member to seek advice from directly, and most young people sought support or confided in the teacher aide or teacher. Finally, those with siblings sought them out. What was apparent was that all participants had a complex understanding of the social environment and social hierarchies within their school.

In the interview extract below, Mandy tells me about the experience of being teased and how difficult it is for her to feel safe.

Normally teasing […] teased by teacher aide or the teacher, teased by students, okay. Teased sometimes by big boys upsetting, – say "are you at X school?" (special school) "Excuse me I'm NOT". Sometimes it's really upsetting me. I just ignore them. Nobody helps with that. Tell nobody. (pause) I love going to school – home. My friend-sometimes naughty- upset, pushing people- throw keys on door. […]. Sometimes runs away. I go to her … say be safe. (Mandy) (includes peer example)

In this example, there is an insight from Mandy into the complex understanding of the school environment and her identity within it, her own sense of belonging, and of protecting her friend who has outbursts of frustration from "teasing".

Bullying as a problem in schools is well documented and it is a threat to the sense of belonging and acceptance to those who are bullied. The Programme for International Student Assessment (PISA) report for New Zealand states that a sense of belonging is strongly correlated with student relationships with their teachers and other students. The PISA assessment showed high levels of bullying in New Zealand schools, and New Zealand 15-year-olds reported the second-highest rate of bullying out of 51 countries, which equates to just under one in five students. The PISA criteria described New Zealand students as frequently bullied, and New Zealand compared poorly in the OECD average of 8.9% (Ministry of Education, 2017b).

This data, however, did not include or differentiate students with a disability. The Children's Commission report on youth reports similar concerns about the experience of bullying in New Zealand, ranging from cyberbullying to verbal and physical bullying, but again does not identify the experience of students with a physical or intellectual disability (Office of the Children's Commissioner, 2017). The Ministry of Education report which drew on responses from 11,000 children identified the high level of bullying across New Zealand schools and again does not include the experience of children and young people with a disability (Education Review Office, 2019). This population is more at risk, but is consistently not included in this data. Research addressing this topic is limited, particularly for young people with an intellectual disability, but that which is documented demonstrates that the incidence of bullying is higher for children with a disability. Internationally, the rate is noted to be two to three times

higher than that of typically developing children (PACER, 2013). Bullying in school involves social power relations and interactions, and because of disability stigma and the labelling of children with a disability as the other, students with a disability are at a higher risk of victimisation in the school context (Chatzitheochari, Parsons, & Platt, 2014, 2016). In considering that New Zealand has a higher rate of bullying relative to most other OECD countries (Education Review Office, 2019), for this student population not to be heard or included in the data is a situation that needs to be immediately addressed.

Social disability identity

The development of identity is a life-long process; however, while acknowledging that over time people at different stages of life have different social identities, identity development is at a critical stage during the adolescent years. Life stage theories of psychosocial development such as Erikson's (1968) psychosocial theory identified important sequential stages of human development. For example, Erikson emphasised care and security in infancy as a key vulnerable stage and achieving identity clarity through the adolescent stage as key to providing solid skills and adaptive resources for progression onto adulthood and the following stages. Identity development in adolescence is impacted by age, gender, physical health and appearance, intelligence, and social skills (Tsang, Hui, & Law, 2012). There are also various peak times for self-esteem in relation to curriculum subjects and physical activity by age and gender for young people (Tsang et al., 2012).

In psychology, the term identity is often used to refer to the self, expressions of individuality, and the groups to which people belong. Disability is a particular identity context, one that marks individuals as part of a group and as members of a minority sometimes subjected to marginalisation, prejudice or discrimination. Disability identity refers to possessing a positive sense of self and feelings of connection to, or solidarity with, the disability community. A coherent disability identity is understood to help individuals adapt to disability, including navigating related social stresses and daily experiences. Disability can occur at any point throughout a life span, thus making it difficult for researchers to establish a consensus model of disability identity development. There is limited

literature on disability identity (Dirth & Branscombe, 2018; Dunn & Burcaw, 2013; Forber-Pratt, Lyew, Mueller, & Semples, 2017) and within the literature that does exist there is very little focus on the experiences of young people. Common themes in scholarship on disability identity the incorporation of disability theory and validation and concepts such as identity, self, a sense of belonging, activities of daily living, mobility, mood, role, and participation (Forber-Pratt et al., 2017).

Gill's (1997) disability identity scale uses 17 statements to identify attitudinal orientation towards disability. The scale recognises the importance of social group membership in disability identity and offers insights into the dynamics of self-categorisation, the psychological experience of disability, group membership boundaries, social mobility, and social roles, and how self-concept and identity affect wellbeing outcomes for people with disability (Forber-Pratt et al., 2017; Dirth & Branscombe, 2018). The scale promotes a social identity approach to disability identity and provides insight into the dynamics of identity formation among the young people in this research.

The young people referred to their disability when describing themselves through statements like "I have Down syndrome". This was a general comment to me throughout our interviews. They were all well aware of the interdependence of issues related to disability identity.

I have Down syndrome, see (shows upturned palm). I like learning, going out, and doing things. Sometimes I get tired. I like school and polytech. I want to get my licence and drive. Some things are a bit hard but I just ask for help. I work at the café. Mum says I'm beautiful, my brother says Big S. My friend C has Down syndrome, I helped him out when he came to the BBQ. Then he went home. I'm good with all our friends, we go out. (Sean)

Here, Sean states hopes and aspirations similar to those of any young person his age. He states clearly that he has Down syndrome and shows his palmar crease as evidence. He seems to describe being tired and having some things being "a bit hard" as a result of his disability. These phrases, "being a bit hard" and "I get tired", were two of the common statements of identity acceptance made by the interviewees. Sean appears to find his identity through his activities of the past and present, mentioning school, and polytech, and his café work. Sean identified others' positive perception of him through the comments of his mother

and brother and through group socialisation. He identified a friendship relationship and mentions that his friend was still learning about socialisation. In this example, Sean's disability identity was interpreted through a social identity approach, where his acknowledgement and affirmation of his disability are reaffirmed through a sense of belonging within the family and social group, SRV within the community, and socialisation. His positive acceptance and self-esteem seem to be derived from these interdependent factors. This identity construction was typical across the interviews, particularly for four young people whose experiences of school, ongoing education, part-time work, self-expression, and disability identity were more strongly evident.

A number of the young people attended a youth social group and made statements like "I have Down syndrome and sometimes I sign if my friend needs it"; "my friends at school don't have Down syndrome at school, just me so that's ok I just find it a bit hard sometimes so I have to get a bit of extra help"; "I know I have Down syndrome because I was born with it"; and, "I am the only one in my family with it and I can get tired sometimes but I like to be busy, go out heaps, and I want a flat too. For these young people, the families had taken a proactive approach to identity development, disability identity, social identity, and social skills strategies for the young people from an early age.

Where this was not the case, it was considered to be due to a number of factors such as maturity, nonverbal communication of a complex topic, and parental skill. These findings are consistent with the literature on identity youth development across nondisabled peers of the same age (Tsang et al., 2012).

The way the social meaning of disability coexists with disability identity development is considered a dual negotiation (Forber-Pratt et al., 2017). The findings show that this dual negotiation of disability identity is crucial for young people with Down syndrome. Sean had developed social skills, a disability identity, and a range of strategies to negotiate social engagement through the buffers built in by broader family, siblings, positive peer groups, and his teacher aide. These specific sets of factors were in place for half of the participants, all of whom were more socially engaged as an outcome. In these cases, disability identity and social identity were practised and talked about from an early age,

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with boundaries and role plays proving helpful at times and with parental social participation and parental skill also helping. The social identity approach to disability identity for young people with intellectual disability deserves major consideration for further examination in this field.

Disability identity was determined by the research participants who worked in national service provision and policy roles to be an important part of wellbeing for this group. However, disability identity was generally not well understood. This point is explained by one participant:

The thing still in New Zealand, we don't talk about disability identity equivalent to any other type of identity or culture. So, we need to be clear about that. 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. (National service provider)

As this quote demonstrates, there is a need to develop the area of disability identity. This need is substantiated in the literature, where there is a call to reframe disability as a diversity topic so as to gain more traction for further discussion of disability identity (Dirth & Branscombe, 2018).

A social disability identity is, therefore, also an essential part of being accepted, an acceptance of self, and, therefore, is a key component of wellbeing for children and young people with a disability.

Conclusion

This chapter has presented the first key element of wellbeing for children and young people with a disability that emerged from the research: acceptance. Acceptance refers to the formal or informal admittance of a young person with Down syndrome into society and the absence of social disapproval. The desire for positive and lasting relationships is among the most pervasive and fundamental of human needs. For the young people with Down syndrome acceptance was often expressed through a sense of belonging at home, within a group, or in the school environment.

At school, acceptance involved feelings of connectedness, feeling cared about, and important to the wider school community. A sense of belonging within

the school environment was powerfully linked to the potential for personal development and learning, and when faced with feelings that they were not being accepted resulted in an increased difficulty with speech and behavioural withdrawal. The link between a sense of belonging and wellbeing was most evident when the young people were included in the regular school environment with the same curriculum as their classmates or with an accommodated curriculum if required.

Social role valorisation, formerly referred to as normalisation, is an important element of the notion of acceptance. SRV is an approach that acknowledges the impact of expected roles and behaviours of people including those who are considered "different", marginalised or of less value. The SRV framework inspired a transformation in the way that society and particularly, the social service sector, perceived and provided service for people with disabilities. The importance of the young people's role through undertaking and accomplishing specific tasks at home, in the class, and in the school community in addition to the positive affirmations given by parents and school staff was evidence of SRV and its relationship to a sense of belonging and acceptance.

In reality, it was found that the impact of the discourses of disability challenged the day-to-day experiences of the young people and their families and these discourses continue to be influential in shaping the service culture. In this chapter, I argue that this is a process of othering that emphasises the differences and limitations of people with disabilities and is implied and applied in practice. The presumption of a lack of competence and expectation by service providers such as teachers led to diminished self-worth. Self-esteem is recognised as being critical for an individual's achievements in academic and life skills and the motivation to learn. A lack of self-esteem has an important effect on the level of wellbeing.

Social acceptance and behaviour were enhanced through families' engaging in prosocial behaviours along with sibling and peer role modelling. Scaffolding behaviour for learning and developing social skills at home and school also contributed to increased self-esteem, happiness, positive peer relationships, and friendships. These practical actions throughout childhood and

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adolescence are shown to result in a more positive identity, which is an essential aspect of wellbeing for children and young people with Down syndrome.

One threat to the sense of belonging and acceptance is bullying. A range of bullying acts was, unfortunately, experienced by the majority of young people in the research and although bullying in schools is well documented, no action was taken by the schools or teachers to alleviate the young person's stress. The families and some school programmes equipped the young people with a range of verbal and behavioural strategies to cope with these distressing encounters.

The social model of disability and identity development of adolescence when evidenced as opportunities to express agency, autonomy, and self-actualisation result in positive social disability identity. Acceptance of self and one's social identity are interdependent and for the young people in this study were strongly influenced by interpersonal relationships.

The figures in this chapter outline the key factors that influence wellbeing. Each figure develops successively to show how the factors build upon each other to culminate in the final figure below.

Figure 6. Acceptance: The influencing factors for a sense of belonging, positive self-esteem, and valued roles.
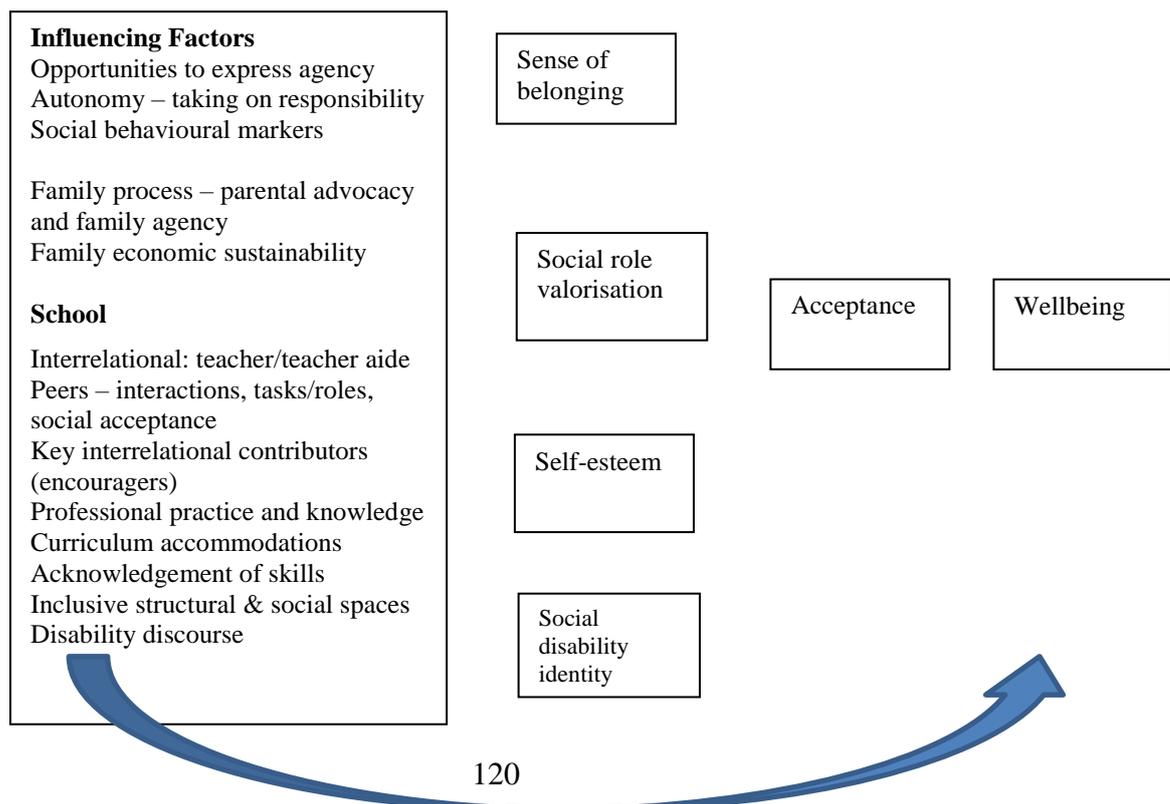
Chapter 5:
Wellbeing as Recognition

Introduction

As indicated earlier, recognition emerged as a key theme in conceptions of wellbeing among the children and young people who were the focus of this study. This finding was backed up by the comments of parents and service providers. The link between recognition and wellbeing is well established (Taylor & Gutmann, 1994; Honneth, 1995, 2001, 2004, 2012) in relation to multiculturalism and the politics of difference and to identity, social justice, and interrelationships. What follows is an analysis of how recognition emerged as a critical feature of wellbeing among children and young people with disability. The chapter begins by considering the vital link that is established between recognition and wellbeing in terms of respect, the processes involved in the distribution of resources through the experiences of service provision, and relationships for the young people and their families. The significance of equal entitlement as a process of social inclusion or social exclusion has broader ramifications when considered in conjunction with the dominant disability discourse of service providers, policy, and, practice. To the same degree, recognition is a crucial element in identity, and social disability identity is a significant feature of wellbeing among children and young people with disability.

Theoretical frameworks that draw attention to the importance of social recognition can be found in the work of Taylor and Gutmann (1994), Fraser (1989, 1995, 1996, 2000, 2003) and Honneth (1995, 2001, 2004, 2012). They acknowledge the importance of recognition in identity formation and the way it provides a normative basis in questions of justice. Taylor stresses recognition in relation to multiculturalism and the politics of difference; Fraser emphasises economic redistribution, social status, and the values of social justice, and Honneth highlights recognition as it relates to identity, social justice, and interrelationships.

According to Taylor, the principle of recognition can be seen as taking two forms: 1) equal recognition and status in the form of equal rights and 2) positive

recognition of the specific differences and distinct rights, needs, and requirements of nonhomogenous groups (Taylor, 1994). The recognition of marginalised or disadvantaged minorities becomes an issue in the politics of difference.

The politics of difference refers to conflicts over the giving or withholding of recognition to different identities and to tensions that are associated with respecting the distinctiveness of the individual or the group or assimilating them into the dominant or majority identity. The politics of difference stresses the compromised authenticity for those who are not systematically recognised or acknowledged such as groups that are marginalised according to socioeconomic status or disability (Taylor, 1994).

Fraser draws attention to the concept of recognition and the way it is linked to redistribution (Fraser, 2000, 2003). She categorises different forms of recognition and redistribution as perpetuating socioeconomic disadvantage, injustice, subordination, and devalued social status. Fraser's focus is on the way the redistribution of resources is related to those who are seen by society as either valuable or less valuable. Recognition requires a framework of distribution that specifically acknowledges differences and which comprises defensible claims for social equality, individual identity and group identities, social status, and values (Fraser, 2001).

Honneth (1995) places critical significance on the intersubjectivity of the social relationships of daily life and the "struggle for recognition" as the reproduction of social life. These are governed by the dominant need for mutual recognition and self-perspective, because an individual can only develop through interaction with others as social partners. To achieve a good relationship with oneself (a positive self-identity), people require an intersubjective recognition of their abilities and achievements by others. Honneth argues that individuals have three clear recognition needs and that these are required to form their self-perspective and identity: 1) forms of relating to self which encompass self-confidence, self-respect, self-esteem, and acknowledged capability; 2) forms of recognition and respect which come about through loving and caring relationships with parents and through community or institutional practices of respect and human rights; and, 3) forms of disrespect which include neglect, abuse, violation

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of rights, bullying, ignoring, excluding, and constant negative feedback. The fulfilment of successful or unsuccessful identity development through the recognition process is dependent on positive or negative interactions and interrelationships within different social spheres or settings and through different expectations.

Given the emphasis on relationships, Honneth develops his tripartite model in a way that shifts the emphasis from institutions to broader social spheres. This conceptual model of recognition comprises: love, with a small number of intimate others such as parents, a partner, or close friends; laws and rights, where through recognition an individual comes to see him or herself as having equal rights; and, solidarity, which relates to the recognition of abilities and traits (Honneth, 1992, 1995). Within this model, solidarity can grow from one's contribution and the performance of autonomy through work. Anderson and Honneth (2004) claim that autonomy is accentuated through mutual recognition, but that it can also be diminished or impaired through a lack of recognition. This claim implies that the development of autonomy among young people can occur through work at school and at home, and that relationships with parents, teachers and other service providers all have significant roles to play.

Taylor (1994) and Lægaard (2010) ask, then, what is the evidence of actions of recognition that are directed at this object and expressed by these means. What are the actions needed to achieve recognition of equal worth and value? In a practical sense, for the purposes of this thesis, the *objects* of recognition were the children and young people with a disability. The *means* of recognition is the acknowledgment of them as having rights to have their needs met through access to good quality health, education, and other services and through the kinds of professional interactions that affirm positive identity development as valued citizens.

Respect

A form of recognition with significant implications for the children and young people with a disability is captured in the idea of "respect". This applied within the family context and the school community. Human development, according to

Honneth, is achieved intersubjectively through recognition and respect in everyday life. He argues that self-identity comes from the interaction with others through recognition of abilities and achievements in the context of reciprocal relationships. Honneth states that the struggle for recognition and the building of self-esteem, capabilities, and social development through relationships, groups, and institutions form the basis of respect or disrespect (Honneth, 1995).

Honneth refers to experiences or practices in the prevailing social order that also reproduce society as an "institutionalised expression of social respect" (Fraser & Honneth, 2003, p. 213). This expression of respect is conveyed through the institutional recognition order of normative standards, for example, educational levels or employment status.

The parent interviews identified the concepts of recognition and respect as a central tenet of wellbeing. Parents actively sought out recognition and respect by making their expectations clear that their son or daughter should (and would) have a good, fulfilling life. This expectation was demonstrated through input that supported the young people in practical and relational ways such as being able to read, to write, to have friendships and relationships, to acquire skills of daily living, and to be independent.

According to the parents (and a number of teachers), this kind of practical action of respect in the school environment would encourage and enable the development of friendships, social skills, and a positive sense of identity and self-esteem and would foster social inclusion, participation, and friendships that endured into extracurricular activity. Examples of successful strategies, routines, and approaches to curriculum, friendship networks, and social skills established in primary school were incorporated into the IEP framework and were maintained and built on in secondary school.

Parents sought out community organisations that demonstrated these practical acts of respect that would support participation in and access to activities typical of childhood and adolescence, for instance, sports clubs, church, and cultural groups. These groups had an organisational culture of an "institutionalised expression of social respect" (Fraser & Honneth, 2003, p. 213)

through their respect for diversity and the access to opportunity they gave to children and young people with a disability.

Mutual, rather than one-way, respect in relationships, be they familial or teacher/student, was interpreted as positive when it encouraged the young people to strive to achieve their full potential. Intersubjective relationships establish mutual recognition and respect to develop self-confidence and identity. Individuals form their identity by receiving recognition from others and through awareness of their own uniqueness and positive abilities; consequently, they want to develop and interact with others in the community where their capabilities are recognised (Honneth, 1995, 1997, 2007). For parents in the study, relationships were important. This factor is clearly explained by this parent:

When Mary was in primary school the teacher aide was one of the differences in our lives at that time. […] she saw Mary and what she could do. That was what made it all work and Mary learnt. (Parent, Mary)

Mary's mother points to the teacher aide who "saw Mary" and Mary's ability to learn as "making it all work". Her mother identified the student and teacher aide's mutual respect and understanding in the learning relationship. Respect from the teacher aide enabled Mary's self-esteem to grow and helped to enhance her learning, and Mary was viewed as a capable learner among her peers and within her school community. This type of reciprocal relationship in the classroom is an example of an institutional form of respect (Honneth, 1995).

However, according to Mary's mother, this approach was not typical of other teachers, some of whom based their ideas about Mary on their perceptions of other students with disability and, thus, illustrates the common issue of students with a disability being treated as part of a homogeneous group rather than as individuals.

The mutual recognition seen in the interview about Mary was also evident in the experiences of the young people in the study, where respectful relationships had a profound effect on their learning and self-confidence. These relationships are referred to as key contributors in chapter 4 (Acceptance).

The interviews with the national service providers revealed an awareness that the recognition of the children's' rights and agency in a respectful way was a

skill that the teachers, teacher aides, SENCOs, special education providers, and paraprofessionals had to have. The interviews revealed that various professionals needed to recognise that they brought their preconceived theories of disability to the children and families they worked with, and that these preconceptions were often based around the idea of burden and the medical model of disability. This observation aligns with earlier points made about the impact of disability discourse on the acceptance of the young people. The service provider recommendation was that all persons involved work towards the "best fit" with the family. This approach reshapes the professionals' role in a way that is more respectful of the family's values and their expectations for their child within the wider context of the family unit and the community.

Fraser refers to the principle of "parity of participation" where recognition is linked with interventions that promote social arrangements that permit all members of society to interact with others as peers (Fraser, 1989, 1996, 2000, 2003: Fraser & Honneth, 2003). Actions taken by the parents to promote and enable parity of participation are the means by which recognition and respect are achieved. An example of how the parents and family lived this experience is given below.

We have lived in the same spot, so all the children were brought up here […] As a family the children have all grown up together, they have done things together, been to school together. […] he has been able to develop and be involved in it all. Everyone knows him, he's doing his thing, just like anyone in the community. That's what we wanted. (Parent, Reid)

Reid's parent reflects their family value of respect through ensuring their son's inclusion in the local community in a way that would promote parity of participation (Fraser, 1996).

The overall experiences of actions by several service providers in the young people's daily lives that reflected respect could be described as inconsistent or as happening only for short periods. Parents demonstrated respect by pursuing things that could help their child reach their potential by acquiring expertise and knowledge and by sourcing resources, personnel, and services. They described being required to do so because of what they described as the absence of respect within the wider education and disability service system. They mentioned, for

example, the poorly planned and often unsuitable curriculum provided through the school years. The difficulties of finding out who, what, when, where, and how to access the best service or of discovering what agency to apply to or identifying what community services were available evidenced a constant example of a lack of respect for equality inclusive of difference. Fraser (2003) states that experiences of respect and disrespect lead to patterns of social stratification, and that lower social status and marginalisation are the result of the cross-cutting actions of subordination. The parents' reports of education service indicated a kind of disrespect which contributed to social stratification processes, subordination, and social exclusion.

At play centre Adele was the only child with a disability, she did everything and just went along with it all and learnt everything. Then secondary school. Well. […] Two years, with nothing carried over, she did no work. So bored, the SENCO not talking to the form teacher – all that, the headmaster was not interested. (Parent, Adele)

In this case, the family worked to ensure respect and recognition for their daughter. As discussed in chapter 4, the circular process of othering is a contributing factor to the subordination of students with "special education needs" regarding spatial locations and variable opportunities for full access to the curriculum. These actions of disrespect are determined in terms of a number of differing and interrelated factors (teacher roles, knowledge, resources, labels, values, expectations) that contribute to promoting or inhibiting wellbeing and respect for a parent's son or daughter with Down syndrome.

Many parents acknowledged that their son or daughter's identity, self-esteem, and levels of ability across the curriculum, extracurricular activities, communication, social interaction, and a range of skills were higher at home than in their school environments. The parents felt this difference corresponded to the different levels of respect demonstrated between the two environments in terms of overall inclusion and expectations of participation and achievement.

Recognition Without Redistribution: Respect Acknowledges a Rightful Claim to Resources

The notion of recognition implied an understanding of the distribution and allocation of funding for children with a disability at school, both in terms of material resources for access to the curriculum and personnel resources such as teacher aides and access to various services like speech therapy. Advocating for this recognition through the distribution of resourcing was a constant point of discussion in most parent-professional interactions relating to the parents' son or daughter with Down syndrome. During their interviews, the parents recounted common experiences where services were provided in a disrespectful way that disregarded their child's personhood and inherently equal value. The young people were identified using separate criteria and labelled and were treated like numbers rather than people. This treatment was said to be symptomatic of the attitudes among service providers in the school and health sector.

Fraser argues that the dualist approach to recognition and distribution allows us to assess social practices both as instances of distributive justice and as instances of recognition, viewing the two as interrelated (Fraser & Honneth, 2003). It is clear from the interviews with parents and providers that recognition is not evidenced or followed for this child population. This parent's experience is typical:

It is exhausting at times; we know all the TAs and provide the school with all the up-to-date international resources on Down syndrome. We pay additional $8000 to the school each year for special education cover for our son and professional development for all the kids with learning needs. Then find out his TA time has been used in another part of the school! The TAs are upset, he's learning so well – we had to go through such a huge thing to get that for him and then the school just does what it likes […] his learning is not taken seriously. (Parent, Sean)

The allocating of one child's ORS fund and family resources to cover other school priorities is common as noted in the IHC complaint to the Human Rights Commission in 2008 and again in 2014 (Baker Wilson,2014). The multilayer social influences evident in that response highlight the complex interaction between policy and institutional influences and the parents' struggle to ensure that resources are appropriately allocated and maintained. Resource

allocation and redistribution practice is exercised through regional service provision or special school fundholders, and, so, parent-professional relationships are an important consideration in the distribution interaction.

Taking a Fraser and Honneth (2003) perspective to assess this social practice of service provision for children and young people with a disability, recognition and distribution are not founded on the core principles of social justice. Scarce resourcing essentially reveals a lack of respect. As Fraser and Honneth (2003) argue, social justice is a core principle of recognition and as such would include a central tenet of distribution of resources. The education service providers talked about limited resourcing and teacher stress levels with class management and resourcing. This issue is well explained here:

Parents need to realise we are juggling a lot of kids […]. We have teachers saying, "I can't handle this kid for 6 hours a day". For us, even though the wellbeing of the student might be paramount, we have got other people […] The thing is it's a scarce resource and we have to give to those most in need, you know prioritise … (Service provider - regional education)

The quote reveals the complex pressures arising from scarce or inadequate resourcing, and such processes were mentioned throughout the interviews about service provision for children with a disability.

The lack of available resources was highlighted as a consistent issue (and here it is worth noting that these service providers had 20 plus years of service provision experience) relative to the needs of children with a disability; when teacher aide hours were low, for example, students could end up being sent home early:

I'm just thinking about the resourcing […] that is what it all hinges on really and it is for those children with special needs, and that's the moderate ones too. So, you think, well if our school hadn't gone out of our way with that other pupil and given teacher aide time, well that child would be just doing what? Learning what? We do curriculum differentiation and we do dual enrolment in Correspondence School, you know, well because not every teacher is going to have that just off the top of their head. I mean I think that proper resourcing to access the curriculum – a school can only do so much. (Service provider - education)

"It all hinges on" resourcing. The educational service providers (teachers, deputy principal, regional staff) acknowledged that the level of resources and

services available to a given student was linked with the parent's level of support, input, knowledge, and skill. This resourcing was also dependent on the parent's relationship with staff; "good" relationships led to more nongovernment organisations being used for support, information, and resourcing (as the parents acknowledged earlier). Due to an inadequate national allocation framework for children and young people with a disability, the recognition of their real needs is tenuously based on the distribution of resources founded on service provider and parent day-to-day relationships.

The issue of recognition and respect was also evident in situations where student and family were doing well, were settled, and achieving. This situation tended to lead to reassessments and conclusions that there was a lack of need, rather than an impressive achievement, and as a result the young people's resource was reduced. Doing well had a negative impact on resources available in contrast to those allocated to the wider student body, where doing well would be recognised and rewarded with access to higher levels of learning and more advanced resources. This was a frustration shared by the majority of the adults interviewed, educators and parents alike.

As with the issue of resource distribution and allocation, parents constantly identified consistency in services as being dependent on the development of positive individual relationships between the parent and the provider (the school, a subject teacher or class teacher, SENCO, a dean, a Ministry of Education provider). The pivotal role of the parent/s in the securing and maintaining of service highlights that respect for the young people was a by-product of these deliberate, effortful relationships, rather than an automatic right. Standardised educational access to the curriculum is assumed by most students and was consistently offered to the siblings of the student with Down syndrome attending the same school or a school within the region. From a theory of recognition and redistribution standpoint, this would be the normative institutional standard of educational provision for children. This contrast in terms of the distribution of resources was a frustration of the rights and of the respect due to all members of the child population, yet it was afforded in practice to only some children.

When she's not your first child you know the different treatment don't you? You have to get onside, build that relationship or things will go nowhere. Most of us as parents, especially kids with Down syndrome or intellectual disability, we know it. You have to build those relationships even with one – the SENCO or dean. It's a way in with resources or support to make sure they stay learning and aren't just left behind. (Parent, Elise)

This quote typifies parent comments, and that finding is substantiated in the literature. Equal entitlement to education for children with a disability was only as good as the proactive positive parent-teacher relationship, which often relied on social skills and particularly mother-teacher engagement for children with intellectual disability (Eisenhowera, Baker, & Blacher, 2007).

Equal Entitlement: Equality in Treatment

The second key facet of recognition for the young people that emerged was recognition as equal treatment. This differs from the idea of recognition as respect in terms of its focus on treatment rather than rights and personhood. Taylor (1994) considers equal recognition as a universal right, something that translates into the positive recognition of difference. The concepts of being equal and equality were highlighted from the analysis of the interviews in terms of the sense of value that was afforded to the young people with Down syndrome. For the parents and young people, the idea of equal treatment and equal recognition was clear, with a clear expectation of being included in the family, sports group, and or school community. Equality in treatment is a unique concept within recognition, since "equal" is not synonymous with "same". The parents explained that when the young people are respected as being of equal value with their peers, that ethos must be broadened so that it can encompass the idea that equal treatment with all students means being given the resources they need to reach their potential, and that this treatment might look different in its practical application such as curriculum accommodation and attention to structural spaces and so on:

We're so keen on regular schooling. It's so much easier as chunks of learning are covered. There is some learning of bad habits but nothing like from a special school […]. But if you want normal kids then you put normal kids together. If you want dodgy behaviour, you separate kids out. If the kids are covered (resourced), they learn more, we could see the progress. […] and we can add to it. It has to be the way. (Parent, Mary)

The concept of equal treatment was understood by the young people, their parents, and a number of the service providers interviewed, but was not a consistent day-to-day experience, indicating that the normative standards of education as the means of recognition are not equally applied across child population groups and that this conflict is significantly evident for children with a disability.

Access to the Curriculum

While the discussion of recognition within educational contexts could centre on debates around inclusion, it is equally important to consider access to the curriculum. Equality in treatment requires ensuring access to the curriculum and learning. That access can either enhance or inhibit the young person's experience of the "role of self" and their capability. The act of equality in treatment involves young people being able to do the same activities as their peer group, when capable, and undertaking different tasks or an adapted or differentiated curriculum where needed. Equal opportunity and access to the full curriculum was found to provide two things: first, progress for the young person within the curriculum; and, secondly, a strong sense of self-identity and achievement within the peer group. For the young people in the study, equal treatment resulted in affirmative statements about the role of self.

Keeping to the curriculum that was being taught to their peers, as much as the young people were capable of doing, and being encouraged to acquire the same skills, but with extra support where necessary, contributed to achievement, SRV, and feelings of completing work that was meaningful and valued. Here, Nelson is referring to a photo of returning from the regular technology class prior to going to his next lesson:

That's me eating nachos, I took them back to class and we are eating them. I made those. The girls say, don't stay there (special needs class) stay with us (regular class). I don't say – but I like it (regular class). […] I do lots of my work with them, it's good. The teacher aide says I'm hard worker she likes that best too. (smile) (Nelson)

Nelson showed me his secondary school timetable which he had in his pocket; it had a mixture of regular classes and special needs class settings. He preferred learning in the regular class with his peer group, where he had the

opportunity for increased social interaction. This mutual acknowledgement of capability, the right to be included, being acknowledged, and having equal entitlement, while also being intersubjectively respected by fellow students, highlights the relevance of Honneth's (1995) framework of recognition in educational practice.

Education service providers were concerned with how a lack of equality in treatment impacted on wellbeing insofar as it contributed to marginalisation. Students with a disability experienced this due to a lack of information on the interagency support available when, for example, a student was part of a class attending a school camp. There were attitudinal barriers and a lack of support for extracurricular activities, which thwarted full access to the school curriculum for the students.

The consensus was that for children with a disability, their teacher aide was their most consistent education service provider, but this belief is another example of unequal treatment in education. Parents reported feeling the question, "who is supposed to teach them?" hung in the air when dealing with educational professionals who lacked interprofessional support and/or opportunities for skill development.

It takes a registered teacher for children to learn, but for our children it's a teacher aide with no training. Mother help. Who else has that? The teacher has trouble differentiating the curriculum – often parents are doing it. Who's doing the PD on this stuff? Certainly not the Ministry. (Parent, Alice)

Alice's mother posed the question of the provision of professional development and reported that Alice was predominantly taught by a teacher aide, while the mother herself provided curriculum differentiation (a skill that not all parents could provide). Teacher training and professional development for the teaching staff working with students with special education needs were identified as a concern across the interviews. Teacher aide prerequisite training was questioned. The amount of time spent on professional development for this student group was not considered equal to the training undertaken by the educators for mainstream students.

I've been to courses on ways that Down syndrome children learn, yes, I have had a bit of professional development, but I wouldn't say that I am specially

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trained for it. I do use the experience that I have had with other children and what I have read to help me to try and deal with the things that come up. (Service provider – education, senior teacher)

The quote shows the teacher interviewee describing her limited professional development in this area over nearly two decades of professional practice. By comparison, the parents interviewed had attended a more extensive range of professional development courses. The range of programmes undertaken by parents included Makaton, Johannsson methods[8], and courses included parenting and behaviour management courses such as Early Years, Positive Parenting, and a range of Down syndrome communication, literacy, and numeracy professional development courses nationally, internationally, and online. This level of skill development meant that the parents had acquired a range of strategies and approaches to learning and development which they discussed with teachers, teacher aides, and other school representatives.

However, the interviews revealed that when families had challenged teachers or the school about issues of equal treatment (in terms of recognition of learning potential, respect, and care for wellbeing), they (the family or the mother) felt challenged, rather than listened to, and, thus, disempowered. Families were left with a lack of support and, thus, a choice between going it alone or complying with limited or inappropriate services. The families who challenged service provision at the local and national level were not supported by the school, the Board of Trustees or the Ministry of Education. Parents overwhelmingly felt that speaking out meant no positive change and it could even mean potentially fewer services for the child with a disability. Elizabeth's mother shared the view that

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[8] Makaton is a language communication programme used to support communication with individuals who have cognitive impairments, autism, Down syndrome, specific language impairment, multisensory impairment and acquired neurological disorders including stroke patients. Makaton was started in the 1970s by speech therapists and is a registered trademark. Makaton workshops and training courses include parents, care workers, teachers, and other professionals and are a nationally and internationally influential programme to address communication needs.
Reeves, D. (2011). Applying choices and possibilities. *Speech & Language Therapy in Practice*, *Winter,* 2011.
Sheehy, K. & Duffy, H. (2009). Attitudes to Makaton in the ages of integration and inclusion. *International Journal of Special Education*, *24*(2), pp. 91-102.
The Johansson methods is a multisensorial early intervention speech and language programme for children whose disabilities are likely to affect their speech and language development such as Down syndrome and autistic spectrum disorder, brain injury, global delay, and other syndromes.
Kirk, M. (2006a). *Speech language service provision for children with a disability: The Johansson Trust.* Presentation to the Bay of Plenty Child Health Advisory Board.

parents were aware that questioning teachers, funding or services was likely to make things worse.

You have to weigh it up. I know of others who have spoken up, challenged what's going on and they end up "the difficult mother" and then their child doesn't get to go to anything, hours are cut next round. In a region they know each other. You have to be one of the "in" parents. (Parent, Elizabeth)

Recognition: "Special" Education Is Now Learning "Support"

Equality of treatment was crucially important for the young people and parents in the study. One example of an area where parents found securing equality challenging and highly variable was the experience of special education services such as the Ongoing Resource Scheme (ORS). The parents all valued this funding, as without it children and young people with a disability would be excluded from accessing regular schools (as was Kirstie's experience). However, first qualifying for it and then accessing the resources and services it provided proved highly variable individually and regionally. It was not support-based and was mediated first, by service providers responsible for how the fund was accessed and then by a second group who decided how the funding was used within the school. The students' hours were moderated each year irrespective of the progress of the individual child or the original ORS funding assessment received, and parents were simply told new students were starting and resources needed to be "stretched thinner". The criteria of the ORS funding policy appear to be fluid and under regular review. ORS Very High Needs funding for the young people continued after leaving school and some areas have new models that combine Ministry of Education funding and Ministry of Health and community options (e.g., individualised funding (IF) and/or Enabling Good Lives). The parents were concerned about what this approach to funding would mean for the opportunities and options for their son or daughter in the future, for instance some considered moving areas again to access better funding. This is a clear example of a lack of equality in treatment of a child with a disability when compared to the child population as a whole. For children with a disability, funding resources are allocated according to an inconsistent and/or unmeasured student ratio and unclear fiscally mediated process.

What happens with the funding that comes in? For a student with high needs, $x. For a student with very high needs $x. […] then we do a split where 30% of it is used to buy the specialist services, so that's the OT, the PT, the psych, the speech language therapists, the advisor on deaf children and special education advisor and then the 70% to provide the teacher aide support in the schools. So that 30% gets huge demand and (staff) just running themselves into the ground. When you actually worked out how much time per term that 30% buys, […] some youngsters they have had sort of 45 hours of specialist support in one term which is possibly their whole year's entitlement. […] So, in effect that allocation is well below the need. […] (Service provider – national education)

For the child population (total student population), education funding initiatives are allocated through additional "targeted funding for educational achievement" (Ministry of Education, 2018a). For school operational funding, there are specific disadvantaged child populations such as those belonging to certain ethnic groups, those achieving certain levels of educational progress and achievement, and those who live in certain geographic locations or fall into certain socioeconomic rankings, with criteria linked to the Ministry of Education operational funding payments. Funding for isolated schools based on geographic locations is based on data from the New Zealand census and aims to raise student achievement outcomes (Ministry of Education, 2018a).

There is no identified equitable approach for additional funding to target student achievement outcomes for children and young people with a disability, nor is there a link to New Zealand census population data. For this specific child population, funding support is the Special Education Grant[9] related to the education National Policy Guidelines for schools and the Board of Trustees.

A further inequality is created by the special education model of education funding and is based on child population data. This systemic inequality in treatment is evident in this quote:

The Household Disability Survey had run in its current form from 1996 to 2006, with comparable child questionnaires for 2001 and 2006. [..]. But going forward, 2013 and after the focus [is] on family care, so informal careers will increase. So, the focus will align with the adult questionnaire […]. The disability survey data, particularly for information for children, will have to

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[9] Special Education Grant: to support students with moderate special education needs, such as learning and behaviour difficulties. The grant is in accordance with the National Administration Guidelines (iii) and (iv). […] The special education grant is made up of a base amount plus per-student funding (Ministry of Education, 2018).

come from generic population surveys, like the Access to Health Services and, of course, this will then depend on the questions they ask. You can use that data better, as it's for the whole population but only if it includes the disability questions you want. […] Moving forwards the focus is to ask for service for elderly versus children. (National service provider).

In this quote, the interviewee acknowledges that New Zealand has adopted a change in the way child disability data is calculated in line with definitions of adult disability. From 2013, child disability data is being collected in 10-year progressions. The Household Disability Survey, which captures child disability trends and population rates, is no longer comparable to the earlier data. This is a major change that seems to have gone under the radar, although Statistics New Zealand itself has stated that this is the most notable change made to the census data collection; it will be both a change in questionnaire and in the collection period (Statistics New Zealand, 2018b). The implication is that data will no longer be available for this specific child population on the same basis as census data is for other population groups. This shift has implications for measuring and, ultimately, funding and implementing government policy and service provision.

Furthermore, the impacts from the systemic level for funding distribution has a secondary consequence at the school level for student planning and class allocation where the lack of data for student numbers and allocation of funding for student resources leaves teachers and schools with a lack of provision.

It seems that we don't know from year to year how many students with disability or special needs we are going to get. You'd think someone would be able to work that out, wouldn't you? We always know for other students. We can't sort out the funding, or get community support or anything for it if we don't know from year to year how many students are going to even enrol with special needs at the school. They don't come out of thin air. […] There's no-one running PD course[s] for them. I know the Down syndrome course covers the autistic material too, all the strategies, a lot of material actually. But we need PD (Service provider – education, secondary)

The secondary school SENCO admits that the lack of data means the school cannot plan each year for the student intake. In addition, disability organisations are providing professional development and resources for the state education system. In fact, both nationally and internationally, professional development for the support of people with an intellectual disability continues to be organised and run by nongovernment organisations and parent groups (Scior et

al., 2016). The lack of resources and professional development highlights the fact that this student population is given lower priority and value in the learning environment and does not receive equal treatment or funding to access the curriculum when compared with the general child population.

In summary, Figure 7 outlines several key factors the young people and their parents experienced that influenced recognition and wellbeing. These are important to consider in a practical conceptual framework of wellbeing.

Influencing Factors
Opportunities to express agency
Autonomy
Self esteem
Goals & aspirations

Family process – parental advocacy, values & social stratification
Parent-professional
Family economic sustainability

School

Actions
Interrelational: teacher/teacher aide
Social interactions (intersubjective)
Professional practice and knowledge
Curriculum accommodations
Inclusive structural & social spaces
Disability discourse
Structural redistribution: Resources
Planning

Respect

Participation
Parity

Redistribution

Recognition

Wellbeing

Equal
Entitlement

Disability
Discourse

Figure 7. Recognition: Influencing factors for respect, and redistribution. Conceptualising wellbeing for children and young people with a disability.

Recognition of Competency and Capabilities

This section looks at recognition of competency. In line with Sen's capability approach, the development of capabilities and opportunity for further

development is critical to wellbeing. Capabilities are what people can do and be—their potential—and so encompass the opportunities for achievement of potential capabilities and what individuals are actually achieving in terms of beings and doings (their functionings) to reach their capabilities. Within the capabilities approach, an analysis of the opportunities of an individual or group to do what they value and to be the kind of person they want to be and to have the same capabilities in life as their peers would involve an analysis of institutional practices and policies that focus on people's capability (Robeyns, 2017). The capability approach offers an alternative framework to economic wellbeing or the accumulation of material resources, affective states or overall life satisfaction (Robeyns, 2017).

In educational settings, a focus on capabilities requires an approach that incorporates a systemic evaluation of both individual learning outcomes and the range of real educational choices available to the young people. The capability approach provides a challenge in that it suggests that, to be effective, service provision and/or educational reviews cannot simply evaluate resources and inputs (such as teachers or years of schooling), but rather need to assess whether learners are able to convert resources into capabilities and after that potentially into functionings. A basic example would be how formal schooling can provide literacy—the capability to read and write—which can then be used to convert a resource such as a newspaper, book, computer or job application into a source of information for an individual. In this manner, we shift the approach from only evaluating inputs, where each child in the class appears to have access to an equal amount of resources, to recognition of capabilities in the realm of evaluating the link between resources and capabilities (Unterhalter, Vaughan, & Walker, 2007). Using this evaluative framework, it is evident that there are considerable inequalities that standard education evaluation methodologies overlook.

Parents affirmed as a result of their understanding of the whole child approach to wellbeing that the regular school environment was the best place for their son or daughter to develop their capabilities, as it offered social engagement, exposure to daily communication, and key learning. The local school was considered a natural childhood environment and within those families, the young people attended school with their siblings. This was viewed as the broader

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perspective of the balance provided by childhood environments, the contribution to communication, and a range of skills and social interaction linked with the local community.

> Going through regular school, full inclusion has stood by him all the way through. Places we've been, not just in (names three local towns) or even other towns where someone's called out "Gidday Reid, how are you", and I don't know who they are, but it's someone that Reid has made an impression on, […] and know[s] him, to acknowledge him, and make him feel like he belongs, and that he's got from school. (Parent, Reid)

The young people's and parents' perspective on the advantages of attending the local school is supported in the review on the benefits of inclusive education for disabled students (Hehir et al., 2016).

The analysis of the comments by the young people suggested wellbeing was linked to the recognition of their capabilities and competencies as young people with Down syndrome. Interviewees proudly provided evidence of achievements at events and or in newspaper articles. Recognition of their capabilities was also clear in the photos gathered as interview support material and in the clearly articulated "I can", "I do", "I am", and "I want" language markers of affirmative statements.

I like that, cooking. I am good. This is a copy of my timetable. When I do work and when I do play. I do P.E. I like English, maths, science and I like art. I can do it, all those ones and I am good. The teacher said. (Nelson)

I can swim, I like swimming and surfing. I don't like P.E. I like having lots of work I can do. I can do cooking, English, social studies, and science with the bunsen burners is beautiful with the flames. […] I go to my IEP. What I think is a good report as I am good as. (Reina)

The two young people's accounts above show their feelings of competence in a range of subjects. This recognition of competence and capability was highlighted as a key component of wellbeing, and, ultimately, highly influential when put into action to help the young people develop skills through training and learning so as to ensure potential capabilities turned into actual competencies. The use of strategies at home and school, with accompanying actions, are examples of the recognition of the students' competence, reinforced and often celebrated in the homes by prominently displayed reward certificates, photos of achievements, and rostered charts of completed chores, daily routines, and school activities.

The young people and their families' expectations were that they would succeed and acquire competence, and they acknowledged this when it happened. The promotion of continued progress, however, took effort, planning, and time. Other ways of recognising capability and competency such as being integrated into classroom learning and not being in a separate curriculum area, when combined with early support in facilitating friendships, all worked together to exponentially increase the potential competencies of the young people and students. Recognition strategies applied in tandem appear to be greater than the sum of their parts in terms of long-term results.

Well, there are quite a few things together. The planning and structure and the supports that go with that right from the start […] Well, they are the skills that as a group, you know, we have the biggest input obviously as parents. That we feel are important for Scott to get on in life. [..] right from the word go. I want this child to read. I need him to write. He needs to be socially accepted within the community. […] I will say "Scott that actually does not look appropriate". I brought Scott up as a normal child. […] put in place what we need along the way to make it work, at school the I.E.P every 12 weeks with set goals, the things and the people to get there and work as a group. (Parent, Scott)

In this response, Scott's mother identifies the factors that work together to build capability for Scott at school and home: regular meetings, goals with support, differentiated meaningful work, access to the curriculum, encouragement, and opportunities for social skill acquisition. Several families in the study emphasised the need to combine these strategies and actions and used similar approaches with their son or daughter from a young age.

Families also, however, reported that their expectations that their child would read, write, and acquire the skills of daily living were often not shared by the various services and schools. The young people in the study tended to function at a higher level at home or out of school, where they were not limited by low expectations. Honneth (1997), as stated earlier, argued that the highest form of recognition and life experience involves the performance of autonomy through work. He also argued that with high self-esteem people are strongly motivated to achieve and, as a result, this desire for achievement has an influence on capability. For the young people, it was clear that in the home their capabilities, achievements, and "work" were recognised, valued, and respected, and they gained a sense of autonomy and self-esteem. The parents described the important

observation that their son or daughter was more capable at home or in an environment where their skills and capabilities were acknowledged, as in this example:

He's good at sports, now he's got the opportunity at it. He's good at shot put and discus Special Olympics and Eve Rimmer games with teacher aide. It's every couple of years and the big games so we're training him up. He's only young now, I didn't realise he had that talent! We're working on that. We've got all this land outside to throw that around on as far as he can. I told the school, help him too. Get him training there and he can go after school and meet a group of friends. (Parent, Nelson)

Nelson's family provides him with the opportunity to expand his capabilities. His mother has attempted to engage the school in the process of developing his involvement in school and after-school sport so as to increase his community activities and networks. The school was hesitant to provide training and generally safety concerns were often used as a barrier to accessing the full curriculum. The need to address this required a fuller understanding of the student's competency (skill level and independence), and the resources to support these types of assessments were often lacking. In a follow-up interview, Nelson told me that a teacher independently took up coaching him so that he could continue to achieve in his sports.

Expectations of Capability

There was clear evidence of disagreement around the concepts of wellbeing, recognition, and respect between the parents and the education service providers. Education service providers seemed to view certain issues (such as inconsistency with student-teacher expectations and student-staff relationships, issues in peer relationships and where lunch breaks were spent, and teasing or bullying of the student with a disability) as almost expected or accepted; parents viewed this as an attitude of disrespect towards their child and a failure to view her/him as a valued part of the wider child population with, and not in spite of, their differences.

These issues, viewed as sad but inevitable realities by school staff, were viewed very differently by parents, because they were aware, based on their child's socialisation at home, that their child could learn to navigate negative

social situations with some training and skill development. Developing the skills to deal with negative interactions such as teasing increased the young people's self-esteem and increased their success in forming friendships with their peers.

Education service providers seemed to interpret inclusion as pushing the child to try harder to fit into the same mould as others in terms of their academic level, skill level, language articulation, and social acceptance/behaviour. This attitude of mind reflects a lack of acceptance of and respect for diversity. Education service providers' recognition of ability or expectation to achieve were not consistently at the same level as those of parents or other service providers (coach, tutors, and choir) in the community.

Service providers felt frustrated by the inequality of worth that exists when trying to provide for different student groups. Another issue of special education and inequality in treatment that was raised was around attitudes towards academic achievement—with teachers having expressed that students with disabilities were at school for social reasons, "to be around other kids"; that they were "not all curriculum orientated", and that "it's okay if the student doesn't learn, you just want them happy". These sentiments were taken by parents as reflecting a lack of valuing of children with a disability as regards their ability to reach their academic potential.

The service providers expressed what they felt was the lived reality for the students and their families, although, at times, they were not comfortable doing so. There was a widely held impression on the part of service providers that in the primary school environment it is easier to include students with a disability, but that schools cannot "be expected to include students after that" and "it only ever happened in a limited way". These comments reflect limited expectations for this child population group and/or limited commitment to recognition of personhood, rights, and equal entitlement to education within the school system. It is important to note that the views of these providers were based on their personal experience and were not necessarily reflective of other locations. For example, some of the schools that students attended were much more inclusive.

The consensus was that "while it is a pity, there's not much hope of change; the best way forward is to be kind, as there is not much point in long-term

planning". These attitudes were exemplified by statements such as "school does not seem right" for children with a disability and, generally, with reports similar to the one given by this education service provider:

Inclusion and attempts at being "regular" are an (underresourced) experiment that teachers are essentially left to manage however they are best able, or unable, in many cases (Service provider – teacher).

Often parents' expectations and school expectations did not align, as shown in the following report about curriculum planning. Here the education provider described planning as simply playtime for a child with a disability rather than learning:

If you have got a special needs child, you are planning a separate programme. If you have a child who is low, you are planning a separate programme. Everyone just says, cut down your programme. But for some kids, it has just got to be completely different, so there is extra planning you show but it's not really planning, it's so that she can play basically. It's a school thing. It's not just me. (Service provider – education)

In contrast, community service providers and other social services often operated out of a philosophy that was more in keeping with the families' values of respect, dignity, recognition, and wellbeing for their son or daughter. Social or community organisations where the whole child approach was applied were sought out and information was shared among parents of children and young people with a disability. These organisations are generally run by parents. Examples of these might be nongovernment disability agencies with an up-to-date, supportive approach and a high level of disability awareness or supportive sports clubs where respect for the students' need to participate and achieve long-term community independence was obvious. A nongovernment provider is described in the following quote about her whole child approach:

You can have the policy, but it is the implementation isn't it. It comes down to the people – that's the thing I've noticed is since J left with her really strong inclusive philosophy […]. These are our children. Our children live in this neighbourhood. […] She started the youth social club too. (Service provider – education)

The parent interviewees highlighted that they often had to educate various professionals in their child's life about disability issues and their child's capabilities. Their comments suggest that it is essential for teachers, as well as

other professionals engaging with children in the fields of health and education, to be aware of how capabilities can be developed, assessed, and maintained and for opportunities to be provided for capabilities to be built (Biggeri et al., 2011). This was not a consistent tenet of education for the 12 young people with Down syndrome interviewed, as was confirmed by the national providers who stressed a need for recognition of age/stage development and the importance of child-centred environments including age-appropriate social experiences. The providers emphasised the need for holistic approaches that recognise developmental stages and that the student's voice needs to be heard in decision-making. Service providers felt that this approach, new in terms of its application to the lives of children with a disability, would impact on their wellbeing and competency and sense of value from an early age.

This approach was often not even on the radar of the support personnel, perhaps because of the intangible, soft-skill nature of these competencies. It was important for the parents that their child with Down syndrome reached their potential in terms of social skills and personal community building while at school, so as to ensure they would have a connection to their wider social community on the other side of school life.

Reporting achievement: A right to write

The national service provider interviews highlighted that the ethos behind their services does see the student as having either the same right to access education to ensure skill acquisition and to build capability as all other students or the right to an expectation of achievement. The implementation of assessments or reporting fluctuated in practical terms, however, and a capability approach to child wellbeing for children with Down syndrome was not evident.

Parents and some educators were very frustrated by the lack of any consistent checking, recording or testing of the abilities of a student with a disability. This omission represented a gap in the whole child approach and a lack of recognition of the capability of the child that left parents seeing it as their role to ensure their child was educated in the basics of reading and writing. Any assessments that did take place differed from school to school. Amanda's parent,

who had other children and was well experienced in education, stated that her request for recognition of her daughter's progress through routine school reporting had been consistently denied.

It is harder for our children to gain knowledge and skills. I think that while they get certain set criteria around 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. Sometimes we have had reports to say that she has not achieved. We have asked for more information in reporting but not got any. (Parent, Amanda)

The experience of acknowledging curriculum achievement and provision of equal access to learning and to the full curriculum was a continuous area of advocacy that parents had to focus on, particularly in the case of core curriculum subjects such as maths and English.

Another issue emerged related to the need to acknowledge the learning styles of children and young people with Down syndrome. Parents were concerned that this issue was often not considered in service provision, as reported here:

They had expectations, which is what is needed and great […] she is a purely visual learner […] we had the IEP and, no, not really any full assessments, she understood so much more than she could answer back. Communication was the biggest one and she has stayed with a speech therapist all through (family-funded Johansson). The teacher aides knew all this and what she could do […] – but you can only take on so much, you know specific strategies, all that, just for maths and learning English at school […] The school is the key time, you might be able to get in extra reading with an iPad […] at the IEP we give them suggestions and all they give was all their why nots. (Parent, Elise)

Capability: Meaningful work/school activities

Previous sections have mentioned the right to meaningful skill acquisition to the level of a young person's potential, with basic examples being reading and writing. The future-focused goal here is one of "meaningful work', which was a theme that emerged from the young people's interviews. The young people clearly differentiated between the significance of the activities they are assigned for

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learning and the unsubstantial, younger age, and stage time fillers.[10] Recognition through being entrusted with meaningful work can take the form of curriculum-based academic participation in class, practical learning with concrete results (such as in subjects like food technology and hard materials), and responsibilities like class-based roles and tasks that might be given to any student within the class (such as a science room clean-up). Recognition of this meaningful work can take the form of positive affirmations from teaching staff, certificates, and other acknowledgements, along with acknowledgement of the potentially higher levels of effort being put in by the individual student to achieve tasks her/his peers find easier. The importance of meaningful work also has a lot of relevance in the home environment, often in the form of tasks and responsibilities that come with positive feedback and the expectation of continued learning and growth in capability.

I like at school doing my work, not the special needs teacher, but when doing my work in class. I like P.E, maths, R.E, English, science, yeah. I like work with the teacher aide to help me in the class. I like work with the teacher. I like work about with the other girls and I work hard too. I can do ASDAN[11] by myself. I have my timetable. I have sewing by myself. But my English is my good schoolwork, in my lessons, and that is schoolwork, schoolwork is good. (Mary)

In this quote, Mary stresses that she enjoys a list of curriculum subjects that she sees as meaningful work. She also states how (teacher aided or unsupported) and where (not in the special needs room) she does her schoolwork. She likes learning with her peer group (other girls) rather than with the special needs teacher. This type of statement was consistent across the young people's interviews and developed into the theme "meaningful work".

Illustrations of meaningful work for the young people often included developing competency within the curriculum alongside their peers. The young people referred to curriculum-based academic participation in class, specifically

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[10] Time-filler tasks for teachers or relief teachers can be easy tasks such as worksheets, games or activities aimed to be used to change the pace of learning, vary patterns of interaction or to take up 10 minutes at the end of class time. Goosey, M. & Gomez. L (n.d.). Warmers and fillers. British Council Spain. Retrieved 2017 from **www.britishcouncil.es**

[11] ASDAN or SPEC acronyms for Award Scheme Development and Accreditation Network http://www.asdan.co.nz Modular based programme of life skills for independence or South Pacific Education Courses http://www.spec.org.nz Key competencies courses linked to the New Zealand curriculum and based on ASDAN programme for students.

identified as doing their own differentiated curriculum, as being important to their wellbeing: "my own work along with others", "my own work, but the same as everyone". The young people clearly found their studies in subjects such as reading, writing, maths, social studies, and science to be meaningful work. This work had significance and purpose, as it made sense to the young people within the class setting and peer group where the young people gained an outcome or contribution from the work such as a skill, class involvement, and learning. The young people showed this participation through the interview support material and photographs. There was also a common theme of practical or skills-based learning, with examples like a woodwork item, a kayak trip, and a tray of muffins. These types of meaningful work activities were mentioned in a range of contexts, across environments at school, and at home.

The young people expressed positive wellbeing when they could see progress and were participating with their peer group, and when the teacher, teacher aide or adult involved gave encouragement (adult encouragers). The impact of positive feedback on their work tasks was clear in the direct correlation between that and their use of "I can" statements in connection with said work/tasks, as well as the pride with which they collected and shared photos and other evidence with "I" statements.

I do like school. I like cooking, when it's good ingredients like for pikelets. I like English, maths, science, social studies too. I have a log book at school – every subject's homework and write in the log book. Then teacher can see I'm working hard, teacher aide is helping, IEP is what do you think? Report – good as, teacher aides happy with me! Work – some is easy, some is very hard. The teacher aides help with our work. Have a problem, ask for help and keep learning, all happy. I am good at learning. (Reina) [Shows researcher her IEP]

Here, Reina explains to me the dynamics of her school life. She shows the assessment and reporting process that is important to her through the log book and record keeping that is checked, confirming that the staff respect her efforts and recognise her progress in concrete terms. This encouragement leads her to offer the positive affirmation of "I am good at learning".

The young people's photos identified key people such as teacher aides, teachers, deans, coaches, support workers, and extracurricular service providers as contributing to wellbeing. These key people were identified earlier as encouragers

in chapter 4 with statements such as "they like me". Structured, regular actions such as keeping a log book, keeping routines that reinforced learning, and consistently offering positive encouraging statements of engagement were essential to building capability and wellbeing of young people with Down syndrome.

The home environment was also conducive to the young people's development by contributing through meaningful work. Tasks like looking after siblings and household chores were responsibilities that added to the family unit in a valuable and valued way. This idea was discussed in chapter 4 "Acceptance" in the context of SRV, with the young people's responsibilities and household tasks being laid out in a set of charts or check lists until the young person was competent in this area.

Issues that get in the way of students with a disability being recognised for their meaningful work are often linked to a lack of understanding around a student's capability and what is considered meaningful within that level of capability. Stages of development and child experience need to be recognised as valid, with care being taken that young people are not babied, infantilised, or patronised due to a lack of identification of what is disability and what is developmentally appropriate, particularly around behaviour and meaningful tasks/skills for adolescence. The young people themselves had expectations of competence in these subjects and expressed frustration with either the lack of support to complete the skill-based activity or the lack of meaningful work experience provided.

Tangible Acknowledgement of Achievements

Tangible acknowledgements of achievements were very important to the wellbeing of the young people. A range of certificates, medals, cups, and media articles that the young people had received were presented in the interviews. These were genuine acknowledgements of competencies that young people had worked towards, either alone or with others, and were not tokenistic. On occasion, these had been presented at a school assembly, sports awards, or prize giving. The acknowledgement of their achievement of this competency was a form of

recognition that contributed significantly to wellbeing by increasing confidence, autonomy, and encouraging the young people to continue to grow.

The importance of these tangible acknowledgements of achievement may be connected to the lack of other positive affirmations of achievement in the young people's lives when compared with their nondisabled peers achieved. The tangible reinforcement is considered as a concrete marker of recognition of achievement, often where the young person had applied her/himself to the meaningful task and had gained capability that was not lost in later years. This is an area that would be of interest for further examination.

For the young people, evidence of capability was due to the interdependence of skill-based learning, ability to practise skills, meaningful work, a range of opportunities to try new skills, and access to the full range of the curriculum. This opportunity was enhanced by key contributors, relationships with staff, coaches or others who encouraged the young people in the school and community, so that this role was not solely left to the family.

Conclusion

Recognition is one of three overarching themes arising from this study. Current social theories of recognition are based on the concepts of Honneth (1995), Taylor (1994), and Fraser (1995). The principle of recognition is described by Taylor (1994) as, first, equal recognition and status in the form of equal rights, equal entitlements as part of our identity. For children and young people with Down syndrome, equal rights and entitlements were found to be tenuous, variable across school regions, and based on unconvincing data and policy. Secondly, there was limited recognition of the specific differences or distinct rights of the young people with Down syndrome. As a result, the services to address needs such as through access the curriculum were inadequate and limited participation within the school community.

Through the evidence on the young people's daily lives, recognition requires a framework of distribution that values social equality and difference. Parents, along with several key contributors within the school or the community, took an active role with planned approaches for achieving goals and providing

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opportunities for the young people in their daily lives. The young people gave practical examples of actions of recognition through responsibilities at home and school, building capability, and through meaningful learning with full access to the curriculum. Parental advocacy for service provision, however, was vital to enable the actions of respect through experiences of inclusion, full participation, and being valued for the young people to achieve wellbeing.

Influencing Factors		
Skill based learning (e.g., Technology curriculum)	Respect	
Self-esteem, autonomy		
Social interaction (intersubjective)		
Curriculum and community participation	Participation Parity	
Equal entitlement		
Resources – personnel and material		Recognition
Data collection	Equal Entitlement	Wellbeing
Interagency support		
Structured spaces of learning		
Professional practice and knowledge, PD	Capability	
Parental advocacy		
Key interrelational contributors		
School practice, home–school /parent–professional relationships	Disability Discourse	
Systemic /institutional supports (policy and practice and ORS funding)		
Acknowledgement of disability discourse and attitudes		

Figure 8. Recognition: Influencing factors for capability, respect, and redistribution.

This figure shows the significance of skill-based learning, meaningful work, acknowledgement of achievements, goals, and long-term planning that contributed to positive wellbeing. These factors were important where the young people could see progress in learning and skill development, and where participating with their peer group and the teacher, teacher aide or adult involved gave encouragement and meaningful feedback. The young people had an expectation of competence that contributed to wellbeing. The tangible acknowledgement of achievements as a contributing member of the class, sports team or school community were a significant contributor to wellbeing.

The significance of respect as a form of recognition was extremely important. The impact of respect in interpersonal relationships within the family

and school and of being part of the local community was clear. These are not the conditions for all children and, thus, the impact of politics of difference on educational entitlements needs to be openly debated and challenged in terms of the way they are viewed in future policy and practice.

Questionable service provision was evident and was seen in actions of disrespect in a number of areas (teacher roles, knowledge, resources, labels, values, lack of expectations) that inhibited wellbeing. Parents reported that their son or daughter's self-identity, self-esteem and levels of ability, communication, and skills were higher at home than in their school environments. The difference in capability across these settings reinforces the findings of others. Respect from teacher aides was a common example that enabled self-esteem, and access to this type of recognition can be seen as an institutionalised form of respect. Frequently, the teacher aide (with no formal qualification) was the most common teaching contact for the young people with Down syndrome. This lack of qualification is not the case for the general student population and indicates an unequal educational and social status within the institution of education. Using Fraser's theory (1996), the subordination of the cultural group (children with a disability) and the economic subordination in terms of the distribution of resources and funding within institutional structures needs to be rectified. The young people's learning capability, future options, and planning need to be considered in detail to uncover how these limitations impact on the current access within the curriculum; the lack of future planning in particular was identified as a major concern in the young people and parent interviews and educational environments.

In the descriptions of experiences of recognition and respect, there was a striking persistence of the importance and multifaceted implications of the lack of access, use, and availability of resources (people and material resources). Special education funding proved highly variable and was mediated by service providers responsible for how the fund was accessed and how the funding was used within the school. There is no equitable approach for additional funding to target student achievement outcomes for children and young people with a disability, nor was there a link to New Zealand census data as there is with other specific child populations to fund and implement government policy and service provision.

The capability approach provides a challenge in that it suggests that to be effective, service providers need to assess whether learners are able to convert resources into capabilities and after that potentially into functionings, a challenge that the providers found difficult to meet. Parents, however, appeared able to meet the challenge and gave descriptions of these actions of recognition of capability and building competencies throughout the interviews with the young people identifying several factors that assisted their autonomy with the positive factors that interplay to build capability at school and home.

Chapter 6:
Supported Independence

Introduction

Definitions of disability and independence are acknowledged as both contested and evolving, particularly with regard to terminology used around intellectual disability (Stokes et al., 2013). According to the UNCRPD(2008), Article 19, independence for persons with disabilities encompasses: individual autonomy, the opportunity to be actively involved in decision-making processes, and the opportunity to access their physical, social, economic, and cultural environment. Based on these criteria, Stokes et al. state that for independence to be achieved it is essential that young people have access to a range of opportunities and resources so that they can make meaningful choices and decisions about the management of their life and environment. Without these opportunities and resources and the acknowledgement that young people with disabilities do not live in isolation but rather within the context of their families and communities, independence is either less likely to be or cannot be achieved (Stokes et al., 2013).

This chapter reviews how support to live, as much as possible, an everyday life in everyday places was a part of wellbeing for the young people who participated in this study. Alongside acceptance and recognition, the notion of supported independence emerged as a central element of wellbeing. In defining supported independence, I draw on principles in the Enabling Good Lives project which the Ministry of Health articulated in 2011 as a part of its work to develop a new model of disability support services (Ministry of Health 2011). That document referred to the need to ensure sufficient services to support ordinary life outcomes and relationship building for people with disability. The idea of an ordinary life emphasised that "disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life" (Ministry of Health, 2011, p. 5). Support for an ordinary life also included "supports to build and strengthen relationships between disabled people, their whānau and community" (Ministry of Health, 2011, p. 5).

Supported independence involves placing an emphasis on service provision in supporting choice and age-appropriate control to enable people to live in the community with the same opportunities that everyone enjoys (Towell, 1997).

Family was at the core of this process and led the drive to support the development of capability among the participants. The provision of appropriate support within the school environment was also critical, as were specific support people within schools. Supported independence included supporting communication and facilitating friendships and social networks. It also included support for recognition and the ability to develop and grow as an individual. Independence was the same for all young people through the opportunity to learn, participate, be engaged, and enjoy activities with friends and family. The difference for the young research participants was that independence required structures to guide them and resources and support.

Independence, as in self-reliance and the building of autonomy, is a human development term and involves developing the abilities or capabilities to take actions, to manage day-to-day activities, and to provide for oneself. Independence involves the self-assessment of individual efforts, resources, judgement, and capabilities, with or without requiring support from others. Both independence and self-management include self-determination and motivation. These are described by Deci and Ryan (2012) as the wilful drive that enables us to pursue personal control over choices and actions. Independence is often limited for people with intellectual disability due to the barriers they experience (Sexton, O'Donovan, Mulryan, McCallion, & McCarron, 2016). There are, however, few studies that investigate independence for young people with intellectual disability, from their perspective (Sandjojo et al., 2019).

When evaluating the quality of life and wellbeing of a population, people with disability fare much worse than their peers in the general population across all indicators. In particular, they are much less likely to be engaged in education, to be in work, and to be involved in the community (Fearnley & Epstein-Frisch, 2014). A great deal of the current research into enhancing or maximising the independence of people with disabilities has tended to focus on the macro level factors that are barriers to an individual's functioning. These include factors such

as physical access, availability of transport, level of skill development, quality and/or availability of supports, and quality of life for those with intellectual disability (Stokes et al., 2013; Friedman & Vanpuymbrouck, 2019; Ncube, Perry, & Weiss, 2018). This is the current situation in New Zealand.

After initially identifying supported independence as a strong emergent theme across the 38 interviews, it became clear to me that this was one of the most significant elements of wellbeing for children and young people with a disability, and that it was a complex, multifaceted part of their lives. What follows is an analysis of supported independence, which includes a discussion of an adapted Ordinary Life Information Gathering Model tool with the young people (National Advisory Committee on Health & Disability, 2003) (see Appendix 2). This chapter concentrates on discussing the conditions for supported independence, highlighting the interviewees' views that support these assertions.

Family at the Core of Supported Independence

The role played by the families of the young people with Down syndrome was repeatedly underlined as being vital to their ability to realise their potential for independence. A family's culture, value systems, and hopes for their child with a disability can all positively influence their child's level of independence. Family members played vital roles as advocates in all aspects of the interviewees' lives, including, but not limited to, all aspects of social and school participation. To support their son or daughter's identity, development, and inclusion, parents, and sometimes siblings, took an active role as this support did not necessarily occur spontaneously.

Family members made special efforts to form strong relationships with individual teachers and teacher aides to ensure their child's role as an equal member of their class was maintained. The need to do so was often increased by the high turnover of staff within a variety of changing service providers. Communication took many forms, including formalised shared diaries, frequent meetings, and digital communication, all of which required extra time on the part of families. Mothers had a central role in advocacy, and siblings were often involved in supporting social skills and school culture. These findings are well

substantiated by other research into young people with a disability. Family support is consistently identified as the single most important contributor to a young person's being able to maximise his/her independence and transition successfully to adulthood (Beresford, 2004).

Several of the parents were active in the school in additional roles such as the PTA, the Board of Trustees, fundraising committees, and culture and sports groups. Such engagement seemed to build a positive reciprocal relationship within the school community for these families, as the payoff was that their son or daughter was included in school events without extra negotiation. Dyke, Leonard, and Bourke (2007) also claim that parents who are supportive, encouraging, and strong advocates with clear expectations of their child's abilities play a crucial role in positive transitions into adulthood. Parental encouragement and expectations that the young people could achieve in all spheres of life were key contributors to their ability to develop the qualities and skills to live independently, a further finding substantiated in other studies (Stokes et al., 2013). The active role of the parents within the day-to-day life of the school enhanced participation and supported independence and wellbeing.

The need to support families

Different groups have widely varying needs. The interviewees reflected that extra support and funding are provided for some groups of children or adults who are valued and recognised as deserving, but that this recognition and support was lacking for children with a disability and their families. This view is revealed below:

Basically, policy would have to have …. some way of, for want of a better word, diagnosing the need that children have, whether that's a learning disability or whether it's Down syndrome, or whether you need people to be able to tell you that there is a level of need there that will require a level of resourcing, … in a policy environment, you do have to have criteria which allow you to identify a population of people who are going to attract additional resources to enable them to live their life within a wellbeing framework and at some point, of course, you are going to have to cut it off. So, you know, in the argument, in policy terms, it's always who qualifies and what criteria for what, for what resource, and there will always be an argument around the margins and some severity. (National service provider)

In this quote, the national service provider explains the difficulty in providing resources for all children and the challenges posed by the complexity of disability assessment for children and families, limited budgets, and the population-based criteria for resourcing. Research into the experiences of children and young people with a disability is limited and tends to be overshadowed by the focus on adults and the cost of providing services. Reviews of child populations tend to be based on statistical data on children with a disability (Connors & Stalker, 2007; Bricout et al., 2004; Shakespeare, 2010; Imrie, 1997; Bax, 1998).

As a result, children and young people with disability are not counted and are not represented in official statistics and, therefore, policy. It is their families who are left fighting for their inclusion. The parents in this research described struggling with attitudes in their communities that assume any inclusion or extra support afforded to their child was an act of benevolence. Parents described being in the position of having to express constant gratitude when their child was included and treated with the same level of support as the wider child population. Their child was likely to be thought of as "lucky", even when he or she was kept on the fringe of the school environment.

It's got more difficult as she's gotten older, I've done a lot of courses and I share ideas and all that with other parents of kids with Down syndrome, it's a learning curve. You know you get told you're lucky she has a teacher aide and all this, but she has that to help her learn to be up with the other kids. I have a tutor for her and speech too. I look at other families, they pick the good bits out and tell me I'm lucky but I've had to sacrifice to put a lot of extra bits in to make everything work and there's nothing about that. The training and resources that just aren't there and no cover for work, going to camps and I have to say thanks every day to keep it happening or we'd be lost. Do other parents say that when their kids go to school in the morning?' (Parent, Reina)

Reina's mother had upskilled, taken courses, taken time from her job, added to the school programme and school resources, and ensured opportunities for Reina through an additional tutor and speech therapy programme. In the context of the school she was perceived as lucky to receive teacher aide funding, and she identified the tension of acceptance, recognition, and wellbeing and the fact that these are not seen as a right for children with a disability in the way they are for all children. Parents made a constant effort to provide a multipronged approach to support independence for wellbeing for their son or daughter.

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The importance of early access to support

Early intervention helps reduce fear and anxiety for the family and can introduce positive proactive strategies, as was evident in the stories of the young people in this research. Early intervention has been recommended by other studies into the lives of children with Down syndrome, and it leads to better outcomes (Karaaslan, & Mahoney, 2013). All but two of the families in this research reported having access to early intervention to support development and learning. Early access to resources to build capability and independence were linked to positive outcomes in terms of future supported independence. Effective intervention was not just directed towards the child, but also the parents and other family members, given their central role in supporting the wellbeing of the child. Families, therefore, became "experts" in the welfare of their child, collecting intelligence about their child's needs. With appropriate support, families became a resource in and of themselves.

Medical professionals were important, especially in the early years, given the particular health conditions the young people and families faced. Medical professionals were most supportive when their focus was on the medical health of the child, and when their practice did not reflect assumptions of the medical model of disability. When service provision was informed by the assumptions of the medical model, the expertise and knowledge of the family and their role caring for their child were jeopardised, to the detriment of the child. In such situations, parents reported feeling their child was seen through the lens of policy and funding models as a type of disability commodity.

Support from social services, when practised from the social model of disability, played a vital role in the lives of children with a disability, particularly when it came to goals around long-term independence. A positive outlook and view of the future on the part of support services went a long way towards encouraging a positive view of self for the individual child and towards maintaining motivation for both the child and the family. Services that were provided with a conscious ethos of promoting participation were most effective, as this is a need governed by a desire to encourage long-term community independence. When this provision was in place from a young age, families and

services were able to enhance supported independence. Nelson explained this well:

That is me at school with my teacher aide D, and yep, she is helping me doing work and stuff. She is helping me doing maths and writing and she is happy with me. I am done, we are happy. I am happy at school. D is sporting and she gets me fit and does stuff in the week with the sports club too. (Nelson)

Here, Nelson identifies the teacher aide as supporting his learning and participation in the community. D, a key contributor, facilitated Nelson's independence through the opportunity to access the community sports club. This key contributor role was endorsed in many of the interviews and showed enhanced supported independence.

Challenging the deficit perspective

Even families with a strong commitment to work hard for their child with a disability were at risk of being disempowered by professionals motivated by a "cure" approach to their child's future. Among the difficulties faced by families wishing to encourage supported independence were professionals who failed to promote "disability culture" as a positive part of family identity. The families were led on a path they may not otherwise have taken if given more information. The need to prepare the child for the transition from school along with other communities of friends or social connections in their neighbourhoods was ignored. This quote clearly reflects the tension between ideals.

Now you can't expect communities to accept kids as part of the ordinary life of the community if you keep placing organisations between the kids and the community […] I just see too many agencies actually involved in kids' lives and I see them all trying to fix things and all trying to take from the family, the responsibility for the child. And I see very few agencies as simply being with the family and simply saying well, what are your hopes and dreams for that child. Why would that change? What are the most important things? Who is going to be your child's friend? Who are you inviting in around this child? Who is going to be your child's godparents? So that the circle of expectation that this child will grow up with, have friends, and be part of the family, will go to school. Nobody engages in that conversation; everyone tiptoes around it. (National service provider)

Families often had a clear idea of the support they needed, but found that professionals thought differently. Attitudes they encountered tended to focus on the burden they were carrying, particularly on a physical level; the ideas that their

child was a "bit of a life sentence" was common, and all of this type of thinking led to inadequate or inappropriate support being offered, with the result that the professionals failed to respond to the needs communicated by the family. For example, families were often offered "respite care" for the child with Down syndrome to stay with alternative carers, when the family would have preferred assistance with household tasks so as to spend time as a family as a whole, including with their son or daughter with Down syndrome.

Well, he gets respite care. I get reminded of the rules all the time. Only use it to stay with people. He stays with his "auntie", you know same place. But I would like it to be for going out on social outings.... They (service providers) don't get it. (Parent, Nelson)

Focusing on physical issues tended to diminish the much more holistic roles being played by family members, who were aware that their child had all the wide-ranging needs of any child. Parents were often told by service providers that they should call on "natural" supports (family, friends, neighbours) before social services or funding. In this situation, however, calling on these so-called natural supports is not necessarily possible or reliable as a regular option. In the event of not having natural supports, funding for social service supports was often available only when the child met strict criteria and was not flexible nor needs-based.

Finally, many of the issues families faced in trying to facilitate supported independence were a reality, because they are operating in a policy system that is not rights-based when it comes to children with a disability. Because this population has historically been and continues to be set apart from the child population as a whole, the normal and basic rights afforded to children are at times seen as "extra" for children with a disability and are not factored into policy and funding. This situation leaves families struggling to simply provide a normal, "ordinary" life for their child, like all other children.

Supported Communication

The ability to communicate effectively is a major route to independence. Supporting communication for children and young people with a disability involves learning about and understanding which skills can help promote ease of

communication and what issues compromise it. Communication skill development, to whatever level of capability is possible for the individual, was seen as vital for many reasons. In the context of supported independence, when children and young people can communicate effectively, they can have a voice in decisions about their life. The ability to communicate also allows them to build relationships, make friends, and increase their confidence in interacting with their peers.

Several of the young people had undertaken the Johannsson speech intervention method from early childhood through to adolescence. This programme was family-funded, as no state service was available, a situation that remains unchanged.

It was accepted by most parents that the young people's communication and language skills in some situations inhibited participation. Language articulation was an area of difficulty for the majority of the young people in the study, with two students becoming increasingly nonverbal as they grew older. Parents, siblings, and teacher aides had assisted some young people with a variety of communication strategies and supports for social participation and inclusion.

I am a good talker. I like it. I can do drama. I have done lots of speech. I help to do signs at social club sometimes. Sometimes if I get shy, it gets harder. So sometimes I can be not sure, but I am good. (Reina)

Reina identifies the complexity of speech language articulation for her and her need to have speech therapy, as well as the impact of some social settings on communication for young people with communication difficulties. She self-identifies as "a good talker". One of the key themes within the communication feedback was that of realistic self-assessment, where the young people knew when they needed to use others as interpreters (such as using a friend to use sign language for information in a social setting or calling on others to translate what is happening in a situation through technology such as a text message). Many different techniques were used to facilitate communication such as slowing speech down, sign language, facial gestures, peeping (whispers), as well as finding people who were easier to communicate with.

Sign language is a key skill that can support communication for some children with a disability, as this can be used to supplement verbal language. Many of the young people in the study had learned sign language. This skill was useful even if verbal skills were quite high, as it provided an alternative avenue for communication if those verbal skills were diminished when under stress, when suffering anxiety, or when in a situation where the young person needed support. Below, Scott's mother gives an example, explaining how his speech is impacted when he is frustrated or stressed.

He just gets distressed. He can't cope. He will, even as far as his speech, he won't be speaking clearly. And I'll know, as soon as he starts his speaking thing happening, I will know that he is under a bit of pressure or something is going on. (Parent, Scott)

Coping strategies were taught to the young people who became less able to communicate when under stress. A small number of young people in the study had been taught phrases by their parents that they could simply repeat when they were teased. These kinds of strategies enabled them to defend themselves and to communicate that they wanted the behaviour to stop, without requiring them to be thinking on their feet in a stressful situation.

For young people with Down syndrome, their ability to relay events accurately can also be reduced by anxiety, so strategies for coping with anxious feelings as they arise can also be very helpful in supporting communication and, thus, independence. These skills were taught to several of the young people who could articulate these strategies in the interviews. Self-assessment came with a corresponding self-awareness and self-esteem from knowing how to navigate social situations.

Supporting Capabilities

The development of capability was central to the idea of supported independence. The parents were acutely aware that developing capability in a way that achieved optimum supported independence, especially for individuals with Down syndrome and intellectual disability, relied heavily on the attitudes, willingness, and commitment of the people involved.

Support within the school system

Support within the school environment was seen as central to supported independence for children and young people with a disability, and this support took many forms and came from many different quarters.

I knew what I wanted … The process was set up from primary school and they were happy to carry on at secondary. We did IEPs every 12 weeks covering where Scott was at, where we wanted him to be at in the next 12 weeks in each subject […] Scott was always at his IEPs so he participates. X from NGO is the coordinator and we go through what we want to achieve and what are the strategies to get to those goals. […] We are all involved, it's about goals and practice, repetitiveness of skills. His IEP at school and his schedule of goals at home. (Parent, Scott)

In this illustration, the factors that enhance wellbeing and support independence for Scott were explained succinctly by Scott's mother. Scott's knowledge of his day, which is capability-orientated, shows respect for Scott's affect and wellbeing.

Although there was acknowledgment of the importance of developing and maintaining capabilities by key personnel, some parents were left with the sole responsibility of advocating for support for their child within their school and with those service providers they felt were necessary. School advocacy was often expected to be accompanied by a high level of contribution to the school in terms of resources, and even in cases where this was possible, it did not always lead to easy access to support. As an added issue, communication between schools, families, and service providers was not seen as three-way, in a loop. Instead, parents were constantly expected to be the go-between, making sure everyone was aware of current issues and had up-to-date information. Amanda's mother explains below how the family became involved in ensuring Amanda's differentiated curriculum was in place at secondary school level. This action involved advocacy to get assistance to write an adapted curriculum from the Ministry of Education in Wellington.

The school experience […] it did bring us all together with a common purpose in the family. X (son) helped me with learning to use electronic communication. W (husband) helped me by writing ideas for community items […] resources, going to Wellington to talk to people. We are one unpaid unit in the system having to do all the work to try and achieve what the system says it

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is there for, it does nothing to make it happen, but they take the money. Every other person in the system is employed in this business. Special Education supports… but you as the mother are unpaid. You and Amanda get no service. If an economist was to analyse it, they would think it was rather a poor use of public money. (Parent, Amanda)

The way in which professionals support children with disabilities and their families has the potential to enhance or to impede child and family outcomes and this point is acknowledged in several studies and reviews. Levels of collaboration were a key marker of a positive parent-professional relationship (Dempsey & Keen, 2008; Dunst & Dempsey, 2007). As Amanda's mother explained, this situation was experienced by other parents in a similar way.

At a practical level, school culture and policies had a major impact at the classroom level. A culture that best supported the young people was one that was strongly committed to inclusivity. Best practice to achieve this end, school-wide, is for it to be enthusiastically endorsed by principals and deputy principals, so it can flow from the top down. Some schools required classes to study diversity modules to teach the value of inclusion in an engaging, age-appropriate way. Other schools had social skills programmes for friendship and positive class-wide behaviour management. Individual education plans (IEPs) were evidenced as fostering supported independence while the young people went through the school system. These are all examples that were used, at times in tandem and at times in isolation, with the young people interviewed. A clear finding was that programmes that supported peer interactions, social skills, inclusive education, and relationships helped develop a structure for supporting ongoing peer relationships and positive class behaviour. This is a finding substantiated in other studies (Brown, Odom, & McConnell, 2008; Tipton et al., 2013).

When these conditions were in place, the young people showed their enjoyment for learning in the school environment:

I really like to learn new things and it's alright, 'cos I do get it. It's really hard sometimes and the teacher can get a bit annoyed. I do really like it and at home they don't get annoyed with me, just take your time. It's hard sometimes. I have to think hard in my head. I ask for help from the teacher or teacher aide or mum. But I do like to learn it. (Adele)

In this reply to the question on learning new things that was part of the OLIGM tool, Adele stated she was engaged and enjoyed learning new things at home and school. She was aware she required help and sought assistance and was also aware of the response or intolerance from her teacher. She persisted with wanting to learn and utilised her mother for help. For the majority of the young people, there was ambition to continue learning such as:

I like to, school is good. And other stuff too, like for work, everything. Then I go to polytech. Some stuff I don't know and I can learn about it. Take your time. I like to learn it, ask someone so just keep on. It's real good. (Reina)

Reina identifies that learning new things is part of what she will continue to do at polytech and then within part-time work. She was clear about her strategy to ask, take her time, and persist, which suggested she had experienced support with this strategy in the past. This approach was evident in a number of the responses. For all the young people, "it's hard sometimes", "I like doing my work" and "I ask mum" were consistent responses.

Not all experiences were this positive, and three of the young people were beginning to disengage from learning. They said "no more for me soon" and two had become increasingly nonverbal in the senior year/s of college. In late adolescence, some young people with Down syndrome or intellectual disability do not express emotional distress through the usual channels of sadness or irritability. In this case, there is an increased likelihood to present with a loss of functional skills including speech and sleep and sometimes continence. This behaviour can start when young people with Down syndrome experience severe emotional stress prior to regression, which may be considered the trigger, and it often occurs towards the end of secondary school (Mircher et al., 2017) [12]. An important aspect discussed by the young people was teamwork and this goes beyond the idea of supported independence, acknowledging the importance of communication between the adult support people in the young person's life. Within the classroom

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[12] For further information on this see Stein, D. S., Munir, K. M., Karweck, A. J., Davidson, E J., & Stein, M T. (2017). Developmental regression, depression, and psychosocial stress in an adolescent with Down's syndrome. *Journal of Developmental and Behavioural Paediatrics. 38*(1), 26-28.

context, several young people talked about the "team". Parents described this as the teacher and the school culture at large. Scott explains this ethos:

These are all the rest of the boys working on their work, what they are doing. These are all the other boys in my class. They know me and I know them. I've been going to school with them; they say "hey Scott he's a character" and I am. I like doing my work and I like school. (Scott)

Scott was at a large secondary school and within the school there was one group of students with whom he has been attending school since primary. Scott was confident at school, as demonstrated by his phrase "they know me", and he is able to articulate where he can go for support or assistance; he considered his classmates his team. This familiarity with his peers was the experience for half of the young people interviewed and was consistent with the young people's having had the same peers from primary through to secondary school.

The atmosphere of the classroom was found to be very important and a result of the teacher role modelling positive behaviour. These soft skills or corrections of unconscious bias from teachers that supported independence and promotion of social disability identity were evidenced in the day-to-day running of the classroom and were crucial within the school culture. The atmosphere of the classroom—the way the teacher reacted to the young person—had a flow-on effect to both the other students and to the other parents. One teacher explained this situation below:

I have had children where there have been behaviour problems and other parents have felt they were not happy with that child being in that class, because it was affecting their child. There can be antifeelings and you have to sort of work through that. […] there are positives in having this child there and how they can help really. I would get the SENCO or DP talking to the parents and I would work through the kids and try and send the message through them back to the parents. The other way is to invite them (other parents) into the classroom to be a mother help and let them see what is actually happening. (Service provider – teacher).

In this response, an experienced teacher describes how she works with the class to ensure a sense of belonging and inclusion, and how she attempts to promote this to and through the student group onto the parent group. Invitations into the classroom are a practical approach to addressing stereotypes or stigma. The "antifeelings" identified here were reported across a number of the service

provider interviews, and actions were taken in some schools to address discrimination and social inclusion.

The needs that are central to the point being made here are those around the development of capability. The classroom environment worked optimally for children with a disability when the team around them, including their peers and their teachers, encouraged them to stretch and learn as they were able and offered help where necessary so that they could keep up with their peers. The role of self was positive when the young people with Down syndrome were able to do the same activities as their peers when they could and do different or modified activities when necessary.

The study also highlighted that having supported independence through consistency in teacher aides who help to promote the development of capability from an early age was crucial. The positive outcomes associated with this consistency were a result of the accumulative comfort level of the young people when the same teacher aides were present at the school and through the corresponding cumulative knowledge gained by the teacher aides of the capability of the young person as a student. While the teacher aide did not need to be directly teaching or supporting the young person, she or he still needed to be present within the school community.

The young people, parents, and service providers all noted that it was important that the young people were recognised and respected and involved in decision-making as their capability grew. This recognition and respect required additional support in the area of communication.

I think the responsibility of support agencies is to work with parents and the child and obviously as the child gets older, their participation (child) 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 […] so that wellbeing for children with a disability is actively encouraged and supported, that we know how the policy will affect children with a disability. […] we all can participate and the reason you don't participate to your maximum is because you are not given the right support. That is what the access barriers are […] (National service provider)

Here, the service provider identified all the tenets of the earlier definition of supported independence: the need for young people to be involved in decision-making; the need for policy and service provision to identify barriers; the need to provide access to opportunities; the need to ensure the rights of children; and, the need to ensure support is in place.

Whilst there are systems in place within schools to promote learning and independence, there are many practices in schools that actually promote dependence. Professional attitudes and/or teaching styles often left the parents in this study with the unspoken message that children with a disability learn best in one-to-one interactions with a teacher aide or unskilled adult. This view acted as a barrier to the young people's fully participating in extracurricular activities. For example, for one student a teacher aide's level of water competence prevented the young person with Down syndrome from taking part in an event, even though the young person himself was competent enough to participate in this water sport independently.

For effective inclusion in the curriculum to occur across home, school, and community, the parents accepted that supported independence was a key factor. Reina's mother speaks of how supported independence works in a practical sense to overcome barriers and the commitment required to ensure engagement and independence.

Thing is, I try and give her as much as possible in education, to entertain her and to experience life like everybody else so she can enjoy life. I'll go out of my way to find out if there is something there, we'll get into it, hopefully she'll enjoy it, we'll give it as much of a go as we can. I have a part-time job and the rest of the time is to support and encourage her wellbeing really. You lose things if you are not involved, being there, giving good feedback at each sport and club event. Then the people you find probably will not keep putting the effort in if you are not involved. […] you must go the extra mile for your child … that's just how it is. (Parent, Reina)

Here, Reina's mother shows the lengths she goes to to keep Reina engaged in community activities with her peers. Reina is independent and is fully engaged in education and community events. Parent or sibling involvement in extracurricular activities to maintain or develop skills in sport, communication, and social engagement was common. The value of environmental learning from peers, from interaction with family, and from free play has historically been

underplayed. Professional-led approaches have led many parents to seek wrap-around support that gets in the way of forming relationships with peers and developing stages of independence (Stokes et al., 2013).

Understanding the support roles

Supporting the independence of young people with a disability involved numerous people in a variety of roles. These roles were important in and of themselves, and they were more effective when coupled with an awareness of the other roles played by other support persons. Typically, wide-ranging support roles were played by teachers, teacher aides, parents, siblings, extended family members, and respite care and support workers. Unofficial but crucial support roles were also played by peers and friends. They helped to guide and inform the young people in terms of what behaviour is considered acceptable and appropriate for those at their age and stage and they provided many important intangible cues that inform social frameworks such as appropriate humour and appropriate boundaries. Rules can be subtly reinforced by friends, as can norms around seemingly small but significant patterns of behaviour such as how and where to spend break time. This type of support role is often unseen, but awareness can be increased through the education of adults in support roles, and in this way, it can be encouraged and facilitated. The other students are often aware of the soft-skills nature of this support role and often fulfil this role through the school years. In some of the interviews, the young people told stories of fun with peers, for example, checking on slang words, what to call a teacher, when to leave a lesson or about student-related activities. These happy accounts relate to the increasing independence and soft-skill aspects of school life.

The young people's photos (featuring several people the students felt close to) illustrated some crossover relationships in their daily lives. They variously clarified the identities using names, associations and roles, such as "a cousin who is my friend" and "school friend who is my mate". For some young people, there was less clarity and more crossovers, with roles such as "my swimming coach who is my friend". This lack of clarity around relationships was a difficulty due to the corresponding lack of clarity about social boundaries.

Where distinctions between relationships, associations, and roles had been made by the young people, it seemed that the parents and/or siblings had assisted with this social skill. In the context of social learning theory, young people who understood role clarity seemed to be learning directly or indirectly from behaviour being taught or modelled by their parents and siblings. In the school context, limited, developing research on students with Down syndrome has identified that minimal formal intervention is required for there to be substantial gains in social skills, behaviour, and daily interactions (Daunhauer, Fidler, & Will, 2014).

In 2012, the government introduced in some areas of New Zealand the New Model for disability support services to provide support, so that disabled people can have the life they aspire to like other New Zealanders. This model was to be focused more on choice, individual control, flexibility of service, and disability supports, as these enable people to meet life goals. The new funding models made provision for support roles in a way that provided for greater autonomy. For some of the young people, this model allowed a change in the way the support role was filled through a support worker who was a young person— either an older college student or university student. The approach utilises individualised funding where the social soft skills of support are reinforced through social inclusion of activities in the community and reinforcement of trends that are common within the peer group both within school and social environments, for instance, music, sports, movies or phrases.

Three of the young people with Down syndrome in this study were able to access activities in the community with the help of support workers who were under 25 years of age. In these cases, the role of the support worker and the support work were clearly identified—the worker was not a friend. As this mother explains:

Sean started individualised funding early because J told us about it (Needs Assessment Service). It started as a trial in our area and we have it as well as respite care which suits us better. Sean can do social things, sport and activities with a young support worker so it's much more age-appropriate. Just once a week. We've told Sean he's a support worker that he employs to do things together that he wants to do. He's not a friend or carer or teacher aide but a support worker so that Sean can get out and about and learn to do all the things he wants to do and be with a young person – not mum! (Parent, Sean)

Here Sean's mother clarifies the role of the support worker for Sean and explains that in the future Sean may be increasingly responsible for managing this role. IF is part of the New Model of disability support services and works well for these families. This option was not available in all areas of the study group; moreover, some families where there was availability did not feel ready or informed enough to take on the role of employing a support worker for their son or daughter.

The discussion above highlights the variability in eligibility for support services and material support such as the disability allowance and the role taken by families and support agencies. Some young people had received more or less access to respite care; some had access to IF; and, some had taken up the child/16 plus disability allowance. There was a lack of information and/or knowledge on how to access these supports and this ignorance influenced access. There are two issues here. First, for families with a child with a disability, there is an impact on the household income and all parents in the study had reduced workforce participation due to care responsibilities. This reality has been well established by other researchers examining the impact on households with children with a disability, as they too have found that such households are more likely to be in income poverty than all other households are (Wynd, 2015; Expert Advisory Group on Solutions to Child Poverty, 2012; Suri & Johnson, 2016: Murray, 2018). These researchers have also found that this comparative poverty is affected by a low uptake of the child disability benefit. Second, the role of support agencies to assist families with information to support the young people with Down syndrome and maximise the material and support services available to them was missing. Also missing was a mechanism for families to access support within the IF package. The need for a knowledge broker who can connect young people to services and manage benefits for transition of vulnerable young people in New Zealand is recognised (Alessi, Munford, Sanders, Johnston, & Ballantyne, 2018). The variability in access and eligibility to economic and personnel for support is related to young people with a disability and it is vital to address it going forward to ensure that this role of support is in place and can create some measure of economic wellbeing.

While acknowledging what was working, the national service providers identified that it was imperative to recognise what was lacking—to recognise areas in need of specialist support, areas where the family themselves need support and/or to continue to develop skills to take the family unit forward and how to make that support is easily accessible—and then to use all this support to build capability for their son or daughter with a disability. Supporting a child with a disability into adolescence and adulthood requires recognising and supporting their ability to learn to independently contribute meaningful work and contribute social value to their communities.

The national service providers were concerned about the understanding of wellbeing, professional practice, and the service gaps. They argued that having someone who would act as a "key worker" and facilitate a consistent, family-inclusive, respectful approach to disability services would be helpful in terms of protecting the rights of the child/young person in these situations. This type of support does exist in cases where individual families or agencies have organised it themselves, often to promote interagency collaboration. However, unfortunately, this practice is not systematic. The experienced national service provider makes the following point:

> So, the main focus that would influence the wellbeing for the child is thinking about that key worker with the family. 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. (National service provider)

The Importance of Structure in Supported Independence

Continuing to move a child with a disability towards supported independence was made much easier and more effective when there was a focus on structure within the child's life and activities. Structure acted as a support that the child could lean on while learning to do more and more things independently. A structure was put in place for Mary from a young age and it had been maintained and had, thus, supported her independence. Mary was able to maintain her busy weekly schedule of secondary school, home chores, sports, cultural, and social activities with the support of a timetable and visual chart system as she explains:

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These are my friends at school (shows photo) … this is my teacher aide, she has a cat. I showed her my photos and I feel happy. This is my form room with my friends and class, is very important. Are you writing that? (Checks I am recording). Friends, family, teacher aides, my class, my timetable for school. Home - youth group and the sports group for soccer, choir, church, my chart … I am happy, I feel happy. (Mary)

Mary's structure is set in place through careful planning. Social participation was linked with organised activities that were not always spontaneous. Appropriate behaviour and expectations were set out before a social event, so that she had a reference point. The detailed planning and organisation outlined in Mary's case were similar across the interviewees. For the young people, these structures along with routines enabled social skills and capabilities to be generalised, then added to as the complexity of activity was increased. Given the strength of this foundation to independence, the young people flourished.

Visual schedules and charts or timetables were important to all of the young people. As they have grown, the visual schedules have become more complex to accommodate an increasing number and range of activities. This tool was used by most families from an early age to support academic skills, communication, social engagement, and the daily activities of the young people. Some of the parents learned this strategy through the Johannsson programme, other professional development courses or their own research. In the limited number of studies on the benefits of visual activity schedules, these are commonly associated with children with autism and only two published studies focus on visual schedules or visual modelling for young people with intellectual disability (Bopp, Brown, & Mirenda, 2004; Koyama & Wang 2011; Spriggs, Mims, Van Dijk, & Knight, 2017). This approach was well utilised by the families and the schools the young people attended with good outcomes for self-esteem, autonomy, and building independence.

The benefit of having a structure was evident in the range of activities undertaken for and by the young people and was evident in the complexity of the skills that the families gave the young people the opportunity to undertake so that they could continue to learn how to manage by themselves. Two of the young people described their daily routines:

I do the calves ready for selling, feeding, and moving the paddocks. It was one now then three, now lots. Get them fat and stuff. If no mother - give them milk bottles. Early, before school. I get up and do it myself. Gates, feed, all of that. (Nelson)

Sometimes I forget. I'm quite good. Mum put a chart in my bedroom. Dad has one too (laughs). Shower every day, go to the toilet, eat breakfast, get dressed, wash my hair, change clothes, you know all that. I'm quite good. I do lots of other things too. (Mandy)

Nelson described his increasing independence with farm activities and the range of skills he was required to perform. His mother had increased the number of calves and the range of tasks as his capability had increased from hand-rearing one calf to feeding and moving calves between paddocks. Mandy undertook a number of independent household activities without assistance and was continuing to work on her morning routine. The provision of the visual prompt as a chart in her room supported her independence through structure. This was accepted as a family strategy and Mandy identified with her father who also had a chart in his work room. Another young person showed his social capability here:

I go out to Friday group. I like to go out to town too. I text friends, say the day, and movie, and time. I can go in to meet my friends at the movies and walk myself. I can walk home with them, show them the way. Ring mum if I need. If it rains, I can show them, and we go on the bus or ring mum! (Sean)

For Sean, supporting his independence has built his capability around social activities and he explains his ability to arrange outings with his friends and navigate home independently. He explained that mum will be on standby as part of supporting his social engagement. The family supports this social engagement and the skills required. By the end of the research, Sean was going to dinner and organising weekends away.

Planned involvement in class tasks was another form of structure that can help foster supported independence. When given the instructions and explanations needed ahead of time, the young person can take on responsibilities in the classroom environment that adhere to the structure of the day, for example activities that happen at a regular time or are part of class. Taking on new challenges and responsibilities with the support of structure can build confidence and capability and support SRV, thus, moving the young person towards supported independence.

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Another step that can be taken to support a child with a disability through structure is adapting the young person's curriculum ahead of time, so that expectations can be communicated, understood, and adapted prior to the beginning of that part of the curriculum. The parent and families were involved in this proactive approach and provided supports from home with concrete examples of the curriculum topics that the young people related to by either vocabulary, photos, items or experiences. When this approach was started in primary school, the young people were settled into learning patterns and enjoyed the interactions with peers and teachers.

Facilitated Friendships

The young people stressed the importance of friendships in their photo records and in their interviews. Opportunities to make friends and manage friendships are a key part of growing up. Friendships were central to identity, a sense of belonging, happiness, and wellbeing. According to research by Mason and colleagues, the creation of environments where children and young people with a disability can develop friendships and meet friends is fundamental to independence (Mason, Loveless, Lewis, Morris, & Clarke, 2008).

Children and young people with Down syndrome can have difficulty establishing relationships with their peers and developing friendships. This difficulty can become more pronounced as they advance through school. Consequently, the parents and service providers suggested that, initially, facilitation played an important role in developing friendships by building familiarity. This point is emphasised here:

As far as friendships and social networks go, a key message I suppose is that their child will do much the same as other children, but that this will only occur with support and that it will be harder to facilitate without it. (Service provider – regional education)

The respondent above observed that for families the role of facilitator is one that involves establishing a group specifically to engage in activities to encourage familiarity and enable friendships to develop—the idea of a friendship network. Some schools had buddy networks that the young people belonged to and friendships had developed from these. When this role of facilitating friendship

via social network or buddy groups is enacted effectively, it is central to friendship and social inclusion.

The young people's experiences of friendship were a vital aspect to their sense of wellbeing. The enormous significance of social participation, engagement, and acceptance for the young people was clear as the young people identified and articulated the complexity of their friendships. The need for assistance to facilitate friendships and support the maintenance of these relationships was also identified by the young people and all interviewees:

Looking after T, I like her, she's my friend. […] I am going to a friend's house tomorrow for a birthday party. H visits sometimes … mum takes me ….
Special occasions and other times. (Mandy)

Mandy tells me she is only able to see her close friend T at school and her other friend, H, when she is available with support from her mother (around making social arrangements and transport). This situation is in contrast to most adolescent friendships and the same is true for Scott:

Mum, she likes doing things with me, and if she can't, she will sort it out and be taking me, like to the movies. We go to dinner, I like that mum, dad and S, and also going with my friends. Sports is fun. I like (reads a list) and I go to the gym and meet others. That is good and happy. I like to go to lots things and mum helps with that. I have lots of fun doing that – this is being happy. (Scott)

Scott also shows that social inclusion and assistance to do things he likes is essential to "being happy", his wellbeing. This was a consistent finding for the young people's participation and inclusion, with the acknowledgement of the involvement of the mother, parents, siblings or support worker as social interpreters to enable "having fun" and being involved.

Research has drawn attention to the fact that the general public's understanding of intellectual disability and its cause are particularly under researched, although one of the main things that is known is that people's reluctance to interact with people with intellectual disability is due to discomfort and anxiety (Foley et al.,2014). This discomfort and lack of understanding could be affecting peer relationships in that they are the influenced by the bias of the broader student group. In practical day-to-day terms this difficulty was evidenced for the young people with Down syndrome by the fact that, in primary school,

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peer relationships were easier. As the young people advanced through school, social engagements and friendship peer activities such as invitations to birthday parties reduced.

When education service providers were key contributors/encouragers and supported or facilitated friendships, the young people's experiences were remarkably enhanced. Unfortunately, this practice was not widespread. In the cases where the school had a social or friendship group programme in place, natural relationships formed from the facilitated starting point. If this approach was in place as early as primary school, it provided support for building social competence through friendship and was more likely to continue through to secondary school. If there was a change of school, there was still a benefit, as the young people maintained the skills learned through the programme. Again, when the structure was in place, the secondary school was more inclined to continue what evidently worked well, and the optimal strategy for transition was to keep this structure in place. The young people were reliant on various levels of adult support or facilitation to ensure these opportunities for social competence and friendship-building were a day-to-day reality.

The need for a proactive approach is well recognised. There are a number of barriers that limit opportunities the young people and all students have to encounter one another naturally during the school day. A number of issues may impede interaction; for example, peers may lack the information or guidance to feel comfortable initiating new relationships; close proximity of teacher aides or other adults may encumber interactions; the use of separate spaces for learning time may segregate students; not being up-to-date with peer culture (music, humour, trends) may impede friendships; social-related aspects of competency for the young people (such as communication, requiring more time to build interactions) may affect the quality of their interactions; and, limited shared activities within the classroom may have an influence on friendship-building. These findings are substantiated in research about friendship with young people with a disability (D'Haem, 2008; Leigers, Kleinert, & Carter, 2017; MacArthur, 2013).

The national service providers identified relationships as being vital to the wellbeing of students with a disability. They considered it a core necessity that young people be supported sufficiently so that they would be confident enough to build friendships with peers. The national providers also stressed communication skill development as being vital to wellbeing, participation, and friendships. The findings suggest that fundamental peer relationships and peer competence difficulties for children with Down syndrome remain. This is an area of wellbeing that the parent interviews highlighted and this is an aspect of social skills development that is seen as best addressed within the framework of contemporary models of peer-related social competence, as found in other studies (Guralnick et al., 2011; Mansour & Wiener, 2014; Franklin, 2016).

Supported Extracurricular/Sports Activities

An important context for a child with a disability to naturally develop friendships is through involvement in sports, organised events, and after-school activities. The significant finding here was that there was no limit to the aspiration to be involved or the range of ideas as to what involvement might look like. For the young person, this spanned from being a spectator to being fully engaged in a sport or activity. The young people wanted to be fully engaged in the community.

I go to the club on Friday with Dad. I watch the rugby. I am a big fan. […] I go to the hairdresser in town. She drives me to town sometimes too. I go to her shop and chat and sweep up, you know […]. I love my M (area she lives). I go to the gym, two days. I have time for one night, can do something. I know lots. (Adele)

In this quote, Adele discusses her regular activities and her established routine at the gym. This involvement in sport was typical across several of the case studies, with the exception of two young people.

The aspirations of adolescents and young adults with a disability or impairment are the same and the differences in wellbeing are clearly not matters of choice. Overall, young people with a long-term health condition, disability or impairment have very similar aspirations to their peers. They are, however, significantly more likely than their peers to be socially isolated and be excluded from the labour force. They also have fewer educational qualifications, are more

likely to experience poverty and hardship, and live in poorer neighbourhoods. They are also more likely to have poorer health (including mental health) and to be less satisfied with their lives (Emerson, Honey, & Llewellyn, 2014; Emerson, Honey, Madden, & Llewellyn, 2009; Llewellyn & Leonard, 2010).

Sport and recreation are often the link to broader community networks and opportunities for young people with a disability to engage in extracurricular activities. When these activities are established at school and they transition into the community, for instance, through a sports club, the young people are more likely to be given further opportunity. For three of the young people in this research such engagement has led to a part-time job at a local business.

Monitoring progress and changing the goal posts to promote further growth is another practical sign of someone's recognising a young person's ability to contribute and supporting its happening. For families, however, ensuring that a range of opportunities continue to be provided to work towards independence is a challenge, as Mary's mother identifies in her response to identifying and maintaining sport opportunities for Mary.

There is lots of sports stuff that Mary is doing. Athletics she loved but stopped because the coach retired. Lots of things get started but aren't going anymore. B from XX community organisation, he supports her sport, a lot of it in his own time. He's great, multisport. She loves a lot of the boys' sports, she's got good ball skills, joins in. Ideal. (Parent, Mary).

It is often difficult to find out about and/or to easily access community services or agencies that will be support rather than obstruct participation.

I look at a lot of options of what is around and let the school know too. I was really put out when I found out about a great swimming coach through the local club and some support available and went along to see the school SENCO was using the service and she knew all about it but hadn't told me. She just thought why would Elise be interested, amazing, what is that about when she's such a great swimmer. (Parent, Elise).

As this dialogue shows, it is the lack of support from the school or service providers, not the young person's ability and aspirations or the family process, that is the inhibiting factor here. Again, this type of experience was common across the interviews.

Another factor that emerged that affected support for extracurricular activities was basic accessibility from a transport perspective. Mobility enabled increasing independence. For some of the young people, using transport was a skill that had been practised with family members, with episodes of trial and error. Examples included bike rides with family following behind, bus trips with someone at each end of the journey or an instruction card for the driver, a plane ride as an unassisted minor, and taxi journeys to various social destinations, with the range of transport options growing as the young people increased their skill, confidence, and independence. By the end of the study, several young people were riding bikes and two young people were taking driving lessons. The young people were supported by their families to travel, as being able to travel independently gave them a further degree of independence and access to the community.

The lack of transportation is a major contributor to social exclusion and Friedman and Rizzolo (2016) argue that it is one of the biggest barriers to community participation for people with an intellectual disability. This finding is consistent with the research overall—people with an intellectual disability are most in need of assistance and early intervention education to navigate transport options and are often dependent on "special" transport simply because they are not provided with adequate training around public transport systems. (Wasfi, Steinmetz-Wood, & Levinson, 2017). Public transport workers are also unlikely to have adequate training about people with intellectual disability and, therefore, are less likely to support them.

In New Zealand, the Ministry of Transport conducts an ongoing survey on information about day-to-day travel nationwide. In collaboration with the New Zealand Transport Authority, the Ministry has a commitment to the Accessible Journey report from the Human Rights Commission (2005) that details the transport and mobility barriers for people with a disability. The annual stocktake of transport accessibility demonstrates further change and improvement are needed to overcome the barriers where individual transport is the norm.

Support for Recognition of the Ability to Develop and Grow

The grounded theory approach in this research laid the foundation for the national service providers to express their own ideas, which is what they did in recognising the ability to develop and grow. With respect to young people with a disability and Down syndrome, recognising the ability to develop and grow changes the student's social status from that of a family or community burden to a person of equal value with all members of any given community or environment. This equal value was described as best being achieved through the encouragement of participation, with support, in the activities being done by their peers.

I mean that whatever the circumstances, particularly of your immediate family, you need extra wellbeing beyond that because you need to also have good support around for a child with a disability. There are people like me (key national advisor) and experience works for us to get some reinforcement […] other support agencies become integral in that process for wellbeing for children with a disability. I think the responsibility of support agencies is to work with parents and the child. (National service provider)

This national service provider acknowledges that wellbeing for children with a disability required additional consideration and the input of people with experience in the sector along with that of support agencies. Relationships have been highlighted repeatedly as key to wellbeing and they factor significantly into the ability to develop and grow.

Recognition of the ability to develop and grow encourages a future-focused perspective. When this begins with the support of professionals (teachers, service providers, coaches) and family members in the young people's life, it can help shape their self-identity and sense of their own future. Some of the young people's interviews reflected that aspects of recognition through supported independence had follow-on effects of wellbeing in statements that expressed their dreams, aspirations, and hopes for the future, for example, attending polytech and living in a flat.

I am going to polytech then I will get a small flat. I can do house work now. I can do cooking. In my flat, I'll be close to home but not home. Not too far but can walk to town and go out and the beach. No bossy mum saying what to do. Mum says great, dad say oh yeah. Learning to do money now. All good. (Adele)

Adele described her plans to move into a small flat with flatmates not far from her family home and not being oversupervised. She identified her ideal where town, night life activities, and a beach are within walking distance, a realistic option given her location. She had learned money management skills and highlighted her growing independence with household maintenance. Of the 12 young people in the study, 4 had aspirations to go flatting and 5 wanted to attend polytech; all of the young people had worked towards these goals with the support and structures in place from earlier years. In follow-up interviews, it was clear that most of the young people had achieved these goals.

There are some very practical elements that should fall into place when a person or service recognises a young person's ability to develop and grow. In some ways this idea links back to the rights discourse around equity and access that was touched on in equality in treatment where we go beyond the basic affording of equal rights. Recognising a young person's ability to develop and grow leads to their progress being monitored and, thus, encouraged. This leads people to partner with the young people and become invested in seeing them succeed.

Conclusion

The chapter has identified how supported independence is a principle of wellbeing. Supported independence for young people with a disability involves their having autonomy and opportunity. In order to be independent, it is essential they have the same access to opportunity as all young people, be it learning, physical, social or economic opportunity. The factors required to strive towards and ultimately achieve supported independence have been highlighted, in terms of the roles and attitudes of family, service providers, medical personnel from the early interactions, community members, and friends at the forefront. Following the grounded theory approach allowed the significance of these factors to come into focus throughout the interview process.

The family is at the core of supported independence and was identified as critical to the ability of the young people to gain their independence. A family's hopes and aspirations for their child with a disability were instrumental in raising

their child's level of independence. Members of the family were advocates in all aspects of the interviewees' social and school life. In order to promote supported independence, parents sought professionals and services that adopted a social model disability perspective. The ongoing challenge of dealing with service provision coming from a deficit ideology meant that parents were constantly negotiating for their child's supported independence and recognition. Early intervention and resources were crucial to supporting families and was often the first contact with the social service sector. Commencing a speech language programme was vital to developing communication skills which needed to be maintained for the young person's social inclusion and independence. Communication was an area that required ongoing attention to support identity and confidence.

Support at various levels is needed to build the young people's functionings across a range of skills and development (capabilities), around the management of their life and environment including academic achievement, activities of daily living, and social interpersonal skills. This support ensures a positive transition into young adulthood and onwards. Early patterns of planned, deliberate access to social institutions built academic and social competence and were underpinned by rights, dignity, respect, and a social disability identity.

Well-resourced social sector support of the family enabled it to enhance their son's or daughter's development and independence through establishing patterns and structure from an early age. The parents interviewed attempted early patterns of routines and structures with long-term goals of independence in mind for their son or daughter. This expectation of achievement was a strong driving motivation. Visual schedules and modelling were well utilised across the study as a form of supported independence for young people with Down syndrome. Friendships and involvement in sports and other extracurricular activities were key to the identity and wellbeing of the young people. For a positive identity and wellbeing to happen, facilitated friendship groups and a commitment to community networks were required. These multiple dimensions of support were more likely to be provided when there was a good understanding of the various support roles.

Figure 9 illustrates and summarises the factors necessary to achieve supported independence for children and young people with a disability. The factors emerged from the interviews with the young people themselves, their parents, and service providers and are categorised as the concepts of capability, goals, self-determination, and economic parity. A positive disability discourse is important to underscore these concepts. The influence of these factors in combination leads to supported independence and wellbeing for young people with a disability.

Influencing Factors

Building capability
– to support child and family
 visual assisted schedules
Support person roles
Family – core support
Resources – to support child and
family
Early intervention/parent-
professional relationships
School practice – support, structure
and planning with home-school
relationship
Communication
Facilitated friendships and social
networks – social interaction
Professional practice and
knowledge

Capability

Goals, Self
determination

Disability
Discourse

Economic
Parity

Supported
Independence

Wellbeing

Figure 9. Supported independence: Influencing Factors for family, and support roles, communication, and goals that build capability.

Chapter 7:
Implications for Practice

Introduction

The aim of this research has been to identify the meaning of wellbeing, and the factors that influence it, from the perspective of children and young people with a disability. The research has focused on young people with Down syndrome and their experiences in their families and in regular schools. Parents, teachers, and other service providers were included as participants. The purpose has been to develop principles to guide policy and practice for working with children and young people in schools and in other service provider contexts. Wellbeing was explored through a series of interviews and the analysis of these has informed the development of a multidimensional framework that seeks to integrate eight core dimensions that contribute to the three principles of acceptance, recognition, and supported independence. These findings and their implications are examined in the following sections.

Three Principles of Wellbeing for Children with a Disability: Key Findings

Acceptance

The findings demonstrated the significance of acceptance and a sense of belonging in the development of confidence and a social disability identity. These are evident in a complex understanding by children and parents of the social environment, of social hierarchies, and a dislike for being excluded or infantilised as young people in school and other social situations. This point was strongly reflected in the aspirations for independence in the activities of daily life where the young person was valued and respected.

The results indicate that acceptance was enhanced through tangible actions and language markers that communicated a sense of belonging within educational and home environments, particularly when these were generalised across a number of settings that could include sports and cultural groups and part-time

jobs. When inclusion within peer groups was maintained throughout childhood and into adolescence, the sense of belonging, SRV, and competency was enhanced.

Key interpersonal relationships were vital to acceptance and belonging. These could be with teacher aides, deans, teachers, coaches, SENCO, deputy principals or school principals and could enhance SRV and enable a social disability identity. Typically, these were reciprocal interpersonal relationships, although the school staff member might not necessarily have been a direct teacher, but rather a member of the ancillary staff or a teacher aide. Interpersonal relationships included relationships with key people in extracurricular areas such as with a coach or encourager/support person in sport and cultural activities such as choir, church, and community engagement. These relationships were a source of enjoyment for the young people, as expressed through their visual records and in the interviews; these relationships were characterised by their longevity, and they were significant in enhancing confidence and a sense of belonging.

Acceptance was critical to confidence, self-esteem, and friendships. The experiences laid down at school within the regular class environment were profoundly shaped by teacher and teacher aide relationships, relationships with other students, and the school culture. This feeling of being accepted was captured throughout in phrases such as "I'm happy at school", "they like me", "he thinks I'm a character" (the teacher). These types of assessments by the young people indicated a sense of belonging and a positive identity, all of which are significant for wellbeing.

Recognition

Wellbeing was also powerfully linked with recognition and it involved respect for the children and young people in a way that valued difference while also recognising their equal rights and equal entitlements. A key dimension of recognition was respect, and this was identified through actions that supported the capability of the young participants and the building of competencies in a way that assisted autonomy. The factors that work together to build capability at school and home are different for young people with a disability than for their

nondisabled peers due to the requirement for additional planning and resourcing. When these were done at home and at school, the young people thrived, and, in several cases, families moved schools or regions to ensure this positive approach. The significance of respect as a form of recognition was enormous and identified as an important dimension of leadership in schools that contributed to the wellbeing of the young person.

An absence of respect was evident in the tolerance of bullying of the young participants. This is an obvious finding that is substantiated in the broader research on the way students with specific learning disabilities, autism spectrum disorder, emotional and behaviour disorders, and speech or language impairments report greater rates of bullying than their nondisabled peers; moreover, the type of bullying remains consistent over time (Rose & Gage, 2017). Not recognising the specific differences, needs, and rights of the young people with Down syndrome also led to denying them access to the curriculum and other opportunities within the school community. When special education requirements, othering, and a lack of equality in treatment were evident, these revealed a lack of recognition of abilities and correspondingly low expectations of the potential to learn and develop. Low expectations translated into actions that limited service provision and equal treatment.

Recognition was also evident in decisions about the distribution of resources and allocation of funding for services. The child disability benefit, access to funding for respite care, and funding for single parents of children and young people with a disability emerged as an indicator of recognition. Resources enabled parents to access information about early intervention approaches to support motor skill development and these facilitated wellbeing by enabling the development of activities such as bike riding, horse riding, and participation in school sports events like athletics and swimming. Access to resources to support the specific health needs of young people with Down syndrome had an important impact in relation to access to health specialists, health tests (blood tests, hearing and vision, and so on), and information on the specific health needs of children and young people with Down syndrome. Without this kind of recognition, access to such opportunities was compromised.

The general lack of resources reflected the lack of recognition of children and young people with disabilities. In the absence of this systemic recognition, families bore many of the additional costs needed to enable the wellbeing of their children. Parents made additional financial contributions to schools and the provision of educational resources, and all families paid for additional services for their son or daughter such as speech therapy or health specialist cover.

Supported independence

Wellbeing was also linked by the participants with the idea of supported independence. This was the idea that wellbeing was associated with living in environments that promoted an ordinary life—doing everyday things in everyday places, at home, and in family life, with opportunities in education and for social participation in the same way as others in similar life stages enjoy. Supported independence included building and strengthening relationships within families, schools, and the wider community. Supported independence involved the kinds of supports and services that promoted choice and age-appropriate control that enabled the young people with Down syndrome to live in the community with similar opportunities to everyone else.

Family played a central role in supporting independence and the development of capability. Their ability to do so was powerfully enhanced when it was complemented by the provision of appropriate support within the school environment and by key individuals who played support roles. Supported independence involved providing good routines and structure to the lives of the young people with disability, supporting communication, and facilitating friendships and social networks, along with appropriate resourcing.

Professionals who did not recognise disability culture as a positive part of family identity were an impediment to promoting these kinds of experiences for young people with disability. The need for disability-focused professional development in teacher training, for teacher aide training, and for ongoing professional development was stressed. The families found the lack of long-term planning and goal setting by the teachers and special education professionals challenging, as parents envisaged a future for their son or daughter which required

support to enable the young people's aspirations to be met. There was a limited appreciation of the need to plan for progression within and from school and this deficiency represented a threat to the development of capabilities. Low expectations for this group meant the developmental needs of the young people with Down syndrome, especially those in senior secondary school, were not met.

Support for the development of capability was much more likely when schools actually operated with a team approach informed by appropriate knowledge and skills than when an ad hoc approach was adopted. Support was also characterised by careful planning and the scheduling of curricular and extracurricular activities to maintain and develop capabilities and skills in sport, communication, social engagement, and activities in the community. Parents, and in most cases siblings, were intensely aware that developing capability in a way that achieved supported independence was influenced by attitudes, role modelling, family commitment, and the willingness and commitment of others who worked with their child.

Acceptance, recognition, and supported independence, therefore, were found to be the foundations of wellbeing for children and young people with a disability.

An Ecological Perspective of Acceptance, Recognition, and Supported Independence

The daily lives of the children and young people with a disability were affected in important ways by the levels of acceptance, recognition, and support for independence within the environments in which they lived. Bronfenbrenner's ecological systems theory outlined in chapter 2 draws our attention to the way different levels of environmental influences affect a child's development, beginning with people and institutions that surround the child and then encompassing national, cultural, and economic forces (1979). His diagram of concentric circles illustrates the process of human development being moulded by interaction between the individual and the environment. The microsystem focuses on the relations between the individual and the environment. The mesosystem focuses on the relationships between two or more microsystems. The exosystem

focuses on the external environments (formal and informal) that influence development. The macrosystem includes these three systems that exist in the subculture or culture as a whole.

The ecological systems perspective on child development is used in child policy development, planning for service provision, and in curriculum documents in New Zealand. The Key Settings model developed by the Ministry of Social Development is an adaption of Bronfenbrenner's theory and is shown below.
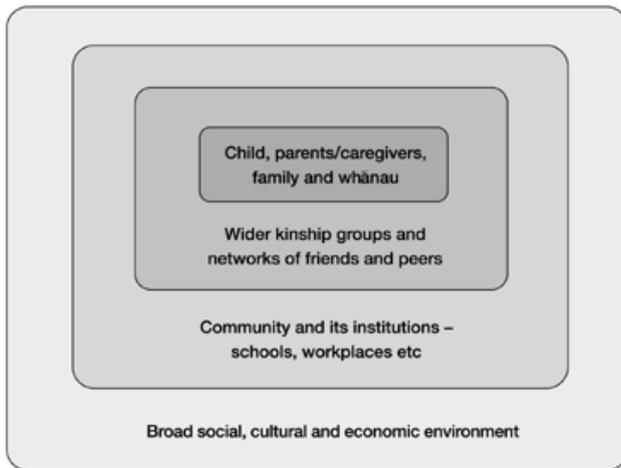
Figure 10. The Key Settings model of ecological systems Ministry of Social Development, 2002a, pp. 14-15.

The ecological systems model was used as a research tool in this study and illustrates the interplay between the systems that affect the life of the young person. It provides a framework through which to consider the whole child and the interlinking systems of influence. The Ministry of Social Development uses this framework to appreciate the key contexts for children in the development of policy and practice (Ministry of Social Development, 2002a). It is also central to the curriculum; for example, the early childhood document states that "families should be part of the assessment and evaluation of the curriculum as well as of children's learning and development" (Ministry of Education, Te Whāriki, 1996, p. 30). Learning Support has a modified ecological service model for the intensive wraparound services (Ministry of Education, 1996, 2018b). As indicated in chapter 3, an adapted OLIG tool was used in the interviews with the young participants to explore their perspectives of their daily environments.

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The Key Settings Model provides a holistic perspective that acknowledges elements of the whole child in New Zealand policy (Ministry of Social Development, 2002a). The interviewees identified various processes in the contexts of home, school, and the community that affected development and wellbeing, and these reflected interconnected service practices and higher-level policy decisions. The ecological approach provides a framework for reviewing how national policy settings for disability have an impact at the individual and family level. Policy that is developed at the macro level and then implemented through the exosystem can be seen in the micro level of the home and school the younger person with a disability attends.

The way disability is understood at the macro level influences the potential for acceptance, recognition, and supported independence within each of the other levels. The disability discourse, or language and interpretations of disability, shapes the expectations that inform multiple areas of social practice. The ecological systems perspective, thus, provides a basis for developing a critique of government policy and service provision.

The notion of a macrosystem level, as Bronfenbrenner states, includes "an acknowledgement that the micro, meso, and exosystems are embedded within a broader subculture of belief systems" (Bronfenbrenner, 1976, p. 5). Beliefs, values, and attitudes related to disability at this level exert a powerful influence across the whole ecological system. In the daily lives of children and young people with disability, this influence can be seen in their interactions with service providers and can lead to either achievements or setbacks in enhancing acceptance, recognition, and supported independence.

Figure 11 shows a modified ecological systems model that has been developed and which identifies the layers of influences and interactions in the young people's lives. The ecological systems perspective here shows the different developmental trajectory of young people with a disability and their interactions with different service providers and institutions that influence them. In this model, the microsystem involves the young people with a disability, their families, and friends. These are the primary relationships within the home, which is where the children and young people spend a majority of their time. The second system level

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involves the school and includes relationships with peers, teachers, other social agencies, disability organisations, and the community. The exosystem level refers to the institutional context through which services are provided; these are influenced by the policy settings for health, education, social service provision, and early intervention. Decisions at the regional or provincial level determine access to the services for the child and influence the level of resources provided to the school and other social service providers. The macrosystem level refers to the broad social, ideological, and economic environment which influences the micro, meso, and exosystems.

National level decisions influence decisions at the regional and provincial level. There is potential for discretion at the regional level, which leads to variation and unequal coverage. For example, the Ministry of Education Success for All policy initiative was aimed at providing "the foundations for demonstrating inclusive practices in education" across the country (Ministry of Education, 2010). However, at the regional level there was no change in practice or the provision of resources, and, consequently, there was limited evidence of increased inclusion (Starr & Janah, 2016).
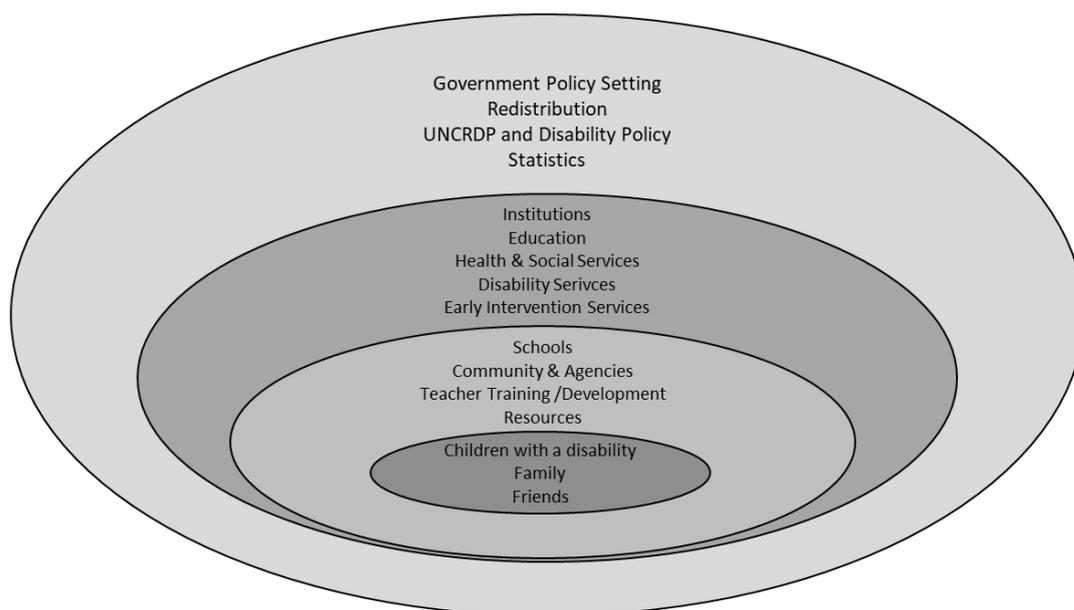
Figure 11. The ecological systems approach to wellbeing for children with a disability. (Kirk, 2019).

In Figure 11, the ecological systems perspective illustrates the interconnecting factors across the four systems.

Acceptance, Recognition, and Supported Independence Across the Ecosystem

At the microsystem level acceptance at home, school, and in the community related to connections with peers, friends, family, teachers, and teammates. Acceptance was achieved through relationships in the regular classroom, engagement in sport, peer interactions and through acknowledgement of skills, learning, and social inclusion. Recognition was most evident: when the young people were included in the school environment and followed the same curriculum as their classmates; when their particular learning needs were accommodated as required; and, when they were involved in the extracurricular options. The interactions with teachers, teacher aides, and school leadership, in addition to positive relationships between the parents, young people, and school staff, were all significant. The young people responded positively in an environment in which their capability was acknowledged and when there were expectations of competency. Supported independence was enhanced through an established structure with built-in support to enable navigation in the and between the home, school, and community environments with the aim of increasing confidence and autonomy.

The mesosystem level draws attention to the way home and school relationships interact to contribute to acceptance and recognition. School practices based on values of recognition and respect provided access to appropriate learning opportunities and the dismantling of learning barriers. Supported independence was influenced by the way support was understood, particularly by the teacher aide and teacher interactions. School leadership that included a proactive approach to professional development, teamwork, and school practice and that reflected values of diversity and inclusion, was also important. Service provision and relationships in these systems were influenced by a positive social disability discourse.

The attitudes and disability ideology held by professionals working with the young people and their families is a significant factor where the exosystem and microsystems interact. The exosystem was conceptualised as including regional institutions that determine the environments and the meso and micro systems, for example, regional branches of the Ministry of Education or individual District Health Boards, and this regionalism contributed to variation in the way government policies were implemented. The exosystem is not a setting or context that the young people experience directly. However, they do experience the influence of regional interpretations of central government policy, given its influence on the ways in which both material and personnel resources are allocated from regional learning support or special school fundholders to schools and Ministry of Education learning support services. National policy and budget allocations set the parameters for what happens at the regional level. Decisions at this level, therefore, influenced the funding of support for families and schools.

The capacity to make informed policy about children and young people with disability was limited by a lack of accurate population data about children and young people with disability. This lack of accurate data affected funding decisions and contributed to the underresourcing of services, which, in turn, placed an unnecessary strain on the relationships and the quality of service provision.

This approach highlights how the macrosystem level influences what is possible at other levels. It highlights the power of attitudes held within the disability discourse to influence policy. Paying attention to the macrosystem level highlights how entrenched approaches to policy and the distribution of resources contributes to the failure to meet education entitlements for children and young people with a disability (Bourke et al., 2001; Wylie, 2000; Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities, 2016; Grant & Matthews, 2015; Moran, 2014; Office for Disability Issues, 2016; Starr & Janah, 2016; Wynd, 2015; Tomorrow's Schools Independent Taskforce, 2018). These factors create the environments that either support or hinder acceptance, recognition, and supported independence.

I posit, therefore, that we can understand wellbeing for children and young people with disability through an ecological systems framework that takes account of the interactions and interrelationships between the young person, her/his home, school, peers, and community. The access to these environments and the opportunities afforded by them either enhances or detracts from wellbeing. When the principles of acceptance, recognition, and supported independence guide social policy, the potential to increase wellbeing for all children with a disability is enhanced through the collection of relevant information, more equitable forms of redistribution, and the development and evaluation of services in a way that is guided by a social rights disability discourse.

A Capability Approach

The capability approach, according to Sen,

> is an intellectual discipline that gives a central role to the evaluation of a person's achievements and freedoms in terms of his or her actual ability to do the different things a person has reason to value doing or being.: (Sen 2009, p. 16)

Sen's and Nussbaum's capabilities approaches have been used in education to consider assessment measures of satisfaction, resources, outcomes, and limitations (Robeyns, 2006; Unterhalter et al., 2007). The capability approach is associated with aspects of health, education, and support of social networks (Robeyns, 2016).

While there is a limited body of research informed by a capability approach on children and young people with disability (Unterhalter et al., 2007; Bickenbach, 2014; Robyens, 2016; Wasserman & Asch, 2013), this approach does provide an analytical framework whereby the home environments, curriculum accommodations, valued aspirations and experiences of learners with disabilities, and those with intellectual disabilities can be evaluated (Terzi, 2010).

In most of the cases, the home environments of the young research participants were structured in such a way as to support the development of capabilities. Routines, visual aids, strategies, processes, and actions within the home and school contexts and participation in a range of activities were identified. A conceptual analysis within grounded theory necessitates that these influences are conceptualised. In this study, the concepts were judged by fit, relevance,

workability, and modifiability (Glaser & Strauss 1967, Glaser 1978, 1998; Strauss & Corbin, 1990, 1998; Charmaz & Belgrave, 2018). Validity in its traditional sense is, consequently, not an issue in grounded theory, which instead should be judged by allowing us to learn from otherwise silent groups, for example, young people with Down syndrome.

The voice of the young people was used to form the grounded theory theoretical framework of the levels of opportunities, interdependence, and/or independence with a focus on capabilities and human development combined with the overarching principles of acceptance, recognition, and supported independence for wellbeing of children and young people with a disability. The categories were developed into eight dimensions identified by young people with Down syndrome, their parents, and the service providers. A whole child perspective was evident—this pointed to a holistic approach to wellbeing. There is a need to stress the interrelated aspects of wellbeing, for instance, the crossover between physical health and medical support with the social model of disability and the impact of early relationships and links to family.

Health was identified as a dimension of wellbeing. It was included as health and fitness, as this was the aspect that the young people emphasised. For them, gaining capability in the functioning of their motor skills, mastery of sports, and achieving a range of health and fitness milestones all contributed to their perceptions of wellbeing. Additionally, interactions with the health profession do become a significant interpersonal relationship for the young person and their parents.

The conceptualisation of factors influencing children and young people's wellbeing is focused on developing concepts and frameworks. There is a limited but growing literature for child-centric conceptual frameworks in Australia, Ireland, and the United Kingdom, although not for children with a disability (Fattore et al., 2007; Rees et al., 2013; The Children's Society, 2013; Hanafin & Brooks, 2009; Minister for Children and Youth Affairs, 2017). The key factors identified in this study have been recorded in Figures 6-12; these key factors have been organised according to the three principles of acceptance, recognition, and supported independence. These factors include experiences of being valued by

peers; being given school roles or tasks; being encouraged to be involved; having new experiences; and, having opportunities to develop through sport, music, core curriculum, and other extracurricular activities. In the framework, these elements have been grouped into broader categories such as curriculum accommodation and SRV and then categorised as a supportive learning environment.

Similarly, factors work in isolation and in unison and the greatest impact on wellbeing is when the influencing factors work in combination because of the nature of their interrelated interdependence. The strength of the study's research approach was apparent in the repeated interviews. The young people and their families confirmed the strategies and actions within the influencing factors in successive interviews. The evidence from successive interviews aided the development of the framework. Successive interviews is substantiated to be a positive method of research with children and young people. Research undertaken over points in time and which later returns to the participants' collected data can identify mismatches and related constructs of wellbeing. Furthermore, this process can strengthen correlations in subjective perceptions and the relationships with hedonic and eudaimonic data (Gonzalez-Carrasco et al., 2019).

Table 5 presents the framework of wellbeing. It contains eight dimensions; these are labelled: Building Capability; Social Disability Identity; Communication; Friendship; Participation; Care, and Support; Health and Fitness; and, Meaningful Access to Environments (and are presented along with their influencing factors):

Table 6

Dimension of Wellbeing for Children and Young People with a Disability in New Zealand. (Kirk, 2019).

Factors which influence wellbeing children and young people with a disability	Dimensions of wellbeing children and young people with a disability	Wellbeing
Meaningful work Skill-based activities Supported learning environments Goal of competency Safety Resourced SRV	**Building Capability**	
Sense of belonging Recognition of ability to learn Age appropriate Social disability identity Autonomy/Independence	**Identity**	
All environments Facilitated groups Opportunities for engagement	**Friendships**	**Acceptance Recognition Supported Independence**
Social communication Language skills Professional services	**Communication**	
All environments School culture Sense of belonging Planned ICT	**Participation**	
Family/home Planned Role of support Economic parity	**Care and Support**	
Planned Sport & Recreation Access to services	**Health and Fitness**	
Family/Home Sense of belonging Local, Resourced Acceptance of diversity	**Meaningful Access to Environments**	
Microsystem	**Exosystem**	**Macrosystem**
Children with a disability Family Friends	**Institutions**	Policy Disability Discourse Data UNCRPD

The interdependence and interrelatedness of the influencing factors and the eight dimensions of wellbeing for children and young people with a disability will now be briefly discussed. For the young people with Down syndrome acceptance was often expressed and interdependently connected through a sense of belonging at home, within a group or in the school environment. This acceptance is seen in peer relationships, where friendships are seen as vital and through facilitated networks and relationships with staff and others as the young people move through the education system. SRV is essential from an early age. Through various roles both at home and school it builds self-esteem and confidence and it supports identity, participation, and access to a range of environments through building competency and skills. Communication skills are also essential. For this reason, parents ensured that the young people were equipped with such things as visual aids and role plays before unfamiliar events; they also used speech language intervention, which was often reinforced at school with similar strategies or language supports, particularly when the young person was unsure or anxious and language articulation became challenged.

All the participants saw communication as a challenge in a number of scenarios: when the young person was interacting in unfamiliar social situations or was under pressure or needed to longer to communicate or had to deal with the nuances of humour or extended discussion. Good spoken language skills are strong predictors of later academic success, whereas difficulties with communication needs are linked with social exclusion and higher risk of school exclusion. For instance, children with unidentified communication needs are at risk of a range of negative outcomes later in life, including impacts on literacy, numeracy and educational attainment, mental health, and employment options (Communication Council, 2015; Royal College Speech Language Therapists, 2018). The value in extra support in terms of communication and facilitating friendships and social skill development was considered highly significant for social inclusion and ongoing development and engagement. This significance was evident in several case studies where social programmes had friendships groups that had worked on communication and friendship networks within the schools.

The frequency of interactions with peers and teachers and engaging in meaningful learning in structured regular school spaces build a sense of

belonging. This feeling of belonging was strengthened through sport and cultural groups, particularly when this building capability was acknowledged (sometimes with certificates) and acceptance of these natural childhood experiences is encouraged. Thus, acceptance of diversity provides more frequent access to environments for children and young people with a disability where acceptance, recognition, and supported independence as the core components of wellbeing can be promoted.

The study findings are commensurate with the findings of the survey of 6000 children and young people undertaken by Office of the Children's Commissioner (2019). The survey which included 8% of children with a disability will be used to inform the New Zealand child and youth wellbeing strategy to be launched late 2019.

A Model of Capability at School

The case studies and research process prompted the next stage of the grounded theory approach, which was to validate the dimensions of wellbeing in the theoretical framework. The next stage was to look at how a theory of wellbeing for children and young people with a disability should focus on levels of opportunities and on interdependent and independent capabilities to gain achievements. These are related to opportunity structures of social institutions (school) and to student experiences of wellbeing.

The grounded theory approach required improving the quality of the theory of the principles of wellbeing as acceptance, recognition, and supported independence. These are shown as processes and actions of influencing factors that can be categorised as the dimensions of wellbeing for children and young people with a disability. Information on the processes and actions that were gathered through the interviews and which pointed to the need for an early intervention, action or strategy-based approach needed to be defined and described so that they could be examined further for context and validity and so collated into the model. The interpretation of the strategies, actions, and relationships reported by all of the participants in the school environment formed the basis of the model.

How would this idea of supporting wellbeing work in practice?

The framework of dimensions of wellbeing for children with a disability was established and from it a model of building capability was developed and tested on a second group of parents and teacher participants whose perspectives were evaluated after completing the research model programme (phase two). The model was translated into the Supporting Teaching Practice for Students with Down Syndrome – STPDS programme.

This STPDS programme focused on the influencing factors with an emphasis on the dimension of building capability, while the supported learning environment's influencing factors within the framework included factors from the interviews. These were: access to resources; training for teachers and teacher aides and SENCO; strategies for social skills; curriculum accommodations; IEP planning; communication at school; visual schedules; networks with peers; disability discourse; and, school culture. This framework was detailed in the programme booklets and a table of the programme structure is available in Appendix 6.

A model of supporting teaching practice (i.e., the STPDS model) was developed from the research; it explained the data and the distinguishing key themes among the common trends and experiences of what the participants have been doing and the actions experienced and expressed, including areas of success, deficiencies, issues or problems. The approach that I have taken to creating a model to test the concepts from the grounded theory analysis is described in the literature by, for example, Stringer (1999) as assessing the means of resolving the highlighted issues or problems and formulating a practical plan to do so. The focus of this model is on building capability using the ecosystems theory as a means to engage the Ministry of Education (macro and exo), the community (micro) through local business funding, and disability organisation involvement with the programme funding. The home and school are the micro systems working together to build capability for the second group of children with Down syndrome in the 42 programme school environments.

The STPDS model focuses on the three emergent principles which underpin the conceptual framework and then on the actions within the dimensions of wellbeing (as the doing and beings) of which one dimension— building capability—forms the basis of the school focus of the model. The factors that influence this dimension are: meaningful work, curriculum accommodations, planning, resources, structured spaces, professional development. and skilled teachers, parent-school relationships, peer interrelationships, class responsibilities/class roles, and it is these that form the basis of a supported learning environment. This model is shown in Figure 12.
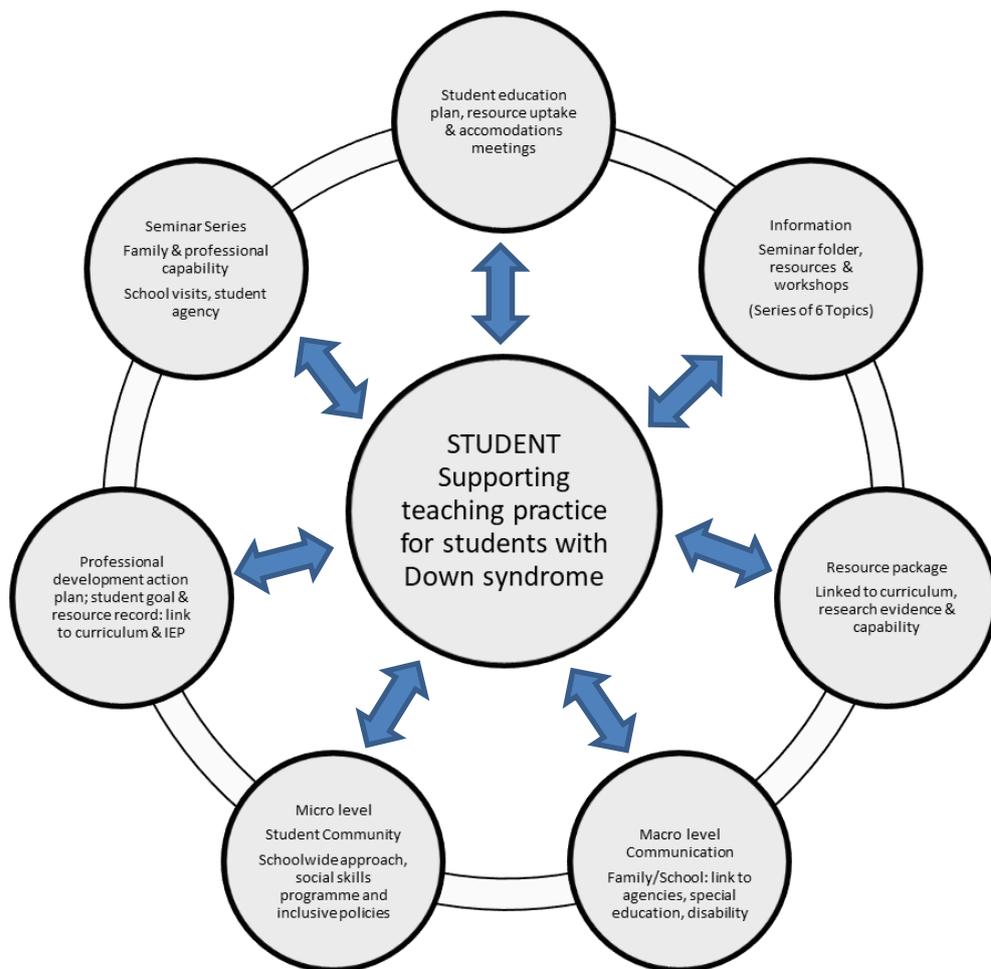

Figure 12. Supporting teaching practice for students with Down syndrome and learning disability in New Zealand (STPDS) (Kirk, 2019).

The Supporting Teaching Practice for Students with Down syndrome and Learning Disability in New Zealand (STPDS) programme was tested in three regions in New Zealand. A key feature of this process was its focus on professional development that incorporates theory, the research findings, national and international evidence-based resources, and practice. An inclusive approach was taken, with all those working with the student/s with Down syndrome (i.e., classroom teachers, teacher aides, specialist teachers, schools and family members, and the Ministry of Education special education team) first being brought together in a formal professional development setting and then being supported with a follow-up school visit. The programme encouraged an ecological approach to bring together the family, school, a nongovernment disability organisation, the local business community, and the Ministry of Education.

Phase two involved 42 regular primary schools and 156 participants who were engaged in the programme over the course of up to 9 months and who implemented the programme's approaches, strategies, and resources in the classroom and schoolwide. There were 44 students with Down syndrome of mixed ethnicity and gender, aged from 8-14 years, attending the schools; all were ORS funded.

The 156 STPDS programme participants were intentionally established as a mixed audience of teachers, parents, family/whānau, teacher aides, senior teaching staff, and Ministry of Education specialist personnel (see Appendix 6.1). It was important to identify an inclusive professional learning model for the STPDS programme to encourage a whole child approach in the school environment and to foster home-school partnerships. Cultural terms and approaches were respected throughout the programme and acknowledgement of this respect was evident in the feedback although this is an area for development.. The school participants were comfortable with the cultural appropriateness of the programme and the resource material. Of the 156 participants, 119 responded to the evaluation by being involved in the focus groups, completing online surveys and providing written testimony about the programme.

A strength of the programme was demonstrated after its completion, with the majority of parents stating that their level of confidence in and knowledge of how their child's school was working with their son or daughter with Down syndrome in a range of learning contexts had improved significantly. This outcome is especially significant, given that the pre-programme focus group had identified that 81% (n=37) of parents felt only mildly confident. The majority, 80%, (n=78), of the teachers who participated indicated an improved level of confidence, knowledge, and skill in supporting students with Down syndrome. Equally, parent participants stated a significantly improved self-assessment in their knowledge, skill, and confidence as parent/s/family/whānau and in their ability to support their child's learning at home. The focus groups showed that school participants also highly valued an improved level of knowledge and skill in terms of working as a team supporting students with Down syndrome and learning disability and a range of other learning needs. The improved approaches to teamwork was accompanied by an improved level of knowledge and skill about indicators of a student's progress against their learning goals as a result of attending this programme. The focus group presentations from the schools included examples of this assessment work.

Although implementation of the programme strategies, resources, and promotion of inclusion varied across schools, there were some commonalities as evidenced in the results from the online surveys. The online surveys were available to the participants at the end of each seminar. While the response rate was approximately only 40%, the findings were consistent with those of the focus groups and interviews.

To illustrate some of the quantified findings from phase two, this table has been selected as a sample of the questions asked in the optional online surveys. The sample demonstrates the success of the programme.

Table 7. Proportion of responses to a sample of questions from the online surveys

	Proportion of Responses (n=61)		
	(%)	(%)	(%)
Evaluate the following statements about supporting students with Down syndrome and learning disability	**Confidence improved**	**Knowledge improved**	**Skill improved**
Understanding of the learning profile associated with Down syndrome and ability to support their child's learning at home or key competency areas within the curriculum at school	100	100	100
Accessing and using resources for supporting students with Down syndrome and learning disability	73	79	73
working as a team supporting students with Down syndrome and learning disability	82	75	75
Learning indicators of a student's progress against their learning goals for students with Down syndrome and learning disability	82	82	82
Appropriateness of programme material for students with Down syndrome of different cultural groups such as Māori, European and Asian	55	55	55
Teaching a student with Down syndrome in a range of learning contexts / learning experiences prior to the Pilot programme	75	75	75
Overall response as a result of completing the programme	94	94	94

One common theme was that attending the programme had given the participants an opportunity to discuss ideas and the use of the range of resources for the individual students within their class and school environment; in several

schools this discussion had led to a change in school policy. Participants identified improved teamwork, open discussion, organisation, and planning; in addition, decision-making processes for that year were more supported, easier, and more clarified as a result of attending the programme.

The school visits were a programme strength in that they consolidated the link from theory to practice. Students with Down syndrome were observed confidently using the programme resources and teachers used the programme folders as an ongoing resource, reinforcing the importance of having high quality presentation material they could refer to and share with colleagues. The display tables were also very successful, with participants able to view, discuss, and critique the current national and international resources relevant to each module topic (see Appendix 7).

In the final stage of the STPDS programme model, the majority (90%, n= 61) of participants reported that the resources and resource packs were excellent, providing easy access for teachers, teacher aides, and families to actively use and engage in conversations about approaches, what they were actively using, and in which contexts. This discussion with the focus groups affirms a proactive approach to inclusive practice that encourages dialogues, approaches to curriculum accommodations, and inclusive school culture.

The STPDS programme successfully established an inclusive approach of teamwork with the student with Down syndrome and his/her family. This was evidenced by feedback from the participants in the focus groups and from the online interaction highlighting the development of an inclusive approach with proactive actions of planning and building capability. The programme contributed to the approaches for educational achievement. The phase two findings validated the influencing factors laid out in the dimensions of wellbeing framework. By providing assessment options, visual schedules, approaches to building capability opportunities and curriculum resources to provide opportunities for curriculum accommodation, the framework built on participants' shared knowledge. This learning was brought together in a formal professional development setting where the classroom teacher, teacher aide, specialist teacher, school and family were supported with interactive workshops, a school visit, and focus group feedback

interactions. With the assistance of community and Ministry of Education funding, the programme utilised a collaboration of evidence-based research, a nongovernment disability organisation, and national and international resources to provide an accumulative professional development over a period of 6 months. This programme provided a forum for shared understanding to support inclusive practice alongside the wellbeing of young students with Down syndrome across regional schools.

Recommendations

The interviews illustrated the limited links across key settings. The research highlights the predominant approach to service provision that relies on children learning human development patterns by "osmosis" in the same trajectories typical of all developing children. There was no evidence of reliable macrosystem augmentation of transdisciplinary approaches or multiagency recognition of participation parity in education, health or social services. If this were the case, it would be evidenced through the redistribution of resources, the requirement of appropriately skilled and qualified professionals in education and health, and through social service disability provision to reflect the commitment to measurable equal outcomes of wellbeing for children and young people with a disability in New Zealand.

The recommendation is to adopt the ecological model to ensure social policy processes provide service provision consistently for child population groups within a whole child and human rights mandate in regular schools for children and young people with a disability—an inclusive approach resourced by national macrosystems.

At the micro level, the findings suggest the difficulty in applying the ecosystems model, given the variation in family, and social institutional capabilities, and the individual and institutional disability discourse that is a major influencing factor that impacts across the micro system for micro exclusion or social inclusion and acceptance. Overcoming these issues requires policy and practice change in leadership based on the values and ethos at the macro level with disability discourse discussion, data collection, and information, so that the

lack of equal treatment for the child population group of children with a disability and their families, across all ethnicities, can be fully debated and discussed.

The relationships between service providers and parents requires attention and so highlights differences in individual, family, and institutional capabilities. The influencing factors of home-school partnerships, parent-professional partnerships, and the lack of professional skill development specifically in areas of curriculum adaptation were addressed within the STPDS programme. Specific professional development programmes that bring parents, schools, and allied professionals together are required to address the home-school barriers that can arise. Too often professional development is addressed at the young people's teachers only, whereas the interviews highlight the central theme of the home as the base for strategies, routines, and planning that reinforce the structures and language that enhance school engagement. Therefore, building the home-school partnership is a vital component in achieving wellbeing for children and young people with a disability.

A fourth recommendation is to fully support the curriculum accommodations at school and the redistribution of resources across social services for children and young people with a disability. The recommendation is at the macro and micro level with recognition and redistribution to ensure equal entitlement through economic sustainability. The welfare transfers can be addressed in terms of equal entitlement through the realignment of the disability allowance, so that it is inflation indexed and remains fixed, so that it is not reduced when a young person takes up minimal work, and so that it is not regularly reviewed for children and young people with a disability.

Future studies should take into account the ecological impact of social policy on children and young people with a disability across all environments. Doing so would ensure that meaningful access incorporating equal entitlements, participation parity, and economic parity could be examined within and throughout the levels of the ecosystem, i.e., households, schools, and social institutions that impact on services for children and young people with a disability. A first step to ensure economic parity and resource distribution would require that macro level data for disabled and nondisabled child data are collected

and collated on the government and nongovernment infrastructures that provide services for children and young people with a disability, in order to meet human rights mandates and government projected wellbeing targets.

Structural changes could be supported and measured through an indictor framework, as with the dimensions for wellbeing for children and young people with a disability. This framework should also be supported with a return to collecting child disability data within New Zealand censuses, in order to maintain the regular collection of data on trends, service implementation, health, education, and social outcomes within this specific child population.

A discussion that needs to be captured is that of the special school network. There is little evidence to support the segregation of children and young people with a disability from everyday childhood environments. Schools need to be able to call on child-centric data if they are to support long-term gains that not only enhance learning, opportunities, social engagement, language skills and long-term gains, but also meet international human and rights mandates. Governmental reticence to fund and support the full inclusion of children and young people with a disability in all aspects of society is contrary to any ideals of wellbeing.

Chapter 8:

Conclusion

Introduction

The aim of this thesis was to explore what wellbeing means for children and young people with a disability in New Zealand. The purpose has been to gain insights that might better inform policies and practices to guide those working with children and young people in schools and in other service contexts. As stated in the introduction, the study pursues this goal through a focus on the experience of children and young people with disabilities in regular New Zealand schools, specifically children with Down syndrome. As children and young people with intellectual disability, they are more likely to experience social and educational exclusion (Bricout et al., 2004, p. 50; Kearney, 2016; Slee, 2018). Young people with intellectual disability experience multiple exclusionary practices that stigmatise and isolate them; these include physical, institutional, and social barriers. The social model of disability was used, as it takes account of these wider societal factors that affect wellbeing. The social model also recognises the ecological systems within which children and young people with disability live and the impact of these systems on their wellbeing (Llewllyn & Hogan 2004; Slee, 2018). Furthermore, this perspective acknowledges that the stigma associated with intellectual disability is associated with service approaches that ignore the capabilities of the person (Simpson, 2011; Scior et al., 2016). This underestimation of potential is reflected in policy approaches to education and special education that continue to structure current policy and practice and that lead to exclusion.

Significance of the Research

The starting point for the research was a concern about fragmented policy and service provision across government and community agencies that was linked to a poor understanding of the needs of children and young people with disability. The absence of adequate data undermined the potential to develop appropriate, consistent responses to support the wellbeing of this group. The proportion of children with a disability, at 11% of the child population, has remained relatively

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stable since the NZHDS in 1996, indicating a significant child population group. By contrast to data on other child population groups, there is very little information on children with disability (Starr & Janah, 2016; Wynd, 2015). The lack of such data is an important factor that contributes to the fragmentation of services and the variability in coverage across the country (Starr & Janah, 2016; Murray, 2018).

Although the Ministry of Education expresses a commitment to inclusive education, there is no enforceable right to education for children and young people with disabilities. The lack of reporting on student achievement and progress points to a lack of evidence of accountability for learning outcomes for this child population. Additionally, the lack of collaboration and cooperation between government agencies results in fragmented service provision. The gaps identified in the *Ordinary Life Report* (National Advisory Committee on Health and Disability, 2003) in services for people with disabilities in New Zealand, particularly those with intellectual disabilities, remain and are of concern. As was reported in 2016, many people with intellectual disabilities are still not able to live valued and "good" lives and do not have equal access to opportunities and citizenship (IHC, 2016). These gaps in service provision also affect families supporting a member with a disability, and this is particularly the case for families in low income households who are less likely to receive adequate special education support or behavioural and social support at school.

Research Approach

The research involved, first, exploring wellbeing from the perspective of children and young people with Down syndrome and the factors that influence wellbeing; second, exploring wellbeing and the factors that influence it from the perspective of their parents and selected service providers; and third, examining the views of the adult participants on three of New Zealand's policy frameworks for supporting children and young people with disability. The study was based around the experiences of 12 children and young people with Down syndrome. A total of 38 interviews were carried out with these young people, their parents, and two groups of service providers, one from the education sector and one from national service providers. The interviews focused on understanding their perspectives of

wellbeing and the factors that influenced it. This analysis led to the creation of a conceptual framework to help schools, parents, communities, and public sector agencies understand and promote the wellbeing of children and young people with disability in New Zealand.

The research was informed by a grounded theory approach and it included a number of innovative ways to obtain the views of the children and young people with disability. These included not only inviting participating children and young people to use cameras as a way of producing information that would support the interview material, but also conducting repeat interviews to gain a fuller picture of the experience of the child or young person and to validate the analysis of their perspectives on wellbeing. The research method enhanced the young people's voice and expression and so was able to provide insight into the complex influencing factors within the multidimensional ecosystems of their daily lives.

On the basis of these findings, I developed a model of practice for working with children and young people with disability—the STPDS model. This model was based on the conceptual framework which had identified the dimensions of wellbeing for children and young people with a disability. In accordance with the processes associated with grounded theory research, in a second phase of the research, I evaluated the STPDS programme through interviews with the parent and teacher participants. Additionally, the programme was tested across three regions in 42 schools, involving 119 participants who were parents and a range of teachers of 44 children with Down syndrome.

Key Findings

The research explored the meaning of wellbeing and the factors that influenced it for children and young people with a disability. Acceptance, recognition, and supported independence were the three principles identified. The findings also showed the importance of early intervention, the whole child approach, the need for communication services, and the benefits of inclusive education practice. These findings confirm the insights of other researchers (Slee, 2018; Booth & Ainscow, 2016; Browne, & Millar, 2016; Hehir et al., 2016; Cole, Murphy, Frisby, Grossi, & Bolte, 2019; Colozzo et al., 2016).

Acceptance as a key principle for wellbeing has the following components: a sense of belonging; positive self-esteem and SRV; inclusive relationships and participation; a disability paradigm that values diversity and an inclusive culture; social acceptance to develop a social disability identity; and, friendships. Acceptance is influenced by a number of factors including positive peer relationships, academic achievement, acknowledgement of skill, and support from parents and teachers or support people who accept the young people and provide positive experiences and opportunities across a range of environments.

The regular school environment was the best place for learning, social engagement, and daily communication. Acceptance in the regular school environment had a deeper impact when the young people remained with a familiar peer group and when these bonds were sustained from primary school through to tertiary education. It was important that learning was supported at school with opportunities to reach the young people's potential in terms of social skills and the building of networks that could be continued on leaving school. Within education there is an emphasis on whole of life learning, and a human development approach would assist this emphasis. To this end, Maslow's hierarchy of needs and Ryff's eudaimonic objective list of quality of life requirements and happiness are essential considerations in this stage of development (Raghavan & Alexandrova, 2014). As with Maslow's other needs, the need to belong was borne out in the interviews and addressed by parents through aspects of service provision for the young people with Down syndrome.

The interviews identified wellbeing as being defined by acceptance and a sense of belonging through experiences and activities in which the child or young person was demonstrably valued and respected. The ability to learn and opportunities to express agency, to be creative, and to contribute were expressly linked to being happy and comfortable, having a strong sense of self-esteem and identity, and feeling well supported. All of these supported the development of autonomy. The home environment was identified as the most significant source of this support. Most of the families had taken a proactive approach to identity development, communication intervention, and prosocial skills strategies from an early stage of their child's life. These elements formed the beginning of a list of

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key factors promoting the wellbeing of children and young people with a disability and were used in the dimensions of wellbeing framework.

The dimensions of wellbeing framework that I have developed is an approach that is substantiated by the theories of wellbeing in the analysis of children, where self-assessments of acceptance and happiness made by individuals of their own talents, capabilities or general sense of worth, and life satisfaction are employed to evaluate their acceptance by others (Fletcher, 2013; Taylor, 2015; Cantor & Sanderson, 1999).

A second important element of acceptance was SRV. The young people and the parents described a sense of belonging through SRV, particularly through systematically increasing the complexity of tasks and roles in the family home and then within the school and the community. The significance of the young people's role was affirmed by daily routines that involved the undertaking and accomplishing of specific tasks at home, in the class, and in the school community.

Social acceptance was enhanced through prosocial strategies and practical actions throughout childhood and adolescence and contributed to increased self-esteem, happiness, positive peer relationships, and friendships. The social model of disability was linked to positive identity development in adolescence, particularly when there was support to overcome barriers and express agency and autonomy. Acceptance of self and social identity are interdependent and for the young people both were strongly influenced by interpersonal relationships. The significant finding is that when the social model of disability was the prevailing ethos, identity development for the children and young people was more positive and contributed to their sense of wellbeing.

Positive peer relationships and friendships increased the young person's self-worth, happiness, and interpersonal competence. Social acceptance was further enhanced at school when there were positive affirmations, social guidelines, and encouragement by key contributors. In the school setting, key contributors enhance a sense of belonging and SRV and help the young people make sense of social spaces.

A lack of acceptance is evident in the process of othering, where the child or young person was treated as intrinsically different. Othering was evident in service provision models that were informed by preconceived notions that children and young people with Down syndrome lacked potential for capability, and this notion led to low expectations of learning. Such attitudes by service providers reflected a medical model discourse of disability and was destructive to the self-worth and motivation of the young people and, therefore, to their wellbeing.

An obvious threat to the sense of belonging and acceptance is bullying. Although the majority of young people in the study had experienced some level of bullying, there was a strong perception that little or no action was really taken by the schools or teachers to alleviate the young person's stress. Despite the scale of concern about bullying within schools more generally, this concern was not seen as extending to children with a disability.

The importance of recognition for children and young people with a disability emerged as a complex, multifaceted, practical reality which was made up of nine elements. These were: respect; recognition with redistribution; equal entitlement and equality in treatment; access to the curriculum; special education; recognition of competency and capabilities; expectation of capability; meaningful work/school activities; and, acknowledgment of achievements. Recognition was seen through actions and practices in the homes and in schools. The factors which were important for the young people were progress in learning and skill development, participation with their peer group, and educators who were involved and gave encouragement and meaningful feedback. These factors contributed to capability and wellbeing. The actions and practices were also evident through key contributors within school environments and were vital to taking good practice from the home to the school. There were also examples of the movement of good practices from the school to the home, where key contributors shared ideas and strategies with families. The examples given were acknowledged as helping to build family capability.

The young people had an expectation of competence that contributed to recognition and wellbeing. The young people all provided a large array of "I can",

and "I like", "I do" statements, including when describing their photo-record, which showed they were undertaking various tasks and skills in a range of environments.

Respect was an important element of recognition, as was evident in the interpersonal relations in the family, at school, and in the local community. Respecting relationships between the young people and the teacher aides enabled self-esteem due to the educator's encouragement and plans for achievement. In the absence of such expectations, there tended to be a lack of resourcing, negative labels, and a lack of professional skill. These affected the sense of a self-identity, capability.

Recognition and respect in the school environment are vital to developing capabilities and participating with their peer group in learning and social environments. When describing their experiences of recognition and respect the young people stressed the importance of considering their learning capability, future options, and planning, particularly in regard to their access to the curriculum, modified or otherwise. Recognition and valuing of difference was related to the degree of material and personnel resources for support. Funding models based on principles of universal entitlement did not recognise the equal, but different, needs of the children and young people with disability and, in fact, worked against the meeting of those needs. Such models contributed to limiting access to the full curriculum and opportunities to learn. The provision of special education through learning support services was variable and inconsistent. Equal, but different, access to opportunity was crucially important to the young people and their families in all environments.

The third key principle associated with the wellbeing of children and young people with a disability was supported independence. Supported independence involved access to a range of opportunities and resources so that they could make meaningful choices and decisions. Planning, when supported within the school environment, enhanced independence, capability, confidence, and wellbeing and underscored the vital role of support people and key contributors, be they teachers, teacher aides, coaches or support workers.

Several components were associated with supported independence; these included early access to services, adequate resourcing such as economic considerations, family values and professional discourse, a focus on the development of capabilities, community, understanding support roles, and the importance of structure and friendships. These factors highlight the importance of access to support services, the related eligibility criteria, and the actual level of material support needed for families and support agencies. Supporting children with a disability into adolescence and adulthood requires recognising and supporting their ability to learn independently, contribute meaningful work, and contribute social value to their communities.

Supporting communication, particularly with a view to supported independence, was vital for the young people with Down syndrome, which implies the need to respond to the particular needs of children and young people with disability in supporting their independence. Supporting these young people required specialist services and specific language intervention programmes.

Support at various levels is needed to build capabilities across a range of skills and development. The family is at the core of supported independence and is the most important contributor to a young person's ability to maximise her/his independence and move successfully into adulthood. It is essential that early patterns of planned, deliberate access to social institutions build academic and social competence and are underpinned by rights, dignity, respect, and social disability identity.

Significance of the Findings

Wellbeing for children and young people with a disability, therefore, is enhanced when there is acceptance, recognition, and support for their independence. These three principles illustrate the dimensions of wellbeing and the interdependence of the factors that influence the achievement of a good life. The principles have potential to inform actions that underscore ways in which policy and practice could be developed to achieve an environment where children and young people with a disability can flourish alongside all children in New Zealand.

This study's approach to disability, children and young people, and wellbeing is unique in the way in which it incorporates a capability approach. Robeyns (2016) has identified the limited scholarship on wellbeing for children and young people with a disability and the lack of focus on capabilities or as she says "capabilitarian wellbeing" (2016, p. 383). Much current practice is informed by low expectations for children with a disability. This deficit approach is evident in the New Zealand context where there is reference to a "Below Level One" learner framework. This study has found that a deficit approach undermines wellbeing and that education based on an assumption of capability has much potential to contribute to improvements in wellbeing, participation, and achievement. In the study, it was obvious that young people with a disability who were given opportunities to engage in inclusive learning, supported by structure, given meaningful work, and offered appropriate guidance had potential to display competency, self-management, high self-esteem, and a positive social disability identity.

The study builds on existing evidence of practice that shows how inclusion contributes towards the development of capability. The evaluation of the STPDS model and concepts of a supported learning environment and whole school approach indicates that adopting a multicomponent, early intervention, whole school approach, with resources, curriculum accommodations, and strategies is beneficial in the promotion of wellbeing. The case for a whole school approach is supported by scholarship on how best to build professional capacity and implement strategies that empower teachers to have a positive impact on the systems (from micro to macro) for wellbeing and achievement (Weare & Gray, 2003; Hargreaves, Shirley, Wangia, Bacon, & D'Angelo, 2018). The finding that recognition for children and young people with a disability is enriched within a capability framework has implications for practice and can inform professional development for those working with this group. Additionally, "recognition" has implications for the resourcing of support services, if the promise of inclusive education is to be realised.

The study also draws attention to the elements that contribute to acceptance, recognition, and supported independence at different levels within the ecological systems framework. The ecological perspective accounts for

interactions, interrelationships, culture and disability discourse between the young person, their home, school, peers, and community. When the principles of acceptance, recognition, and supported independence are used as the basis for social policy and along with accompanying funding, the potential to increase wellbeing for all children and young people with a disability will be realised.

The aim of the research was to discover what wellbeing means for children with a disability. Following the analysis, a conceptual framework of wellbeing was developed. Eight dimensions of wellbeing were operationalised and they represent the influencing factors in this child-centric framework. In New Zealand, there is no overall policy research focus on the quality of life of children and young people with a disability. This child wellbeing framework has potential to allow, at the most fundamental level, the monitoring of the implementation of social services and other initiatives such as policy and resources. A framework such as this one could also serve as an important tool for tracking outcomes over time and identifying what is working well and areas of quality service provision, and its use could allow immediate response to shortfalls or unmet needs. As Ben-Arieh et al. (2001) states, national indicators assist "societies to inform their policies, galvanise and reward effort, mark their achievement, introduce accountability and be a means by which sustained pressure can be brought to bear for the fulfilment of political promises" (p. 7).

Limitations and Recommendations for Future Research

This was a qualitative study with a small sample and the focus was on gaining insights into what wellbeing meant for children and young people with disability. There is a need for further research with a greater number of children and parents, more male representation, and a wider range of ethnicities, in order to gain a fuller account of the experiences among this population group. Further research could incorporate a larger and more diverse population of children and young people with a disability which would enable a quantitative analysis of the factors influencing wellbeing. Such research could contribute to refining the conclusions reached in this thesis and would be useful in advocating for improvements in service provision to promote higher levels of wellbeing for children and young people with a disability. Although two of the case study families were Pasifika

and Māori, and the schools in the STPDS programme were multicultural, there is also a need to examine wellbeing within these specific cultural contexts.

Given the sensitivity of the research topic, recruitment of the participants was more difficult than initially presumed. While initial levels of interest were positive, there was apparent hesitation from some special education personnel to pass on the research invitation to potential participants, citing an issue with "recording" the views of students and parents of children with a disability in the school environment. This response could be interpreted as gatekeeping, and it may have affected the number and type of participants who were involved. Gatekeeping in this context is certainly an issue that needs to be explored further.

In the second stage of the research, which sought to validate the conceptual framework, quantitative data was collected from the STPDS programme participants, but was not part of the study for this thesis and, therefore, it is not recorded here.

Recommendations

Wellbeing for children and young people with a disability is best understood through an ecological systems framework. A whole child approach would be best served by a multifaceted systems approach to service delivery. In order to ease access to services, information, and service personnel across institutional bodies, the ecological systems model should be used.

New Zealand has a higher rate of bullying that most other OECD countries (Education Review Office, 2019) and within the data gathered on this issue the voices of children and young people with a disability are silent. For this student population not to be heard or included in the data is a situation that needs to be immediately addressed.

A complex phenomenon such as wellbeing is best captured in the dimensions of wellbeing for children and young people with a disability framework. Indicators assign meaning and practical content to the notion of wellbeing. Rooted in values and ideology and theories of childhood, they reflect realities and contribute to the conceptions of policy and politics. In this sense, the

Children and Young People with a Disability: Dimensions of Wellbeing framework has potential to be used as a tool for policy construction to shape a better future for these young people.

Adopting a multicomponent, pre-emptive or early intervention, whole school approach to the promotion of wellbeing, with resources, curriculum accommodations, and strategies is the most advantageous and evidence-informed approach for schools. Children thrive in regular local schools and 25 years of special education reviews are not required to show that education for children with a disability is still under resourced. Segregation into special schools and satellite units is a backward step and a process of institutional subordination. The government needs to make a commitment to fund, train, and pay teachers, monitor outcomes, and measure the educational potential and capability of the child or young person with a disability on the same basis as is done for all other children. Doing so requires an approach similar to that adopted in Victoria, Australia or Ireland where children with disability are recognised and valued as children in their own right at the local school and in natural childhood environments.

Human rights is key to understanding the importance of ensuring appropriate resources are available for a child with a disability as part of the child population as a whole. This fundamental understanding would guide any assessments being made and, thus, enhance rather than limit supported independence. For this reason, professional training schedules need to incorporate human rights and disability studies into professional development.

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Appendix 1. Interview Guides for Children, Parents and The Two Service Provider Groups.

Appendix 1 Interview Guide for Child Participants

1. Background

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

Prompts; photos

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? Transcribe 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?

Is there anything else you want to tell me about?

Thank you for your help with my project.

Appendix 1. 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)'s 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 adult participant – service provider and parent participant the frameworks

INTERVIEW GUIDE CONTINUES FROM HERE SAME AS FOR SERVICE PROVIDER

Appendix 1. Interview guide - Service provider and National service provider

1. Background of adult participant

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. Dimensions of wellbeing for children and young people in New Zealand
Children and Young People: Indicators of Wellbeing in New Zealand, 2005 Page 136

2. The Key Settings Model - *Guide to Applying the Whole Child Approach* page 25

3. The Right to Education Wheel - Human Rights Commission

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. 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? **Service Providers**
- What broad policy, funding or regulatory frameworks affect your child with a disability? **Parent**

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 emphasised when we are thinking about children with a disability?

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

- 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 2. Selected Policy Frameworks for Interview Models

2.1. Children and Young People: Ordinary Life Information Gathering Tool
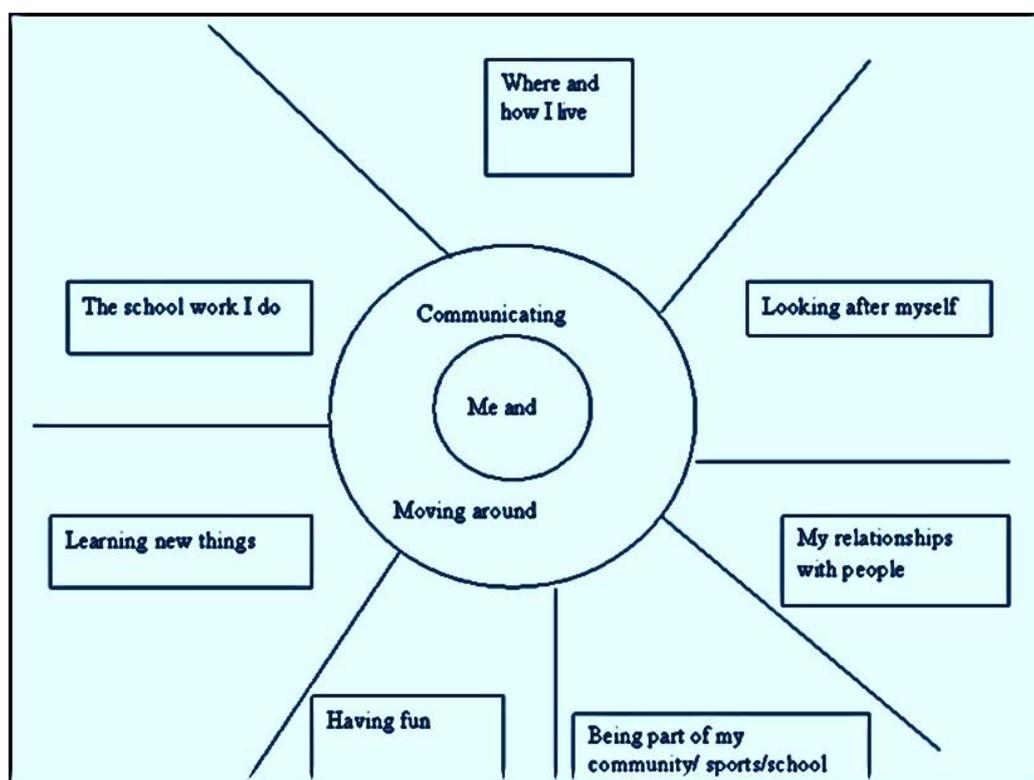
An A4 Laminated Model was used as the research tool

Source: National Advisory Committee on Health and Disability. (2003). To have an ordinary life. Kia whai oranga 'noa'. Wellington: Ministry of Health and Office of Disability Issues – adapted by Kirk, M (2006) Wellbeing for children and young people with a disability: A conceptual framework. Unpublished manuscript. Hamilton: University of Waikato

The Ordinary Life Information-Gathering Model puts the young person in the centre, and covers:

ME and – we all have ways of doing things, who would be in this circle with you. The abridged statement is used as from the pre-test the original statement was

considered too complex and to be leading the response for young people. (***My culture*** we all have ways of doing things that are right for us, and our families and whānau (NHC, 2003:15).

Communicating – expressing needs and thoughts, and understanding what others are saying is necessary for people to have control over their daily lives (NHC, 2003:15).

Moving around – getting around our home and neighbourhood is an important part of belonging to

a community (NHC, 2003:15). School /sport or cultural group added if a prompt was needed.

Where and how I live – having a home is an important and fundamental right. This component of the model included where home is, who else lives there, and how things like cooking, cleaning, and household maintenance are managed (NHC, 2003:15). The adaption made for young people was acknowledgement of our ability to contribute and have an understanding of what others are doing is necessary for people to learn to have control over their daily lives.

What makes an ok life for you? What makes life good for you? **Added** Can you tell me or show me, if you had to put a list together, what would be on your list about That might go in there?

Looking after myself – health impacts on every aspect of our ability to engage in living (NHC, 2003:15). The adaption included how the young person managed activities of daily living like hygiene, clothing, preparation for school, sport and preparation of light meals or snacks.

My relationships with people – we all need to have other people in our lives and to know that we are loved and capable of giving love (NHC, 2003:15).

Being part of my community /sports/ school – we all need to belong and be accepted (NHC, 2003:15). *Sports*/*school* were added as environments for children and young people.

Having fun – we all need to have recreation and leisure time, to smile and laugh and have reciprocal relationships with others (NHC, 2003:15).

Learning new things – everyone needs and has the ability to learn and grow (NHC, 2003:15).

The School work I do – everyone wants to do interesting things with their life, and needs to be recognised as having social value (NHC, 2003:15). The adaption included the addition of *school* and removal of *paid and unpaid work* as school is the setting predominant social setting for children and young people. Employment was not explored within the thesis.

2.2. Adult Interviews: The Key Settings Model
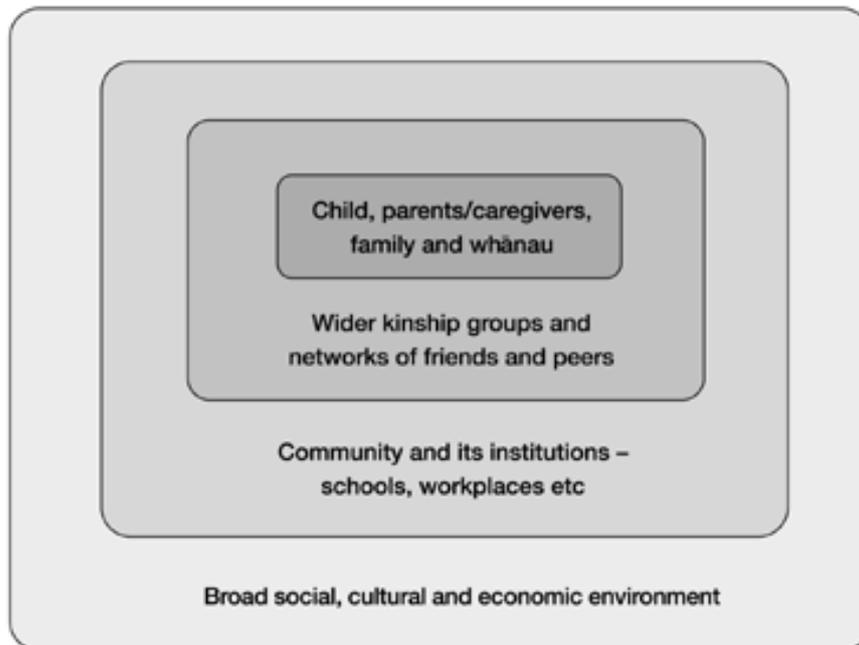
These settings are seen as influencing children's health and wellbeing in New Zealand. An individual child's wellbeing is seen as developing in relation to a number of interlinking settings which are:

- 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 (2002b 14/15). *Whole Child Approach. A guide to applying the whole child approach.* Wellington: Ministry of Social Development

2.3. Adult interviews: Children and Young people: Indicators of Wellbeing in New Zealand. Outcome domains

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

Ten outcome domains have been selected for inclusion in an indicators framework

for the 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. (2005) *Children and young people: Indicators of wellbeing in New Zealand.* Wellington: Ministry of Social Development (2005, p.136).

2.4. Adult Interviews: The Right to Education

- Human Rights Commission, Te Kāhui Tika Tangata. (Human Rights Commission, 2004, p.262)
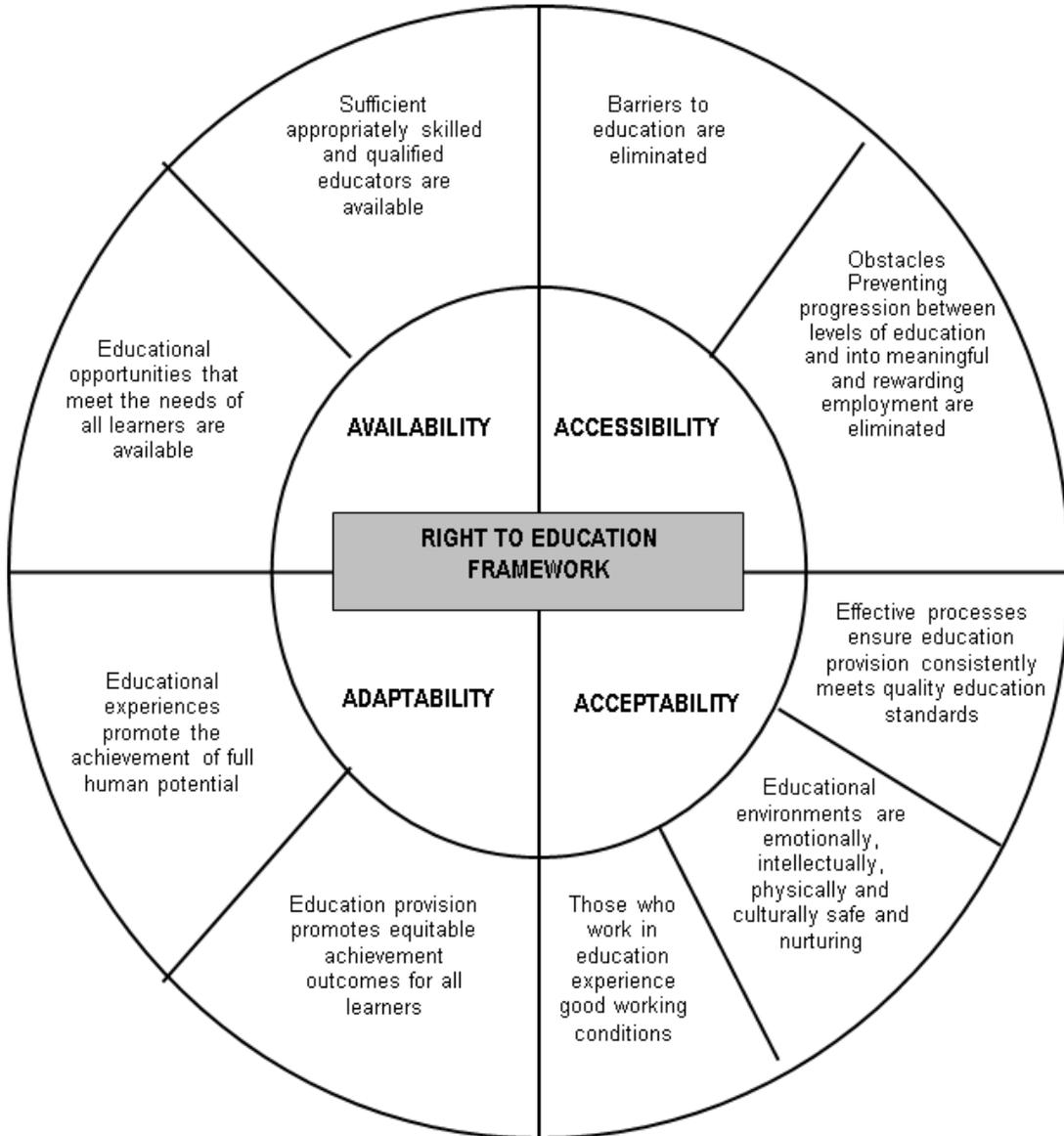
The *Right to Education Framework* has been designed to be applicable to education in Aotearoa New Zealand. The human rights standards and considerations are interdependent, that is, the achievement of one is not necessarily evidence for the full achievement of the right to education. The *Right to Education 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 3. Information Sheets and Consent forms

3.1. Parent of Student Participant Information Sheet

Wellbeing for Children and Young People with a Disability in New Zealand

Researcher   Maree Kirk

As part of my doctorate study I now am following up my research into *Wellbeing for children with a disability in New Zealand.*

I have established 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. Drawing from a young person's experience and understanding…………………..is invited to take part in an interview the aim of which is to again explore her perceptions of wellbeing for young people with a disability four years on.

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. I may use some of the photos taken for the interviews for my thesis, conference presentations or further publications that may arise from the research. **……………..** may withdraw any information or photos from the interview during the interview or at the final stage of the transcript. The findings of the interview, the photos, analysis and final report will be used as the basis for my doctorate thesis. You are welcome to review the findings once I have completed the thesis. A copy of the final thesis will be made available at the University of Waikato.

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:

If ……………….. takes part in the study, she has the right to:

- Refuse to answer any particular question, or to retract information given in the interview from the study up to two weeks after the final meeting.
- Ask any further questions about this study that occurs to you or …………. during participation.
- Be given access to a summary of the findings from the study when it is concluded.

You are able to contact the Ethics Committee, me or my supervisor with queries or for further information. **Thank you for your assistance**

Chairperson, Human Research Ethics Committee,
Faculty of Arts and Social Science,
University of Waikato,
Private Bag 3105,
Hamilton.
Email: charl@waikato.ac.nz

 Maree Kirk
Phone 00 000000
Email: Dr. Jo Barnes
Phone 07 8384662
Email jobar@waikato.ac.nz

3.2 Adult Participant Consent Form

In signing this consent form you are agreeing that the purpose of the use of the photographs has been clearly explained to you. You are acknowledging that that you have read the information sheet and agree to take part in this aspect of the publication of findings from the research 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 will be given a copy of this letter for your reference.

A copy of the research report will be made available at the University of Waikato.

Thank you again for your assistance with my research project

…………………………………………….

Maree Kirk

Researcher   Date

…………………………………………….

Participant (Name)

…………………………………………….

Signature   Date

Chairperson, Human Research Ethics Committee,
Faculty of Arts and Social Science,
University of Waikato,
Private Bag 3105,
Hamilton.
Email: charl@waikato.ac.nz

Maree Kirk
Phone 00 000000
 Email kirkgrey@ihug.co.nz
Dr. Jo Barnes
Phone 07 8384662
 Email jobar@waikato.ac.nz
Dr. Maxine Campbell
Phone 07 8386115
Email maxine@waikato.ac.nz

3.3 Children's Information Sheet for Use of Photographs

Dear

This information sheet is to ask for your permission to use some of your photos that were part of the study for my University work.

What it's about

I am going to publish an article / present a talk about the study of what wellbeing means for children with a disability. So if you agree I would like to use some of the photos you took about what life is like for children with a disability at school to help show adults what things are important.

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 the use of your photos. This is like the consent form you did for the meetings we had. This is to make sure I have only got the photos you and your mum and dad agree that I can show other people.

What happens with the study?

After I have talked to you, I will use the ideas from the study and some of the photos to put in an article / presentation to explain to other adults what things are important for what wellbeing means for children with a disability at school. Your real name will not be used so you can be kept private but your ideas will help people reading the article or listening to the presentation understand about wellbeing for children with a disability.

If you want to know more about the use of the photos

If you, or Mum or Dad, think of questions you can ask me or my teacher or the Ethics Committee at the University. Our names are;

Maree Kirk   Dr. Jo Barnes   Dr. Maxine
            Campbell

Our Contact Details are:

You are able to contact the Ethics Committee, me or my supervisor with queries or for further information

Chairperson, Human Research Ethics Committee, Faculty of Arts and Social Science, University of Waikato, Private Bag 3105, Hamilton. Email: charl@waikato.ac.nz	Maree Kirk **Phone** 00 000000 **Email** kirkgrey@ihug.co.nz Dr. Jo Barnes **Phone** 07 8384662 **Email** jobar@waikato.ac.nz Dr. Maxine Campbell **Phone** 07 8386115 **Email** maxine@waikato.ac.nz

Thank you

3.3.1 Children's Information Sheet for the Interview

Dear

This information sheet is to ask for your permission to have an interview or some interviews, that is talking to me to use your ideas as part of the study for my University work.

What it's about

I am going to publish an article / present a talk about the study of what wellbeing means for children with a disability. So if you agree I would like to use some of things we talk about, what you think about what life is like for children with a disability at school to help show adults what things are important.

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 the interview/s. This is the consent form the meetings we will have. This is to make sure I have only got what you think about what makes life good for you and your mum and dad agree that I can tell other people.

What happens with the study?

After I have talked to you, I will use the ideas from the study and some of the photos to put in an article / presentation to explain to other adults what things are important for what wellbeing means for children with a disability at school. Your real name will not be used so you can be kept private but your ideas will help people reading the article or listening to the presentation understand about wellbeing for children with a disability.

If you want to know more about the interviews

If you, or Mum or Dad, think of questions you can ask me or my teacher or the Ethics Committee at the University. Our names are;

Maree Kirk   Dr. Jo Barnes   Dr. Maxine Campbell

Our Contact Details are:

You are able to contact the Ethics Committee, me or my supervisor with queries or for further information

<table>
<tr>
<td>
Chairperson, Human Research Ethics Committee,
Faculty of Arts and Social Science,
University of Waikato,
Private Bag 3105,
Hamilton.
Email: charl@waikato.ac.nz
</td>
<td>
Maree Kirk
Phone 00 000000
Email kirkgrey@ihug.co.nz
Dr. Jo Barnes
Phone 07 8384662
Email jobar@waikato.ac.nz
Dr. Maxine Campbell
Phone 07 8386115
Email maxine@waikato.ac.nz
</td>
</tr>
</table>

Thank you

3.4. Consent Form Children

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 use of my photos from the "Wellbeing for children with a disability in New Zealand" project and I understand it.

I know that……………………..

I don't have let my photos be in the project unless I want them to be.

Mum and Dad have agreed that I can let some of my photos be used in the publication / presentation of the project.

I can choose to take out some of the photos if I don't want Maree to have them or I don't want her to show the photos to other people.

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

No bad things will happen to me if I change my mind about using my photos to do with the project.
I would like to let you use the photos from the project**.**

…………………………………My signature (name)
…………………………   The date

3.4.1. Consent Form Children

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 interview "Wellbeing for children with a disability in New Zealand" project and I understand it.

I know that……………………..

I can talk with Maree in the project when I want to. It is about me.
I don't have talk with Maree in the project – I decide.

Mum and Dad have agreed that I can meet Maree and talk to her.
I can choose where we meet and when we meet.

If I get tired or want to stop, I can tell Maree. I can ask Mum or Dad to tell her if I want to.
If I ever have any questions, I can ask Maree about them or get Mum or Dad to phone Maree's teacher, Jo or Maxine, to ask her.

No bad things will happen to me if I change my mind about using my photos to do with the project.
I would like to let you use the photos from the project**.

…………………………………My signature (name)
……………………………   The date

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3.5. Adult Information Sheet

Researcher   Maree Kirk

As part of my post graduate study I am undertaking a research project on the topic *Wellbeing for children with a disability in New Zealand: a conceptual framework.* I am interested in establishing some of the dimensions of wellbeing as identified by children with a disability and their parents and service providers in the community context of the school. Drawing from your experience 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. You may withdraw any information from the interview during the interview or up to two weeks after the interview has taken place. The findings of the interview, analysis and final report will be used as the basis for my doctorate study. You are welcome to review the findings once I have completed the research. A copy of the final thesis will be made available at the University of Waikato.

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 up to two weeks after the interview.
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 up to two weeks after the interview.
Ask any further questions about this study that occurs 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 the Ethics Committee, me or my supervisor with queries or for further information

Chairperson, Human Research Ethics Committee, Faculty of Arts and Social Science, University of Waikato, Private Bag 3105, Hamilton. Email: charl@waikato.ac.nz	Maree Kirk **Phone 00 0000000** **Email** kirkgrey@ihug.co.nz Dr. Jo Barnes **Phone** 07 8384662 **Email** jobar@waikato.ac.nz

Thank you for your assistance.

3.6. 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 or to retract information that you have given in the interview from the study up to two weeks after the interview.

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

A copy of the research report will be made available at the University of Waikato.

Thank you again for your assistance with my research project

……………………………………………….

Maree Kirk

Researcher   Date

……………………………………………….

Participant (Name)

……………………………………………….

Signature   Date

| Chairperson, Human Research Ethics Committee, Faculty of Arts and Social Science, University of Waikato, Private Bag 3105, Hamilton.   Email: charl@waikato.ac.nz | Maree Kirk **Phone** 00 0000000 **Email** kirkgrey@ihug.co.nz Dr. Jo Barnes **Phone** 07 8384662 **Email** jobar@waikato.ac.nz |

3.7. Information Sheets and Consent Forms STPDS: Students, Parents, Teachers and Schools

This information sheet is to ask for your permission to use some of your photos that were part of the Pilot.

What it's about

I am going to write a report about what we did and what we learnt. So if you agree I would like to use some of the photos we took about what happens at school and the photos of you learning to help show adults what things are important.

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 the use of your photos. This is to make sure I have only got the photos you and your mum and dad agree that I can show other people.

What happens with the evaluation?

After I have visited you at school and your teacher has taken some photos, I will use the ideas from the study and some of the photos to put in a report to explain to other adults what things are important for learning for children with a Down syndrome at school. Your real name will not be used so you can be kept private but your photos will help people reading the report understand about learning and teaching ideas for children with Down syndrome.

If you want to know more about the use of the photos

If you, or Mum or Dad, think of questions you can ask me

Maree Kirk

My Contact Details are: bopdsaproject@gmail.com

Maree Kirk
Phone 00 000000
Email kirkgrey@ihug.co.nz
Dr. Jo Barnes
Phone 07 8384662
Email jobar@waikato.ac.nz

Chairperson, Human Research Ethics
Committee,
Faculty of Arts and Social Science,
University of Waikato,
Private Bag 3105,
Hamilton.

Email: charl@waikato.ac.nz

3.7.1. Student's information sheet for use of photographs and consent

Teaching practice and

learning for me

CONSENT FORM

FOR STUDENTS

I have read the information sheet (or someone has read it to me and talked about it) for the use of my photos from the "Supporting teaching practice for students with Down syndrome and cognitive delay in New Zealand" project and I understand it.

I know that………..

I don't have let my photos be in the report unless I want them to be.

Mum and/ or Dad have agreed that I can let some of my photos be used in the publication / presentation of the project.

If I ever have any questions I can ask Maree about them or get Mum or Dad to email Maree to ask her.

No bad things will happen to me if I change my mind about using my photos to do with the report.

I would like to let you use the photos from the report.

……………………………………………….   My signature (name)

……………………………………………….   The date

3.7.2. STPDS adult information sheet for use of photographs and consent

Supporting teaching practice for students with Down syndrome and cognitive delay in New Zealand – Pilot programme
Researcher   Maree Kirk

Thank you for your participation in the evaluation of the Pilot *Supporting teaching practice for students with Down syndrome and cognitive delay in New Zealand.*

I am interested in establishing some of the perspectives of the participants as a result of attending this programme identified through classroom practice such as any changes in teaching strategies, knowledge or skills, use of resources, approaches, record keeping, indicators or assessments by teachers, teacher aides or by students with a disability and their parents. As you are aware this evaluation is aimed at drawing from your experience to explore perceptions of the programme.

I would like to request one or two photographs (for a **photo record**) and an accompanying statement on each of the two topics that might typify your perception / your schools view of the Pilot programme with regard to:

- An influence on teaching experience / practice
- An indication of a student's progress against their learning goals

The findings of the photo record and statement analysis will be used in the evaluation report to the Ministry of Education.
I would like to request your consent to use these photographs as a **photo record** for the evaluation report. I will also draw on some of this material in my PhD study. A copy of the final Evaluation report can be made available to each school.

I have also taken a photo record of some aspects of school practice or of a

student working as part of a school visit. I would like to request your consent to use these photographs of an aspect of school practice or of a student working as part of a school visit.

Separate photograph consent has been requested from the parents and the students within the Pilot programme.

I would like to request your consent to use the selected photographs you submit or that I take on the school visits and statements for the evaluation. The anonymity of the participants will be maintained in that 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. For any queries or further information, you can contact me via email.

Thank you for your assistance.

3.7.3. Adult participant consent form Parent / Teacher / School

1. In signing this consent form, you are agreeing that the purpose of the use of the photographs has been clearly explained to you. You are acknowledging that that you have read the information sheet and agree to the use of the photographs as part, in this aspect, of the publication of findings from the evaluation of the programme.

2. In signing this consent form, you are agreeing that the purpose of the use of the photographs has been clearly explained to you. You are acknowledging that that you have read the information sheet and agree to the use of the photographs as part, in this aspect, for presentation or publication of findings for further post graduate study.

You do not give up your legal rights by
signing this consent form. This letter is for
your reference.
Thank you again for your assistance

…………………………
Maree Kirk
Researcher   Date

……………………….
Participant (Name)

…………………………………………………. School

Signature   Date

Appendix 4. A Guide to Applying the Whole Child Approach

What questions do I need to ask?

Ideally, you need to consider the whole child approach at the very beginning or in the planning stages of your policy or programme development. You might have reached a certain stage in your work and realised it is important to consider how to apply the whole child approach, including involving children and young people.

At whatever stage you first consider applying the whole child approach some key questions need to be asked in relation to your particular policy or service provision:

What will be the effects on children of this policy, programme or service?
- How will this policy affect children's access or participation?
- How will children's health or wellbeing be affected?
- How will children's knowledge or independence be affected?

Will there be differential effects?
- Will different groups of children be affected in different ways?
- Will benefits/risks be different for boys or girls or for different groupings of children according to age, ethnicity, disability/ability, geographic location, as consumers or clients of services?

How can we involve children in work on this policy?
- In what ways can we ensure children affected by this policy are able to share their ideas and perspectives to inform this work?

Source: Ministry of Social Development. (2004). A guide to applying the whole child approach. P.6.

Appendix 5. Borgatti: Axial Coding Framework

An example of the basis of an axial coding framework by S. Borgatti (ND)

The frame consists of the following elements:

Element	Description
Phenomenon	This is what in schema theory might be called the name of the schema or frame. It is the concept that holds the bits together. In grounded theory it is sometimes the outcome of interest, or it can be the subject.
Causal conditions	These are the events or variables that lead to the occurrence or development of the phenomenon. It is a set of causes and their properties.
Context	Hard to distinguish from the causal conditions. It is the specific locations (values) of background variables. A set of conditions influencing the action/strategy. Researchers often make a quaint distinction between active variables (causes) and background variables (context). It has more to do with what I find interesting (causes) and less interesting (context) than with distinctions out in nature.
Intervening conditions	Similar to context. If we like, we can identify context with *moderating* variables and intervening conditions with *mediating* variables. But it is not clear that grounded theorists cleanly distinguish between these two.
Action strategies	The purposeful, goal-oriented activities that agents perform in response to the phenomenon and intervening conditions.
Consequences	These are the consequences of the action strategies, intended and unintended.

Source: Borgatti, S. (ND). Axial coding framework. Retrieved from
http://www.analytictech.com/mb870/introtogt.htm

Appendix 6. STPDS Programme Outline

Date	Topic	Resources received
Month 1	**Introductory Seminar Maree Kirk**	**STPDS Online Forum**
	Programme Introduction Specific learning profile for students with Down Syndrome & cognitive delay • Specific learning profile of strengths • Implications for interventions and education • Evidence based practice, what the research tells us	**Enabling Learners Primary** resource book given to each school **Material loaded onto the Forum**
	Inclusive Classroom Practice Dr XXXXXX	
	• Universal design for learning guidelines • Learning contexts • Roles within the inclusive context • Interactive session	**Learners with Down syndrome** for parents **Material loaded onto the Forum**
	Seminar1 Speech and language Literacy Maree Kirk	
	• Speech and language in the school years • Vocabulary and grammar, language and communication • Interactive session with international literacy resources.	**Material loaded onto the Forum** **STPDS PACK per school**
	Key Competency Understanding symbols and text	
Month 2	**Seminar2 Communication SLT XXXXX**	**Forum**
	• Visually mediated communication • Social communication and language articulation • Schedules • Home /school schedules and help with	**Material loaded onto the Forum**
	Key Competency Participation and contribution	
Month 3	**Seminar3 Numeracy Maree Kirk and XXXXX Numeracy**	**Forum**
	• Numeracy – evidence-based skills • Learning contexts, research evidence • Numeracy and how to adapt the curriculum • **Education Resource Pack©**	**Material loaded onto the Forum** Laminated schedule examples per school
	Key Competency Thinking, understanding symbols and text	
Month 4	**Seminar4 Social Skills and behaviour 2 Educational**	
	• Managing difficult times • Interactive session- brainstorm approaches • Learning contexts	
	• Social skills and behaviour: Research evidence • Social inclusion strategies for success • Friendship • Realities in the classroom, school wide approaches	**Material loaded onto the Forum**
	Key Competency Managing self, relating to others	
Month 5	**Motor Skills Occupational Therapist MOE**	
	• Overview of motor skills and development • Classroom occupation therapist assistive equipment • Prewriting skills	Flexible placement
	IEP & Technology Maree Kirk	
	• IEP and the Key Competencies • Technology Skills: Apps. iPads and you • Learning contexts **Education Resource Pack©**	**Material loaded onto the Forum**
Follow up	**Event Information** for parents, family whānau	
	School visits and school presentations	

Appendix 6.1. STPDS Programme Participants

The table below describes the number of schools, participants by role and gender.

Table 8.   STPDS Adult programme participants

	All	Christchurch	Wellington	Bay of Plenty
Number of Schools	42	16	14	12
Principal/SENCO/Teacher	78	35	24	17
Teacher Aide	32	15	6	8
Parent/Grandparent	37	14	10	9
MOE	19	8	4	4
Service Provider (private specialist)	1		1	
Total	156	72	45	39
Male	15	7	4	4
Female	141	65	41	35

Schools were selected by the regional Ministry of Education office and the Regional Down Syndrome Association. Priority was given to primary schools with students with Down syndrome aged 5 to 8 years old who were in the junior area of the primary school. Schools selected for the programme were expected to have students identified as ORS funded student/s with Down syndrome and students identified as having learning disability. Consideration was given to a range of primary schools including schools such as those in urban and rural location, with high percentages of Māori, Pasifika, and English as a second language or identified with a low decile ranking. The 42 schools in the final sample included primary, full primary and composite schools providing an age range of students with Down syndrome.

Appendix 7. Participant-Produced Visual Material: The Research Photos

The research used the visual sociology method. The mosaic approach was to support communication of views, and explain abstract concepts for discussion in the interview/s. Photo voice was valuable for the comprehensive descriptive information that the young people wanted to provide. The research tool was used to give independence and ownership to their perspectives and experiences.

The young people were given a disposable camera to record their activities during the day. On some occasions the young people also requested others to take photos that they wanted to use in his/her interview/s. The young people were also given two photo albums along with a local store gift voucher to have the photos developed. The photos taken by the young people were used through the interviews as they described their perspectives of wellbeing and experiences at home, school and in the community. With the young person and myself both having a copy of the photos the young person was able to communicate their ideas to me. For a full explanation of the research method and the mosaic approach and visual methods see Chapter 3.

The photos are broadly grouped below to give a snap shot of over 400 photos submitted with the data. The data included interview support material and some of the items from the support material such as the schedules and a cake are illustrated below. The visual data analysis is covered in chapter 3.

These photographs provide a snapshot of photo voice with phrases from the interviews and does not include all aspects of the research analysis and to maintain anonymity images of the young people are not included.

	A sample of photo voice
My Work	
	These are photographs depicting the interview process of using a dictaphone and a variety of the young people's interview support material.
I can	
	These are photographs the students chose to show the range of activities they enjoyed and were capable of doing at home, school and in the community.
I like school	
	These are photographs showing the regular classroom spaces including a timetable and where the students learn the curriculum with their peers.
At home	
	These are photographs showing the young people's chores of feeding the pigs at home, caring the dog and their personal work space
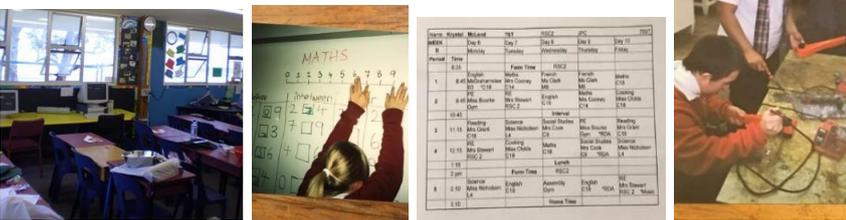
The goal of phase two of the research was to gain an understanding of the experience of the STPDS programme that was based on the STPDS model (see Figure 2, chapter 3). A photo record of student-teacher interactions was collected on the school visits. The following photo record illustrates the strategies in the classroom and examples of the students' schoolwork.

| **A sample of photo record** |
| --- |
| |
| A close-up photo (left) of the slope board to assist the student's fine motor skills. The student is within the regular classroom. Class schedule with the students more detailed schedule with the teacher aide pointing towards a task (right). |
| The vertical visual schedules were arranged following the programme as a logical sequence for the students to work from. There are class wide student groups including the student with Down syndrome. The student with Down syndrome's larger detailed schedule with visual reward prompts is displayed alongside the class group. |
| |
| Periods of curriculum work are broken up with periods of break time using the 'first' 'then' choice option from the programme for the student. The approach is used to develop self-regulation, task completion and prosocial skills. Student working with an accommodated curriculum and small group work. The visual supports are available to the group. School |
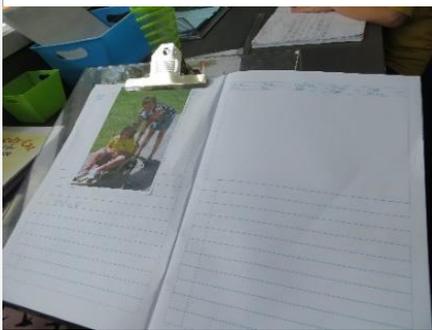
A is using United Kingdom DownsEd Reading and Language Intervention from the programme resources.
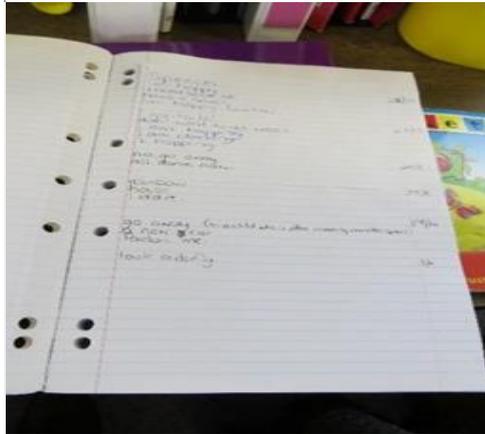
Primary School B fully embraced the STPDS programme and the photo record shows the students word bank, (left photo) topic book and planned, organised area of curriculum material (photo bottom below left).

The STPDS Education Resource Pack resources have been utilised following the programme. The photos above show the literacy resources. The teacher aide worked with the teacher on the literacy programme and literacy resources were developed for a larger student group. The photo below shows the teacher aide working with a student with Down syndrome.