

g♥4kidds

Great Outcomes for Kids Impacted
by Severe Developmental Disabilities

Canadian Children with Severe Developmental
Disabilities: A Survey of Health, Well-being and
Social Inclusion



What is GO4KIDDS?

GO4KIDDS stands for Great Outcomes for Kids Impacted by Severe Developmental Disabilities. It was a Canadian, multi-year research program about school-aged **children and youth with severe and complex developmental disabilities**. By this we mean moderate to severe intellectual disabilities, autism spectrum disorders, dual diagnosis, physical disabilities, and genetic syndromes, or combinations of these.

GO4KIDDS included several different studies, using different kinds of research methods, to help us better understand the **health, well-being, and social inclusion** of these children and youth, as well as that of their parents. For more information, see <http://www.go4kidds.ca>



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One aspect of GO4KIDDS involved a **nationwide Survey** asking parents about their children's skills and behaviour, physical health, mental health and behaviour problems, social participation, and well-being. The survey also asked about parents' experiences of the impact on them (both positive and negative) of raising a child with severe developmental disabilities.

Over **400 parents** generously contributed their time to complete the Survey. Some highlights of the results of the Survey are presented in the rest of this booklet. We intended to give a snapshot of the health, well-being, and social inclusion/participation of children and youth with severe developmental disabilities and of the experience of these families.

We believe these results have important implications for our healthcare, social services, and education systems. We encourage widespread circulation of this document to stimulate discussion and constructive solutions by parents and professionals to improve our systems so that all children with severe developmental disabilities may experience Great Outcomes.

Demographics: Who participated in our study?

We contacted over 500 agencies who serve youth with developmental disabilities across Canada and asked them to circulate our invitation flyer to parents and other family caregivers. To be included in the survey, children needed to have a diagnosis of an Intellectual Disability and/or Autism Spectrum Disorder.

Participants



411
caregivers
completed
the survey



12% completed
the French
survey



90%
were
mothers



74%
were
married

Caregivers' age varied, from 24 to 65 years, with an average age of 42.

Where do the participants live?

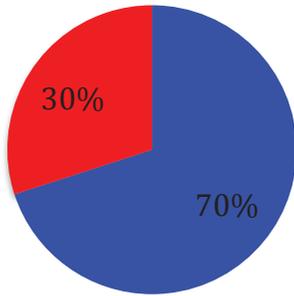


Demographics:

Who were the children in our study?

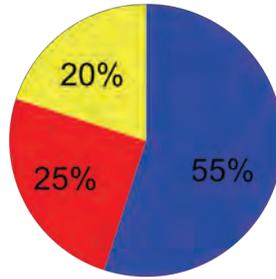
All of the children in the study had a developmental disability.

Child Gender



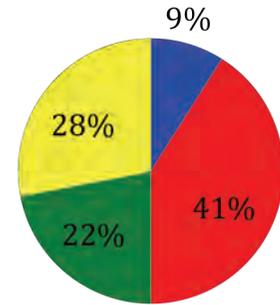
■ Male ■ Female

Additional disabilities



■ ASD ■ Physical Disability ■ Other

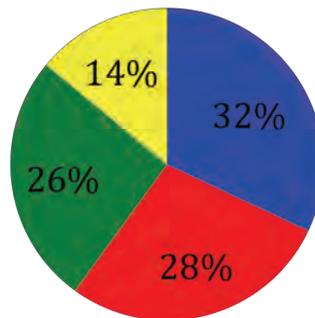
Age Group



■ Preschool age (3-5 yrs)
■ Elementary school age (6-10 yrs)
■ Middle school age (11-13 yrs)
■ High school (14+)

- The children with developmental disabilities ranged in age from 3 to 21 years (with an average age of about 11).
- The sample varied in terms of the level of support that the child required according to their caregivers, with 60% requiring support in most or almost all aspects of their daily lives. This was consistent across all age groups of children. So we were successful in recruiting the sample we intended to study, that is, children with severe and complex needs.

What level of help or support is needed for your child? (e.g., toileting, dressing, eating, etc)



■ Almost all aspects of life
■ Most, but not all, aspects of life
■ Some aspects of life
■ Only a few aspects of life

Child Results:

What did we find out about children's physical health?

We asked caregivers to report on their children's health and health service use.



95% have a primary family doctor



22% have more than 2 medical appointments per year



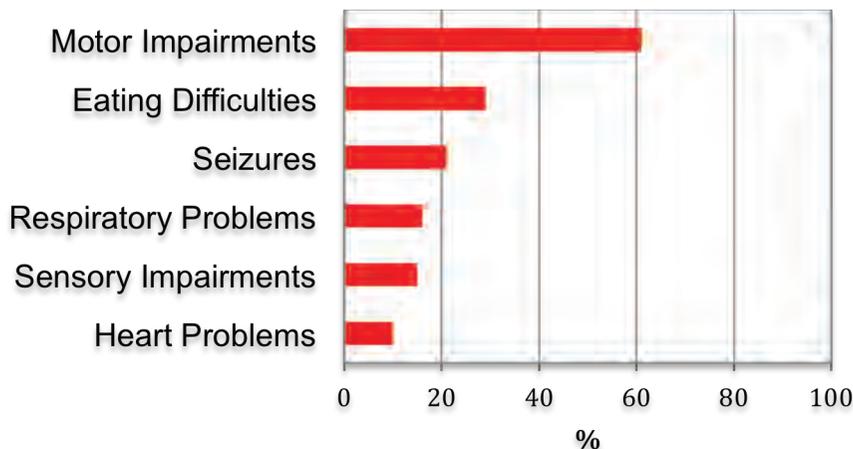
16% have stayed overnight in the hospital in the last year



11% have visited the emergency room more than 3 times in the last year

"He is turning 10 and this is the first year he has been in school full days, the first year he has not been in ER 3 times and the first time in several years he has not been hospitalized."

Other Health Concerns



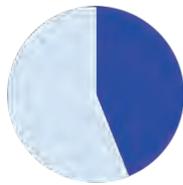
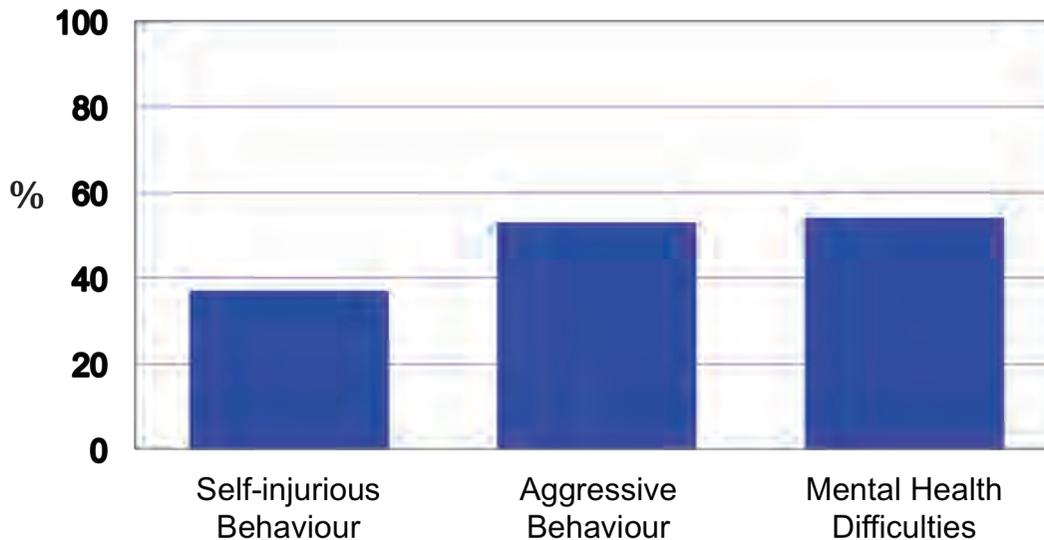
We can support children with developmental disabilities and their families by making sure they have regular access to competent medical care and allied health care. Catching any new emerging problems early is critical.

- Most caregivers consider their children in at least average health, despite the fact that many still experience chronic physical health problems, such as
 - motor impairments (ranging from being extremely clumsy to needing special equipment such as a wheelchair)
 - eating difficulties (ranging from excessively picky to requiring a feeding tube)
 - seizure disorders
- There was a small subgroup of children who used many medical services in the last year, who are the children with the highest level of physical health needs.

Child Results:

What did we find out about children's behaviour and mental health?

We asked how many children regularly experienced the following difficulties.



44% of the caregivers reported that their child has two or more of these difficulties

- Over 50% of the sample regularly displayed either aggressive behaviour or mental health difficulties (like anxiety or depression).
- Rates were higher for children with the additional Autism Spectrum Disorder diagnosis, as shown below.

	With ASD	Without ASD
Self-injurious Behaviour	32%	15%
Aggressive Behaviour	40%	28%
Mental Health Difficulties	55%	35%

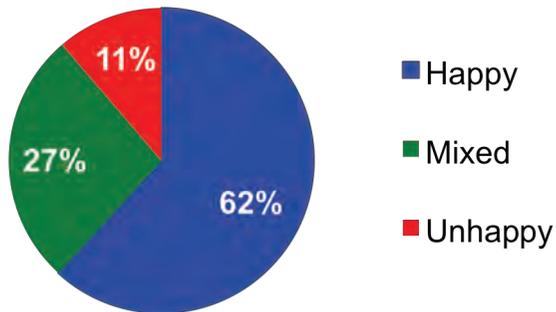
We can support children with DD and their families by making sure that professionals better recognize mental health issues in this population and promote quicker access to appropriate evidence-based interventions. It is crucial to target behaviour problems before they get worse, which will help both children and families.

Child Results:

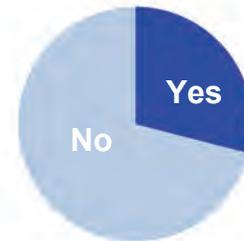
What did we find out about children's well-being?

We asked parents the following two questions about their children.

How happy would you rate your child?



Do you think your child is achieving his/her potential?



Only 29% parents answered yes

- 62% of children were rated as being generally or mostly happy. Unfortunately, almost three-quarters of parents reported that their child was not achieving his/her potential.

"I love my daughter, she is funny and loving and her laugh is the best sound in the world."

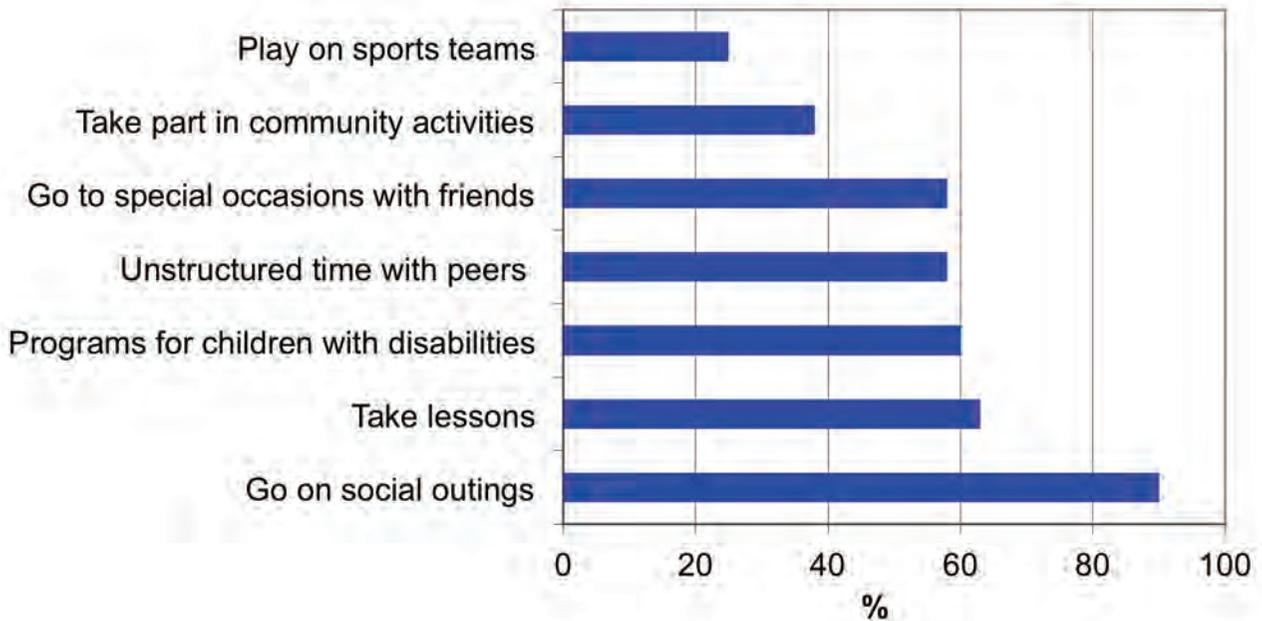
"You need to spend much more time and efforts in things that typically developing children pick up naturally in order to help your own kid to reach his/her full potential."



Child Results:

What did we find out about children's social inclusion?

We asked parents what activities their children participate in.



"Our difficulty is access to recreational services for our son. If we want him to participate (which he can do only in limited ways), we have to drive to other communities. Also, we cannot find respite or other people in the community to work with him i.e., in sports, Sunday school, walks, bike rides. The burden is on us to be everything to him including friend, peer. He is not included in groups or any outings/events outside of school because of both his skill level and his need for 1-1 support."



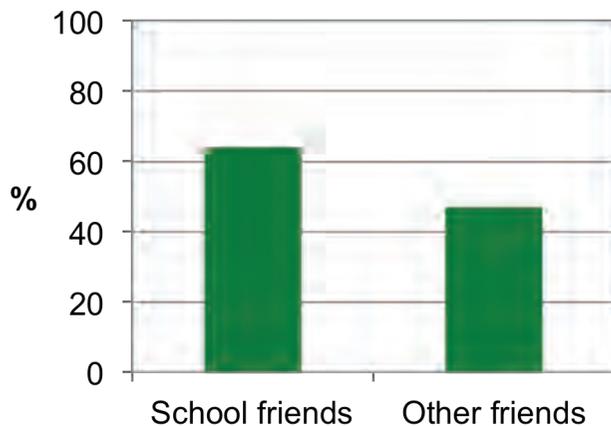
- Most children do participate in social outings in the community, typically with their caregivers present, and many also take structured lessons outside of school.
- It is concerning that over 70% of children are not playing team sports and over 60% are not able to be involved in community activities such as Brownies/Cubs.

Child Results:

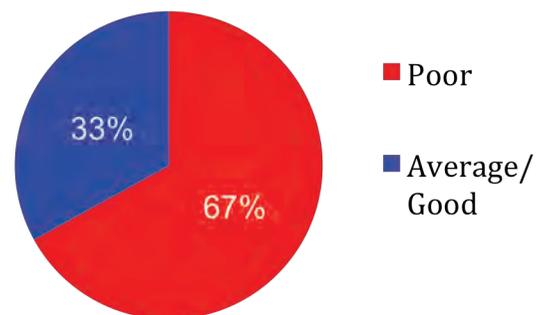
What did we find out about the children's friendships?

We asked parents about the number and kind of friendships their child has.

Children who have at least one friend



Quality of Friendships



- According to caregivers, one-third of the children have no friends even at school and over half the children have no friends outside of school.
- Caregivers often reported that the quality of the friendships that do exist was less than would be expected for children without developmental disabilities.

All children deserve the opportunity to experience meaningful social experiences and friendships in their community. However, some children may need specialized support or adapted community options.

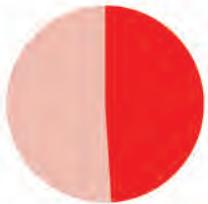


"I feel uneasy judging my son's friendships by society's standards - he may be entirely content with the level of engagement he has with others even if it doesn't look like 'friendship' to some."

Parent Results:

What were the challenges parents faced?

We asked parents about their health, mental health and their experience of burden as a result of caring for their child.



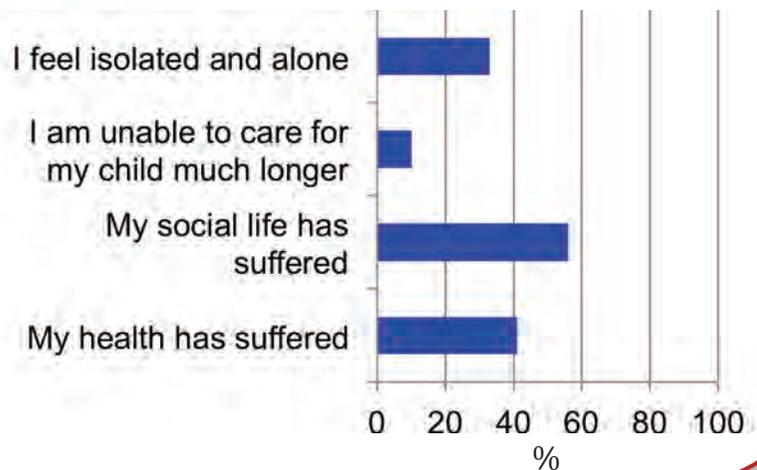
49% of parents reported poor health



41% of parents reported mental health concerns, of which 15% were significant, and 26% were mild



33% of parents reported a high level of burden as a result of caring for their child



“Things that should be simple, like going to the grocery store or getting a haircut or even going to the park become a challenge. I’m good at predicting my child’s behaviour, but I can’t control the world around us so managing these simple situations become like going through a minefield.”

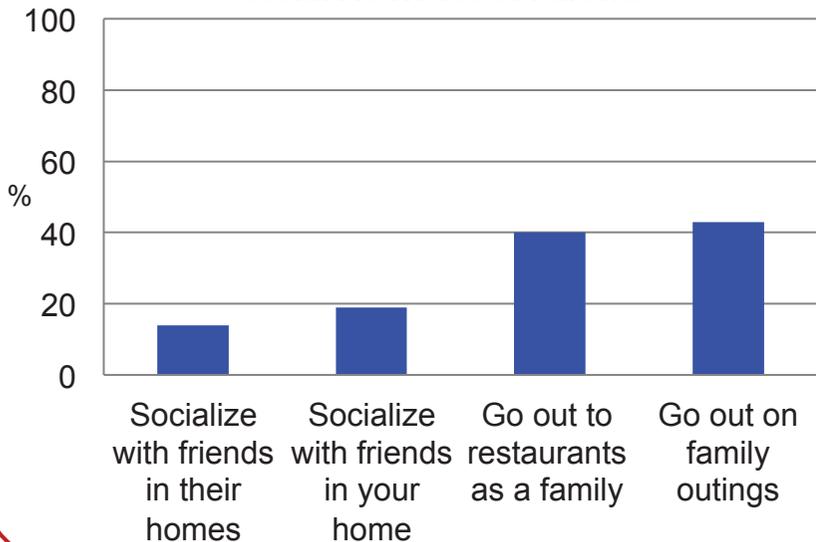
“It has been a hard battle so far, and my son is only ten. We have a long road ahead. I hope it gets easier, but I fear I may be being unrealistic.”

“Not all disabilities are readily visible and we have been excluded from social functions including family events/parties because of our child’s disabilities. We struggle to access services designed for our son’s needs as well as advocate for him within the school system. Every day is a battle to protect his social and emotional well being within society.”

Family Results:

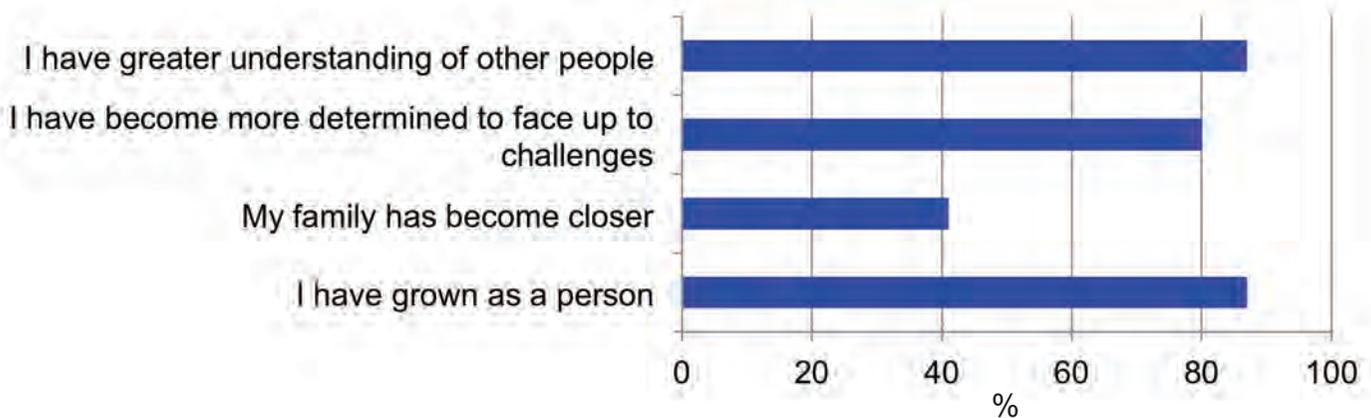
What positive outcomes did families report?

Social Activities of Parents



We can support parents and caregivers of children with DD by recognizing the challenges they face and resilience they possess. We also need to ensure that better supports are available to families when they really need them to prevent crises from occurring.

Positive Gain



In spite of some very real challenges, parents are remarkably resilient, often finding great satisfaction in their lives. Many report gaining a number of positive experiences in raising a child with a development disability. Positive outcomes include bringing the family closer together, becoming more empathic, building more character and becoming more resilient.

“The love that I have for my son is sometimes overwhelming. I must remind myself of how far we have come, how much we have sacrificed, to strengthen my resolve to keep going, and that I am doing the right thing. It is an exhausting labour of love.”

Further information about GO4KIDDS

GO4KIDDS also included three smaller, in-depth studies:

- **The Social Inclusion Study.** This was a multi-method study of children's social inclusion in school and community settings. It included detailed information from direct observations, interviews, and questionnaires across multiple settings.
- **The Family Quality of Life Study.** This study involved detailed interviews of over 60 families about their quality of life across nine domains, using an interview that has been used in many other countries.
- **The Healthcare Survey.** Over 200 parents of youth aged 10-16 completed a detailed survey of services they needed, which ones they used, and how satisfied they were.

Further information about various GO4KIDDS research findings is available on the GO4KIDDS website: www.go4kidds.ca. There is a list of papers and presentations, including links to conference posters.



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