

Children and Youth with Special Needs

Summary Report of Findings



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The CCSD is also grateful to staff of the many community-based agencies across Canada who took the time to respond to our survey. By sharing your experiences and expertise, we can begin to recognize some of the challenges that children and youth with special needs face in trying to participate fully in our society. Obviously, we need to understand what are the barriers to social inclusion before we can begin to address and overcome those barriers.

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Background

There has been a great deal of interest recently in Canada regarding children who face special needs as a result of a physical, emotional, intellectual or learning disability. Researchers and Canadian groups that advocate on behalf of children and youth with disabilities have been attempting to determine how many children live with special needs, and what impact this has on their ability to participate fully in society.

The recent review by the Canadian Coalition for the Rights of Children on how Canada is doing with regards to the UN Convention on the Rights of the Child investigated the conditions for children with disabilities. They estimated that there are 535,000 children and youth under the age 20 who have some form of disability, using Statistics Canada's Health and Activity Limitation Survey (HALS) of 1991.¹ According to their report, 85% of these children were considered to have mild disabilities, 11% had moderate disabilities, and 4% severe disabilities. According to HALS results, in the group aged 0 to 14 years with disabilities:

- almost 7% have a health problem or chronic long-term condition;
- 46% have a disability or long-term health condition, which limits or prevents participation in school, play or other pursuits;
- almost 11% have a long-term emotional, psychological, nervous or mental health condition limiting their activity;
- learning disabilities are the most common long-term condition;
- a higher proportion of boys are affected by all conditions; and,
- almost 18% use a technical aid, such as a hearing aid, medically prescribed footwear or a brace.

In the 15- to 19-year-old age group with disabilities:

- 8% use a technical aid for mobility or agility limitations;
- 6% use technical aids to assist seeing or hearing; and,
- almost 8% require an attendant or companion on short trips.

They report that the number of children with disabilities continues to increase as medical advances significantly improve survival rates. For example, the rate of multiple births has increased, in part due to the increased use of fertility medications. A number of children who are

¹ According to HALS, children (aged 0 to 14 years) were considered to have a disability if they had any one of the following characteristics: difficulty hearing, seeing or talking; a chronic condition such as diabetes or muscular dystrophy; use technical aids, such as crutches, hearing aids or braces; a long-term condition or problem that prevented or limited participation in school, at play or in any regular age-appropriate activity; attendance at a special school or in special classes; a long-term emotional, psychological, nervous or mental health condition; or any other general limitation. Youth (aged 15 to 19) were considered to have a disability if they: had difficulty completing one or more of 17 activities of daily living (such as walking a flight of stairs, cutting food or reading a newspaper); or were limited in the kind or amount of activity they could perform at home, school, work or for recreation due to a long-term physical condition, emotional, psychological, nervous or mental health condition, a mental handicap or health problem (Canadian Coalition for the Rights of Children, 1999).

part of a higher order birth – that is, twins, triplets, quadruplets, quintuplets – face life with serious disabilities. In addition, knowledge, skill and technology provided in the birthing and neonatal intensive care environment has resulted in very low birth weight babies surviving at a higher rate today than even 10 years ago. Many of these babies face significant disabilities.

The Canadian Coalition for the Rights of Children concluded that children with disabilities in Canada have varying opportunities to live full lives. They state that while Canada has publicly funded health and education systems that are designed with “everyone” in mind, these systems do not necessarily meet the particular needs of children with disabilities. They concluded that children with disabilities are vulnerable members of society. Early identification and intervention services – vitally important to their development – are not universally available. The supports and services necessary to ensure their Convention rights are commonly thought of as privileges, rather than the entitlements that they truly are for these children. The quality of care and support available varies according to what part of the country the child lives in, and programs are limited or reduced in times of fiscal restraint. They state that public services do not sufficiently recognize the extra demands placed on the families of children with disabilities, and the families need better financial, physical, social and emotional supports.

In 1994, the McCreary Centre Society explored chronic illness and disability among young people in British Columbia (BC), particularly in what sets youth with disabilities apart from mainstream youth when it comes to health issues. They used data collected on the Adolescent Health Survey of 1992, which was a survey of students in Grades 7 through 12 enrolled in public and independent schools in BC. They found that 75% of BC students have health concerns or problems. They found that 22% of students are limited in some way because of a health problem. They concluded that 9% of BC students are chronically ill or disabled. That is, their activities are limited in some way by one or more of the following health problems – diabetes, epilepsy, scoliosis, arthritis, asthma, hard of hearing, attention deficit disorder, physical handicap or hypertension. The study examined the health attributes and behaviours of students with chronic or disabling conditions and compared them with those of students without health problems. The analysis found that while there are similarities, there are also striking difference. Students with chronic conditions or disabilities miss more days of school and they are more likely to have concerns about their body image and shape. In terms of mental health, students with chronic illnesses or disabilities appear to be at higher risk for mental health problems. They are also more likely to be sexually active and engage in behaviours associated with contracting STDs or becoming pregnant. Finally, when compared to adolescents without health problems, teens with chronic illnesses or disabilities are more likely to use illegal drugs, alcohol and tobacco.

The Canadian Institute of Child Health (CICH) report, *The Health of Canada's Children*, used the National Population Health Survey (NPHS) to study children and youth with disabilities. They reported that according to the 1996-97 NPHS estimates, there were approximately 564,575 children and youth in Canada, from birth and 19 years of age, who had disabilities, accounting

for 7.7% of that population.^{2,3} According to the NPHS, chronic conditions are common among youth: 37% of males and 33% of females aged 12 to 14 years reported having a chronic condition. The rate increased with age: 40% of males and 49% of females aged 15 to 19 years reported having a chronic condition. The CICH concludes that “Canada has overlooked the needs of children with disabilities. Families of infants and children with disabilities are caught up in a fragmented social service system that ignores their additional fundamental needs. Many mothers of children with disabilities have to leave the workforce and subsist on welfare. Fragmented social service systems make access to services frustrating, time-consuming and often impossible.” (CICH, 2000, p. 248)

According to the 1988 National Child Care Survey (NCCS) done by Statistics Canada and the National Day Care Research Network, about 241,000 families with at least one child under 13 years of age (roughly 8.8%) have a child with a long-term condition or health problem. In 68,000 families, parents reported that their child’s condition or health limited the kind of work they were able to do or the hours parents could work. About 77,200 families reported that their child’s condition limited the child care options that would otherwise be available for that child, and 38,000 parents noted that their child’s condition or health problem limited the child care options they could consider for other children in the family.

All of the above named investigators agree on the fact that there is a paucity of information about children and youth with special needs in Canada – who they are, what their lives are like, and what kinds of communities they are included in, or excluded from. All agree that there is a need for more reliable data to answer the many unanswered questions we have about children with special needs or disabilities, and to better monitor how well we are meeting their needs. The CICH recommends that “a detailed, more comprehensive survey, focussing on the health and well-being of children and youth with disabilities and the details of their day-to-day lives is urgently required to better understand the relationship between different disabilities and various economic, social and personal factors. Without this information, it is difficult to understand how best to assist children and youth with disabilities and their families. The absence of accurate and up-to-date information about children and youth with disabilities may explain, in part, the inadequate response of all levels of government in meeting the needs of these families.” (CICH, 2000, p. 228)

The 1998 Health Behaviour in School-Aged Children survey asked students to indicate if they had a long-term illness or medical condition. Between one-quarter and one-third of males and females in Grades 6, 7, 8, 9 and 10 responded “Yes.”

The most prevalent illnesses or medical conditions in the total sample were allergies (15%),

² For a child to be considered to have a disability, the respondent (usually a parent) answered “yes” to the following question: “Because of a long-term physical or mental condition or a health problem, is your child limited in the kind or amount of activity you/he/she can do?”

³ The Roeher Institute estimates that an additional 145,000 children and youth (aged 0 to 19) could be “found” in the NPHS data if more variables were examined. It also highlights the difficulties of looking at “inclusion” strictly through a medicalized prevalence framework.

asthma (12%), hearing difficulties (1%), endocrine conditions (0.7%), persistent headaches/migraines (0.6%), cardiac problems (0.4%), and difficulties with vision (0.4%). There were no differences between boys and girls in Grades 6 and 7, although differences appeared in Grades 8, 9 and 10. Differences across the grades were small for males, although there was a gradual increase in medical conditions for females from Grade 6 to Grade 9.

Table 1
Students who had a long-term
illness or medical condition (%)

Grade	Male	Female
Grade 6	28%	28%
Grade 7	30%	30%
Grade 8	29%	33%
Grade 9	28%	36%
Grade 10	26%	36%

Source: King, AJC; Boyce, WF; and King, MA.

Trends in the Health of Canadian Youth, 1999, Figure 6.10.

According to the Adolescent Health Survey in British Columbia, 9% of young people attending schools in the province had a chronic illness or disabling condition. That is, their activities were limited in some way by one or more of the following health problems: diabetes, epilepsy, scoliosis, arthritis, asthma, being hard of hearing, attention deficit disorder, physical handicap or hypertension. More females than males reported having a chronic illness or disability: 11% of females and 7% of males had a serious health problem. The proportion of students with chronic conditions or disabilities was fairly consistent across grade levels. However, slightly fewer students in Grade 7 (7%) reported having a chronic condition or disability. There were only small variations among regions of the province, with the interior region having the highest prevalence of adolescents with disabilities (11%) and the Greater Vancouver region having the lowest prevalence (8%).

Table 2
Chronically ill or disabled students
as a percentage of student population, 1994

Grade	Male	Female
Grade 7	6%	8%
Grade 8	7%	9%
Grade 9	8%	13%
Grade 10	8%	11%
Grade 11	8%	12%
Grade 12	7%	11%

Source: The McCreary Centre Society. *Adolescent Health Survey:*

Chronic Illness and Disability Among Youth in B.C., 1994, Figure 2.

The Survey compared the concerns and challenges faced by adolescents with chronic illnesses or

disabilities with those of their healthy peers. The data showed that adolescents with chronic illnesses and disabilities were quite similar to youth without health problems in terms of their social/family background and success at school. However, there were some important differences when it came to school attendance. Adolescents with chronic illnesses or disabilities reported missing more school than their healthy counterparts both because health problems limited the amount of time they spent at school (8% versus 1%) and because they skipped school (42% versus 31%).

Not surprisingly, students with chronic illnesses or disabilities were more likely than healthy students to rate their health as fair or poor (29% versus 9%). In addition, however, adolescents with chronic illnesses or disabilities had significant concerns about their body image and shape. For example, when compared to adolescents without health problems, chronically ill or disabled adolescents were less likely to have a positive body image (38% versus 53%) or to be satisfied with their weight (78% versus 87%), and they were more likely to binge eat (46% versus 29%).

Adolescents with chronic illnesses or disabilities were also at risk of having mental health problems. In terms of suicide experiences in the previous year, students with chronic health problems were more likely to have considered suicide (28% versus 11%), planned a suicide (24% versus 9%), attempted suicide (15% versus 4%), and more likely to have been injured in a suicide attempt (4% versus 1%). As well, compared to teens without health problems, adolescents with chronic illnesses or disabilities were more than twice as likely to report a history of physical and/or sexual abuse (38% versus 17%). Finally, more young people with serious health problems had low self-esteem (17% versus 5%).

There were differences between young people with chronic illnesses or disabilities and those without, in terms of their sexual behaviour. For example, 38% of adolescents with a chronic illness were sexually active, compared with 26% of students without health problems. Likewise, differences were apparent in sexual practices such as using alcohol and drugs before having intercourse (32% of students with a chronic illness versus 23% of students without a health problem), or using a condom the last time they had sexual intercourse (52% of students with a chronic illness versus 61% of students without a health problem). Adolescents with chronic illnesses or disabilities reported higher rates of ever having had an STD (7% versus 3%) and ever having been or caused a pregnancy (13% versus 7%).

Higher rates of alcohol use were also reported by adolescents with a chronic illness or disability, as compared to teens without health problems. Specifically, 75% of adolescents with a chronic illness had ever used alcohol, whereas 60% of adolescents without health problems had ever used alcohol. In addition, adolescents with chronic or disabling health conditions were more likely to report having consumed alcohol on six or more occasions in the month preceding the survey (21% versus 14%) and to report binge drinking one or more times in that month (43% versus 34%). In addition to drug and alcohol use, adolescents with chronic conditions reported higher rates of tobacco use: 34% of adolescents with a chronic illness had smoked cigarettes either occasionally or regularly in the previous month, compared to 21% of teens without a health problem.

The Bloorview MacMillan Centre did research to compare the health behaviour of youth and adults with disabilities. For youth, they utilized the survey tool from the “Health Behaviours in School-Aged Children with Disabilities.” They surveyed 319 youth in Ontario, aged 11 to 16 years, with disabilities. They also utilized a revised version of this survey tool, “Healthy Living for People with Disabilities,” and reported on 280 respondents aged 19 to 35, who had a disability before the age of five years.

A comparison of the adult and youth surveys indicated that there were significant differences between the groups. Most notably, the youth experienced headaches, irritability and nervousness more often than did the adults; the youth had more trouble making decisions; felt loved and appreciated less often than did the adults; and felt needed and useful less often.

Adults were more likely than youth to report that their disability affected their health “very much” – 19% versus 8%. Thirty-six per cent of youth with disabilities reported that they were “very healthy” compared to 32% of adults who made that claim.

Young people were more likely than adults to eat junk food and they were less likely to report that they never exercised. They were as equally likely as adults (43% versus 42%) to watch TV more than four hours per day.

The youth were more likely than adults to report that they were “very happy” and less likely to feel lonely very/quite often. They were more likely than adults to report having more than one close friend (82% versus 71%), and less likely to report that they sometimes felt helpless (28% versus 45%).

Purpose

This report provides two important new pieces of research to our understanding of children with special needs. The National Longitudinal Survey of Children and Youth (NLSCY) provides a wealth of information regarding how children and youth are faring in Canada. To date, there has not been an examination of children with special needs within that database. This report provides that overview. In addition, this report gathers the perceptions and experiences of service providers and policy makers who are concerned with children and youth with special needs. Through a survey of community-based agencies across Canada, along with provincial and national organizations, the adequacy of the service sector is explored.

Methodology

The first part of this report is based on analysis from the National Longitudinal Survey of Children and Youth (NLSCY). This survey was developed by Statistics Canada and Human Resources Development Canada. It is a unique survey of Canadians from birth to adulthood, providing a single source of data for the examination of child development. The NLSCY provides a national database on the characteristics and life experiences of children and youth in Canada as they grow up.

The NLSCY was designed to follow an ecological or holistic approach to measuring child development. The survey captures the diversity and dynamics of the factors affecting child development. Information is collected on a wide variety of outcomes (such as health, language, cognitive, social, emotional, behavioural) and determinants. The latter include characteristics of the child's family (socio-economic status, structure, parenting style, family functioning, social support), child care, school and neighbourhood. Questions are designed to uncover the results of interactions that occur throughout the child's development and socialization, such as the impact of family structure and socio-economic status. Environmental factors are also important in understanding the kinds of resources that are available to the family and the child.

The NLSCY has a large sample size which permits extensive research at the national level, and it is also sufficient for analysis at the provincial or regional levels as well. An initial longitudinal cohort, aged 0-11 in 1994, is being followed every two years to age 25; this cohort currently numbers about 15,000 young people. The NLSCY design and sample were constructed to permit production of both cross-sectional and longitudinal estimates. The sample makes it possible to produce estimates at the national level for the specific age cohorts and at the provincial level for aggregated age groups.⁴

The main respondent in the NLSCY is a household member who is the "person most knowledgeable" (or PMK) about the child or children. In most cases, the PMK is the child's mother. In addition, children aged 10 to 11 were asked to fill out a self-completed questionnaire in 1994, as were children aged 10 to 13 in 1996.

Analysis of the NLSCY data provides an overview of the proportion/number of children living with an activity limitation, children living with a learning disability, and children living with certain long-term conditions (physical and emotional). Using these data, this report examines two important questions:

1. What is the relationship between the determinants of health and children with special needs?
2. What is the experience of children with special needs in terms of social inclusion, and how do they participate in various aspects of society and life?

In order to answer these questions, cross-tabulation analysis is conducted examining the relationship between a number of the determinants of health (such as income, labour force experience of the parents, educational attainment of parents, gender, immigration/language status, family structure and relationships, the physical/social environments of the children, and

⁴ The data as set out in this report meet all of Statistics Canada's quality guidelines for data release based on information contained in the co-efficient of variation tables supplied by Statistics Canada. If information did not meet their guidelines for release, it was suppressed or flagged with a footnote indicating that the estimate was less reliable due to small sample size, as required by Statistics Canada. Since the NLSCY sample makes it possible to produce estimates at the national level for the specific age cohorts, it is understood that each proportion cited in this report is based on such estimates.

the children's personal health practices) and children with special needs. Next, the cross-tabulation analysis is conducted examining the relationship between children with special needs and a number of indicators of social inclusion. When constructing these cross-tabulations, it would have been interesting and useful to examine children with one special need, those with two special needs, and those with three or more special needs. This would have provided some indication of severity of special need. However, in the majority of cases, the cell size became either unreliable or too small to report. Therefore, the data are not presented this way. A further limitation relating to the NLSCY data and severity of special needs is that these data do not capture children living with very severe disabilities (for example, those children living in institutions).

The second part of this report is based on a survey of community-based agencies conducted by the Canadian Council on Social Development. The purpose of this survey was to understand the capacity of community-based organizations to respond to the needs of children and youth with special needs. For the purpose of the survey, children and youth with special needs were defined to include: children/youth with physical disabilities; children/youth with chronic physical health problems; children/youth with emotional health problems; children/youth with developmental disabilities; and children/youth with learning disabilities. This was consistent with the NLSCY data analysis. There were 112 respondents to the CCSD survey, a 56% response rate.

Analysis based on the National Longitudinal Survey of Children and Youth (NLSCY)

Specific Special Needs

Just who are the children with special needs? The NLSCY provides us with a number of variables that can be used to describe children with special needs. There are variables describing the proportion of children who have been diagnosed by a health professional within a six-month period prior to the survey as possessing a chronic condition or activity limitation. These include children who have allergies, asthma, bronchitis, a heart condition, epilepsy, cerebral palsy, kidney disease, mental handicap, learning disability, emotional problem, some other condition, or an activity limitation. In addition, the data describe children who have a physical disability. These include physical disabilities related to vision, hearing, speech, mobility, and manual dexterity. Finally, the survey examines the child's experience with pain or discomfort. In order to create an "index" or single measure that would describe a child with special needs, all of these variables were analysed. Both Cycle 1 (1994) and Cycle 2 (1996) of the NLSCY were investigated. The investigation was limited to children aged 11 years or younger, in order to match the age limitations of the first cycle of the NLSCY.

Chronic Conditions – Physical

The most commonly reported physical chronic condition was allergies, in both the 1994 and 1996 NLSCY. Examination of the data show that approximately 13.7% of children aged 11 years or younger in 1996 had allergies (as diagnosed by a health professional), compared to 14.3% in 1994. Older children (aged 6 to 11 years) and a greater proportion of male children than female

children had allergies in both 1994 and 1996. Allergies were estimated to affect approximately 657,100 children in 1994 and 638,200 children in 1996 (see Table 3).

In 1994, 5.6% of children had at least one asthma episode in the previous year, as did 5.4% in 1996. A greater proportion of older children (aged 6 to 11 years) than younger children had asthma in both survey years – 6.1% for the older children and 4.7% for the younger children in 1996. In both years, boys had a higher incidence of reported asthma than did girls (6.4% versus 4.0% in 1996).

Fewer children had bronchitis in 1996 (112,600 or 2.4%) than in 1994 (134,100 or 2.9%). As with allergies, however, older children and male children were comparatively more likely to have bronchitis in both years (Table 3). Children with diagnosed heart conditions increased slightly from 1994 to 1996 (0.9% to 1.1% or from 42,100 to 51,500 children). While there were differences between the number and proportion of younger and older children as well as between male and female children with heart conditions, they were fairly minor (Table 3). The incidence of children with diagnosed epilepsy was relatively small in both 1994 (0.2%) and 1996 (0.4%), representing 10,200 children in 1994 and 16,900 children in 1996. Figures by gender and by age group for children with epilepsy cannot be provided due to the very small sample sizes associated with epilepsy in the NLSCY. Similarly, the number and proportion of children with cerebral palsy in 1994 were too small to report, however in 1996, the figures were 0.3% or 13,800 children in Canada. Kidney disease affected 17,200 children in 1994 and 19,600 children in 1996. This represented 0.4% of all children in each of the two years. Differences by gender and age group in both years were negligible.

Learning Disabilities, Emotional Problems and Intellectual Disabilities

Information regarding learning disabilities and emotional behavioural problems were measured on the NLSCY for children aged 6 years or older who were attending school. In 1996, approximately 4.1% of these children were diagnosed as having a learning disability, compared to 3.7% in 1994. The actual number of children with a learning disability in 1996 was 97,700, which contrasts with the 85,500 in 1994 – an increase of approximately 12,000 children. Male children were more likely to have a learning disability in both 1994 (4.6%) and 1996 (5.5%) than were female children (2.8% in 1994; 2.7% in 1996). The incidence of identified emotional problems, on the other hand, was relatively lower: 1.7% of children aged 6 to 11 were identified with an emotional problem in 1994, as were 1.8% in 1996. However, male children in both 1994 and 1996 were slightly more likely to have an emotional problem than were female children (see Table 3).

In 1994, 13,300 children, or 0.3%, were diagnosed with a mental handicap compared to 0.4% (or 19,100 children) in 1996. As with other conditions, we cannot provide a breakdown by gender or age group due to the very small sample sizes associated with this condition in the NLSCY.

Other Chronic Conditions

There are many chronic conditions that were not specifically catalogued by the NLSCY. Children possessing these conditions were captured by the “other chronic condition” question. There were

approximately 200,800 children aged 11 years or younger (4.4%) in 1996 diagnosed with a chronic condition other than those already mentioned to this point, up from 175,100 children (3.7%) with some other chronic condition in 1994. The proportionate increase was largest for male children aged 11 or younger, increasing from 3.9% in 1994 to 4.8% in 1996. Female children with some other chronic condition witnessed a proportionate increase from 3.6% in 1994 to only 3.9% in 1996.

Activity Limitation

Information was also collected regarding whether children interviewed for the NLSCY were limited in their normal activity. For children aged 11 or younger, 3.8% of children in 1996 – up from 3.1% in 1994 – were diagnosed as having an activity limitation. As with some of the chronic conditions, male children aged 11 or younger were more likely to be diagnosed as having an activity limitation (3.7% in 1994; 4.4% in 1996) than were female children (2.5% in 1994; 3.2% in 1996).

Physical Disabilities

The NLSCY provides information regarding a number of physical disabilities that children and youth may experience. These include:

- Vision impairments;
- Hearing impairments;
- Speech impairments; and,
- Problems with mobility.

In addition, the NLSCY investigates the child's experience with chronic pain.

The questions regarding the above physical disabilities were asked of all parents⁵ of children aged 4 to 11 in Cycle 1 (1994) of the survey. In Cycle 2 of the survey in 1996, they were only asked of those parents of children who were identified as having one of these disabilities. Therefore, we are only able to examine the incidence of these conditions through the whole population during 1994. In order to be consistent with the other analysis, we examined these conditions among children aged 6 to 11.

For children aged 6 to 11 in 1994, 1.6% were identified as having a hearing impairment; 1.4% were identified as having speech impairment; and 0.8% were identified as having a mobility impairment. (We are unable to report on the proportion of children with a vision impairment as the number was too small to be released.) Less than one per cent (0.8%) of children had pain to the point that it prevented certain activities. Boys and girls were equally likely to have these conditions, with the exception of speech problems – 1.5% of boys had difficulty with speech compared with 0.8% of girls.

⁵ The NLSCY interviewed the 'person most knowledgeable about the child' to ascertain information about children. This was the mother in more than 90% of cases.

Index of Children with Special Needs

These data illustrate that there are large variations in the degree to which particular chronic conditions and physical disabilities afflict children aged 11 years or younger. Summarizing these data into a single measure enables us to examine the population of children living with any chronic condition or physical disability. As well, this measure could provide us with some idea of the number and proportion of children affected by more than a single chronic condition. Thus, we essentially want to capture the larger population of special needs children in one measure. The way to do this is to construct an index of special needs children composed of each of the individual health measures covered in our discussion above, one measure for each of 1994 and 1996 (where data permit).

Construction of an index of special needs children is relatively straightforward. We can simply sum the various measures of chronic health and activity limitation such as that for each health issue a child has been diagnosed as having, which will correspond to an increase of one on the index of special needs. For example, a child with only one chronic health problem or activity limitation will have a score of one on the index. A child with two chronic health problems or activity limitations will have a score of two on the index, and so on. We have divided the indices into two groups: those which refer to children aged 11 and younger, and those which refer only to children aged 6 to 11 years. This was necessary because questions about emotional problems and learning disability conditions were not asked of children under age 6, nor were the questions regarding physical disabilities. As well, we have created indices which include children with allergies, and indices which exclude these children. This was done because children with allergies are clearly the largest single group of special needs children and we wanted to obtain some idea of the effect that this would have on any index.

Using these conditions, we end up with four indices for each of 1994 and 1996 (see Table 4) and two more indices for 1994 only. Index 1 represents all children aged 11 and younger with a chronic condition or activity limitation, excluding emotional problems and learning disabilities (since these questions were not asked of younger children). Observing the results for Index 1, we see that almost one-quarter of all children aged 11 or younger in 1994 and 1996 had one or more special needs (24.0% and 23.1%, respectively). This represents approximately 1.1 million children in Canada in both years. The distribution of children in our index for both 1994 and 1996 is very similar. Slightly less than 2% of all children aged 11 or younger had three or more special needs in 1994; in 1996, the figure was 1.5%. A somewhat higher proportion of children in 1994 than in 1996 had two special needs (4.6% compared to 4.1%). The same proportion of children had one special need in 1994 and 1996, 17.5%. Overall, there was little change between the proportions in 1994 and 1996 in Index 1.

As mentioned, the greatest single proportion of children with special needs have allergies. To gain some appreciation of the effect this might have on our index, we constructed Index 2 so as to exclude the incidence of allergies (Table 4). Exclusion of children with allergies reduces the proportion of special needs children aged 11 or younger to approximately 13.8% in 1994 and 13.2% in 1996. Nevertheless, over 600,000 children in Canada were still classified as having a

special need in 1994 and 1996.

Index 2 also reduces the proportions of children with special needs at each level, when compared to Index 1. For example, there are now only 0.8% of children aged 11 or younger with three or more special needs in 1994 and 1996. However, while the proportions in Index 2 and Index 1 do differ, there is a similarity between the two years. That is, approximately equal proportions of children in both 1994 and 1996 have no special needs, one, two, or three or more special needs for both Index 1 and Index 2. Any differences between the years are relatively small.

Our first indices did not factor in the effect of children with emotional problems or learning disabilities because these only applied to older children. These two special needs variables for children aged 6 to 11 are integrated into Index 3 for both 1994 and 1996 (Table 4). We observe in Index 3 that approximately 30% of all children aged 6 to 11 in both 1994 (31.6%) and 1996 (31.4%) had a special need. This represents over 700,000 children with a special need in both 1994 (723,741 children) and 1996 (743,907 children). For the most part, these children had only one special need, approximately 22% in both 1994 and 1996. Just over 6% of the children had two special needs in 1994 and 1996. Slightly fewer (2.5%) had three or more special needs in 1996 than in 1994 (3.3%).

Index 4 excludes children with allergies. We immediately notice that excluding these children does effect the proportion of children having a special need, as was observed for Indices 1 and 2 (Table 4). In both years, 19% of children aged 6 to 11 were classified as special needs in Index 4, after having excluded those children with allergies. There is a reduction in the proportions of children aged 6 to 11 at each level of Index 4 when compared to Index 3. Over one-tenth of these children in both 1994 and 1996 were categorized as having one special need (13.0% and 13.8%, respectively). Much lower proportions of children in this age group had two special needs, 4.2% in 1994 and 3.4% in 1996. Similarly, there were approximately 2% of all children aged 6 to 11 with three or more special needs in both 1994 and 1996 (1.8% and 1.5%, respectively).

Our first four indices included children with chronic conditions or activity limitations, emotional problems and learning disabilities, but did not factor in the effect of children with physical disabilities. Overall, approximately 3% of children aged 6 to 11 have at least one physical disability – that is vision impairments, hearing impairments, speech impairments, problems with mobility and chronic pain.

These dimensions of a special needs variable for children aged 6 to 11 are integrated into Indices 5 and 6 for 1994 (Table 4). (Data for 1996 are not available). We observe in Index 5 that approximately 33% of all children in 1994 aged 6 to 11 had a special need. This represents roughly 760,000 children. For the most part, these children had only one special need, 22.1%. Approximately 7% had two special needs and 4.1% had three or more special needs.

Index 6 excludes those children with allergies (Table 4). Around 21% of children aged 6 to 11 were classified as special needs children in 1994 according to Index 6, after having excluded children with allergies. There is some reduction in the proportions of children at each level of

Index 6 when compared to Index 5. Approximately 14% of children aged 6 to 11 were categorized as having one special need. Much lower proportions of children in this age group had two special needs, or three or more – 4.5% and 2.6%, respectively.

Our indices show that there are relatively large numbers and proportions of children with special needs in Canada, whether we include or exclude those with allergies. We also observe that many of these children possess two, or three or more special needs. It is wrong, therefore, to simply think of special needs children as a homogenous group where each child has one discreet special need. Instead, we must consider the effect that multiple special needs may have on these children and their participation in society.

Continuing the Analysis

Inclusion in society is a basic human right. For children and youth with disabilities, inclusion means removing barriers and providing supports in order to allow them to participate in all aspects of life to the best of their abilities. The findings presented in this document show that there are many special needs children in Canada, with a multiplicity of differing needs. By far the largest proportion of children aged 11 or younger have allergies, followed by asthma, activity limitations, bronchitis, and children with some other diagnosed chronic condition. Large proportions of children aged 6 to 11 have learning disabilities and emotional problems. Older children and male children generally tended to experience higher incidences of special needs. Observing the indices which we constructed we see that fully one-fifth of all children in Canada aged 11 or younger have a special need.

These data provide us with the opportunity to investigate further the conditions of the lives of Canadian children with special needs – to examine the conditions of their lives and how they are included in their communities. For the purposes of this analysis, we have chosen to use Index 6. There are a number of reasons for this. A large proportion of children in Canada have learning disabilities and emotional problems, therefore we felt it critical to include them in the analysis. This resulted in the analysis being limited to children aged 6 to 11. In addition, 3% of children were found to have a vision, hearing, mobility, or speech disability, or problems with pain. Therefore, it was critical not to exclude these children. Finally, it was decided to choose an index that did not include children with allergies. While allergies can be very debilitating for children, there was no way to determine the severity of the allergy from the data. Finally, using this index we were forced to conduct the analysis on 1994 data. However, there was little change between 1994 and 1996 on all of the indices where we had comparable data, so examining the 1994 data would provide us with a reasonable estimate.

For the purposes of this analysis, children are identified as either having no special needs, or as having one or more special needs. While it would be interesting to investigate those children with one special need compared to those with more than one, in the majority of cases, the sample size became too small in the cross-tabulations, and the numbers were either marginal or not releasable.

Therefore, using Index 6, which includes all children aged 6 to 11 who have a chronic condition, activity limitation, physical disability, emotional problem and/or learning disability, enables us to investigate the relationship between the determinants of health and children with special needs, as well as the experience of special needs children with regard to their everyday lives.

Table 3
Incidence of Individual Conditions, by Year

	1994	1996
Child has allergies (aged 0 to 11)	14.3%	13.7%
Child has asthma (aged 0 to 11)	5.6%	5.4%
Child has bronchitis (aged 0 to 11)	2.9%	2.4%
Child has heart condition (aged 0 to 11)	0.9%	1.1%
Child has epilepsy (aged 0 to 11)	0.2%	0.4%
Child has cerebral palsy (aged 0 to 11)	--	0.3%
Child has kidney disease (aged 0 to 11)	0.4%	0.4%
Child has mental handicap (aged 0 to 11)	0.3%	0.4%
Child has learning disability	3.7%	4.1%
Child has emotional problems (aged 6 to 11)	1.7%	1.8%
Child has other condition (aged 0 to 11)	4.4%	3.7%
Child has hearing impairment (aged 6 to 11)	0.9%	n/a
Child has speech impairment (aged 6 to 11)	1.2%	n/a
Child has mobility impairment (aged 6 to 11)	0.4%	n/a
Child has vision impairment (aged 6 to 11)	--	n/a
Pain prevents activity (aged 6 to 11)	0.8%	n/a
Child is limited in normal activity (aged 0 to 11)	3.8%	3.1%

Source: National Longitudinal Survey of Children and Youth, 1994 and 1996.

Incidence of Individual Conditions, by Age Group and Year

	1994		1996	
	0 to 5 years	6 to 11 years	0 to 5 years	6 to 11 years
Child has allergies	10.0%	18.6%	9.0%	18.2%
Child has asthma	4.8%	6.5%	4.7%	6.1%
Child has bronchitis	2.4%	3.4%	2.0%	2.8%
Child has heart condition	0.8%	1.1%	1.0%	1.2%
Child has epilepsy	--	--	--	--
Child has cerebral palsy	--	--	--	--
Child has kidney disease	--	--	--	--
Child has mental handicap	--	--	--	--
Child has learning disability ¹	n/a	3.7%	n/a	4.1%
Child has emotional problems ¹	n/a	1.7%	n/a	1.8%
Child has other condition	3.6%	5.1%	3.0%	4.5%
Child has hearing impairment ¹	n/a	1.6%	n/a	n/a
Child has speech impairment ¹	n/a	1.4%	n/a	n/a
Child has mobility impairment ¹	n/a	0.8%	n/a	n/a
Child has vision impairment ¹	n/a	--	n/a	n/a
Pain prevents activity ¹	n/a	1.4%	n/a	n/a
Child is limited in normal activity	2.9%	4.8%	2.4%	3.9%

Source: National Longitudinal Survey of Children and Youth, 1994 and 1996.

Table 3 (con't)
Incidence of Individual Conditions by Gender and Year

	1994		1996	
	Female	Male	Female	Male
Child has allergies	12.6%	15.9%	12.2%	15.1%
Child has asthma	4.3%	7.0%	4.0%	6.4%
Child has bronchitis	2.2%	3.6%	2.1%	2.7%
Child has heart condition	0.9%	0.9%	1.0%	1.2%
Child has epilepsy	--	--	--	--
Child has cerebral palsy	--	--	--	--
Child has kidney disease	--	--	--	--
Child has mental handicap	--	--	--	--
Child has learning disability ¹	2.2%	4.6%	2.7%	5.5%
Child has emotional problems ¹	1.4%	2.0%	1.5%	2.1%
Child has other condition	3.9%	4.8%	3.6%	3.9%
Child has hearing impairment ¹	0.9%	0.9%	n/a	n/a
Child has speech impairment ¹	0.8%	1.5%	n/a	n/a
Child has mobility impairment ¹	0.5%	0.4% *	n/a	n/a
Child has vision impairment ¹	--	--	n/a	n/a
Pain prevents activity ¹	1.0%	0.7% *	n/a	n/a
Child is limited in normal activity	3.2%	4.4%	2.5%	3.7%

Source: National Longitudinal Survey of Children and Youth, 1994 and 1996.

¹ Data only for children aged 6 to 11 years

* Marginal – estimates are less reliable due to high variation

-- Number suppressed, sample too small

n/a Not available

Table 4
Indices of Children with Special Needs

Index 1: Children aged 11 years and younger with a chronic condition or activity limitation, excluding emotional problems and learning disabilities			Index 1: Children aged 11 years and younger with a chronic condition or activity limitation, excluding emotional problems and learning disabilities		
Number of special needs	1994	1996	Number of special needs	1994	1996
None	75.9%	76.9%	None	3,495,446	3,590,998
One	17.5%	17.5%	One	805,425	817,232
Two	4.6%	4.1%	Two	213,215	192,207
Three or more	1.9%	1.5%	Three or more	88,237	71,130
Total	100%	100%	Total	4,602,323	4,671,567
Index 2: Children aged 11 years and younger with a chronic condition or activity limitation, excluding allergies, emotional problems and learning disabilities			Index 2: Children aged 11 years and younger with a chronic condition or activity limitation, excluding allergies, emotional problems and learning disabilities		
Number of special needs	1994	1996	Number of special needs	1994	1996
None	86.2%	86.9%	None	3,966,036	4,058,143
One	9.9%	10.1%	One	453,965	469,531
Two	3.1%	2.3%	Two	144,473	106,608
Three or more	0.8%	0.8%	Three or more	37,849	37,286
Total	100%	100%	Total	4,602,323	4,671,568
Index 3: Children aged 6 to 11 years with a chronic condition or activity limitation (including allergies, emotional problems and learning disabilities)			Index 3: Children aged 6 to 11 years with a chronic condition or activity limitation (including allergies, emotional problems and learning disabilities)		
Number of special needs	1994	1996	Number of special needs	1994	1996
None	68.5%	68.6%	None	1,573,513	1,625,448
One	21.7%	22.7%	One	497,455	537,582
Two	6.6%	6.2%	Two	150,519	146,628
Three or more	3.3%	2.5%	Three or more	75,767	59,697
Total	100%	100%	Total	229,254	2,369,355

Table 4 (con't)
Indices of Children with Special Needs

Index 4: Children aged 6 to 11 years with a chronic condition or activity limitation (excluding allergies, including emotional problems and learning disabilities)			Index 4: Children aged 6 to 11 years with a chronic condition or activity limitation (excluding allergies, including emotional problems and learning disabilities)		
Number of special needs	1994	1996	Number of special needs	1994	1996
None	81.0%	81.3%	None	1,859,770	1,925,882
One	13.0%	13.8%	One	299,707	325,918
Two	4.2%	3.4%	Two	96,926	81,639
Three or more	1.8%	1.5%	Three or more	40,850	35,914
Total	100%	100%	Total	2,297,254	2,369,353
Index 5: Children aged 6 to 11 years with a chronic condition, activity limitation or physical disability (including allergies, emotional problems and learning disabilities)			Index 5: Children aged 6 to 11 years with a chronic condition, activity limitation or physical disability (including allergies, emotional problems and learning disabilities)		
Number of special needs	1994	1996	Number of special needs	1994	1996
None	66.7%	n/a	None	1,532,291	n/a
One	22.1%	n/a	One	507,905	n/a
Two	7.1%	n/a	Two	162,353	n/a
Three or more	4.1%	n/a	Three or more	93,687	n/a
Total	100%	n/a	Total	2,296,236	n/a
Index 6: Children aged 6 to 11 years with a chronic condition, activity limitation or physical disability (excluding allergies, including emotional problems and learning disabilities)			Index 6: Children aged 6 to 11 years with a chronic condition, activity limitation or physical disability (excluding allergies, including emotional problems and learning disabilities)		
Number of special needs	1994	1996	Number of special needs	1994	1996
None	78.8%		None	1,809,111	
One	14.1%		One	324,325	
Two	4.5%		Two	104,174	
Three or more	2.6%		Three or more	58,625	
Total	100%		Total	2,296,236	

Detailed Analysis: Children with Special Needs

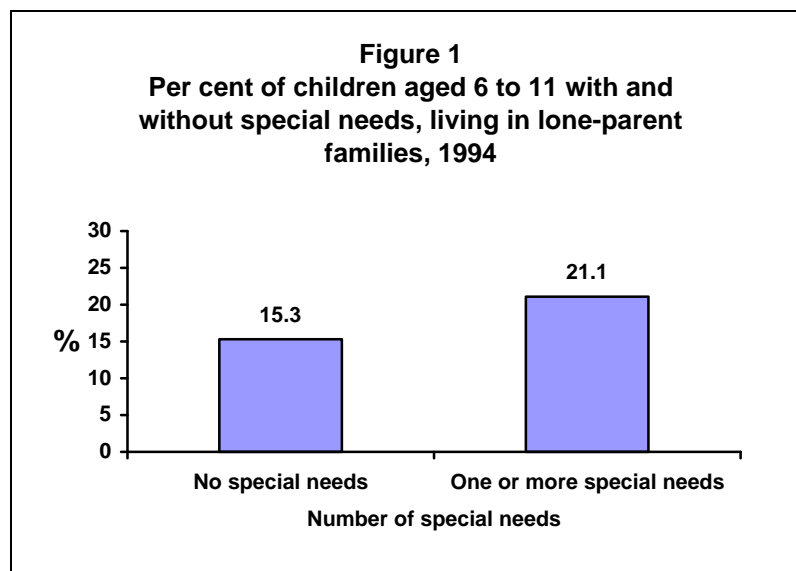
Who are the Children with Special Needs? What are the Conditions of Their Lives?

According to this Index of special needs, in 1994, 21.2% of children aged 6 to 11 years had one or more special needs. This accounted for approximately 487,000 children. The proportion of boys with special needs was higher than that of girls – 18.4% of girls had special needs compared with 23.9% of boys.

It is well known that children's upbringing and the environments within which they grow and develop have a profound effect on their development, and on their likelihood of reaching their own unique potential. Therefore, it is important to examine the conditions of the lives of children with special needs.

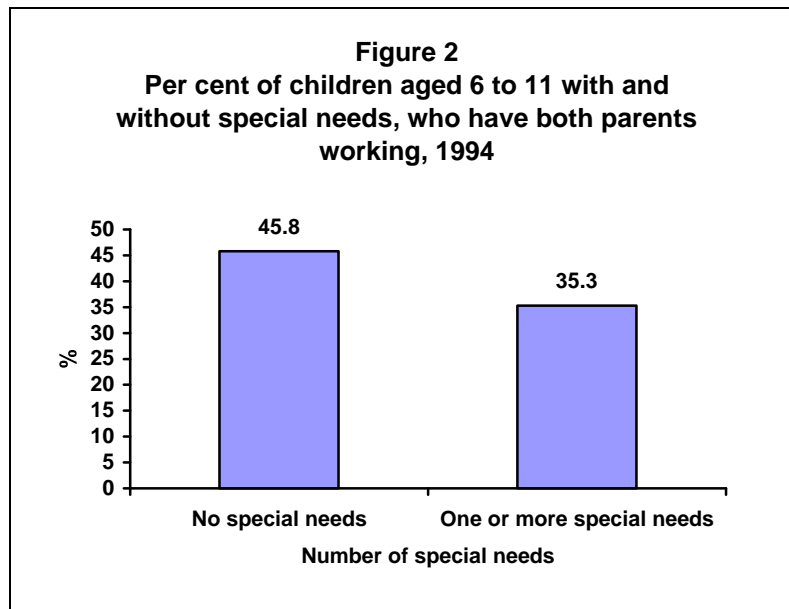
Family Structure

Children with special needs are more likely to live in lone-parent families – 21.1% of all children with special needs lived in a lone-parent family. Only 15.3% of children with no special needs lived in a lone-parent family.



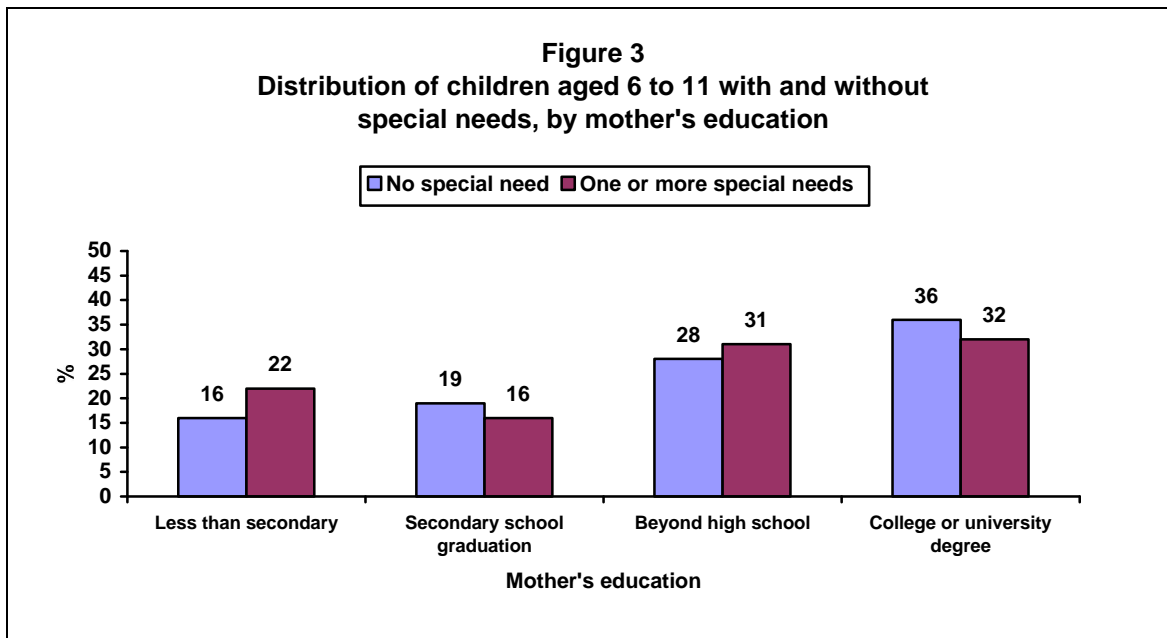
Mother's Labour Force Activity

Children with special needs, living in two-parent families, are less likely to have both parents working full-time. Of all children with special needs, 35.3% had both parents working full-time, compared with 45.8% of children with no special needs.



Mother's Education

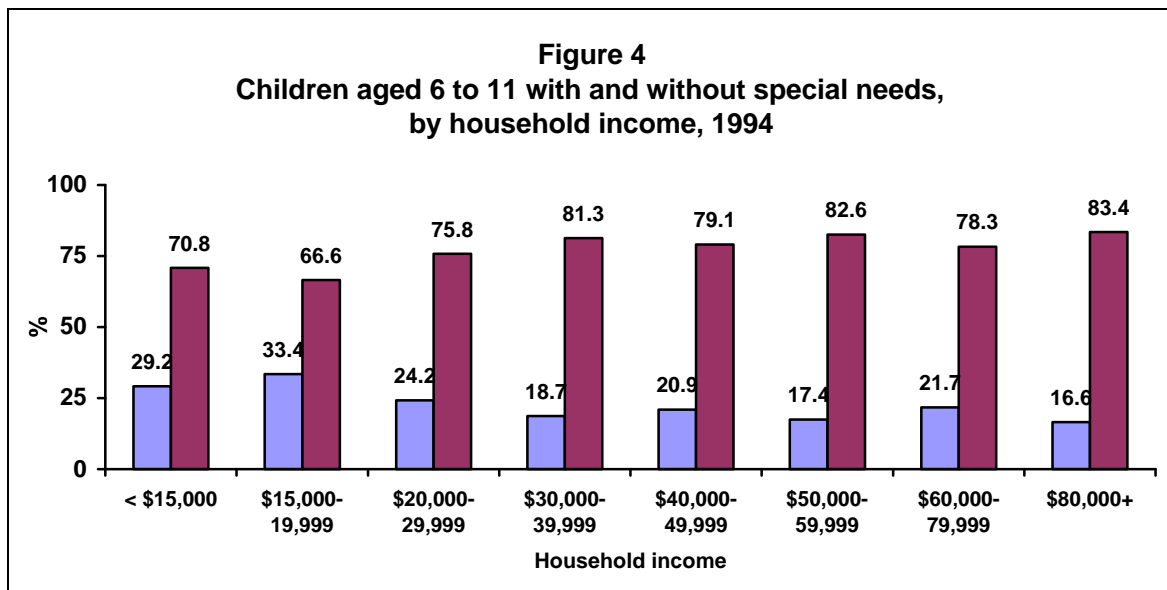
Twenty-two per cent of all children with one or more special needs had a mother who had less than a high school education, compared with 16% of children without a special need. Thirty-two per cent of children with one or more special needs had a mother who had completed a college or university degree, compared with 36% of children with no special needs.



Household Income

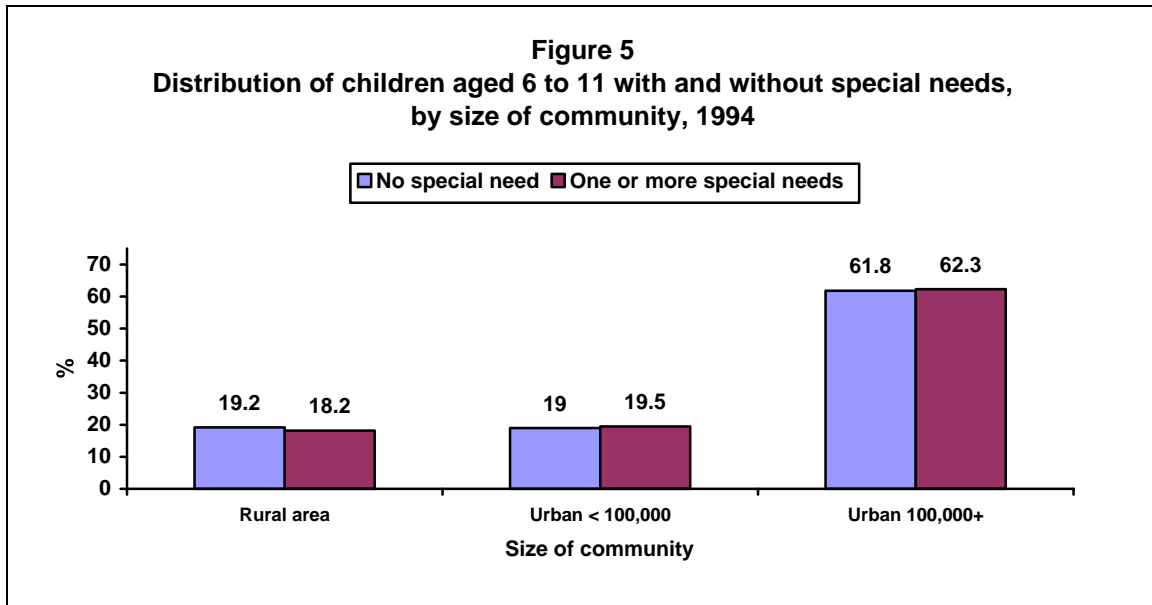
There appears to be an association between income and children with special needs. Almost 30% of children in families with less than \$15,000 household income had special needs.

Comparatively, only 16.6% of children in families with a household income of \$80,000 or more had special needs. Conversely, approximately 71% of children in families with less than \$15,000 household income had no special needs, whereas 83% of children in families with a household income of \$80,000 or more had no special needs.



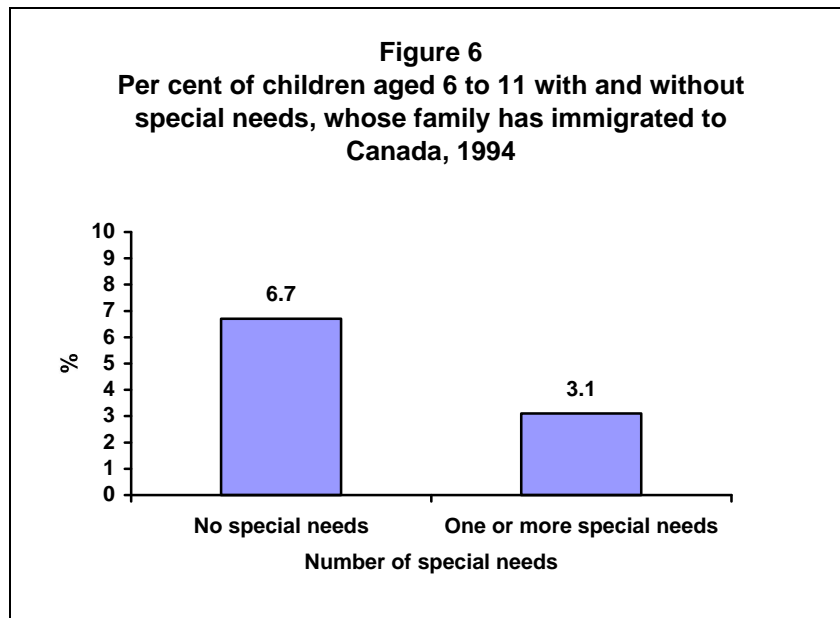
Community

There was no difference between children with special needs and those without special needs with regard to the size of community in which they lived.



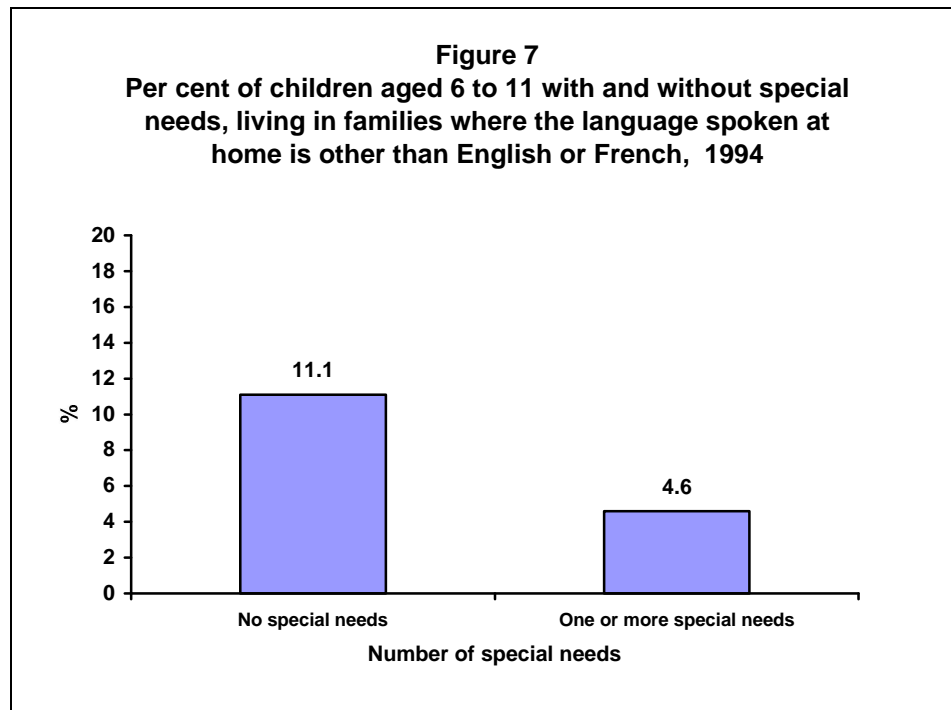
Place of Birth

Children with special needs are less likely to live in families which have recently immigrated to Canada – 3.1% of all children with special needs lived in families which had immigrated to Canada, compared with 6.7% of children with no special needs.



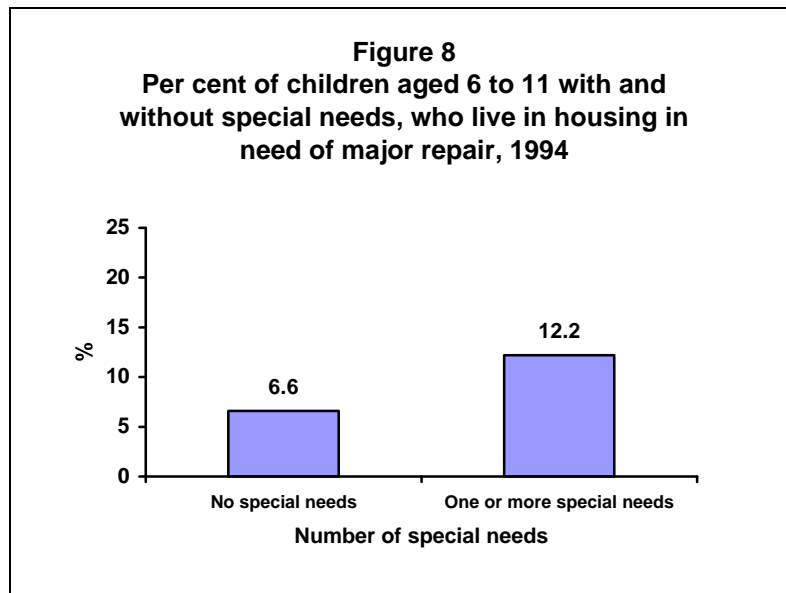
Language Spoken at Home

Children with special needs are less likely to live in families where a language other than English or French is spoken at home – 11.1% of all children without special needs lived in a family where a language other than English or French is spoken at home, compared with 4.6% of children with special needs.



State of Housing

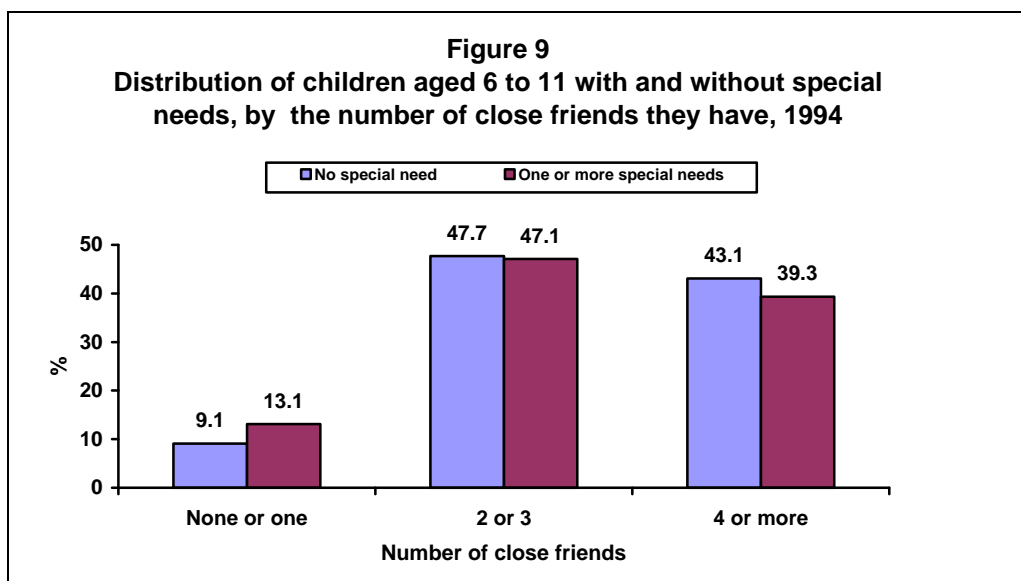
Children with special needs were more likely to be living in problem housing. Of all children with special needs, 12.2% live in housing in need of major repairs, compared with 7% of children without special needs.



Do Children with Special Needs have a Support Network of Friends?

Close Friends

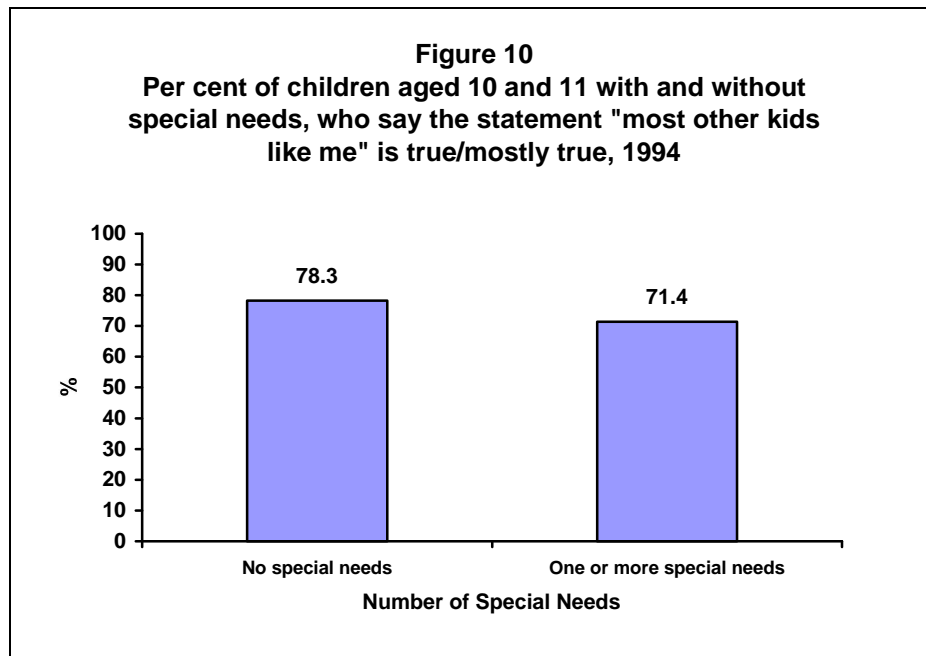
The majority of children with and without special needs have two or more close friends. According to their parents, children with special needs are slightly less likely to have close friends than are children without special needs – 9.1% of all children aged 6 to 11 with special needs were reported as having no close friends or one close friend, compared with 13.1% of those without special needs. Conversely, 43.1% of children without special needs reported having four or more close friends, compared with 39.3% of children with special needs.



Again, when asked, most children aged 10 and 11 with special needs and those without special needs say they have a lot of close friends. However, children with special needs are less likely than those without to report that they have a lot of close friends – 89% of 10- and 11-year-olds without special needs said that this statement was true or mostly true, compared with 82.5% of children with special needs.

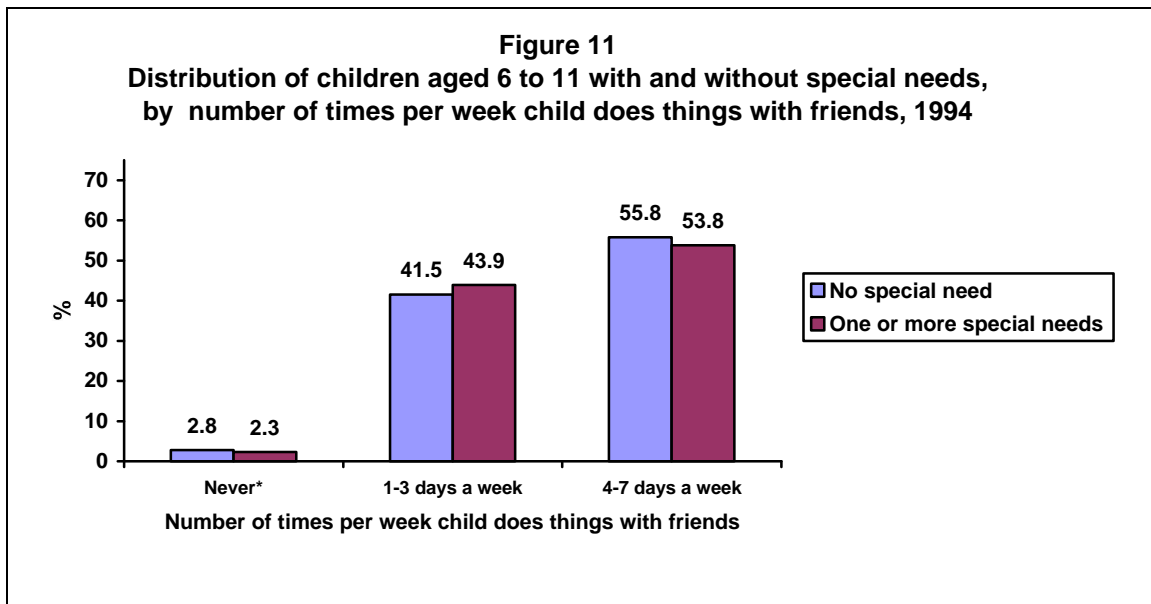
Feelings about Peers

Most children feel that most other kids like them. Once again, however, 10- and 11-year-old children with special needs are less likely to feel that it is true, or mostly true, that most other kids like them. When asked this question, 78.3% of children with no special needs felt that this statement was true or mostly true, compared with 71.4% of children with special needs.



Spending Time with Friends

More than half of all children aged 6 to 11 do things with their friends four to seven times a week. Children with special needs spend just as much time with their friends as do those without special needs – 55.8% of children without special needs spent time with friends four to seven times per week, compared to 53.8% of children with special needs.

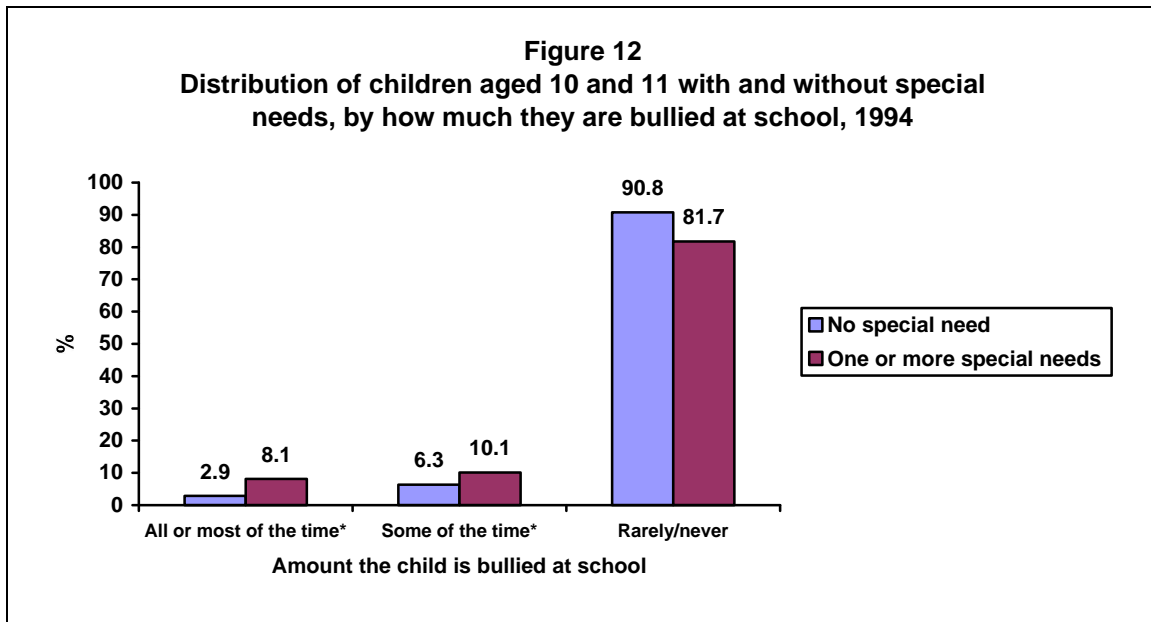


* Marginal – estimates are less reliable due to high variation for children with special needs

Are Other Children Mean to Children with Special Needs?

Bullying

The vast majority of children are rarely or never bullied in school. However, children with special needs are more likely to be bullied – 81.7% of children with special needs reported that they were never bullied in school, compared with 90.8% of children with no special needs.

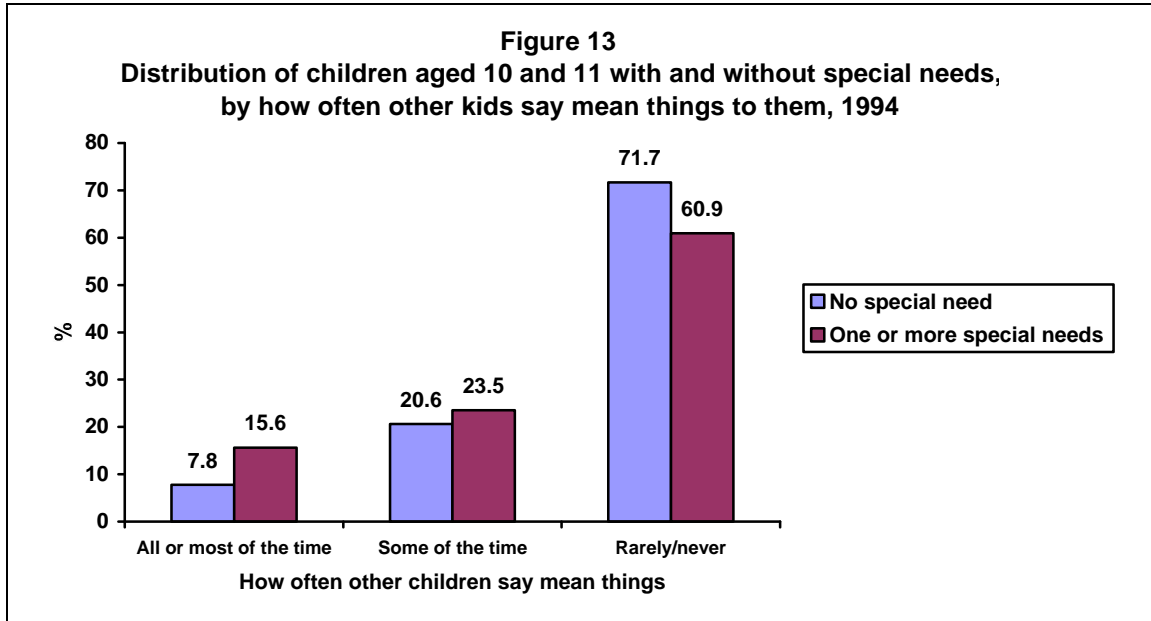


* Marginal – estimates are less reliable due to high variation for children with special needs

Children with special needs are also more likely than those without special needs to be bullied on the way to school.

Children Say Mean Things

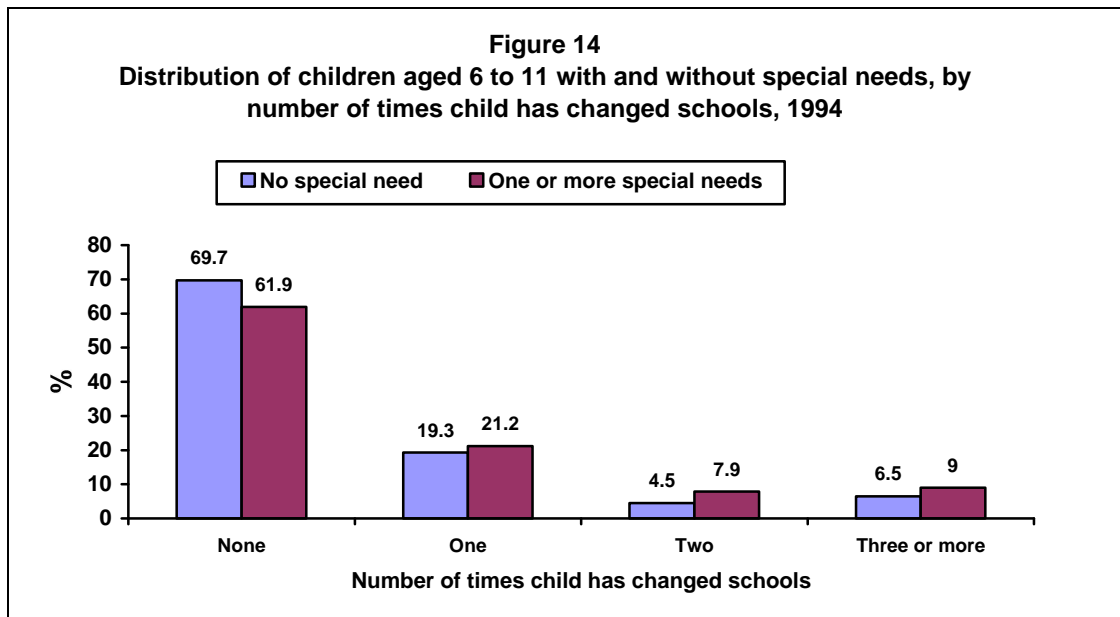
Once again, the majority of children aged 10 and 11 report that children rarely or never say mean things to them. However, children with special needs are more likely to experience this problem. When asked this question, 15.6% of children with special needs reported that children said mean things to them all or most of the time, compared with 7.8% of children without special needs.



What is the Experience at School for Children with Special Needs?

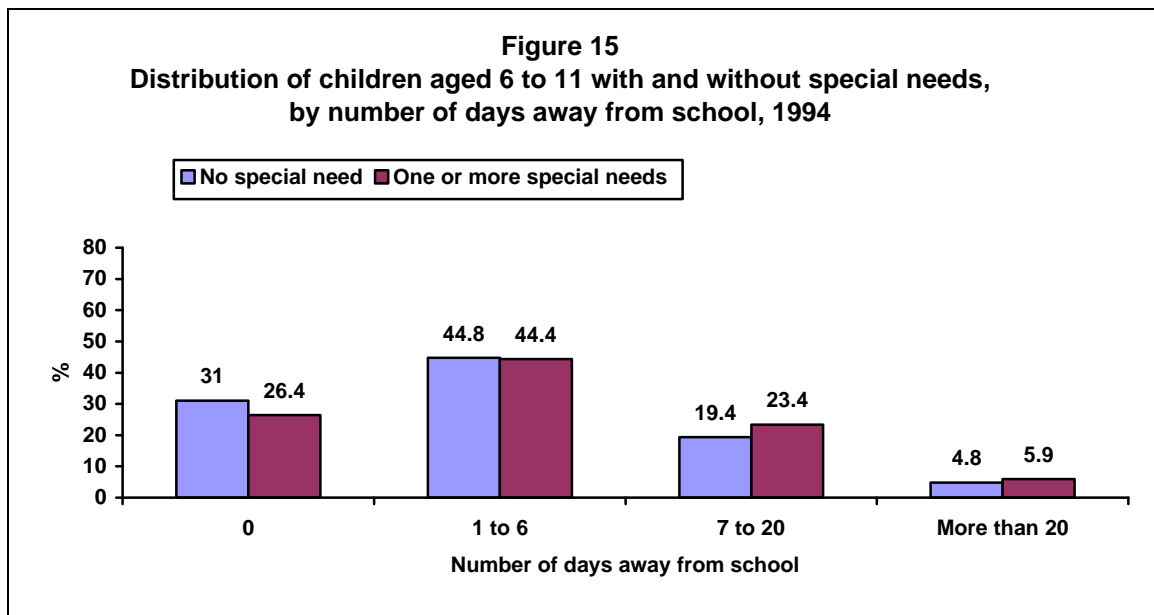
Changing Schools

Children with special needs are more likely to change their school at least once, compared with children with no special needs – 61.9% of all children aged 6 to 11 with special needs had never changed schools, compared with 69.7% of children without special needs.



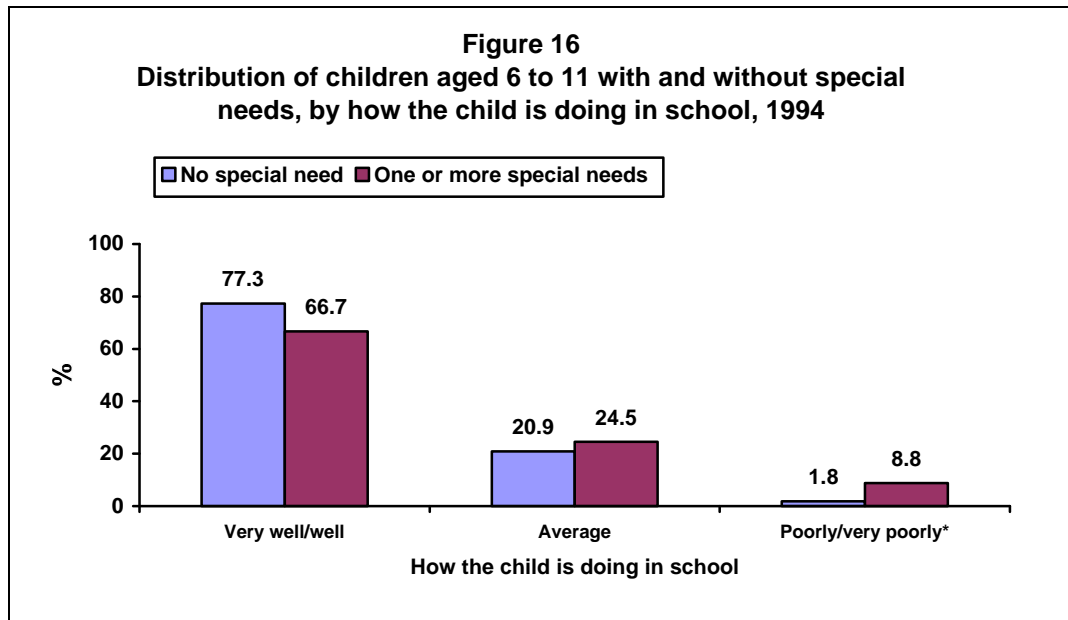
Missing Days at School

The majority of children miss at least one day of school each year. Children with special needs are less likely to have perfect attendance at school, and they are more likely than children without special needs to miss more than seven days. Thirty-one per cent of children with no special needs did not miss any days from school, compared with 26.4% of children with special needs. Among children with special needs, 23.4% missed seven to 20 days of school, compared with 19.4% among children with no special needs.



Doing Well or Poorly in School

The majority of children with or without special needs are identified by their parents as doing very well or well in school. However, 66.7% of children with special needs were reported by their parents to be doing well or very well, compared with 77.3% of children with no special needs. Children with special needs are more likely to be doing poorly in school according to their parents – 8.8% of the children with special needs were reported by their parents to be doing poorly or very poorly in school, compared with 1.8% of children with no special needs.

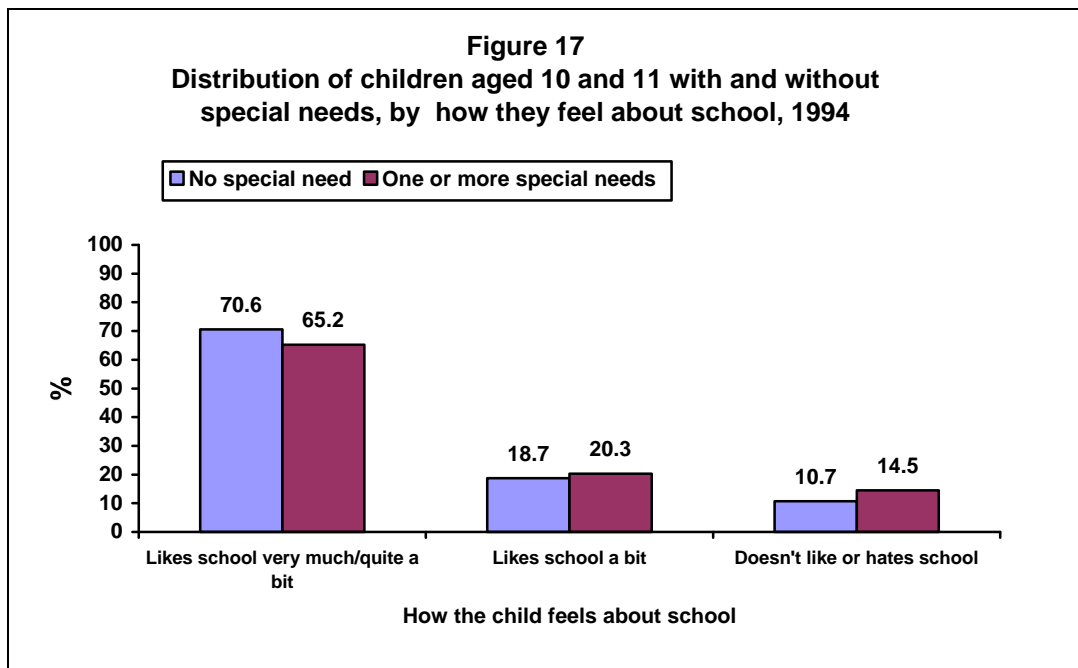


* Marginal – estimates are less reliable due to high variation.

As well, when asked directly, 10- and 11-year-old children with special needs are less likely to report that they are doing well or very well in school than are children without special needs – 69.6% compared 79.6%, respectively.

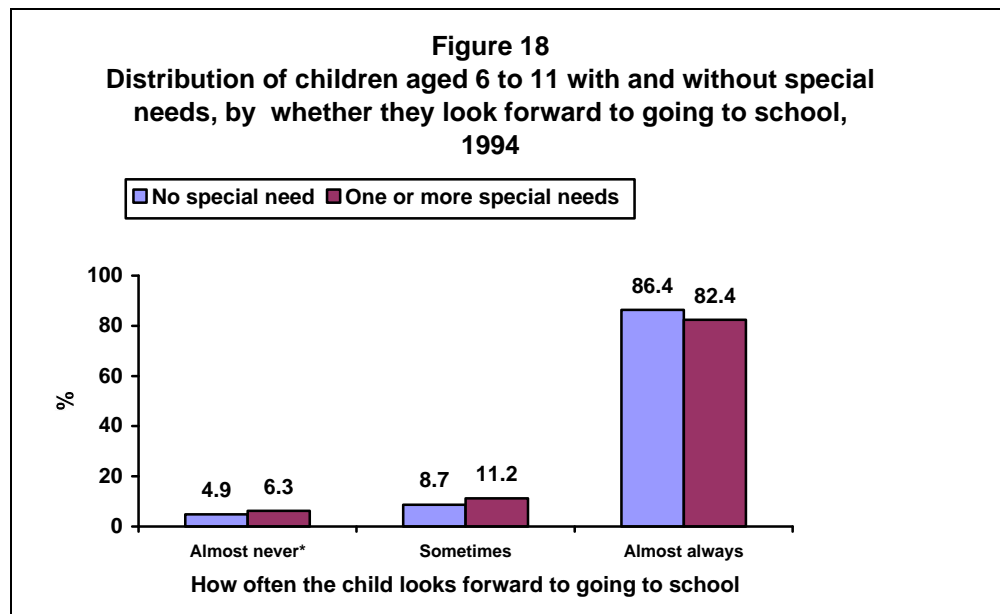
How Children Feel about School

The majority of children like school a lot. However, children aged 10 and 11 who have special needs are less likely to say that they like school a lot, and they are more likely to hate school than are children without special needs. Of all children with special needs, 65.2% said they liked school quite a bit or very much. Almost 71% of children without special needs said that they liked school quite a bit or very much. At the other end of the spectrum, 14.5% of 10- and 11-year-olds with special needs reported that they either didn't like or hated school. This compares with 10.7% of children without special needs.



Look Forward to Going to School

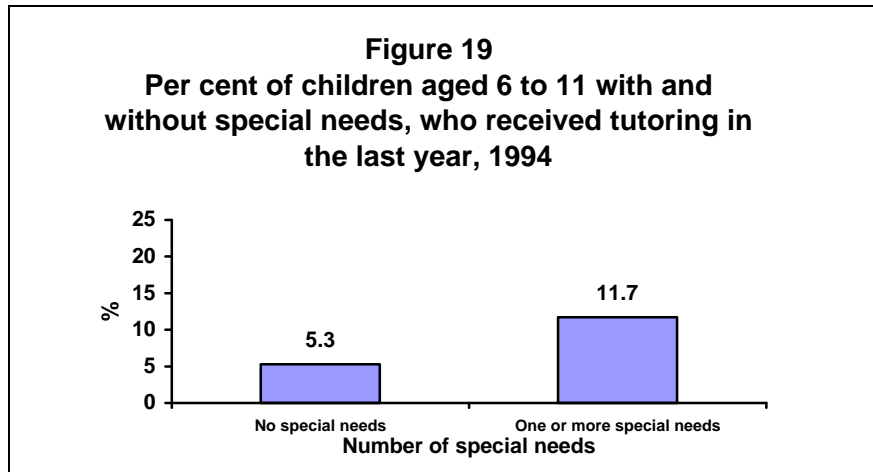
While the vast majority of children almost always look forward to going to school, children with special needs are slightly less likely to look forward to going to school than are children without special needs. According to their parents, 82.4% of children aged 6 to 11 with special needs almost always looked forward to going to school, compared with 86.4% of children with no special needs. When asked, 17.7% of 10- and 11-year-olds with special needs said that they rarely or almost never looked forward to going to school, compared with 15.6% of children without special needs.



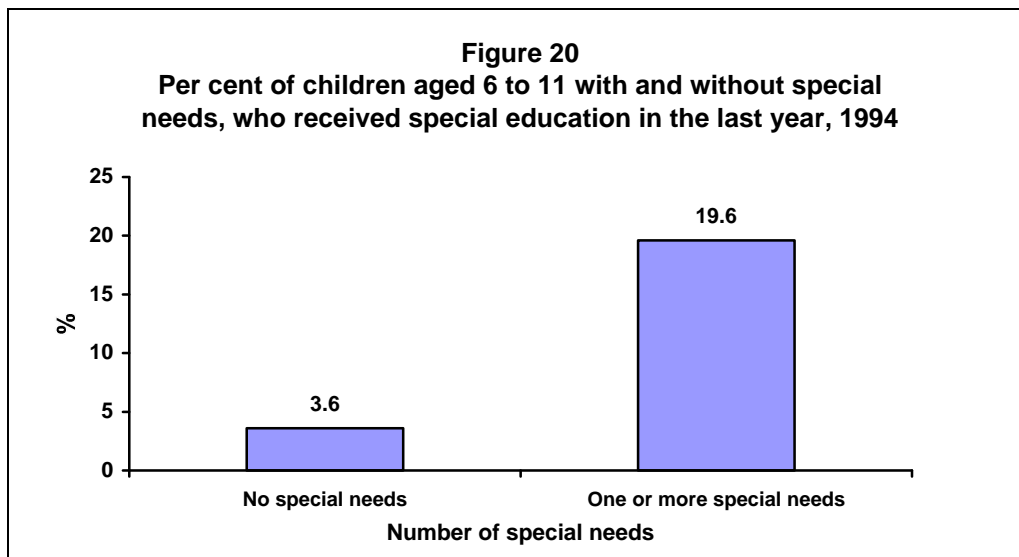
* Marginal – estimates are less reliable due to high variation for children with special needs

Receiving Help with School

Children with special needs are more likely to receive tutoring or extra help than are children without special needs – 11.7% of children aged 6 to 11 with special needs received tutoring/help in the year prior to the survey, compared with 5.3% of children without special needs

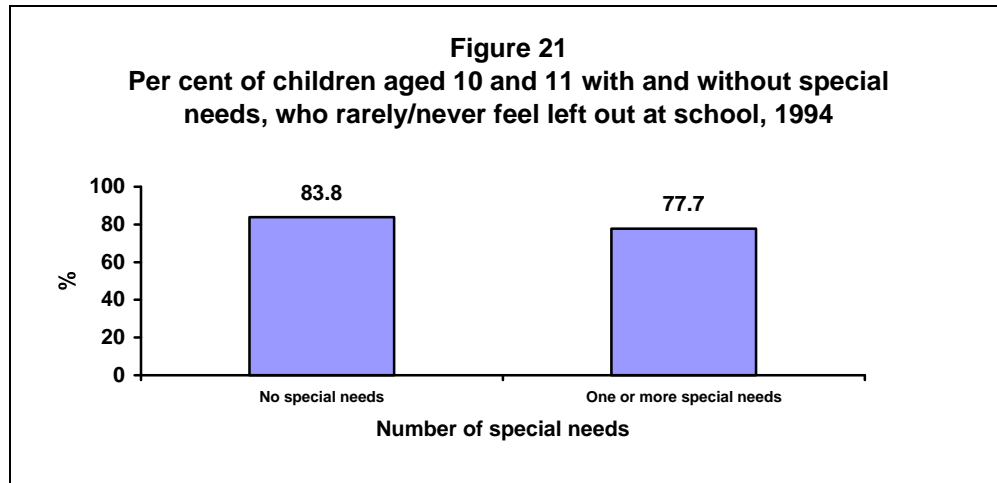


Children with special needs are more likely to receive special education than are children without special needs – 19.6% of children aged 6 to 11 with special needs received special education in the last year, compared with 3.6% of children without special needs

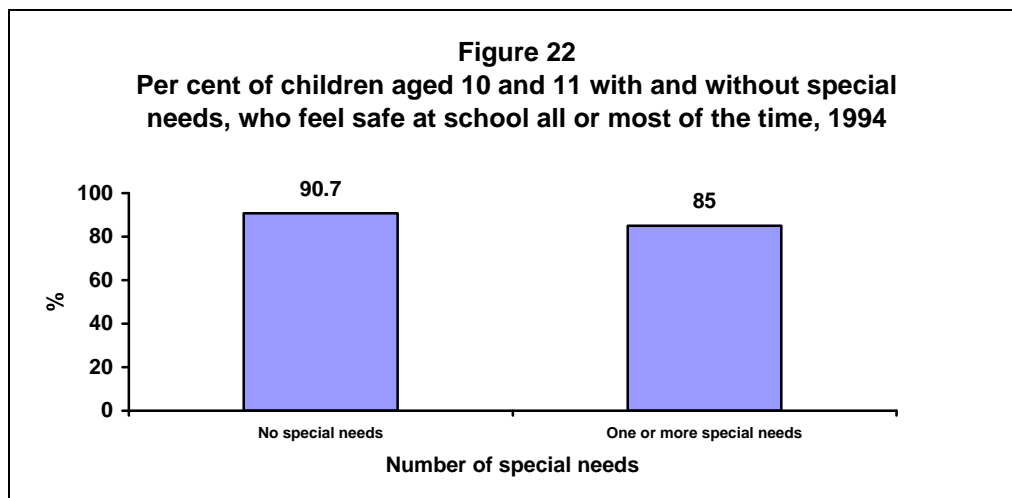


How do Children Feel at School?

The majority of children rarely or never feel left out at school. However, this is somewhat less so for children with special needs – 8.2% of 10- and 11-year-olds with special needs said that they felt left out at school all or most of the time, compared with 4.1% of children with no special needs.



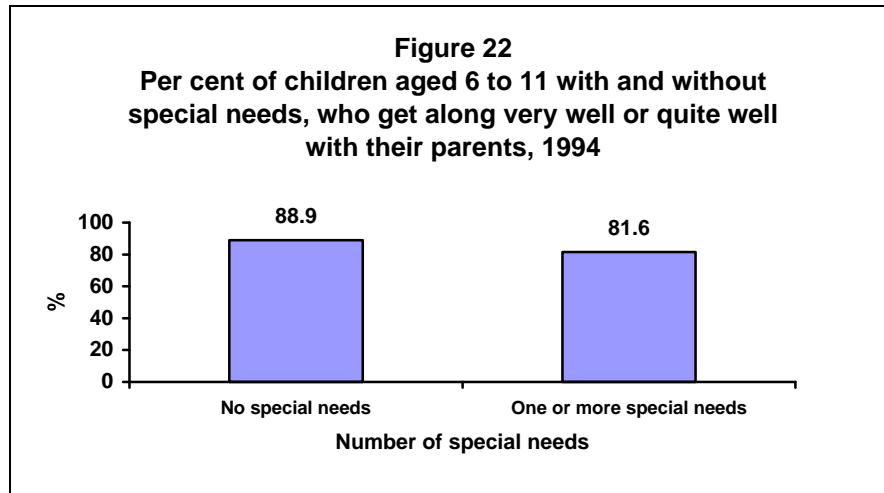
The majority of children, with or without special needs, feel safe at school. However, children with special needs are somewhat less likely to feel this way than are children without special needs – 90.7% of all children aged 10 and 11 without special needs said they felt safe at school all or most of the time, compared with 85% of children with special needs.



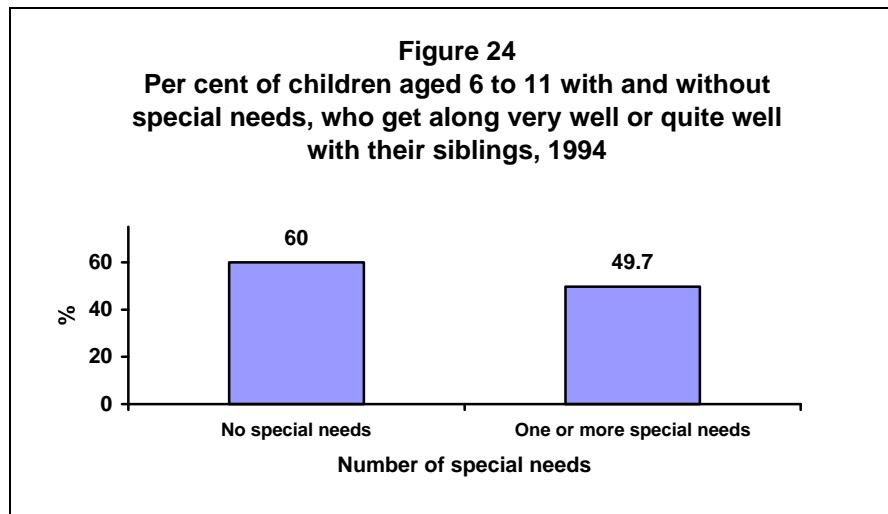
When asked directly, 88.7% of all children aged 10 and 11 without special needs said they felt safe at school all or most of the time, compared with 84.1% of children with special needs.

Relationships with Others

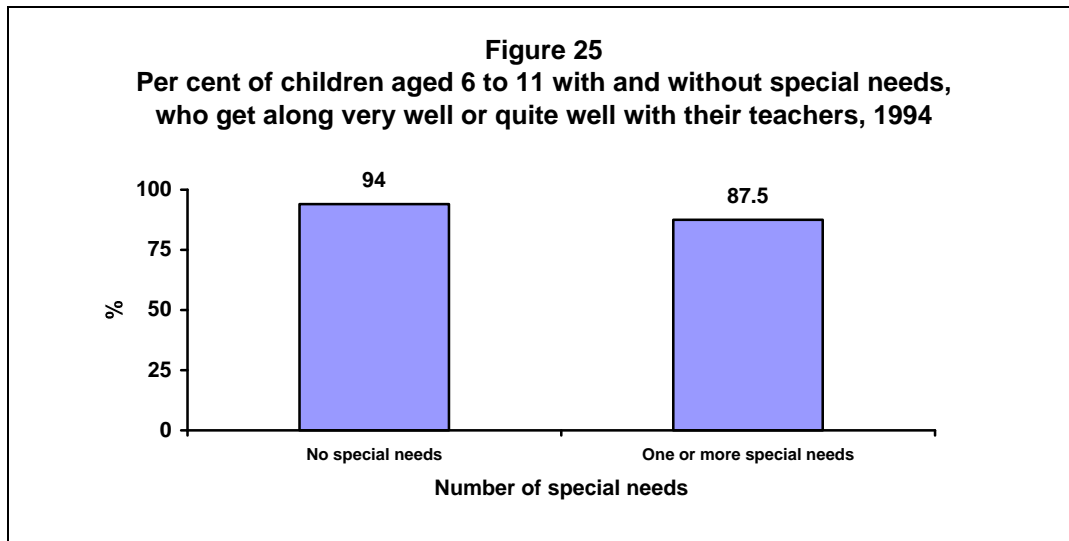
The majority of children get along well with their parents, siblings and teachers. However, children with special needs are somewhat less likely to do so in all three cases: 88.9% of all children aged 6 to 11 without special needs got along with their parents well or very well, compared with 81.6% of children with special needs (according to their parents).



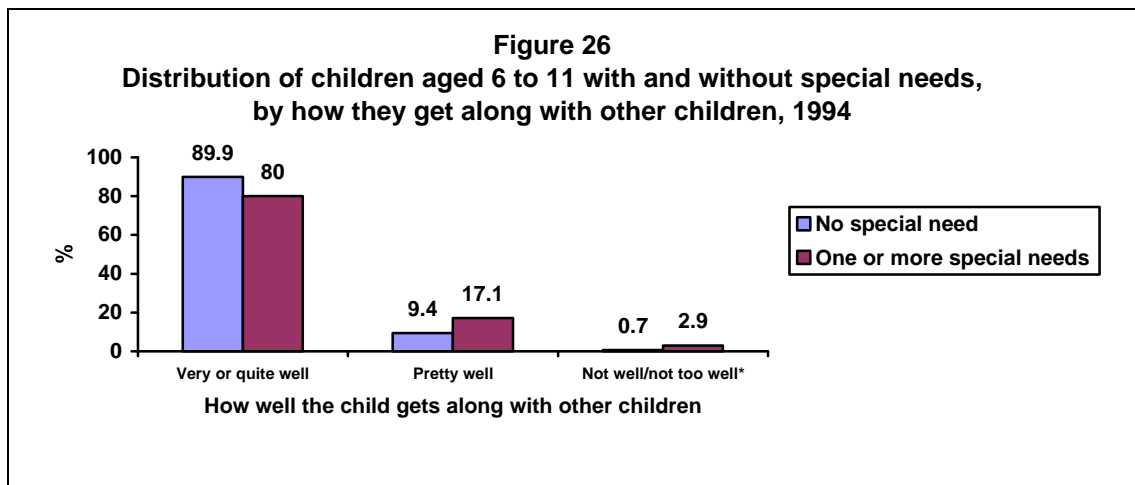
Children with special needs are less likely to get along well with their siblings than are children without special needs – 60% of all children aged 6 to 11 without special needs got along with their siblings well or very well, compared with 49.7% of children with special needs (according to their parents).



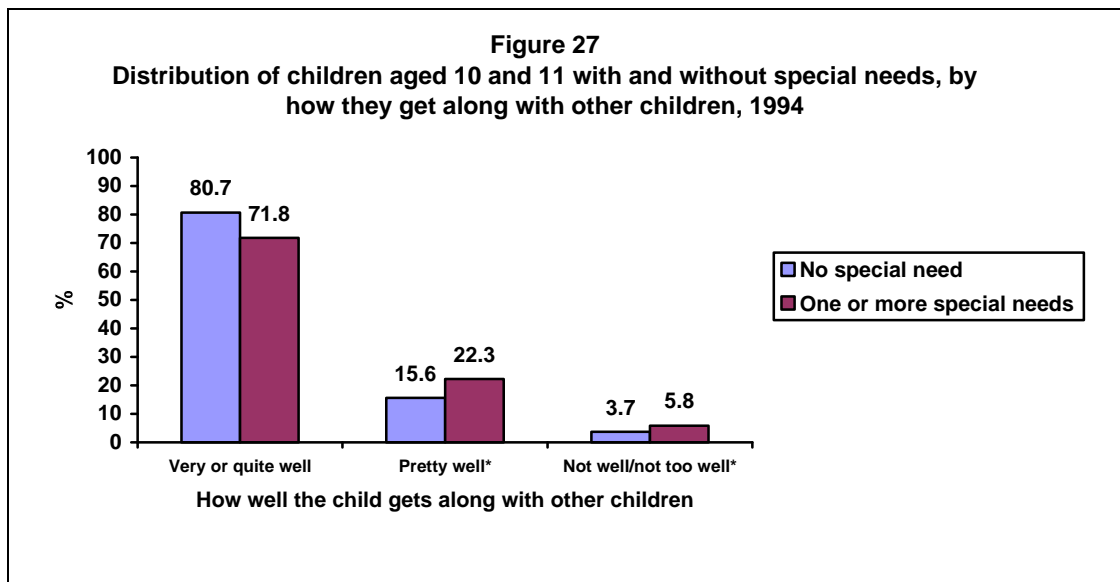
Among all children aged 6 to 11 without special needs, 94% of got along with their teachers well or very well, compared with 87.5% of children with special needs (according to their parents).



The vast majority of children get along well with other children. However, children with special needs are somewhat less likely to get along well with other children than are children without special needs – 89.9% of all children aged 6 to 11 without special needs got along with other children well or very well, compared with 80% of children with special needs (according to their parents). When asked directly, 80.7% of all children aged 10 and 11 without special needs got along with other children well or very well, compared with 71.8% of children with special needs.



* Marginal – estimates are less reliable due to high variation.



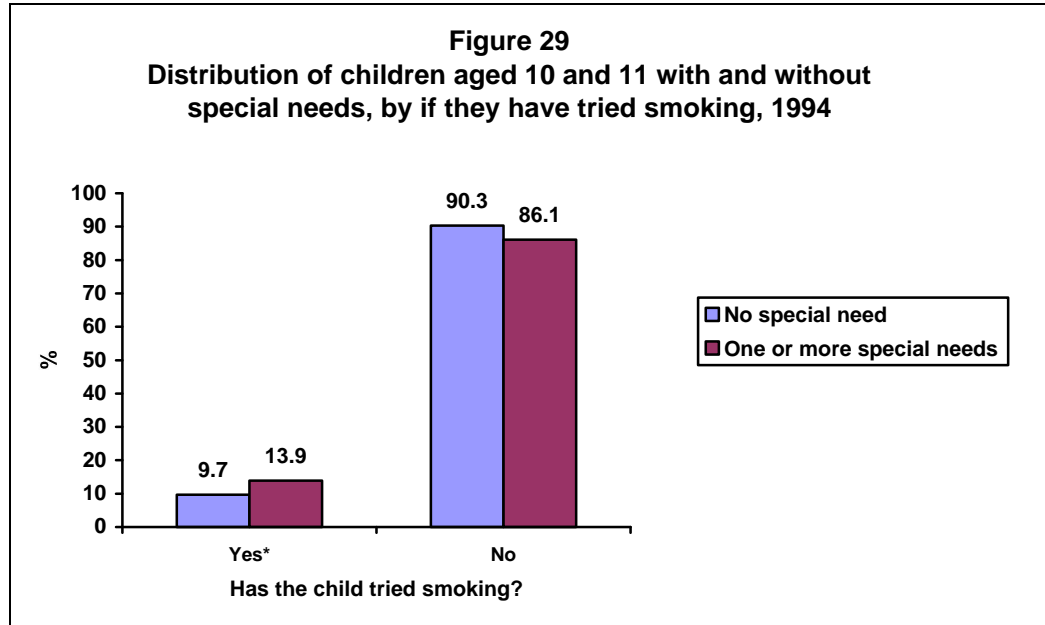
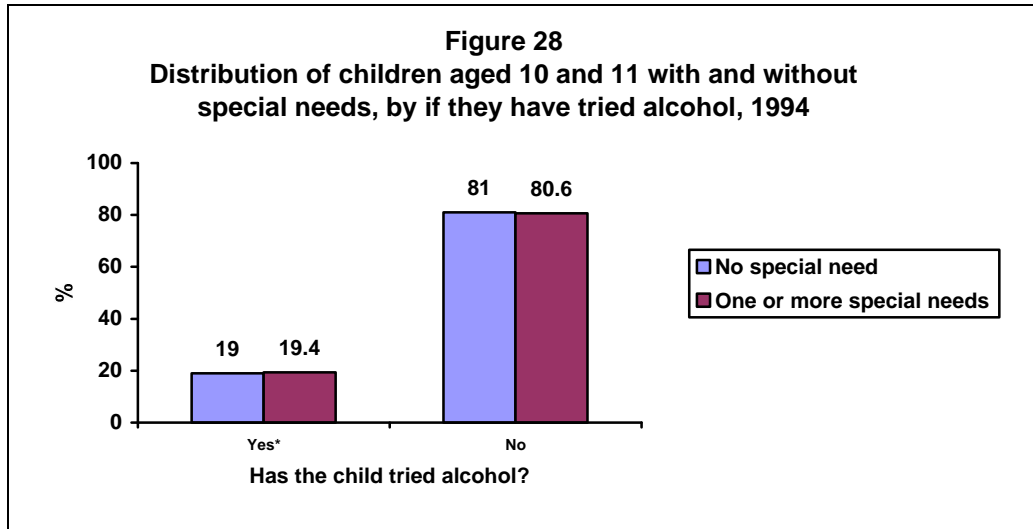
Marginal – estimates are less reliable due to high variation.

Participation in Recreation

Children aged 10 and 11, with and without special needs, are equally likely to participate in recreation once a week or more (98.9%), as are children aged 6 to 11 years (92.5% of children without special needs, compared with 91.6% of children with special needs).

Using Drugs and Alcohol

Children aged 10 and 11 with special needs are no more likely than those without special needs to have tried alcohol – 19.4% versus 19%, respectively. Children with special needs were more likely to have tried smoking – 13.9% versus 9.7%, respectively.



* Marginal – estimates are less reliable due to high variation for children with special needs

Discussion

This analysis of the NLSCY is enlightening in a number of ways. Given this definition of children and youth with special needs, it appears that some of these children and youth are at higher risk of living without a number of the conditions necessary for their optimal development, and they are not integrated and included socially and academically at the same level as their peers. While these differences are small in many cases, they reappear over virtually all of the variables.

The income gradient associated with living with special needs is particularly troublesome. It is well known that families with children and youth with special needs require more, not less, resources to provide their children with optimum conditions for development. While it is impossible to determine cause and effect, it is also interesting to note that mothers (in dual-parent families) of children with special needs are less likely to be in the workforce, and they are less likely to be highly educated. It is also troublesome to see that children with special needs are more likely to be living in problem housing – placing them at double disadvantage.

Socially, it is encouraging to see that children and youth with special needs report having many friends, and that they spend time with their friends. The majority of children with special needs feel that most kids like them. However, once again it is troubling to see that in virtually all of these indicators, children with special needs have a somewhat less positive experience socializing with their peers, and this, at a crucial time in their social development.

Most children with special needs get along well with their parents, siblings, teachers and friends, as do children without special needs. However, it is cause for concern that on all of these indicators, children with special needs score lower than their peers without special needs.

The experience of children and youth with special needs at school is consistently less positive than it is for their peers without special needs. They miss more school, they change schools more often, they perceive themselves as not doing as well at school (as do their parents), they feel somewhat less positively about school, and they are slightly less likely to look forward to going to school. Again, while these differences are not large, they are consistently in the same direction. The good news in school is that they are more likely to get extra help and special education. It is impossible from this data to determine if the amount of help they receive is sufficient.

Finally, it was encouraging to note that children with special needs were not more likely than their peers without special needs to have tried alcohol. However, one in five children aged 10 and 11 had done so! It is worrisome that they appear to be more likely to have tried smoking.

Report of the Survey

To complement the analysis of the NLSCY, the Canadian Council on Social Development conducted a survey of community-based agencies regarding their services for children and youth with special needs. The purpose of this survey was to understand the capacity of community-based organizations to respond to the needs of children and youth with special needs. The survey included two types of agencies. The first were agencies that have a broad mandate to serve all children and youth, including those with special needs such as Boards of Education, Provincial Departments of Education, Provincial Public Health Departments/CLSCs, local/regional Community Health Centres and Municipal Recreation Departments. The second type of agencies were community-based provincial and national organizations which specifically have a mandate to serve children and youth with special needs.

For the purpose of the survey, children and youth with special needs were defined to include: children/youth with physical disabilities; children/youth with chronic physical health problems; children/youth with emotional health problems; children/youth with developmental disabilities; and children/youth with learning disabilities. This was consistent with the NLSCY data analysis.

There were 112 respondents to the survey, a 56% response rate. The following table shows the types of agencies that responded to the survey.

Type of Agency	Number of Responses
Boards of Education	25
Provincial Departments of Education	6
Community-based health agencies	17
Community-based social services agencies	32
Municipal Recreation Departments	20
Provincial organizations serving children and youth with special needs	8
National organizations serving only children and youth with special needs	4
Total	112

There were respondents from all provinces and the Yukon and Northwest Territories. The following table shows the distribution of respondents by province.

Province	Number of Responses
British Columbia	13
Alberta	11
Saskatchewan	7
Manitoba	6
Ontario	35
Quebec	7
New Brunswick	11
Nova Scotia	10
Prince Edward Island	5
Newfoundland	2
Northwest Territories	3
Yukon	2

While the survey does not purport to represent all service agencies in the country, it provides an overview of experiences from a diverse group of providers. Many recurrent themes emerged from this group.

Barriers to Services for Children with Special Needs

The vast majority – 85 agencies, or 76% – responding to the survey reported that there were barriers that impeded children and youth with special needs from accessing services in their community. And the agencies consistently identified the same barriers. The most commonly identified barrier was the lack of availability of trained staff, including specialists, aides, therapists and support workers. Financial barriers were next on the list. This included the families' inability to pay for services, along with the inadequacy of funding available to make the services accessible. Physical accessibility to services in the community was the next most commonly cited barrier. Public and professional attitudes ranked high, with 7.4% of respondents identifying it as a barrier.

Barriers to Services	Per cent of respondents identifying the barrier
Trained staff	23%
Financial	21%
Physical accessibility of facilities	14%
Transportation	9%
Public attitudes	7%
Lack of awareness of services	6%
Geographic	4%
Lack of coordination/communication	4%
Lack of instructional materials	3%
Cultural/language barriers	3%
Families cannot provide support	2%
Volunteers	2%
Children not involved in planning	1%
Other	1%

The agencies surveyed were all working creatively to find ways to enable children and youth with special needs to get the help they needed. While 85 had identified barriers impeding children and youth with special needs from accessing services in their community, all 85 had made efforts to reduce those barriers.

Making Services more Accessible

Many of the organizations surveyed were engaged in practices to help them make their services as appropriate and as accessible as possible to the children and youth with special needs that they served.

Over half of the agencies surveyed (53%, 59 agencies) reported that they had employees and/or volunteers with special needs similar to those faced by the children and youth that they served. Twenty-seven of those 59 agencies stated that they had employees/volunteers from some of the groups that they served, 15 had employees/volunteers from many of the groups that they served, and 11 had employees/volunteers from all of the groups of children and youth with special needs that they served. When asked to specify the capacity in which these employees/volunteers worked within the organization, the agencies reported the following:

	Number with employees/volunteers with similar special needs¹	Per cent of total number of respondents
Direct service providers	43	38%
Advisors to service providers	19	17%
Board members	25	22%
Other capacities	20	26%

¹ Respondents could choose more than one response

Other capacities included:

- Assistant/support staff
- Clerical staff
- Members of committees of board, advisory committees, program committees
- Focus group members
- Support service providers
- Providing public relations for the program
- Conducting fundraising

The vast majority of the respondents (79%, 89 respondents) reported that they provided training to staff on issues as they pertain to children and youth with special needs. When asked if this training was provided for some staff, all staff, or whether it was optional, the respondents reported the following:

	Number of respondents	Per cent of total providing training
Training required for all staff	26	33%
Training required for some staff	35	44%
Training optional	18	23%
Total	79	100%

Among agencies who reported that the training was provided to some staff only, in the majority of cases, the training was given to those employees/volunteers who were directly involved in offering programs to children and youth. These included teachers, teaching assistants, instructors, camp leaders, child care staff, volunteers, and health/social service professionals. Many also included training for program administrators and board members.

The majority of agencies had a system in place to collect feedback from the children and youth with special needs in the communities they served. Sixty-eight respondents, or 61% of all respondents, stated that they had such a system in place. These included both formal and informal approaches. The formal approaches were evaluation surveys, focus groups, and user feedback questionnaires. Informally, providers had regular discussions with participants where they solicited input.

Unmet Needs

The vast majority of agencies surveyed stated that, in their opinion, the children and youth with special needs in their community had needs that were not currently being met by their own organization, nor by any other organization in their community. Eighty-eight respondents (79% of all respondents) stated that this was the case. Respondents were asked to list the top three unmet needs that they had identified for children and youth with special needs in their community. Eighty-six respondents identified one unmet need, 71 identified two, and 49 identified three unmet needs. The most commonly mentioned unmet need was in services for children and youth with emotional problems or mental health services. Next came recreation services and services in the school system.

The following table describes the kinds of unmet needs that were identified:

Type of unmet need	Number of respondents identifying this unmet need
Services for children with emotional problems	24
Recreational services	15
Special education/services in schools	15
Speech/hearing services	14
Limited programming overall	13
Not enough professionals to provide services	13
Early identification/intervention	10
Services for children with neurological/behavioural needs	10
Respite care/support	10
Financial barriers for families/family poverty	9
Rehabilitation services	8
Physical accessibility to facilities	8
Parental/family support	7
Information about programs/advocacy	6
Social opportunities/community inclusiveness	5
Programs/services for teens	5
Services for medically fragile children	5
Programs after graduation/transition programs/life skills	5
Transportation	5
Assistive technology/access to technology	4
Child care	4
Culturally appropriate services	3
Services in remote/rural areas	3
Services for children with learning disabilities	2
Home care/home support	2
Specialized foster homes	1

Respondents were asked whether, in their opinion, these unmet needs had changed over the last five years, that is, had the unmet needs increased, decreased or stayed the same. Forty-three per cent indicated that the unmet needs had increased, 16% said they had decreased, and about one-quarter (27%) said they had stayed the same.

In the last five years:	Per cent of respondents identifying unmet needs
Unmet needs have increased	43%
Unmet needs have decreased	16%
Unmet needs have stayed the same	27%
Unmet needs have increased and decreased	1%
Don't know	13%

Respondents were asked if their resources to work with children and youth with special needs had changed in the last five years. Approximately one-third of respondents reported that financial resources had increased, and a similar proportion reported that they had decreased. Just under one in three respondents reported that financial resources had stayed the same. Four out of 10 respondents reported that their human resources had increased, however this remains the biggest unmet need! One-third reported that human resources had decreased, and just over one-fifth said they had stayed the same. More than half of respondents reported that other resources had increased. The other resources include: websites/information technology, general workload, volunteers, computer equipment, training, physical space and environment, and project-related resources.

	Financial resources	Human resources	Other resources
In the last five years:			
Resources have increased	36%	42%	56%
Resources have decreased	34%	34%	22%
Resources have stayed the same	28%	22%	17%
Resources have increased and decreased	1%	1%	
Don't know	1%	1%	6%

Generally, respondents did not feel that they had the resources they needed to work with children and youth with special needs. When asked if they had sufficient resources to serve children and youth with special needs, 7% said yes, 90% said no, and 3% either did not know or did not answer.

Do you have sufficient resources to serve children and youth with special needs?	Per cent
Yes	7%
No	90%
Unknown/no answer	3%

Discussion

According to the CCSD's survey of 112 Canadian agencies serving children and youth in the community, the needs of children and youth are not being served adequately. There are many barriers to service for these children and their families. Some of them are characteristics of the services themselves, such as inadequate funding; others involve problems facing families, such as inadequate financial resources and an inability to provide support. Still other barriers are community-wide, such as attitudes of the public and some professionals. There are physical attributes that still bar children from services, such as the physical inaccessibility of facilities and the lack of transportation.

The vast majority of these agencies report that they do not have the resources they need to adequately serve children and youth with special needs. This, despite a number of them reporting that both financial and human resources had increased in the last five years. However, these increases are clearly not keeping up with the demand!

What is the result of all of this? A number of unmet needs. One of the most serious challenges facing service providers is the lack of trained personnel. This included professional personnel, such as specialists in mental health services, rehabilitation specialists and special education specialists. It also included a number of other kinds of personnel as well, such as aides, family and child support personnel, and early identification/intervention personnel. Children with mental health problems and those with behavioural difficulties seem to be the worst off. Respondents reported that there were not enough services for these children, both in the community and in the schools. They reported that they did not have enough trained professional staff to work with these children. And they did not have adequate social and recreational services where these children could spend their time.

In light of all of this, agencies are still doing a great deal to try to improve the situation. They are employing, both as paid staff and volunteers, children, youth and adults with special needs. They are offering training to their staff – and in the majority of cases, such training is mandatory. And they are seeking feedback from the children and youth that they serve.

Conclusions

The National Longitudinal Survey on Children and Youth (NLSCY) provides us with further insights into the lives of children living with special needs. Given the definition that was chosen for this analysis – children living with learning disabilities, emotional problems, intellectual disabilities, chronic conditions, activity limitations or physical disabilities – a number of concerns emerge.

A substantial number of Canadian children are living with special needs. Fourteen per cent of children aged 6 to 11 have one of these special needs. However, of more concern, is the fact that seven per cent live with two or more special needs. This means that almost 325,000 children in this age group has on special need, and a further 163,000 live with two or more special needs. These data confirm what other research has identified in the past – such as that done by the Canadian Institute of Child Health and the McCreary Centre Society (CICH, 2000; McCreary Centre Society, 1994).

Furthermore, we have seen that these children face a number of challenges within the social and economic context of their lives. Most troubling in these findings is the association between low income and children with special needs. These findings are corroborated by the recent research of the Canadian Policy Research Networks (CPRN) – Enabling Citizenship: Full Inclusion of Children with Disabilities and their Parents. CPRN concludes that “An adequate income is the first element needed to create positive child outcomes. This research makes clear, however, that parents of children with disabilities face unique financial challenges and, for most, making financial ends meet is difficult” (Valentine, 2001, p xiv).

Children with special needs run the risk of being socially excluded from a number of opportunities that the majority of Canadian children take for granted. This research has indicated that children with special needs are not full and active members of their communities. For example, this is born out in the fact that when compared with children without special needs, those with special needs are less likely to feel positive about school, are more likely to miss school, are more likely to be bullied, and are less likely to participate in recreation. Again, this confirms the research of the Canadian Coalition for the Rights of Children who concluded that “children with disabilities in Canada have varying opportunities to live full lives (Canadian Coalition for the Rights of Children, 1999).

The Canadian Council on Social Development's original survey of 112 Canadian agencies demonstrated that **children and youth with special needs are not being served adequately and that there are many barriers to services for these children and their families**. This results in a number of unmet needs. In their report, the Canadian Policy Research Networks has concluded that "full citizenship demands the easy access to inclusive supports, services and community settings. They argue that the provision of a package of portable and flexible supports targeting the particular needs of children with disabilities and their families must be readily accessible in local communities" (Valentine, 2001, p 68). This is clearly not the case.

Article 23 of the UN Convention on the Rights of the Child recognizes that children with disabilities have the right to enjoy full and decent lives. However, this report has shown us that this opportunity is not fully enjoyed by all children with special needs.

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