

THE EXPERIENCE OF SCHOOL FOR NEW ZEALAND STUDENTS WITH DOWN  
SYNDROME: PARENTAL PERSPECTIVES

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requirements for the Degree of  
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**Abstract**

The perspectives of New Zealand parents of children with Down syndrome regarding their children's experience of school were explored in the present analysis, based on a study carried out by the Champion Centre, an early intervention service in Christchurch, New Zealand. Participants were 137 parents of children with Down syndrome who had experienced the New Zealand formal education system. They took part in a survey, designed to explore the outcomes and achievements of individuals with Down syndrome in New Zealand. The results of the present analysis indicated that parents are typically satisfied with the experience their children with Down syndrome have of school. It highlighted considerable variation in the experiences they have of school, but also emphasised some general trends and themes. Such efforts to clarify individual as well as shared characteristics and experiences among children with Down syndrome will contribute to ongoing efforts to enhance their experience of school and consequently, their active, valued participation in the classroom, school, and society in general.

## **The Experience of School for New Zealand Students with Down Syndrome: Parental Perspectives**

To date, the literature reflects a reasonable amount of interest in the experiences of individuals with Down syndrome, but relatively little that is relevant to their education and even less that is specific to the New Zealand context. There are no precise figures concerning how many children are born with this syndrome every year in New Zealand, although the most recent international estimates place it at approximately one out of every 600 to 800 live births (Alton, 1998). Considering the current New Zealand birth rate of 15.1 births per year out of every 1000 people in a country of around 4.2 million, it is likely that approximately 80 to 106 children with Down syndrome begin school each year in this country (Statistics New Zealand, 2009). While this number may appear small, Down syndrome is the most commonly identified genetic disorder, as well as the genetic disorder most frequently associated with intellectual disability (Davis, 2008).

### ***An Innovative Research Initiative in New Zealand***

The Champion Centre is an early intervention service located in Christchurch, New Zealand, providing services for children with special needs, including children with Down syndrome. It recently initiated a study to illuminate the outcomes and achievements of individuals with Down syndrome in New Zealand. A questionnaire was designed, developed, and sent to parents of children with Down syndrome who were members of the New Zealand Down Syndrome Association (NZDSA). It enquired about different aspects of life, including early intervention, health, education, employment, leisure activities, and services received. However, much of the data gathered through this endeavour had yet to be analysed and interpreted. The present author had the opportunity to partake in this process through the current dissertation.

***The Present Study and Its Potential Impact***

This dissertation is based on the study carried out by the Champion Centre and reports analyses of the experiences students with Down syndrome have of formal education in New Zealand from the perspective of their parents. It explores parents' satisfaction with their children's overall school experience. It also explores their views regarding their children's experience of specific aspects of it, namely elements of school they find particularly enjoyable, unpleasant, difficult, and easy. Finally, this dissertation explores parents' opinions on the specialist support their children receive whilst at school, namely their suggestions for the continued development of services whose goal is to support children with special needs, such as Down syndrome, during formal education.

The research that is being undertaken through this dissertation is hopefully beneficial for parents of children with Down syndrome, and for educators, educational researchers, and policy-makers in New Zealand. Parents are primarily responsible for choosing the type of school their children attend and many with a child with Down syndrome face this decision with considerable anxiety and uncertainty. The intense discussion and disagreement amongst educational researchers and others concerning the best educational placements for children with Down syndrome does little to relieve parents' angst. Other sources of concern for parents may include the quality and degree of classroom support provided and the stance taken by the school, teachers, other staff, and pupils towards their children. New Zealand educators, educational researchers, and policy-makers, who are concerned with improving the educational outcomes and consequently, the general quality of life of individuals with disabilities, can also benefit from this dissertation. There are widespread discrepancies between educational policy and its implementation in practice in New Zealand, which demand ongoing attention (MacArthur, Kelly & Higgins, 2005).

It is hoped that through this dissertation parents, educators, educational researchers, policy-makers, and other interested parties will gain greater insight into the experiences of primary and secondary students going to school in New Zealand. Although they experience many difficulties at school, this study contributes to a growing literature base, which shows that students with Down syndrome can learn and participate in education. However, the support they receive within this context and its relevance to their specific strengths and difficulties is a crucial contributing factor. It is hoped that this research will contribute to ongoing efforts to assist students with Down syndrome to attain the vision expressed in the New Zealand National Education Goals, for “all students to realise their full potential as individuals, and to develop the values needed to become full members” of society (New Zealand Ministry of Education, 2004).

### ***A Review of Down Syndrome and Its Effects***

Over the course of the past century, dramatic progress has been made in understanding Down syndrome and its effects on developmental progress and outcomes. This growth in understanding has contributed to significant improvements to the quality of life of individuals with this syndrome. The education of students with Down syndrome is one particular area in which considerable change has taken place in recent years, although much potential remains for continued improvement.

Down syndrome is one of the most common neurodevelopmental genetic disorders and the most common genetic cause of intellectual disability. It is caused by one of three potential aetiologies, whereby the presence of an extra chromosome detrimentally affects brain development (Davis, 2008). The most common aetiology, relevant to approximately 92% of cases, involves a process of non-disjunction at meiosis one and two. Specifically chromosomes 21 within the egg or sperm fail to divide before conception and an extra

chromosome is consequently carried into the cells of the embryo. As a result, all cells in the body have 47 chromosomes rather than the standard 46 (Rynders & Horrobin, 1996; Davis, 2008). Translocation is one relatively rare form of Down syndrome, occurring in approximately 3 to 4% of cases, whereby the extra chromosome connects to another chromosome. Another rare form of Down syndrome is mosaicism, relevant to approximately 2 to 4% of cases, whereby only some cells contain an extra chromosome (Rynders & Horrobin, 1996; Davis, 2008). The mosaic form of Down syndrome appears to be associated with more favourable outcomes than the other two, in terms of cognitive development and physical health specifically (New Zealand Ministry of Health, 2001).

Although appearing typical at birth, the brain affected by Down syndrome shows clear signs of microencephaly by adulthood. In particular, the hippocampus, prefrontal cortex, and cerebellum are smaller in size (Teipel, Alexander, Schapiro, Möller, Rapoport & Hampel, 2004). The harmful effects of the extra chromosome on the structure and function of the developing brain contributes to a number of salient features typically observed, albeit to different degrees, in individuals with Down syndrome. Most noticeable are physical anomalies such as dysmorphic facial features and growth retardation (Davis, 2008). Cognitive development is also compromised. An early longitudinal study by Carr (1988) reported that children with Down syndrome typically demonstrated declining IQ scores over time. Their mean ratio IQ decreased from 80 to 45 between six months and four years of age, from 45 to 37 between four years and 11 years of age, and slightly increased by 4.7 points between 11 years and 21 years of age (Carr, 1988).

### ***Challenging Common Assumptions and Expectations***

There exists a widely accepted Down syndrome stereotype, which holds that individuals with this condition are placid, humorous, happy, affectionate, and musical

(Wishart, 1998). In a recent Australian study, this stereotype was strongly endorsed by both experienced teachers and members of the community (Gilmore, Campbell & Cuskelly, 2003). The stereotype appears constructive, but is in effect both erroneous and harmful. It has no empirical basis, developing largely out of early clinical impressions of individual cases (Wishart, 1998). It suggests that individuals with Down syndrome are all the same, when in fact they show as much individual variation as any other group, due to biological influences as well as the influence of experience and learning on their development over time (Silverman, 2007). For example, although intellectual difficulties are common to children with Down syndrome, they demonstrate considerable variability in cognitive abilities. A recent study reported the cognitive abilities of a representative sample of children with Down syndrome when they were first assessed at approximately age nine. Nineteen percent of this sample achieved IQ scores between 50 and 70, 78% achieved scores between 20 and 50, and 3% achieved scores of 20 or below (Turner, Alborz & Gayle, 2008). Turner and colleagues (2008) viewed this spread in IQ scores as indicative of a wide range of intellectual disability, from moderate to severe to profound.

The Down syndrome stereotype also contributes to and reinforces the related belief that realistically, little should be expected from individuals with this condition (Wishart, 1998). Low expectations regarding the potential of individuals with Down syndrome are prevalent, accentuated by considerable uncertainty about the level of competence that should be expected from them over time (Turner & Alborz, 2003). Pessimistic views are even common amongst teachers, who play such a crucial role in fostering the learning and development of children with Down syndrome. Two separate studies, which explored the attitudes of trainee teachers, and experienced teachers and members of the community, reported a number of misconceptions regarding the nature of Down syndrome (Wishart & Manning, 1996; Gilmore et al., 2003). For example, participants in both studies typically

underestimated the average life expectancy of a person with Down syndrome to be 30 years or less, despite being approximately 50 years and above. In the earlier study by Wishart and Manning (1996), the majority of the trainee teachers were pessimistic about the potential for development of children with Down syndrome. For example, they underestimated the typical age at which developmental milestones are achieved as well as the academic potential of students with this syndrome (Wishart & Maning, 1996). The teachers and community members in the later study conveyed relatively accurate beliefs, which may reflect a growing awareness of the nature of Down syndrome and its effects on development (Gilmore et al., 2003).

Nevertheless, there is growing evidence to suggest that children with Down syndrome can achieve beyond what many believe possible. For example, in a British study carried out by Turner and Alborz (2003), levels of academic ability achieved by a representative sample of children with Down syndrome were investigated over their time at school. As already described, this sample ranged in cognitive abilities when first assessed, indicative of moderate to profound intellectual disability (Turner et al., 2008). By the time the children left school, 75% were reported to have achieved skills in reading, writing, and numeracy expected of a five year old. Approximately half of the sample achieved some skills in reading and numeracy expected of a seven year old. Finally, 25% were reported to have achieved skills in reading, writing, and numeracy expected of an 11 year old, and some skills in numeracy expected of a 14 year old (Turner & Alborz, 2003).

### ***An Emerging Profile and Its Implications for Learning***

Children with Down syndrome do vary significantly in the extent to which they are affected by their condition, and yet they share a unique profile of fundamental strengths and difficulties, which hold important implications for their ability to learn and participate

in an educational context (Fidler, 2005). One major difficulty most children with Down syndrome demonstrate is in language development. For example, Laws and Bishop (2003) reported that the language abilities of children with Down syndrome were significantly compromised in comparison to their non-verbal cognitive level. In their study, children with Down syndrome were more compromised in expressive language than in receptive language abilities, although both were a significant challenge relative to controls. Children with Down syndrome also demonstrated a relative difficulty in verbal processing (Davis, 2008). Jarrold, Baddeley, and Phillips (2002) reported that in comparison to controls, children with Down syndrome demonstrated a specific difficulty with verbal short-term memory. Some elements of motor development and hearing are also often affected by Down syndrome (Davis, 2008).

Children with Down syndrome also show a number of relative strengths. Some aspects of their visual-spatial processing ability appear to be unaffected by their condition (Fidler 2005; Davis, 2008). For example, Fidler, Most, and Guiberson (2005) reported that in comparison to children and adolescents with other developmental disabilities, children and adolescents with Down syndrome demonstrated better visual perceptual abilities and word identification skills. Children with Down syndrome also tend to demonstrate better social and behavioural functioning when compared to other children with developmental disabilities (Davis, 2008). Rosner, Hodapp, Fidler, Sagun, and Dykens (2004) compared the social competence of individuals aged four to 49 with Down syndrome, Prader-Willi syndrome or Williams' syndrome. Participants with Down syndrome performed significantly higher in social competence as measured by Achenbach's Child Behaviour Checklist (CBCL). Specifically, they related better to other people and were more likely to be actively involved in community groups (Rosner et al., 2004). The participants with Down syndrome were typically four to five years younger in age and 12 to 16 points lower



in IQ compared to the other two groups. Neither gender nor cognitive ability was reported to have an effect on the results, but higher social competence scores were reported with increasing age. Nevertheless, when compared to their typically developing peers, children with Down syndrome are typically more likely to demonstrate behavioural difficulties, such as non-compliance and stubbornness (Dykens, Shah, Sagun, Beck & King, 2002).

Personality is another important aspect of the behavioural phenotype associated with Down syndrome (Fidler, 2006). There have been many attempts to describe similarities in the personalities of individuals with Down syndrome, with most endorsing the positive stereotype previously described. However, there is very little empirical support for this stereotype. Moreover, research has often been flawed methodologically. Participants have typically been asked to list those personality characteristics they associate with individuals with Down syndrome. This approach only serves to confirm that the stereotype continues to flourish (Wishart, 2001). Children with Down syndrome have also been described in the literature as demonstrating a unique motivational style, demonstrating lower task persistence and higher off-task social behaviour specifically (Fidler, 2006). For example, Kasari and Freeman (2001) compared the task-related social behaviours of children with Down syndrome, children with mental retardation, and typically developing children matched according to cognitive abilities. They reported that when children with Down syndrome were asked to complete either a solvable or an unsolvable puzzle they looked to the experimenter more often and requested assistance more often. Additionally, they did not persist at tasks as long as children without Down syndrome, taking longer to finish the puzzles (Kasari & Freeman, 2001).

Attempts to clarify the nature of a behavioural phenotype associated with Down syndrome have met with disapproval. Many researchers are hesitant to group children with intellectual disabilities under any label as it reinforces the deficit model of disability.

According to this model, the child's difficulties are emphasised and intervention is targeted at remediation of the individual rather than the systems that surround them. It has legitimised segregating children with disabilities in separate special schools (O'Brien & Ryba, 2005). Although the deficit perspective is gradually losing credibility in favour of the social model of disability, both in New Zealand and further afield, it is also proving somewhat tenacious (Rietveld, 2005). As such, the concerns related to labelling children with Down syndrome are reasonable. Caution is needed in grouping children with Down syndrome together and in using labels such as "the Down syndrome profile". Children are unique, with their own strengths, difficulties, and educational needs.

Despite the uniqueness of each child with Down syndrome, it is undeniable that they also share common characteristics related to the effects of their condition on the structure and functioning of the brain. To ignore these common features would be detrimental to meeting their educational needs in particular (Wishart, 1998). Current efforts to understand the nature of Down syndrome and its effects provide the foundation from which to explore the experience children affected by it have of formal education in New Zealand. This is a beneficial route of enquiry because it highlights areas that need improvement, in assessment and intervention for example. However, to understand the experience children with Down syndrome have of school, attention must also be given to the context within which education occurs during those formative years and the extent to which it promotes or hinders learning and development.

### ***Going to School in New Zealand with Down Syndrome***

Currently, parents of children with Down syndrome are largely responsible for choosing the type of school their children attend. They can be enrolled at school from five years of age and it is compulsory between the ages of 6 and 16. Primary education begins

with Year 1 and continues to Year 8. Years 7 and 8 can be undertaken at a primary school or at an intermediate school. Secondary education begins with Year 9 and continues to Year 13. At each level of schooling, children with disabilities such as Down syndrome may be enrolled in a regular school, a regular school with a special unit, or a special school. For the latter option, a Section 9 Agreement is necessary, which is signed by the family, the special school, and also Special Education, a service provided by the New Zealand Ministry of Education (New Zealand Ministry of Education, 2009). In agreement with MacArthur and colleagues (2005), the terms *regular education* and *special education* are used in the present dissertation to differentiate between inclusive settings where children with disabilities are taught alongside their typically developing peers and those where they are taught separately.

Until the 1980's, parents did not have the present right to determine the type of school their child attended in New Zealand. There was no legislation on which to base the right of children with disabilities to access a free and equal education. Enrolment of such children in regular education was viewed as a privilege instead. Only children with less severe forms of disability were typically enrolled at regular schools, but were often restricted to special units within those schools. Children with moderate to profound disabilities, including Down syndrome, were typically placed in day units run by non-profit organisations such as Intellectually Handicapped Children (IHC) (O'Brien & Ryba, 2005).

Significant changes in educational legislation and policy in New Zealand in the 1980's were influenced by a local and global movement to modify the predominant conceptualisation of disability. Whereas emphasis was historically placed on the individual and their "deficits", the limitations inherent in policy and practice came under increasing pressure for reform (O'Brien & Ryba, 2005). The social model of disability grew in

popularity, with its emphasis on the barriers within society that limit individuals with disabilities. The social perspective underpins the current vision of New Zealand as an inclusive society that values difference and diversity, as reflected in the amended Education Act 1989 (Rietveld, 2005). According to the Education Act 1989, all people with special education needs, such as Down syndrome, are “entitled to enrol at and receive education at state schools as people who [do] not” have such needs (New Zealand Government, 2008). This legislation was significant because it gave parents the right to choose the context within which their children with disabilities were educated (O’Brien & Ryba, 2005).

Since the change in legislation, developments in educational policy in New Zealand have endorsed the principles and values of the Education Act 1989 and there has been a strong movement towards embracing an inclusive education system. The research literature reflects a wide range of definitions for the term *inclusion*, from where the student is simply placed within a regular school to where they are provided with increasing opportunities for participation within it, alongside lessening exclusionary experiences (MacArthur et al., 2005). Rietveld (2008) differentiated between *ineffective* or *illusory* inclusion and *facilitative* inclusion, in which every student is considered a valued, integral member of the classroom and wider school community.

Children with disabilities such as Down syndrome continue to face many obstacles in accessing appropriate learning opportunities, whilst fully participating alongside their typically developing peers at school (MacArthur et al., 2005). Currently, the special education policy framework, *Special Education 2000*, provides the basis on which inclusion in regular education settings should be commonplace for most students with special education needs that range from moderate to very high (MacArthur, Kelly & Higgins, 2005). The large majority of children with Down syndrome fall under the

Ongoing and Reviewable Resourcing Scheme (ORRS) component for students with moderate needs (O'Brien & Ryba, 2005). Under this scheme, most children with Down syndrome should be able to receive funding for extra support at school such as specialist teaching or programmes, based on an assessment of their level of educational and personal support needs. However, the transformation of policy into practice continues to face many challenges today (MacArthur et al., 2005). For example, the discrepancy between policy and practice was highlighted in a recent New Zealand study, which compared the experiences of two typically developing children and two children with Down syndrome in the transition from a regular preschool to primary school. There were many inconsistencies reported across schools, in the extent to which inclusive philosophies were adopted and implemented, irrespective of whether the child had Down syndrome or not (Rietveld, 2008).

Although there is a strong drive towards an inclusive education system in New Zealand, it is as yet unclear whether regular education is indeed superior to special education in terms of educational outcomes. On one hand, there is some evidence to suggest the superiority of regular education. For example, Laws, Byrne, and Buckley (2000) compared the outcomes of students with Down syndrome who attended regular or special schools in England based on the approach taken by the county they lived in. One favoured regular education and the other favoured special education. The students were matched according to age where possible. Students in regular education were reported to perform significantly better on verbal measures of language and memory development. No differences were reported in non-verbal abilities (Laws et al., 2000). In another study, Buckley, Bird, Sacks, and Archer (2006) compared the outcomes of adolescents who were educated in a regular or special education setting based on where they lived. The students were presumed to have been functioning at similar levels when they started school, although no specific

measures were taken by the authors to clarify this. The greatest benefits associated with inclusion in a regular education context were reported in expressive language and literacy, which preceded gains in numeracy and general academic accomplishments. Advantages were also reported in aspects of social development, because those adolescents were more socially mature, confident, and appropriate in their behaviour with others than their counterparts in special education were. Conversely, no social inclusion gains were reported to be associated with regular education, such as better social skills or greater involvement in the community. Moreover, students educated in this context were less likely in their later teens to have close friends, a boyfriend or girlfriend, or their own, independent social life. This was the only area in which teenagers educated in a special education context were reported to be more advantaged (Buckley et al., 2006).

Research that reports the superiority of regular education over and above special education has been criticised on a number of accounts. Some authors have concluded that a review of current research yields no “clear endorsement for the positive effects of inclusion” (Lindsay, 2007, p. 16). Only a minority of studies have focussed on the effectiveness of regular as opposed to special education and although benefits have been reported, they have typically been modest (Lindsay, 2007; Turner, Alborz & Gayle, 2008). Moreover, research in this area has been plagued with methodological difficulties and limitations (Lindsay, 2007). For example, as shown by the study carried out by Buckley and colleagues (2006), the level at which students are functioning is often not assessed formally before they begin school, which may exaggerate the benefits associated with inclusion. Rather than focussing on the specific setting within which education occurs, more attention may need to be given to the processes that occur within it instead (Lindsay, 2007).

In order for students with Down syndrome to develop in their learning whilst being educated in regular education, the process of inclusion, through which participation increases and exclusion decreases, is important, but insufficient. The extent to which the head teacher, along with other educators, is knowledgeable about the student's unique educational needs and tailors the support provided accordingly is a key contributing factor in their progress (Starr, Foy, Cramer & Singh, 2008). That teachers are often poorly prepared in this regard is an area of concern for both parents and educators alike (Wolpert, 2001; Starr et al., 2008). A recent New Zealand study reported a number of barriers to effective learning for students with Down syndrome, which included the teacher failing to consider the child's individual learning style and their unique strengths and abilities (Rietveld, 2005). For example, in teaching mathematics to new entrants with Down syndrome, teachers consistently did not provide the children with scaffolding that was relevant to their level of understanding, tending to provide non-specific feedback or merely repeat their original instructions (Rietveld, 2005). There are ongoing efforts to clarify more specific teaching methods and strategies that build on the relative strengths of children with Down syndrome, in areas such as numeracy and reading (Hodapp & Freeman, 2003; Buckley, 2007).

The conflicting views teachers often hold regarding the inclusion of children with Down syndrome in their classrooms may reflect an awareness of their own insufficient training or the lack of specialised support and resources available to them (Fox, Farrell & Davis, 2004). For example, in one Australian study experienced teachers recognised there were social, educational, and emotional advantages to including students with Down syndrome, for the child and their classmates. However, they did not necessarily believe that the needs of these children were best met in a regular setting. They were just as likely to consider education in a segregated context, such as a special school, to be most

appropriate (Gilmore et al., 2003). In the New Zealand context, teachers in regular education are often expected to teach children with disabilities such as Down syndrome, but are unlikely to have specialised training in this area. Indeed this disparity was highlighted by one of the teachers in a New Zealand study, who stated, “We’re not trained to teach this type of child” (Rietveld, 2005, p. 135). Moreover, the teacher aides who typically provide additional learning support to children with Down syndrome in New Zealand often do not have specialised training either (Rietveld, 2005).

### ***Parents Perspectives on their Children’s Education***

Although not specific to the New Zealand context, the research suggests that parents of students with Down syndrome consider full-time placement in a regular education classroom to be the best context within which their children’s educational needs will be met. When Kasari, Freeman, Bauminger, and Alkin (1999) compared the opinions of parents of children with Down syndrome to those of parents of children with autism, the former were more likely to choose a regular education classroom with extra, specialised support as their preferred choice of educational placement. They were noticeably less likely to choose special education as an option, even if their children were to spend some time in a regular classroom. An analysis of qualitative comments made suggested that most parents maintained this preference because they felt it was “the right thing to do” (Kasari et al., 1999). The trend in preference for an inclusive educational placement was particularly relevant to the parents of younger children. Whereas the parents of older children also tended to prefer education in a regular classroom, they were more willing to consider the alternative of special education with some time spent in a regular education context. The preference for inclusion was also more relevant to the parents of children



currently in regular education, rather than those with children in early intervention or special education (Kasari et al., 1999).

Currently, there are no New Zealand figures related to the numbers of students with Down syndrome educated in either a regular or special education context. Nevertheless, international developments hint at trends relevant to this country. Cunningham, Glenn, Lorenz, and Shepperdson (1998) have provided the most recent review of trends in educational placements for children with Down syndrome, which are specific to the United Kingdom. From this review, they estimated that roughly 70 to 80% of students with Down syndrome start school in regular education and that approximately 35 to 40% finish primary school in this context. Twenty to 25% of students with Down syndrome were estimated to complete secondary school in regular education (Cunningham et al., 1998).

Understanding the views of parents of children with Down syndrome regarding their children's experience of formal education is critical, because they know them most intimately and tend to be their best advocates (Starr et al., 2008). In general, parents are reasonably satisfied with their children's education and are as satisfied as parents of other children with disabilities are (Laws & Millward, 2001; Starr et al., 2008). Moreover, there are no apparent differences in satisfaction between primary and secondary school or regular and special schools (Laws & Millward, 2001). It appears that the educational placement itself is less of a concern compared to what actually takes place within it (Starr et al., 2008).

Parents of children with Down syndrome appear to be particularly knowledgeable about their children's condition and its effects when compared to other parents of children with disabilities. Fidler, Hodapp, and Dykens (2002) compared the perspectives of parents of children with Down syndrome, Williams' syndrome and Prader-Willi syndrome, and found the former to be most informed about their children's condition. For example, they

were generally able to identify well-established behavioural strengths and difficulties, particularly those that tend to be more salient such as relative difficulties in expressive language, whereas the other parents were not (Fidler et al., 2002). In another study, parents of children with Down syndrome and parents of children with other disabilities were aware of their children's need for particular, syndrome-related assistance in the educational context. For example, when asked what changes they would make to their child's current educational programme, parents of children with Down syndrome were more likely to suggest improvements to speech and language therapy services and tuition in reading. Many parents also requested more teacher aide support, although to a lesser degree than did other parents of children with disabilities (Fidler, Lawson & Hodapp, 2003).

### ***Conclusions***

The progress made in understanding Down syndrome and its effect on learning holds great promise for parents, educators, and schools responsible for the educational needs of students with this condition. Nevertheless, there remain many uncertainties, which require further clarification. The goal of the current study is to contribute to this process, by exploring the experience of students with Down syndrome of formal education in New Zealand as perceived by their parents. Firstly, the present analysis will explore parents' satisfaction with their children's overall experience of school. It will also explore parents' perspectives regarding various aspects of that experience, namely those aspects they consider their children find most enjoyable, least enjoyable, most difficult, and easiest. Finally, this study will explore parents' opinions regarding the specialist support their children with Down syndrome receive that promote learning and participation in education, namely their suggestions for the continued development of such services.

## Method

This Method section presents the design of the present analysis, conducted on data obtained through the study carried out by the Champion Centre. The first part of this section describes the research conducted by the Champion Centre and its director, who sought to illuminate the unique life experiences and outcomes of individuals with Down syndrome in New Zealand. In order to achieve this goal, a questionnaire was designed, developed, and sent to members of the NZDSA. Through this process, a wealth of information was gathered. However, much of the raw data remained to be analysed and interpreted. In the second part of this Method section, the present analysis is described, which was carried out by the current author. This analysis was a continuation of the research begun by the Champion Centre and focussed specifically on analysing and interpreting information gathered, which related to the experience of students with Down syndrome of formal education.

### *The Context: Research by the Champion Centre*

#### *Sampling procedure, participants, and response rate.*

The study carried out by the Champion Centre used a register of all the members of the NZDSA and their postal addresses to compile a list of potential participants. Members of the NZDSA included family members, friends, and individuals over 18 years of age who wanted to join this association to access the support and services it provided. They paid an annual thirty-dollar fee for this membership. All members of the NZDSA, which numbered 473 at the time, were mailed a study packet. By the closing date, 181 eligible study packets were returned, which represented 38.3% of the total sample of potential participants. The participant who completed the questionnaire had been asked at the beginning of it to specify their relationship to a person with Down syndrome. Of all 181

participants, all but one specified that they were a parent of a child, adolescent, or adult with Down syndrome. The remaining participant specified that they were a guardian. For the purposes of this dissertation the term *parents* will be used, where relevant, to refer to the entire sample, including the single participant who was a guardian. Additionally, the term *children* will be used to refer to the offspring of participants, including those who were adults aged eighteen years and older. Thus, the larger sample on which the present analysis is based included 181 parents of children with Down syndrome who were members of the NZDSA.

***Study questionnaire: Design and description.***

The questionnaire used in this study was developed by the Champion Centre and its director who, through it, sought to understand long-term outcomes for individuals with Down syndrome in New Zealand. In order to develop the questionnaire and its items previous studies related to Down syndrome were reviewed. From this literature review, a number of general themes and relevant areas became apparent, from which specific questions were constructed. A concerted effort was made to construct questions that provided factual information, but that were also constructive in this endeavour.

Following its initial design, the questionnaire was assessed to ascertain face validity. Those involved in this process were a university professor who had experience in questionnaire research, a parent of a child with Down syndrome who was also a research analyst for Statistics New Zealand, the executive of the NZDSA, and clinical staff from the Champion Centre. Through this process, a number of suggestions were made to improve the readability of the questionnaire, which were then implemented. The questionnaire was then piloted on a group of six parents who were currently or previously involved in a programme run by the Champion Centre for children with Down syndrome. Those parents

were specifically asked to be involved due to their proven honesty and frankness. One further modification was suggested by these parents and subsequently made to the questionnaire. Finally, an application for a review of the questionnaire and its methodology was made to the University of Canterbury Human Ethics Committee, which was approved. A copy of this letter of approval can be found in Appendix A.

The questionnaire consisted of seven main questions areas, with one or more questions within each section. The sections covered a range of different aspects of life, including early intervention, health, education, employment, leisure activities, and services received. The questions were designed either as yes or as no questions, likert scales from 1 to 7, or as open-ended questions. Additionally, throughout the questionnaire, participants were given the opportunity to expand on their responses. A copy of the entire questionnaire can be found in Appendix C.

### ***Data collection.***

The National Executive Officer of the NZDSA mailed the potential participants a study packet containing a cover letter (Appendix B), the questionnaire (Appendix C), an entry form for a prize draw, and a self-addressed, stamped envelope. The cover letter (a) described the study and its benefits for children with Down syndrome in New Zealand, (b) clearly stated that participation was voluntary and that responses would be anonymous, (c) outlined what participation would involve, and (d) requested that the recipients participate in the study. The cover letter also invited recipients to take part in a follow-up project by completing and returning an attached personal contact form, which clearly repeated that responses would be anonymous. Finally, the cover letter expressed appreciation to the recipients. The entry form for the prize draw described the compensation for participation,

consisting of three free annual memberships to the NZDSA that would be included in a prize draw.

Although no specific deadline was explicitly stipulated for the questionnaire, a date was set for the prize draw, which served as the closing date. A week after the closing date a reminder was sent by the NZDSA via their emailing system to encourage further returns. Three further completed study packets were returned but were not included in the final sample. However, they were retained as contacts for a future follow-up study.

### *The Current Analysis by the Present Author*

#### *Sampling procedure, participants, and response rate.*

The present analysis only included those participants who had a child with Down syndrome who was currently or previously in formal education in New Zealand. In light of this, all participants who identified that their children currently or previously attended primary, intermediate, or secondary school were included. One hundred and thirty-seven participants (75.7% of the larger sample) met this criterion. Of those participants excluded from the present analysis, 43 had a child who had not yet started formal education and one participant had provided inadequate responses from which to determine this information.

Of the final sample of 137 participants included in the present analysis, all identified themselves as a parent except one, who identified themselves as a guardian. The length of membership to a Down syndrome support group or association was specified by 133 participants (97.1% of the current sample) and ranged from 3 months to 48 years ( $M=13.1$ ;  $SD=7.4$ ). Although participants were not directly asked to state their child's gender, it was possible to ascertain this information from the qualitative comments made by 128 (93.4%). Participants who had a son with Down syndrome numbered 78 (56.9%) and those with a daughter numbered 50 (36.5%). The age of the children ranged

substantially, from five to 50 years old ( $M=15.28$ ;  $SD=8.63$ ). Children who currently attended school numbered 106 (77.4%) and ranged in age from five to 21 years ( $M=11.7$ ;  $SD=4.7$ ). Children who had already left school numbered 31 (22.6%) and ranged in age from 19 to 50 years ( $M=27.4$ ;  $SD=7.9$ ).

***Study questionnaire: Description.***

The present analysis only focused on responses to questions withdrawn from the first, fourth, and seventh question areas of the questionnaire, because these questions were considered relevant to understanding parents' views of their children's experience of formal education specifically. Other sections of the questionnaire will be included in future analyses.

In the first question area, participants were asked to provide demographic information. They were first asked to identify the age of their child and then their relationship to their child, namely whether they were a parent or a guardian. Finally, they were asked to identify the length of their membership to a Down syndrome support group or association.

In the fourth question area, participants were asked to provide information related to their child's education. Firstly, they were asked to identify the type of school their child had ever been enrolled in, whether (a) home-school, (b) full mainstream, (c) partial mainstream, or (d) special school or unit. Then they were asked to rate on a scale of 1 (*not satisfied*) to 7 (*very satisfied*) how satisfied they were with their child's past or present experience of primary, intermediate, or secondary school. Thirdly, participants were asked what aspect or aspects of school their child found most enjoyable, least enjoyable, most difficult, and easiest. They were provided with a number of examples, namely "educational, social, friendship building, hobbies, sporting etc". They were also asked to

be specific. Fourthly, participants were asked whether their child received any qualifications, prizes, other awards, or honours while at school. Responses to this particular question were not included in the present analysis because they were not considered to be relevant to it. Finally, participants were asked whether their child had left formal education and, if so, at what age.

In the seventh question area, participants were asked questions related to New Zealand services for individuals with Down syndrome. Firstly, they were asked to describe any specialist help their child currently received such as “speech therapy, specialised skills training or teacher aide support”. Secondly, they were asked to rate on a scale of 1 (*dissatisfied*) to 7 (*satisfied*), how satisfied they were with the level of support they had received from public services such as “medical services, employment support or housing”. They were also provided with an opportunity to elaborate on their responses. Responses to this second question and any related elaborations were not included in the present analysis, as it was not possible to determine if the ratings corresponded to services relevant to formal education specifically or not. Thirdly, participants were asked what improvements to services they would like to see in for their child. Finally, they were asked what additional services they would like to see available for their child. Responses to this final question were not included in the present analysis because they appeared to be primarily repetitions of suggestions made for improvements to services that already existed.

#### ***Data preparation for analysis.***

In order to prepare the data for the present analysis, responses to the relevant questions previously described were used to cluster the participants into comparable groups. In the first stage of this process, participants were grouped according to the age of



their child in years, namely (a) 5 to 9.9, (b) 10 to 14.9, (c) 15 to 19.9, (d) 20 to 24.9, and (e) 25 and older.

Participants were then grouped according to whether their child was currently in (a) primary school, (b) intermediate school, (c) secondary school, or whether (d) they had already left formal education. It was possible to determine this information from the participants' ratings of satisfaction with primary, intermediate, or high school, combined with their response to the request to identify whether their children had or had not left formal education.

Then participants were grouped according to the type of educational placement their child attended, at the level of primary, intermediate, or secondary school. They had been asked to list the type of school their child had ever been enrolled in, whether home school, full mainstream, partial mainstream, or special unit or special school. The majority of the participants made additional qualitative comments, identifying which type of educational placement corresponded to their child's current and/or previous level of schooling. However, from a review of the responses provided and qualitative comments made it became apparent that there was inconsistency in the participants' conceptualizations of these four terms.

Due to evident inconsistencies in participants' conceptualizations of types of educational placements, responses were grouped into three broad categories. These categories related to education that took place primarily within a (a) regular education context (RE), (b) special education context (SE), or (c) home-school context (HS). Responses included in the *RE* category were "full mainstream" and "partial mainstream". From the responses provided and qualitative comments made it appeared that participants considered education in a regular classroom with teacher aide support to be either *full mainstream* or *partial mainstream*. Responses included in the *SE* category were "special

school or special unit”, “special school and partial mainstream”, and “special unit and partial mainstream”. From the responses provided and qualitative comments made it appeared that participants considered *special school and partial mainstream* and *special unit and partial mainstream* to refer to children who were primarily educated in a special education context but also spent some time in a regular education setting. Responses included in the HS category were “home-school” and qualitative mention of “correspondence school”.

In addition to clustering participants into comparable groups, the responses that they provided to open-ended questions were also categorized in preparation for data analysis. To begin with, responses to the question of what specialist support services the child currently received were grouped into the following categories: (a) Teacher aide, (b) specialist teacher, (c) speech and language therapist, (d) physiotherapist, (e) occupational therapist, (f) other education-related support (e.g. music, art, or sport therapists), (g) medical support, or 8) nothing, if no services were currently received. These categories were discussed with a psychologist working for a government agency in the special education sector. Through this discussion all of the categories but *medical* were determined to refer to services that directly support children with Down syndrome to learn and participate in formal education. Therefore, only those responses that referred to one or more of the seven remaining specialist services were included in the present analysis.

The responses to the question of the improvements needed to services currently offered to individuals in New Zealand were then reviewed and grouped according to conceptual similarities. Once again, only those responses that referred to services that helped children to learn and participate in formal education were included in this categorization process. The initial categories were also discussed with a psychologist currently working for a government agency in the special education sector. Through this

discussion, a number of suggestions were made regarding potential improvements to the validity of these categories. These suggestions were ratified, leading to the final categories. The first category included suggestions for improvements to the allocation and distribution of government funds for children with Down syndrome within the special education sector. The second category included references to the provision of either (a) speech and language therapist support, (b) teacher aide support, or (c) non-specified support. The third category included reference to professional development for teachers, teacher aides or specialist teachers. The final category included other relevant suggestions, which could not be classified according to the previous categories.

In the final stage of data preparation, participants' responses to the four questions related to their children's experience of formal education were coded. These questions enquired about those aspects of school their child found most enjoyable, least enjoyable, most difficult, and easiest. To begin with, the responses provided for each of the four questions were reviewed and then grouped into conceptually similar categories. The present author and the principal supervisor for the dissertation then met on three separate occasions to discuss the validity of these initial categories, and through this process, they were modified and refined. A discussion was then held between the present author and the second supervisor, the director of the Champion Centre, through which the latter suggested further improvements, primarily of a semantic nature. These suggested improvements were endorsed in a subsequent discussion between the present author and the principal supervisor and final alterations were made to the categories.

The categories considered to encapsulate the participants' responses to the questions of the most enjoyable, least enjoyable, most difficult, and easiest aspects of school for their children were (a) education, (b) personal and learning development, (c) social, (d) communication with others, and (e) other. The category of *education* included

responses that referred to learning in general or to more specific academic or non-academic subjects or activities. Within this category, the following subcategories were developed: (a) Numeracy (e.g., mathematics), (b) literacy (e.g., reading), (c) the arts (e.g., drama), (d) sport and other organised activities (e.g., swimming), and (e) other (e.g., woodwork). The category of *personal and learning development* included responses that referred to characteristics of the child or their learning environment that affected their ability to learn and participate in formal education. The *social* category included responses related to the child's social development, such as learning how to relate to others, and their experience of social interactions with others, such as the extent to which other children befriended them. The *other* category included relevant responses that did not fit within the other categories.

### ***Data analysis.***

Prior to categorizing the participants' responses to each of the four questions previously described, inter-coder reliability was calculated for the predetermined categories within each. In the first stage of this process, the present author and the principal supervisor for the dissertation individually coded the responses of 20 randomly selected participants according to the predetermined categories. Using percent agreement, the results were then compared, between the present author and the principal supervisor. The inter-coder reliabilities yielded through this process were high and of an acceptable level. For the coding of responses to the question of what the children found most enjoyable about school, inter-coder reliability was 0.94. Inter-coder reliability was 0.94 for the coding of responses to the question of what the children found least enjoyable about school. Inter-coder reliability was 0.96 for the coding of responses to what the children found most difficult about school. For the coding of responses to the question of what the

children found easiest about school inter-coder reliability was 0.99. In light of acceptable levels of inter-coder reliability, the predetermined categories were retained and the participants' responses to each of the four questions were coded in preparation for the present analysis.

In order to determine if there were significant associations between the gender, age, current level of school, or type of educational placement of participants children and observed variables, a series of chi-square analyses were then computed, the results of which are described within the Results section. An alpha level of .05 was used for all statistical tests. Significant and non-significant associations are presented in tabular form rather than in the text for the purposes of readability where appropriate.

## **Results**

### ***Trends in Educational Placements***

Of the final sample of 137 participants, 106 (77.4%) had a child who was currently in formal education and 31 (22.6%) had a child who had already left formal education. Children currently in formal education included 57 (53.8%) in primary school, 11 (10.4%) in intermediate school, and 38 (35.9%) in secondary school. Additionally, it was possible to determine the type of educational placement of the majority of children currently in formal education (90.6%). Sixty-two children were currently educated in a regular education classroom (57.4%), 28 were educated in a special education classroom (26.4%), and six children were home-schooled (5.7%). It was not possible to ascertain the current type of educational placement of the remaining children (9.4%), because their parents had not provided this information.

The different educational placements of those children currently in formal education, at the levels of primary, intermediate, or secondary school are shown in Table

1. Of those children currently in primary school, it was possible to determine the type of educational placement of all but one (98.2%). It was possible to determine the type of educational placement of all but two children currently in intermediate school (72.7%). Finally, it was possible to determine the type of educational placement of 81.6% of children currently in secondary school.

Table 1

*Proportion of Students Currently at School Expressed as Percentage (n=106) Enrolled in Different Educational Placements at Each Level of School*

Educational placement	Level of school		
	Primary (n=57)	Intermediate (n=11)	Secondary (n=38)
Regular education	75.4 (43)	63.6 (7)	31.6 (12)
Special education	14 (8)	18.2 (2)	47.4 (18)
Home school	8.8 (5)	0 (0)	2.6 (1)
Unclear	1.8 (1)	18.2 (2)	18.4 (7)

As shown in Table 1, there was a notable difference in the proportion of children attending regular primary schools compared to regular secondary schools. However, from Table 2, which depicts the history of educational placements for children currently in secondary school only, it is evident that children typically transferred from regular education into a special education setting, as they grew older. Whereas at least 71.1% of children currently in secondary school had attended a regular primary school, only 31.6% remained in this setting for their secondary education.

Table 2

*Proportion of Students Currently at Secondary School Expressed as Percentage (n=38)  
Enrolled in Different Educational Placements over Time*

Educational placement	Level of school	
	Primary (n=38)	Secondary (n=38)
Regular education	71.1 (27)	31.6 (12)
Special education	10.5 (4)	47.4 (18)
Home school	0 (0)	2.6 (1)
Unclear	18.4 (7)	18.4 (7)

### ***Satisfaction with Overall School Experience***

Of those participants with a child currently at school, all but three were included in analyses of the level of satisfaction of parents with their child's experience of school (97.2 %). The remaining participants were excluded because they provided a range of ratings rather than one. The large majority of participants retained in this analysis indicated that they were satisfied with their child's current experience of school. Specifically, of those participants with a child currently at school, 76 (71.7%) indicated they were satisfied (circled either numbers 5, 6 or 7 on a scale ranging from 1 to 7), 17 (16%) indicated they were neutral (circled number 4), and 10 (9.4%) indicated they were dissatisfied (circled either numbers 1, 2 or 3). A chi-square analysis demonstrated that observed frequencies were significantly different from what would be expected,  $\chi^2(2, N = 103) = 76.56, p < .05$ . To determine if there was an association between the gender, age, current level of school, or type of educational placement of participants' children and their ratings of satisfaction, a series of chi-square analyses were computed. As shown in Table 3, these analyses yielded no significant associations at an alpha level of .05.

Table 3

*Proportion of Participants with a Child Currently at School Expressed as Percentage (n=106) Satisfied, Neutral or Dissatisfied with their School Experience According to Different Categorical Variables*

Level of satisfaction	Gender				Chi <sup>2</sup>	p value
	Male (n=60)		Female (n=39)			
Satisfied	66.7 (40)		82.1 (32)		2.09	.15
Neutral	20 (12)		10.3 (4)		1.84	.18
Dissatisfied	10 (6)		7.7 (3)		-	
Age group (in years)						
	5.0-9.9	10.0-14.9	15.0-19.9	20.0-24.9		
	(n=42)	(n=29)	(n=28)	(n=7)		
Satisfied	85.7 (36)	72.4 (21)	60.7 (17)	28.6 (2)	-	
Neutral	9.5 (4)	20.7 (6)	17.9 (5)	28.6 (2)	-	
Dissatisfied	4.8 (2)	6.9 (2)	14.3 (4)	28.6 (2)	-	
Level of school						
	Primary (n=57)	Intermediate	Secondary			
		(n=11)	(n=38)			
Satisfied	80.7 (46)	81.8 (9)	55.3 (21)	-		
Neutral	14 (8)	9.1 (1)	21.1 (8)	-		
Dissatisfied	5.3 (3)	9.1 (1)	15.8 (6)	-		
Educational placement						
	Regular education (n=62)	Special education (n=28)				
Satisfied	75.8 (47)	64.3 (18)	0.41	.52		
Neutral	17.7 (11)	17.9 (5)	-			
Dissatisfied	6.5 (4)	10.7 (3)	-			

- Chi-square analysis not appropriate due to small cell sizes

The change in parents' satisfaction with their children's experience of school over time was analysed by comparing the level of satisfaction they indicated for secondary



school to that indicated for primary school. It was possible to determine the change in satisfaction over time of 35 of the 38 participants with a child currently in secondary school (92.1%). As shown in Table 4, most parents indicated a decreasing level of satisfaction, followed by those who indicated an increasing level of satisfaction, and finally, those who indicated no change in satisfaction over time. It was not possible to determine the change in satisfaction over time of three parents (7.9%) due to missing or unclear data related to their satisfaction with their children's primary or secondary school experience. A chi-square analysis demonstrated that observed frequencies were not significantly different from what would be expected,  $\chi^2(2, N = 35) = 4.34, p = .11$  (see Table 4).

Table 4

*Proportion of Participants with a Child Currently at Secondary School Expressed as Percentage (n=38) More, Equally or Less Satisfied with their School Experience over Time*

Change in satisfaction			Chi <sup>2</sup>	p value
Increase	No change	Decrease		
28.9 (11)	18.4 (7)	44.7 (17)	4.34	.11

### ***Perceptions of Children's Experience of School***

The next stage of data analysis concerned participants' responses to questions related to the most enjoyable, least enjoyable, most difficult, and easiest aspects of school for their children, which were categorised as previously described. To determine if there was an association between the gender, age, current level of school, or type of educational placement of participants' children and these observed variables, a series of chi-square analyses were carried out. Analyses yielded a number of significant associations at an alpha level of .05. The participants of children who were currently home-schooled were

excluded from any further analyses of the association between type of educational placement and categorical variables due to small cell sizes.

In relation to the most enjoyable aspects of school, all but three participants in the current sample provided a valid response (97.8%). Participants cited social aspects (72.3% of the current sample), followed by education and its components (67.2%), personal and learning development (27.7%), and other aspects (5.1%). In terms of the social category, the specific subcategories most often cited were friendship (33.6% of the current sample) and interactions with other children (24.8%). In terms of the education category, the specific subcategories most often cited were sport and other organised activities (40.9% of the current sample), the arts (32.1%), and literacy (19.7%). Analyses did not yield any significant associations, which are shown in Table 5.

Table 5

*Proportion of Participants Expressed as Percentage (N=137) who Cited Various Aspects of School Most Enjoyable for their Children According to Different Categorical Variables*

Aspect	Gender		Chi <sup>2</sup>	p value
	Male (n=78)	Female (n=50)		
Social	75.6 (59)	68 (34)	1.06	.30
Education	73.1 (57)	60 (30)	2.67	.10
Personal and learning development	29.5 (23)	26 (13)	0.20	.65
Other	6.4 (5)	4 (2)	-	

- Chi-square analysis not appropriate due to small cell sizes

Table 5 (continued)

*Proportion of Participants Expressed as Percentage (N=137) who Cited Various Aspects of School Most Enjoyable for their Children According to Different Categorical Variables*

Aspect	Age group (in years)					Chi <sup>2</sup>	p value
	5.0-9.9 (n=42)	10.0-14.9 (n=29)	15.0-19.9 (n=29)	20.0-24.9 (n=20)	25.0+ (n=17)		
Social	73.8 (31)	79.3 (23)	65.5 (19)	75 (15)	64.7 (11)	-	
Education	69 (29)	75.9 (22)	69 (20)	65 (13)	47.1 (8)	-	
Personal and learning development	28.6 (12)	34.5 (10)	13.8 (4)	35 (7)	29.4 (5)	-	
Other	9.5 (4)	3.4 (1)	6.9 (2)	0 (0)	0 (0)	-	
	Level of school						
	Primary (n=57)	Intermediate (n=11)	Secondary (n=38)	Left school (n=31)			
Social	77.2 (44)	72.7 (8)	60.5 (23)	77.4 (24)	-		
Education	70.2 (40)	90.9 (10)	68.4 (26)	51.6 (16)	-		
Personal and learning development	33.3 (19)	18.2 (2)	23.7 (9)	25.8 (8)	-		
Other	7 (4)	0 (0)	7.9 (3)	0 (0)	-		
	Educational placement						
	Regular education (n=62)						
Social	74.2 (46)			71.4 (20)	0.16	.69	
Education	66.1 (41)			85.7 (24)	3.34	.07	
Personal and learning development	27.4 (17)			35.7 (10)	0.56	.46	
Other	4.8 (3)			10.7 (3)	-		

- Chi-square analysis not appropriate due to small cell sizes

In response to the question of the least enjoyable aspects of school, 86.1% of the participants provided a valid response. The categories cited by participants in relation to least enjoyable aspects of school were personal and learning development (46% of the current sample), education (42.3%), social (15.3%), and other (7.3%). As shown in Table 6, participants with a child aged five to nine years of age were significantly more likely to cite personal and learning development as one of their child's least enjoyable aspects of school than those with an older child were, as were those with a child currently in regular as opposed to special education. Additionally, participants with daughters were significantly more likely to cite education as one of the least enjoyable aspects of school than those with sons were.

Table 6

*Proportion of Participants Expressed as Percentage (N=137) who Cited Various Aspects of School Least Enjoyable for their Children According to Different Categorical Variables*

Aspect	Gender		Chi <sup>2</sup>	p value
	Male (n=78)	Female (n=50)		
Personal and learning development	46.2 (36)	46 (23)	0.42	.52
Education	32.1 (25)	54 (27)	4.14	.04*
Social	16.7 (13)	14 (7)	0.47	.49
Other	5.1 (4)	12 (6)	-	

- Chi-square analysis not appropriate due to small cell sizes

\*  $p < .05$

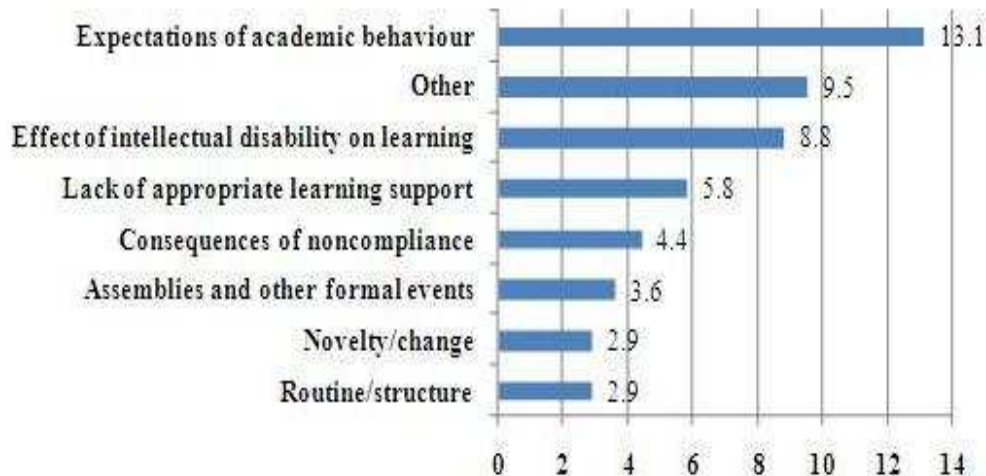
Table 6 (continued)

*Proportion of Participants Expressed as Percentage (N=137) who Cited Various Aspects of School Least Enjoyable for their Children According to Different Categorical Variables*

Aspect	Age group (in years)					Chi <sup>2</sup>	<i>p</i> value
	5.0-9.9	10.0-	15.0-19.9	20.0-24.9	25.0+		
	( <i>n</i> =42)	14.9 ( <i>n</i> =29)	( <i>n</i> =29)	( <i>n</i> =20)	( <i>n</i> =17)		
Personal and learning development	69 (29)	51.7 (15)	27.6 (8)	25 (5)	29.4 (5)	15.92	.00*
Education	28.6 (12)	51.7 (15)	48.3 (14)	55 (11)	35.3 (6)	8.00	.09
Social	9.5 (4)	13.8 (4)	17.2 (5)	25 (5)	17.6 (3)	-	
Other	14.3 (6)	0 (0)	6.9 (2)	5 (1)	5.9 (1)	-	
	Level of school						
	Primary	Intermediate	Secondary	Left school			
	( <i>n</i> =57)	( <i>n</i> =11)	( <i>n</i> =38)	( <i>n</i> =31)			
Personal and learning development	63.2 (36)	63.6 (7)	23.7 (9)	32.3 (10)	-		
Education	36.8 (21)	45.5 (5)	52.6 (20)	38.7 (12)	-		
Social	10.5 (6)	18.2 (2)	15.8 (6)	22.6 (7)	-		
Other	10.5 (6)	0 (0)	5.3 (2)	6.5 (2)	-		
	Educational placement						
	Regular education ( <i>n</i> =62)		Special education ( <i>n</i> =28)				
Personal and learning development	59.7 (37)		25 (7)		4.65	.03*	
Education	41.9 (26)		42.9 (12)		1.52	.22	
Social	11.3 (7)		14.3 (4)		-		
Other	9.7 (6)		7.1 (2)		-		

- Chi-square analysis not appropriate due to small cell sizes \*  $p < .05$

In relation to the category of personal and learning development, the specific subcategories most often referred to by participants related to the context within which learning occurred. For example, expectations of academic behaviour such as sitting still and following instructions were referred to by 13.1% of the current sample, 5.8% referred to learning support that failed to take into account the effects of Down syndrome, and 4.4% referred to the consequences of non-compliance. The effect of Down syndrome on the child's ability to learn and participate in education was referred to by 8.8% of participants in the current sample. All of the various subcategories of personal and learning development referred to by participants as the least enjoyable aspects of school for their children are illustrated in Figure 1. In terms of the category of education, the specific subcategories most often referred to were sport and other organised activities (13.9% of the current sample), literacy (13.1%), and numeracy (11.7%).



*Figure 1.* Proportion of Participants Expressed as Percentage ( $N=137$ ) who Referred to Various Subcategories of Personal and Learning Development as Least Enjoyable Aspects of School for their Children

Of the current sample, 91.2% of participants provided a valid response to the question of the most difficult aspects of school for their child. The most frequently cited category was education (54% of the current sample), followed by personal and learning development (34.3%), communication (23.4%), social (16.1%), and other (2.2%). As shown in Table 7, educational factors were significantly more likely to be referred to as a particularly challenging aspect of school for children aged 10 to 14 and 15 to 19 years old, compared to children aged five to nine years or 20 years and older. In terms of the category of education, the specific subcategories most often cited by participants were numeracy (30.7% of the current sample), and literacy (24.8%). In relation to the subcategory of literacy, 20.4% of the current sample referred to writing and 10.9 % referred to reading. In relation to the category of communication, participants cited expressive language difficulties (16.8% of the current sample) and receptive language difficulties (5.1%).

Table 7

*Proportion of Participants Expressed as Percentage (N=137) who Cited Various Aspects of School Most Difficult for their Children According to Different Categorical Variables*

Aspect	Gender		Chi <sup>2</sup>	p value
	Male (n=78)	Female (n=50)		
Education	53.8 (42)	54 (27)	0.00	.96
Personal and learning development	38.5 (30)	30 (15)	1.10	.30
Communication	23.1 (18)	24 (12)	0.01	.93
Social	12.8 (10)	20 (10)	1.15	.28
Other	3.8 (3)	0 (0)	-	

- Chi-square analysis not appropriate due to small cell sizes

Table 7 (continued)

*Proportion of Participants Expressed as Percentage (N=137) who Cited Various Aspects of School Most Difficult for their Children According to Different Categorical Variables*

Aspect	Age group (in years)					Chi <sup>2</sup>	p value
	5.0-9.9 (n=42)	10.0- 14.9 (n=29)	15.0- 19.9 (n=29)	20.0-24.9 (n=20)	25.0+ (n=17)		
Education	45.2 (19)	72.4 (21)	69 (20)	40 (8)	35.3 (6)	9.84	.04*
Personal and learning development	42.9 (18)	41.4 (12)	17.2 (5)	45 (9)	17.6 (3)	8.94	.08
Communication	26.2 (11)	17.2 (5)	20.7 (6)	25 (5)	29.4 (5)	-	
Social	19 (8)	20.7 (6)	13.8 (4)	10 (2)	11.8 (2)	-	
Other	2.4 (1)	0 (0)	0 (0)	0 (0)	0 (0)	-	
	Level of school						
	Primary (n=57)	Intermediate (n=11)	Secondary (n=38)	Left school (n=31)			
Education	52.6 (30)	72.7 (8)	65.8 (25)	35.5 (11)	-		
Personal and learning development	40.4 (23)	45.5 (5)	26.3 (10)	29 (9)	-		
Communication	24.6 (14)	18.2 (2)	18.4 (7)	29 (9)	-		
Social	19.3 (11)	18.2 (2)	13.2 (5)	12.9 (4)	-		
Other	1.8 (1)	0 (0)	0 (0)	0 (0)	-		

- Chi-square analysis not appropriate due to small cell sizes

\*  $p < .05$



Table 7 (*continued*)

*Proportion of Participants Expressed as Percentage (N=137) who Cited Various Aspects of School Most Difficult for their Children According to Different Categorical Variables*

Aspect	Educational placement		Chi <sup>2</sup>	p value
	Regular education (n=62)	Special education (n=28)		
Education	59.7 (37)	64.3 (18)	1.55	.21
Personal and learning development	37.1 (23)	28.6 (8)	0.14	.71
Communication	25.8 (16)	10.7 (3)	1.87	.17
Social	22.6 (14)	3.6 (1)	-	
Other	1.6 (1)	0 (0)	-	

- Chi-square analysis not appropriate due to small cell sizes

In response to the question of the easiest aspects of school experienced by their child, 78.8% of participants provided a valid response. The most commonly cited categories in relation to this variable were as follows: Education (51.1% of the current sample), social (23.4%), personal and learning development (15.3%), and other (5.8%). In terms of the category of education, the specific subcategories most often cited were the arts (21.1% of the current sample), literacy (19%), and sport and other organised activities (16.1%). As shown in Table 8, analyses did not yield any significant associations.

Table 8

*Proportion of Participants Expressed as Percentage (N=137) who Cited Various Aspects of School Easiest for their Children According to Different Categorical Variables*

Aspect	Gender					Chi <sup>2</sup>	p value
	Male (n=78)		Female (n=50)				
Education	44.9 (35)		58 (29)			2.98	.08
Social	24.4 (19)		24 (12)			0.00	.97
Personal and learning development	15.4 (12)		16 (8)			0.01	.92
Other	7.7 (6)		2 (1)			-	
Age group (in years)							
	5.0-9.9 (n=42)	10.0-14.9 (n=29)	15.0-19.9 (n=29)	20.0-24.9 (n=20)	25.0+ (n=17)		
Education	61.9 (26)	44.8 (13)	48.3 (14)	50 (10)	41.2 (7)	-	
Social	26.2 (11)	24.1 (7)	17.2 (5)	25 (5)	23.5 (4)	-	
Personal and learning development	7.1 (3)	34.5 (10)	10.3 (3)	25 (5)	0 (0)	-	
Other	0 (0)	6.9 (2)	10.3 (3)	5 (1)	11.8 (2)	-	
Level of school							
	Primary (n=57)	Intermediate (n=11)	Secondary (n=38)	Left school (n=31)			
Education	59.6 (34)	45.5 (5)	44.7 (17)	45.2 (14)	-		
Social	24.6 (14)	27.3 (3)	23.7 (9)	19.4 (6)	-		
Personal and learning development	17.5 (10)	18.2 (2)	15.8 (6)	9.7 (3)	-		
Other	0 (0)	18.2 (2)	7.9 (3)	9.7 (3)	-		

- Chi-square analysis not appropriate due to small cell sizes

Table 8 (*continued*)

*Proportion of Participants Expressed as Percentage (N=137) who Cited Various Aspects of School Easiest for their Children According to Different Categorical Variables*

Aspect	Educational placement		Chi <sup>2</sup>	p value
	Regular education (n=62)	Special education (n=28)		
Education	54.8 (34)	42.9 (12)	0.18	.67
Social	27.4 (17)	25 (7)	0.04	.85
Personal and learning development	17.7 (11)	10.7 (3)	-	
Other	4.8 (3)	7.1 (2)	-	

- Chi-square analysis not appropriate due to small cell sizes

### ***Education-Related Specialist Support Received***

Of the 106 participants with a child currently at school, all but two (98.1%) provided a response to the question of whether their child received education-related support services, with the large majority specifying some form of support (96.2%) and only 2 (1.9%) specifying that their children received no support. Thus, among 102 children who were identified as receiving education-related support, most received teacher aide support and many received speech and language therapist support, as shown in Table 9. Indeed, 67 children (63.2% of the current sample) received both teacher aide and speech and language therapist support. Table 9 also highlights other categories of education-related support received by children of the current sample. Chi-square analyses were carried out to determine if there was an association between the gender, age, current level of school, or type of educational placement of participants' children and the type of specialist support they received, the results of which are shown in Table 10. Children who

were currently enrolled in a special education context were significantly more likely to receive the support of *other* education-related support services than those who were enrolled in a regular education context. Of those children currently receiving specialist support services, 19.6% received the support of one type, 44.1% received the support of two, 19.6% received the support of three, and 16.7% received the support of four or more.

Table 9

*Proportion of Students Currently at School Expressed as Percentage (n=106) Receiving Various Education-Related Support Services*

Teacher aide	87.7 (93)
Speech and language therapist	67.9 (72)
Specialist teacher	16 (17)
Physiotherapist	12.3 (13)
Occupational therapist	10.4 (11)
Other	33 (35)

Table 10

*Proportion of Students Currently at School Expressed as Percentage (n=106) Receiving Various Education-Related Support Services According to Different Categorical Variables*

Specialist support	Gender		Chi <sup>2</sup>	<i>p</i> value	
	Male ( <i>n</i> =60)	Female ( <i>n</i> =39)			
Teacher aide	83.3 (50)	100 (39)	-		
Speech and language therapist	63.3 (38)	79.5 (31)	1.56	.21	
Specialist teacher	15 (9)	20.5 (8)	0.31	.58	
Physiotherapist	11.7 (7)	15.4 (6)	0.16	.69	
Occupational therapist	8.3 (5)	15.4 (6)	-		
Other	35 (21)	28.2 (11)	0.89	.35	
	Age group (in years)				
	5.0-9.9 ( <i>n</i> =42)	10.0-14.9 ( <i>n</i> =26)	15.0-19.9 ( <i>n</i> =27)	20.0-24.9 ( <i>n</i> =7)	
Teacher aide	95.2 (40)	88.5 (23)	92.6 (25)	71.4 (5)	-
Speech and language therapist	78.6 (33)	73.1 (19)	63 (17)	42.9 (3)	-
Specialist teacher	21.4 (9)	15.4 (4)	14.8 (4)	0 (0)	-
Physiotherapist	11.9 (5)	15.4 (4)	14.8 (4)	0 (0)	-
Occupational therapist	11.9 (5)	7.7 (2)	14.8 (4)	0 (0)	-
Other	26.2 (11)	30.8 (8)	44.4 (12)	57.1 (4)	-

- Chi-square analysis not appropriate due to small cell sizes

Table 10 (*continued*)

*Proportion of Students Currently at School Expressed as Percentage (n=106) Receiving Various Education-Related Support Services According to Different Categorical Variables*

Specialist support	Level of school			Chi <sup>2</sup>	p value
	Primary (n=54)	Intermediate (n=11)	Secondary (n=38)		
Teacher aide	96.3 (52)	72.7 (8)	86.8 (33)	-	
Speech and language therapist	81.5 (44)	63.6 (7)	55.3 (21)	-	
Specialist teacher	20.4 (11)	18.2 (2)	10.5 (4)	-	
Physiotherapist	13 (7)	9.1 (1)	13.2 (5)	-	
Occupational therapist	9.3 (5)	9.1 (1)	13.2 (5)	-	
Other	27.8 (15)	36.4 (4)	42.1 (16)	-	
	Educational placement				
	Regular education (n=62)	Special education (n=28)			
Teacher aide	98.4 (61)	71.4 (20)	-		
Speech and language therapist	72.6 (45)	57.1 (16)	1.30	.25	
Specialist teacher	19.4 (12)	7.1 (2)	-		
Physiotherapist	9.7 (6)	17.9 (5)	-		
Occupational therapist	4.8 (3)	21.4 (6)	-		
Other	25.8 (16)	50 (14)	6.15	.01*	

- Chi-square analysis not appropriate due to small cell sizes

\*  $p < .05$

### ***Potential Improvements to Education-Related Support Services***

Of the 121 participants who made suggestions for the improvement of services in general for children with Down syndrome, 64 (52.9%) made specific suggestions for the improvement of education-related support services. Chi-square analyses were carried out to determine if there were significant associations between the gender, age, current level of school, or type of educational placement of participants' children and if participants suggested improvements to education-related support services. The results of these analyses are shown in Table 11. Specifically, parents with younger children were significantly more likely to make such suggestions than those with older children. Parents with children in the earlier stages of school (primary and intermediate) were also significantly more likely to make such suggestions, compared with those who had children in secondary school or who had left school. Additionally, parents with children in regular education were significantly more likely to make suggestions for the improvement of education-related support services than were those with children in special education. Table 12 shows the specific areas highlighted by participants as in need of improvement.

Table 11

*Proportion of Participants Expressed as Percentage (N=137) who Made Suggestions for the Improvement of Education-Related Support Services According to Different Categorical Variables*

Gender		Chi <sup>2</sup>	p value
Male (n=78)	Female (n=50)		
47.4 (37)	50 (25)	0.49	.48

Table 11 (*continued*)

*Proportion of Participants Expressed as Percentage (N=137) who Made Suggestions for the Improvement of Education-Related Support Services According to Different Categorical Variables*

Age group (in years)					Chi <sup>2</sup>	p value
5.0-9.9 (n=42)	10.0-14.9 (n=29)	15.0-19.9 (n=29)	20.0-24.9 (n=20)	25.0+ (n=17)		
76.2 (32)	62.1 (18)	34.5 (10)	15 (3)	5.9 (1)	39.09	.00*
Level of school						
Primary (n=57)	Intermediate (n=11)	Secondary (n=38)	Left school (n=31)			
73.7 (42)	72.7 (8)	31.6 (12)	6.5 (2)		47.88	.00*
Educational placement						
Regular education (n=62)		Special education (n=28)				
74.2 (46)		35.7 (10)			9.09	.00*

\*  $p < .05$

Table 12

*Proportion of Participants Expressed as Percentage (N=137) who Referred to Various Aspects of Education-Related Support Services Needing Improvement*

Allocation and distribution of government funds	19.7 (27)
Speech and language therapy	18.2 (25)
Teacher aide support	13.9 (19)
Non-specific request for more support	5.8 (8)
Professional development for educators	6.6 (9)
Other relevant suggestions	6.6 (9)

The suggestions for improvements to education-related support services included the allocation and distribution of government funds for children with Down syndrome



within the special education sector. Participants focussed on a wide variety of potential modifications within this topic. One participant suggested, “A fairer system of allocating funds other than ORRS”, such as “self-managed funds for children with moderate delays”. Another participant suggested, “More ORRS funded hours of support” for children with Down syndrome, “increased if [the] child is not doing well, not decreased as is the present case”. Another participant suggested, “Double the amount of ORRS funding per child and allow for more ORRS funded children”. One participant focussed on the funding given to special schools specifically and requested, “More funding for special schools and recognition of their essential existence”.

Participants also referred specifically to improvements needed in the provision of speech and language therapy (SLT) and teacher aide (TA) support, with others referring broadly to the need for more support in general for students with Down syndrome. Within the topic of speech and language therapy support, participants referred to a number of different modifications needed. For example, one participant suggested, “More speech therapists” and another suggested, “More SLT on a regular basis”. Another participant suggested, “More SLT or better utilization of such a scarce resource, such as group therapy sessions”. One participant highlighted the difficulties accessing speech and language therapy in the rural areas, stating, “I would love to be able to access a SLT to work regularly with our son. This could be a private arrangement even we would pay the teacher, but there is a real national shortage it seems, and probably especially so because of our rural location and relative distance from a city”. Most of the suggestions related to teacher aide support expressed a desire for an increase in the hours of support provided. For example, one participant suggested, “Full time teacher aides” and another suggested, “A consistent level of teacher aide hours” and to not have to “fight for what [their] child [was] entitled to”. Another participant did not want “the worry each year of TA hours

potentially being reduced”. One participant referred to the need for a full time teacher aide in the first few years of school, “so that routine [could] be established and learning started”. Another participant suggested that it would be beneficial for children with Down syndrome to receive full-time teacher aide support when they begin school so that “schools [would not] feel pressured about having the child full time”.

Professional development for teachers, teacher aides and specialist teachers was highlighted as another area in need of reform. One participant referred to the need for more “specialist training to help teachers and [specialist] teachers at school with more specific learning goals and help to make resources and programmes more effective and appropriate for children with Downs Syndrome and their specific learning requirements or needs”. Another participant requested better professional development for both teachers and teacher aides. Another suggested, “Compulsory, updated, credited papers for teaching degrees about disabilities”.

Finally, a number of participants made suggestions for the improvement of education-related support services that could not be classified according to the previous categories. For example, one participant suggested, “Improved Occupational Therapy provision once at school” as “it is left up to schools who often don’t have the specialist skills required”. Another participant referred to the support children receive from the school, requesting “a wider range of skills based or life skills training for children”. One participant suggested, “Easier and faster processing for technology applications at schools”.

## Discussion

### *Impact of Findings*

From the present analysis, it would appear that New Zealand parents of children with Down syndrome are typically satisfied with their children's experience of school. Parents in the current sample were significantly more likely to be satisfied with their children's experience of school (71.7%), than neutral (16%) or dissatisfied (9.4%) with it. These results support the findings of previous research to some extent. For example, the majority of parents indicated that they were satisfied in another recent study (47.4%), although much less than parents in the present analysis (Starr et al., 2008). The study by Starr and colleagues examined the satisfaction of parents of children with Down syndrome, autism spectrum disorders, and learning disabilities. They focussed on satisfaction with education specifically, rather than the broad focus on overall school experience in the present case. As a result, the difference in satisfaction across the two studies is not surprising, because parents in the present analysis were asked to relay a general impression rather than a specific analysis of an aspect of their children's school experience. The present analysis would also suggest that over time, many parents become less satisfied with their children's experience of school, although not significantly more than those who become more satisfied or who experience no change in satisfaction. Satisfaction increased for 44.7% of parents from primary to secondary school, increased for 28.9%, and remained constant for 18.4%.

The criteria that contributed to parents' satisfaction with their children's experience of school were not explicitly explored, but were indirectly investigated instead. Parents were asked to highlight those aspects of school they considered their child found particularly enjoyable, unpleasant, challenging, and easy. There was considerable variation in the responses provided by parents, which emphasises the unique experience each child

with Down syndrome has of formal education in New Zealand. Yet, although this analysis does emphasise the uniqueness of each child and their circumstances, a number of general trends and themes were also apparent.

Many parents consider education to be an area in which their children with Down syndrome demonstrate competence and/or compromise at school, as suggested by results of the present analysis. Education and its various components were specified amongst the most difficult aspects of school by 54% of the current sample and amongst the easiest aspects by 51.1%. Numeracy and literacy appear to be areas of particular difficulty for children with Down syndrome, as 30.7% of the current sample cited numeracy and 24.8% cited literacy specifically. Areas of particular strength within education appear to be the arts, literacy, and sport and other organised activities, cited by 21.1%, 19%, and 16.1% respectively. Further analysis of responses included in the category of literacy, revealed that parents viewed writing to be more of a challenge for their children than reading.

In attempting to understand why children with Down syndrome demonstrate competence or compromise in certain aspects of education, the literature is a useful guide. For example, many skills involved in numeracy depend on short-term verbal memory, which has been reported to be compromised in children with Down syndrome relative to their level of receptive vocabulary (Jarrold et al., 2002). Rietveld (2005) highlighted that these skills are particularly relevant to the early stages of instruction in mathematics, when children are learning to count for example. Writing is largely dependent on fine motor skills, which are also often compromised in children with Down syndrome (Davis, 2008). Indeed the qualitative comments made by two parents suggested as much. One parent attributed their child's difficulties in writing to "poor fine motor skills" and another attributed it to "low muscle tone".

Moreover, it would appear that with increasing age education and its components become more challenging for children with Down syndrome. The present analysis suggests that educational subjects and activities are more challenging for those children aged 10 to 19 years of age than for those aged five to nine years. Although factors associated with the increasing challenge education presents require further exploration, this finding may reflect the effect of Down syndrome on the developing brain and cognitive ability over time. An early longitudinal study reported steady declines with increasing age in the mean ratio IQ of children with Down syndrome (Carr, 1988). The present analysis also suggests that education and its components were less challenging for children aged 20 years and over, who had typically already left school. However, this finding may reflect a change in parents concerns once their children leave school, from education to employment, for example, and requires further investigation.

Many parents consider educational subjects and activities to be amongst the most enjoyable and/or unpleasant aspects of school for their children with Down syndrome. As many as 67.2% of the current sample considered them amongst the most enjoyable aspects and 42.3% considered them amongst the least enjoyable. Non-academic aspects of education, such as sport and the arts, were considered particularly enjoyable, as well as literacy, albeit to a lesser degree. Specifically, from the present analysis, 40.9% of the current sample cited sport and other organised activities, 32.1% cited the arts, and 19.7% cited literacy. Sport, literacy, and numeracy were viewed as particularly unpleasant aspects of education, cited by 13.9%, 13.1%, and 11.7% of the current sample respectively. The previous findings highlight the immense variability amongst children with Down syndrome, with differences in levels of cognitive and physical ability over time likely influencing the extent to which education is experienced as enjoyable or unpleasant at different stages (Davis, 2008).

Children with Down syndrome appear to enjoy the positive social experiences they have at school, such as building friendships and socialising with their peers. Indeed 72.3% of the current sample referred to such factors. However, these children do not necessarily find social relationships and interactions easy. For example, only 23.4% of the current sample cited it as such. Moreover, it is clear that some children have to deal with negative social experiences at school, albeit particularly challenging (16.1%) and/or unpleasant (15.3%). These negative experiences include difficulties in knowing how to relate to other children, having few meaningful friendships, and having to cope with rejection or harassment from peers.

In accordance with previous research, it appears that communication with others, particularly via expressive language, is another challenging aspect of school for children with Down syndrome. Communication in general was spontaneously mentioned as a difficulty by 23.4% of the current sample, with 16.8% referring specifically to expressive language difficulties and 5.1% referring to receptive language difficulties. This finding reflects those reported by Laws and Bishop (2003), who reported that expressive language is more likely to be compromised compared to receptive language in children with Down syndrome, although both tend to be a challenge.

From the present analysis, it seems that the extent to which many children with Down syndrome find school unpleasant may be largely affected by the context within which learning occurs and, to a lesser degree, the influence of their condition on their ability to learn. Indeed the category of personal and learning development was cited by 46% of the current sample as one of the least enjoyable aspects of school, particularly for younger children and children in regular education. The majority of parents who cited this category referred to the context within which learning occurred. For example, in terms of the learning environment, some children did not enjoy the expectations of compliant

behaviour in the classroom, such as sitting still for periods and following the teacher's instructions (13.1%). This finding may reflect that of Dykens and colleagues (2002), who reported that in comparison to their typically developing peers, children with Down syndrome were more likely to demonstrate behavioural difficulties, such as non-compliance and stubbornness. As shown by the present analysis, personal and learning development was also an area of difficulty for many children with Down syndrome, as 34.3% of the current sample cited it as such. It was also considered an enjoyable (27.7%) and/or easy aspect (15.3%) of school.

In New Zealand, most children with Down syndrome fall under the ORRS funding component for students with moderate needs and should be eligible for extra support at school once verified (O'Brien & Ryba, 2005). The present analysis would suggest that the large majority of schoolchildren with Down syndrome receive some form of education-related support (96.2%), which is likely to be under ORRS. However, parents were not asked to specify this information explicitly. Indeed qualitative comments made by parents suggest that some have sought private support for their children. Of the children of the current sample, most received teacher aide support (87.7%) and many received speech and language therapist support (67.9%). Other less common specialist support services identified by the current sample were specialist teachers, physiotherapists, and occupational therapists. These findings most likely reflect the effects of Down syndrome on development and the subsequent need for extra support in those areas affected by it. For example, Down syndrome is always associated with some degree of cognitive difficulty and is often associated with challenges in language development (Davis, 2008), hence the frequency of teacher aide and speech and language therapist support received. If under ORRS, children with Down syndrome should be allocated specialist support based on a

thorough assessment of their level of educational and personal support needs (O'Brien & Ryba, 2005).

Children with Down syndrome educated in a special education context would appear to be more likely to receive the support of other education-related specialists, compared to those in regular education. In the present analysis, these specialists included art, sport, and music therapists, for example. This finding may reflect the likelihood that special education settings have more resources from which to provide for the varied needs of children with special needs, such as Down syndrome. Gilmore and colleagues (2003) explained the apparent uncertainty of teachers with regards including children with Down syndrome in their classrooms, as indicative of an awareness of the lack of appropriate resources for such students in regular education contexts.

Parents of young children, in the early stages of school, would appear to be most concerned with the provision of education-related support services for their children. This finding, from the present analysis, likely reflects an awareness of the demonstrated value of early rather than delayed intervention (Davis, 2008). Additionally, as previously suggested it may also reflect changing concerns for parents as their children approach the transition from school into independent life in the community. Services involving employment and housing support for example, may become more relevant to such parents.

The present analysis would suggest that parents of children with Down syndrome desire a number of changes to education-related support services, beginning with the allocation and distribution of government funds within the special education sector. Of the current sample, 19.7% referred to the need for improvements of that nature. The provision of speech and language therapist, and teacher aide support are other relevant concerns, cited by 18.2% and 13.9% of the current sample respectively. The lack of training and ongoing professional development of teachers, teacher aides, and specialist teachers in the



New Zealand context is another concern, although to a lesser degree (6.6%). To some extent, these results reflect the findings reported in an American study carried out by Fidler, Lawson, and Hodapp (2003). In this study the parents of children with Down syndrome, Prader-Willi syndrome, and Williams syndrome were asked what changes they would make to their child's current educational programme to meet their child's needs more appropriately. Parents of children with Down syndrome were aware of their children's need for syndrome-specific assistance at school, referring to improvements to speech services (33.3%) and to teacher aide support (17.9%). Many of these parents also requested more reading services (23.1%), which was not repeated in the present analysis. This difference between the present analysis and the study by Fidler and colleagues (2003) may be attributed to different foci between the two. Whereas Fidler and colleagues (2003) focussed on suggested changes to educational programmes, the present analysis focussed on improvements to education-related support services (Fidler, Lawson & Hodapp, 2003).

### ***Practice Implications***

The present analysis and its findings suggest a number of implications for the delivery of educational and developmental services for children with Down syndrome, and for those involved in their delivery, particularly parents, teachers, and teacher aides. For parents, it may be enlightening to review a summary of the insights shared by others in the similar circumstance of raising a child with Down syndrome. Additionally, this overview may also be useful for educators who at some point may need to collaborate with a parent, with the shared goal of appropriately and effectively supporting their child with Down syndrome within the classroom and broader school environment. The present findings imply that an individualised educational approach is ideal, considering the uniqueness of each child and their circumstances. However, the approach taken must also be grounded in

a comprehensive understanding of Down syndrome and its common effects. For example, the strengths, difficulties, likes, and dislikes of individual children with Down syndrome should be considered in the design of educational programmes for them, which stimulate an interest in learning. The present study suggests aspects of the school experience that may be most appropriate to consider at the outset, such as difficulties in numeracy and writing, which appear to be common.

The present analysis also presents implications for those in government and related services that are responsible for decision-making at the level of policy and its broad implementation. The parents in the current sample highlighted their concern that children with Down syndrome are in need of more support early on within the public arena to be able to benefit more fully from their time in formal education. Many parents considered that there was a need for a fairer and more consistent approach to the allocation and distribution of government funding of specialists such as speech and language therapists and teacher aides. Indeed, there is widespread recognition that the New Zealand special education arena in general requires ongoing evaluation and further development (O'Brien & Ryba, 2005).

### ***Study Limitations and Strengths***

The methodology employed for the present analysis was largely constrained by the design of the larger study. For the broad purpose of illuminating the experiences and outcomes of people with Down syndrome in New Zealand, that methodology was largely appropriate. Indeed this research was largely exploratory; one of the first of its kind in the New Zealand context. It was also appropriate and useful for gaining parent perceptions of the experience that children with Down syndrome have of formal education. Nevertheless,

the present analysis has also highlighted limitations and areas of potential development for further research on this topic.

Although the study on which the present analysis is based was largely exploratory in nature, there are certain methodological limitations that must be noted. To begin with, the list of potential participants was drawn from the membership base of the NZDSA, which calls into question the extent to which the views expressed in the present analysis were representative of most parents of children with Down syndrome. Membership of the NZDSA in and of itself suggests a highly motivated parent; one who actively seeks information and support in promoting the development of their child. Conversely, it is likely that the views expressed represent those of parents who may be particularly well informed. Additionally, they may also be the views of those parents who are particularly concerned with the quality of life of their children and desire its improvement. Most research of this nature has utilised parent associations such as the NZDSA for potential participants (e.g. Laws & Millward, 2001; Fidler et al., 2002). Future studies need to design recruitment procedures that minimise the potential for systematic respondent bias.

The response rate of 38.3% suggests that it may have been useful to offer more fair compensation for the time participants took to complete and return the survey questionnaire. The only compensation offered was the option of entering into a prize draw to receive one of three free annual thirty-dollar memberships to the NZDSA. Parents, who responded despite little compensation for doing so, were therefore likely to be those who were particularly motivated to express their views, albeit helpful or not. However, the large majority of parents in the final sample appeared intent on being constructive in this endeavour, with only one parent refusing to complete the questionnaire as she felt a qualitative approach through interviewing parents would have been more appropriate. As a courtesy to the time and effort taken by participants in completing and returning the

questionnaire, it may also have been useful to offer them compensation of direct feedback regarding the research findings, to demonstrate that their contribution was valued and useful. Indeed, the frustration of one parent was evident, who stated, “Questionnaires are really as welcome in my life as telephone marketing and people door knocking, collecting for this or that organisation. Completing questionnaires is just another non-productive job for me”.

Through the present analysis, limitations also became apparent in the design of the questionnaire. Firstly, participants were not explicitly asked to state certain key demographic characteristics such as their child’s gender. As a result, this information had to be determined where possible from qualitative comments made by parents. Secondly, at the beginning of the section concerning education, participants were asked to identify the types of educational placements their child had been in over the course of their time at school and were provided with five possible options. However, these options were not clearly defined, which gave rise to apparent discrepancies in how they were conceptualised by parents. Thirdly, participants were not explicitly asked to match type of educational placement to level of schooling, with the present analysis thus reliant on determining this information where possible from qualitative comments made. Fourthly, parents were asked to rate their satisfaction with current services and were provided with an opportunity to elaborate, but were not asked to identify specifically which services their ratings corresponded to. As a result, these ratings could not be included in the present analysis, as it was not possible to determine if they did or did not apply to services that supported children in their learning and participation in education.

Nevertheless, the present analysis does highlight certain aspects of the school experience considered most significant to parents, which could be incorporated into future research efforts. For example, areas of particular relevance appear to include educational

subjects and activities, social development and relations or interactions with others, and the extent to which characteristics of the individual child and their learning context promotes development. In future research of this nature, parents could be asked to rate these aspects of the school experience as well as their overall satisfaction with it. Additionally, they could be asked to elaborate on those specific ratings of satisfaction.

Another limitation of the present analysis was the approach taken in categorising participants' suggestions for the improvement of education-related services. Inter-coder reliability should have been established in the categorisation of those responses considered relevant or not children's learning and participation in education. Inter-coder reliability also should have been determined in the categorisation of the actual responses according to conceptual similarities. Moreover, the suggestions provided by parents reflected considerable variety, creativity, and depth, which required a more in-depth qualitative analysis and interpretation other than simply coding them according to conceptually similar categories. However, time constraints have limited such an approach at present.

### ***Areas for Future Development***

Several further issues remain to be discussed, in relation to development of the current methodology in future research efforts. The present analysis was based on a methodology that explored parents' perspectives specifically, who are typically the best advocates for their children (Starr et al., 2008). Yet it is imperative that the views of people with Down syndrome are not ignored. A few parents appear to have attempted to include their children in the process of completing the questionnaire, shown by some noting whether statements were their own opinion or those of their child. Future research could be more active in attempting to gather the perspectives of children with Down syndrome in relation to their experience of formal education. In the studies reviewed for the present

analysis, only one attempted to clarify the thoughts of children with Down syndrome in relation to school (Fox et al., 2004). The children were interviewed in a variety of ways about their likes and dislikes, friendships and attitudes to schoolwork, but the findings that related to this part of the methodology were not reported. The authors did however highlight substantial variability in the quality and quantity of information that this process yielded, which unsurprisingly was largely determined by the child's age and level of functioning (Fox et al., 2004). Accordingly, future research should attempt to clarify the level of cognitive functioning of children with Down syndrome where possible. Previous research has reported considerable variability in the abilities of children with Down syndrome, which would have a significant effect on their experience of formal education (Turner & Alborz, 2003; Turner et al., 2008).

Future research could also focus specifically on the experience of children with Down syndrome in formal education rather than including it within a broad study of the lives of people with this condition. Although the current methodology was largely appropriate due to the exploratory nature of this research, it also presented a number of challenges to the present analysis, as already described in the limitations. The extensiveness of the initial study also limited an in-depth exploration of individual topics, including education. Continued efforts to illuminate children's experience of school must make this as an exclusive goal. For example, the meaning that could be drawn from participants' ratings of satisfaction with their children's experience of primary, intermediate, or secondary school was limited because they were not offered an opportunity to specify the criterion on which they based their ratings. It is unclear why parents felt satisfied, neutral, or dissatisfied with their child's experience of school at one or more of these different levels. It was most likely affected by the values and expectations

they held, as well as their child's day-to-day experiences, which would need to be explored further.

The change in parents' satisfaction over time also needs to be explored further. Further analysis of factors potentially associated with parents change in satisfaction over time was limited in the present case, but could be an avenue for future research to pursue. It may be linked to the change in educational placements over time for this group of children currently in secondary school. For example, whereas 71.1% were enrolled in regular education in primary school, only 31.6% were currently enrolled in a similar context in secondary school. Parents who favour inclusion may choose to enrol their child in a special education context in secondary school in the face of growing social concerns, such as few close friends, which have been reported to be a challenge for children with Down syndrome in regular secondary education (Buckley et al., 2008).

### ***Conclusions***

In conclusion, the present analysis has offered parents, educators, educational researchers, policy-makers, and other interested parties some general insights into the experience of school for New Zealand students with Down syndrome. It has indicated that parents are typically satisfied with the experience their children with Down syndrome have of school. It has highlighted aspects of school considered by parents to be particularly pertinent to the nature of that experience, affecting the extent to which their children find school enjoyable, disagreeable, difficult, and easy. It has also highlighted avenues for improvement to current endeavours to support children with Down syndrome in their learning and participation at school. Finally, this analysis has drawn attention to potential areas of development in further research enquiries concerned with the experience of school for students with Down syndrome. The present analysis provides direction to ongoing

efforts to enhance the experience of school for these students, through the development of programmes that stimulate and motivate their learning. Such efforts are critical to promoting the development of skills necessary for individuals with Down syndrome to participate fully in their classrooms, schools, and society, as active, valued, and integral members.



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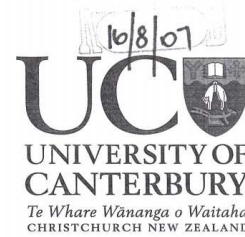
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## Appendix A: Human Ethics Committee Approval

Human Ethics Committee

Secretary

Tel: +64 3 364 2241, Fax: +64 3 364 2856, Email: human-ethics@canterbury.ac.nz



HEC Ref: 2007/96

15 August 2007

Dr Susan Foster-Cohen  
The Champion Centre  
C/- Burwood Hospital  
Private Bag 4708  
CHRISTCHURCH

Dear Susan

The Human Ethics Committee advises that your research proposal "Outcomes of early intervention for children with Down syndrome" has been considered and approved. However this approval is subject to the incorporation of the amendments you have provided in your email of 10 August 2007.

Yours sincerely

A handwritten signature in black ink, appearing to read 'M Grimshaw'.

Dr Michael Grimshaw  
*Chair, Human Ethics Committee*

## Appendix B: The Survey Cover Letter



## New Zealand Down Syndrome Association

*The NZ Down Syndrome Association is a family/whanau driven organization for people whose lives have been changed by Down syndrome.*

Dear New Zealand Down Syndrome Association member:

We need your help in understanding the long-term achievements of children with Down syndrome in New Zealand. Please find enclosed a questionnaire which we would be most grateful if you could complete. Your participation is voluntary and your answers will be anonymous, so please feel free to say what you think/feel.

The questionnaire is part of a research project based at the Champion Centre and headed by Centre Director Dr. Susan Foster-Cohen. The project is funded by the McKenzie Charitable Foundation and the questionnaire and research design have been approved by the University of Canterbury Human Ethics Committee.

The information gathered will be compiled and used to inform others of the situation in New Zealand through publications and presentations to specialized groups and the general public.



Please return the questionnaire in the prepaid envelope provided to:

Dr. Susan Foster-Cohen, Director

The Champion Centre

Private Bag 4708

C/- Burwood Hospital

Christchurch

Also enclosed is an invitation for you to be part of a follow-up project. We hope that you will consider being part of this next phase of the project and will return the form in the same envelope as your questionnaire.

Many thanks for your support of this important work. Should you want to talk to someone at the NZDSA about this research or any other issues that impact your family, please do not hesitate to contact your local coordinator.

Sincerely,

ZVaccarino

Zandra Vaccarino,

National Executive Officer,

New Zealand Down Syndrome Association.



## New Zealand Down Syndrome Association

*The NZ Down Syndrome Association is a family/whanau driven organization for people whose lives have been changed by Down syndrome.*



The Champion Centre  
TAMARIKI TOIORA

### Invitation to be part of the follow-up project

The questionnaire you have been sent is not coded in any way that could link your answers to you. Your responses will remain anonymous.

However, we would like to gain some more in-depth information by following up the questionnaire through phone interviews with families that are willing. If you would like to be one of those families, please fill out the form below and return it with your questionnaire.

.....

Yes, I am willing to be contacted by the research team at the Champion Centre/University of Canterbury for a follow up conversation to my questionnaire. I understand that at any time I have the right to withdraw from the project.

Signed \_\_\_\_\_

Name:

Address:

Phone:

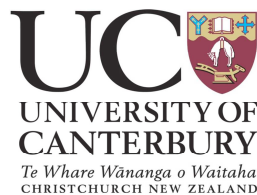
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## Appendix C: The Survey Questionnaire



**New Zealand  
Down Syndrome Association**

*The NZ Down Syndrome Association is a family/whanau driven organization for people whose lives have been changed by Down syndrome.*



### **A Survey of experiences of people with Down syndrome in New Zealand**

The Champion Centre, together with the New Zealand Down Syndrome Association, is trying to get a clearer picture of the experience of children and adults with Down syndrome in New Zealand, and what services they need to reach their goals. We would be most grateful if you would fill out this survey to help us in this work.

Your answers to our questions will be used to produce a report for circulation through the New Zealand Down Syndrome Association, and for more general publication. All information will be kept **strictly confidential**.

#### **Question 1**

- (a) Your child's age: \_\_\_\_\_
- (b) Your relationship to child (e.g., parent, guardian, etc.): \_\_\_\_\_
- (c) How long have you been a member of a Down syndrome support group or association? \_\_\_\_\_

#### **Question 2**

Please tell us about your child's greatest successes to date. (Consider life skills, relationships, social/leisure/sports activities, education, etc.) Please be specific.

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**Question 3: Early childhood (up to entering Primary School)**

(a) Did your child receive early intervention through an agency?

Yes No (Please circle one).

(b) If no, was there a service available in your area at the time?

Yes No (Please circle one)

If yes, please provide:

1) The name of the provider (e.g., Group Special Education, SES, Champion Centre, CCS):

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2) The age of your child when receiving early intervention (e.g. from birth to three years old)

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3) The type(s) of intervention they received (e.g., speech and language, physiotherapy, music...)

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**Question 4: Education**

(a) What kind of school situation is/was your child in? Please tick all that apply or have applied in the past. Please elaborate if you would like to:

- |                                |                          |
|--------------------------------|--------------------------|
| homeschool                     | <input type="checkbox"/> |
| fully mainstream               | <input type="checkbox"/> |
| partially mainstream           | <input type="checkbox"/> |
| special unit or special school | <input type="checkbox"/> |
- 
- 

(b) How satisfied were you/are you with your child's school experience? (Please tick the appropriate boxes below.)

Primary school

Not satisfied	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Very satisfied
	1	2	3	4	5	6	7	

Intermediate school (if not attended, please indicate N/A)

Not satisfied	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Very satisfied
	1	2	3	4	5	6	7	

Secondary school

Not satisfied	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Very satisfied
	1	2	3	4	5	6	7	

(c) What aspect(s) of school (educational, social, friendship building, hobbies, sporting, etc.) did your child

i) Find the most enjoyable? (Please be specific.)

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ii) Find the least enjoyable? (Please be specific.)

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iii) Find most difficult? (Please be specific.)

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iv) Find easiest? (Please be specific.)

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(d) Did your child receive any qualifications, prizes or other awards or honours while at school? Please describe anything that has brought you and/or your child satisfaction, pleasure or pride while at school.

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(e) Has your child left compulsory education?

If yes, at what age did they leave? \_\_\_\_\_

**Question 5: Post-school experience (if appropriate)**

- (a) If your child has left school, are they
- a) Working?
  - b) Studying?
  - c) Otherwise engaged in an activity?

Please circle the appropriate option and elaborate if you would like.

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**Question 6: Quality of Life (all respondents)**

(a) What sort of living arrangement does your child currently have? (please circle the appropriate number).

- 1) Living at home.
- 2) Living independently (Please indicate level of assistance)
- 3) Other (Please specify)

(b) How would you describe your child's general satisfaction with their life today? (Please tick the appropriate box below.)

Discontented ☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5   ☐ 6   ☐ 7 Contented

(c) What does your child most like to do with friends and/or family?

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(d) What does your child most like to do with free time?

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(e) What are your child's biggest frustrations in life?

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(f) What are your child's biggest satisfactions in life?

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(g) Has your child faced any major health issues? (Please be specific)

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**Question 7: Services for people with Down syndrome in New Zealand.**

(a) Please describe any specialist help (e.g. speech therapy, specialised skills training, teacher aide support) your child is **currently** receiving.

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(b) How satisfied are you with the level(s) of support from public services (e.g. for medical services, employment support, housing)? (Please tick the appropriate box below.)

Dissatisfied   ☐   ☐   ☐   ☐   ☐   ☐   ☐   Satisfied  
                         1        2        3        4        5        6        7

Please elaborate if you would like to:

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(c) What improvement(s) to services would you like to see in New Zealand for your child?

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(d) What additional services would you like to see available in New Zealand for your child?

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Please return this questionnaire to: The Champion Centre, Private Bag 4708, C/-  
Burwood Hospital, Christchurch. If you have any queries, please contact: Susan  
Foster-Cohen at (03) 383 6867 or e-mail: [susan@championcentre.org.nz](mailto:susan@championcentre.org.nz)

**Feel free to use the space below to provide any other feedback you would  
like**