

Examining the Needs of Families of School-Aged Children with an Autism Spectrum Disorder



Summary of Results from the Family Needs Study



The **Family Needs Study** was initiated in 2008 as a way to assess the unmet needs of families who have school-aged children with an autism spectrum disorder.

Recently, a substantial increase in the numbers of individuals seeking autism services has resulted in a strain on the service system in terms of the provision of health, social, and educational supports for those with an autism spectrum disorder. Moreover, many parents of children with an autism spectrum disorder report difficulty finding and accessing services¹.

This lack of support seems to increase once children enter school and, in many regions, no longer have access to early interventions such as applied behavioural analysis (i.e., early intensive behavioural intervention). However, despite these observations, little research has focused on identifying unmet needs among families of school-aged children specifically.

The **Family Needs Study** had two goals:

1. To describe the unmet needs identified by parents of school-aged children with an autism spectrum disorder, and
2. To determine whether a relationship exists between these unmet needs and the level of functioning of the child.

This report contains a summary of the findings of this study.

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In This Summary

- Unmet needs identified by families of school-aged children with an autism spectrum disorder
- The relationship between these unmet needs and the level of functioning of the child

Want more information?

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Disclaimer

The findings and interpretations expressed herein are those of the authors, and do not necessarily reflect the opinions of the Canadian Institutes of Health Research.

About Us

The National Epidemiologic Database for the Study of Autism in Canada (NEDSAC) was established in 2001 with funding from the Canadian Institutes of Health Research (CIHR) Interdisciplinary Health Research Team Program, as part of the Autism Spectrum Disorders—Canadian-American Research Consortium (grant #RT-43820, JJA Holden, Queen’s University). Directed by Hélène Ouellette-Kuntz (Associate Professor in the Departments of Community Health & Epidemiology and Psychiatry at Queen’s University), NEDSAC received an additional five years of funding from CIHR in 2006 (grant #79556).

The **Family Needs Study** was conducted within NEDSAC, as part of a Master’s thesis by Hilary K. Brown (Department of Community Health & Epidemiology, Queen’s University) under the supervision of Hélène Ouellette-Kuntz.

Acknowledgements

We gratefully acknowledge the families in each region who took part in this study. Without you, this study would not have been possible.

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Overall, 499 families were eligible to participate, and **101 took part** (20.2%).

The Family Needs Study

Families were invited to participate through the National Epidemiologic Database for the Study of Autism in Canada, a surveillance program for diagnosed cases of autism spectrum disorders among children in Manitoba, South Eastern Ontario, Prince Edward Island, and Newfoundland and Labrador. Families were also invited to participate through the Autism Spectrum Disorders—Canadian-American Research Consortium, a research registry of families of children with autism spectrum disorders.

Invitees included parents of children who:

- Had a diagnosis of an autism spectrum disorder (i.e., autistic disorder, pervasive developmental disorder-not otherwise specified, Asperger’s disorder, or autism spectrum disorder),
- Were between 6 and 13 years of age, and
- Were living in one of the study regions (i.e., Manitoba, South Eastern Ontario, Prince Edward Island, or Newfoundland & Labrador).

Those who participated completed the Family Needs Questionnaire², the Impact on Family Scale³, the Scales of Independent Behaviour-Revised⁴, service use questions, and several parent and child demographic questions.

Who Participated?

Children in the sample had an average age of 9.5 years and were diagnosed, on average, 4.9 years earlier. The two tables (below and on the following page) describe other characteristics of those who participated:

Child Characteristics	%
Diagnosis on the autism spectrum	
Autistic disorder	42.6
Pervasive developmental disorder - not otherwise specified	7.9
Asperger’s disorder	24.8
Autism spectrum disorder	24.8
Male gender	86.1
Had a secondary disability (e.g., developmental delay, ADHD)	45.5
Taking medication for attention / behaviour problems	40.6



Parent Characteristics	%
Parent Education	
High school diploma or less	25.8
College diploma	37.6
University degree or higher	36.6
Average yearly household income	
Less than \$45,000	27.8
\$45,000 to less than \$85,000	42.5
\$85,000 or more	29.7
Married or common law	80.2
Made changes to employment status to care for child with autism spectrum disorder	65.3
Had more than one child with a disability	19.8

Goal 1: Describe Unmet Needs

Parents rated a list of 51 needs according to the need’s importance and according to whether or not the need was unmet. The top needs are listed below:

I need...	% rated as important	% rated as unmet
for my child’s friends to feel comfortable around my child.	97.0	70.3
information about special programs and services available to my child and my family.	93.1	77.2
the children in my child’s classroom to understand that my child cannot help his/her unusual behaviours and difficulties.	93.1	74.3
for my child to have social activities other than with his/her own parents and siblings.	92.1	78.2
for my child to have friends of his/her own.	91.1	74.3
services continuously rather than only in times of crisis.	89.1	74.3
to have my child’s after-school friends understand his/her problems.	84.2	71.3

Top Unmet Needs

1. Information about services
2. Social inclusion for the child
3. Continuous service provision



Recommendations (Goal 1)

The unmet needs identified here point to areas of the service system which could be improved by either developing new resources or expanding and improving currently existing resources. (See left insert for examples of current efforts which could be expanded or adopted in different regions.)

Examples

Central Location for

Information: “Guide to Community Services in KFL&A Counties for Children with Autism Spectrum Disorders”

(available: www.autismontario.com/)

Raising Autism Awareness in

Schools: Campaign to increase acceptance of students with autism spectrum disorders.

(available: www.togetherforautism.ca/)

Continuity of Support:

“Clinical Navigator” position in United States: works with individuals and families to assess needs and determine which services are needed; provides referrals and help finding resources.

(available: www.alexianbrothershealth.org/)

The unmet need for information is important given that children in the sample were diagnosed with an autism spectrum disorder almost five years previously. It is not only families of newly diagnosed children who need guidance; difficulties finding services persist well into the school years.

- **Recommendation:** Work needs to be done to ensure that the school and the family physician have information about programs and supports that they can effectively provide the family.

Social concerns are especially important to families of school-aged children. Yet, there is an absence of social activities and social acceptance for children in this age group.

- **Recommendation:** School and community programs should focus on facilitating extra-curricular activities and friendship opportunities for school-aged children with an autism spectrum disorder.

The unmet need for continuous service provision reflects an overburdened and fragmented service system. Discontinuity is particularly an issue for families of school-aged children, most of whom no longer have access to time-intensive early intervention services.

- **Recommendation:** Improve continuity of care by appointing a key worker/case manager to families.



Goal 2: Determine Relationship between Child’s Functioning and Parents’ Unmet Needs

It is important to identify child characteristics which may be associated with parents’ level of unmet need. This may help service providers identify children whose families may require increased support. One potentially important characteristic is the level of functioning of the child.

Measures of self-help, communication, and social skills as well as challenging behaviours (self-injury, aggression, repetitive behaviours) were used to determine the child’s level of functioning (low, moderate, or high)⁴.

Definitions

Level of unmet need:

Proportion of important needs which are unmet.

Level of child functioning:

- (1) Deficits in self-help, communication, social skills;
- (2) Presence of challenging behaviours.

Figure 1

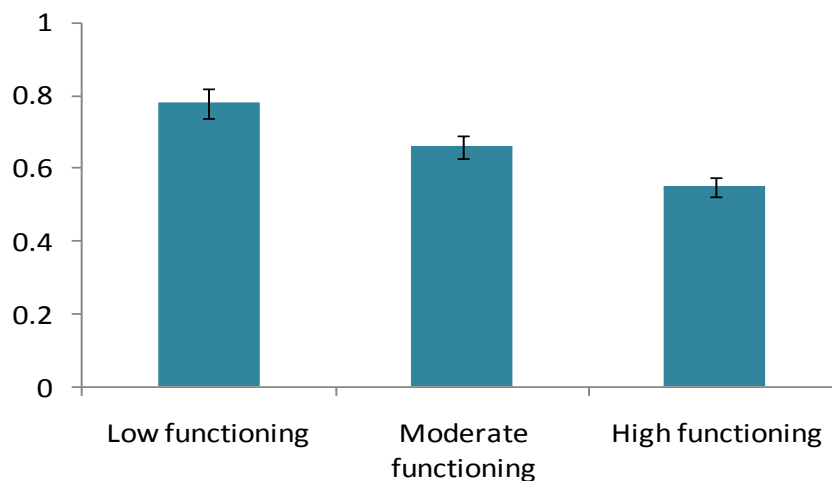


Figure 1 shows the proportion of important needs which were rated by parents as “unmet” for each of these child functioning groups. As the level of the child’s functioning increased, the level of unmet need decreased. This suggests that families of higher-functioning children have the least number of unmet needs.

Impact on the Family

However, the picture is different when other factors are taken into account. Previous research has shown that families deal with a child’s disability in different ways³. Specifically, the extent to which parents feel autism has an impact on the family varies. This is likely to affect the relationship between the child’s functioning and parents’ unmet needs. (See next page.)



The child's **functioning** and its **impact** on the family affects parents' perceptions of unmet need.

Figure 2

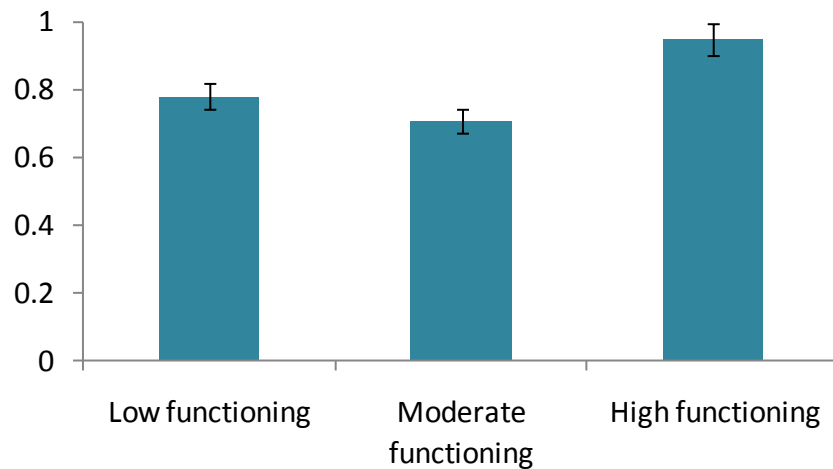


Figure 2 shows the proportion of important needs which were rated by parents as “unmet” for each child functioning group. In contrast with Figure 1, this figure depicts the situation only among families who perceived a high level of impact.

Families who are having difficulty coping with their child’s disability may feel the burden of unmet need more when the child is nearly independent and is not receiving the support he or she needs to fully participate with typical peers in educational, social, or other activities. In other words, there may be sub-groups of families who have high-functioning children but who feel a high level of impact of the child’s autism spectrum disorder on their family. These families may require increased support.

Recommendations (Goal 2)

Assumptions can be made about the needs of a child and his or her family on the basis of the child’s diagnosis on the autism spectrum (e.g., autistic disorder vs. Asperger’s disorder).

However, our study demonstrates that a more useful indicator of family need is an assessment of how the child is functioning as well as how the family is dealing with the child’s disability.

- **Recommendation:** Adjust how eligibility criteria for services and supports are made so that they involve determining how the child and the family are functioning.



References

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3. Stein RE, Jessop DJ. (2003). The Impact on Family Scale revisited: Further psychometric data. *Developmental and Behavioural Paediatrics*, 24(1), 9-16.
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Considerations

One limitation to this study is the fact that only 20.2% of families who were invited to participate completed the study. However, we were able to compare children of parents who participated to children of parents who did not. Overall, children of those who participated were younger than those who did not. Moreover, regions were not proportionally represented. (We therefore do not make regional comparisons.) However, children of parents who participated were similar to those who did not in terms of their gender and their diagnosis on the autism spectrum.

Conclusions

Concern about the welfare of families of children with an autism spectrum disorder has been expressed at the policy level in Canada¹, the United States, and the United Kingdom. This study addressed the need for information about the unmet needs of families of school-aged children with an autism spectrum disorder and about characteristics associated with these needs. Such information may be useful to policy and service planning in prioritizing the improvement of the system of supports for families of school-aged children with an autism spectrum disorder.

Next Steps

We have submitted our results to scientific journals (*Research in Autism Spectrum Disorders* and *Journal of Autism and Developmental Disorders*). This summary is being distributed to Autism Societies, to government agencies responsible for the provision of autism services in each of the study regions, and to the families who participated in the study. If you have any questions or comments about this report, please email nedsac@queensu.ca.

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Full study available: <http://qspace.library.queensu.ca/handle/1974/810/browse?type=author&order=ASC&rpp=20&value=Brown%2C+Hilary>