

# *Challenges associated with the diagnosis of ASD*



# Awareness

***Challenges associated with the diagnosis of ASD: A survey  
on the perspective of parents and individuals diagnosed  
with ASD***

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# Introduction

Calming a [meltdown](#)

<http://www.youtube.com/watch?v=OgfZ8jFxvv>

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# Background

- In a study completed in 2010-2011 parents and individuals with autism spectrum disorders reported that schools had difficulty:
  - implementing appropriate behavioral programs that met their needs and often escalating the behaviors
  - that schools often did not program for learning issues such as written/fine motor issues

# Background

- that schools often did not program for sensory issues or lacked an understanding of how to program for sensory issues
- Lacked an understanding co-existing mental health issues and the impact on the student and their families
- teachers, and staff and administration in the school system failed to prevent them from being victimized (Penney, 2013).

# Current study

- This current study was a follow-up on these themes and attempted to:
  - Validate the themes presented (Penney 2013) by surveying a wider audience and not just those individuals and families with a diagnosis of ASD and mental health.

# Current study

- The study recruited individuals and parents of individuals and explored their school-based experiences broadly and mental health was not the focus.

# Purpose

- The purpose of the research was to survey parents and individuals diagnosed with ASD to determine whether these same themes are found in a broader Canadian population. The research addressed the following four (4) questions:
  - 1. From the perspective/experience of parents and adult diagnosed with ASD do teachers, administrators, and school staff have the appropriate knowledge and skills to implement an appropriate behavior plan to prevent behavioral escalation in the classroom?

# Purpose

- 2. From the perspective/experiences of parents and adults diagnosed with ASD do teachers, administrators, and school staff have the appropriate knowledge and skills to implement an appropriate education plans that addresses learning and sensory needs of individuals diagnosed with ASD?

# Purpose

- 3. From the perspective of parents and individuals diagnosed with ASD do teachers, administrators, and school staff have awareness of the significant risks associated with a diagnosis of ASD and victimization?
- 4. From the perspective of parents and individuals diagnosed with ASD do teachers, administrators, and school staff have knowledge and skills required to prevent students with ASD from being victimized within the school?

# Methodology

- Individuals for this study were recruited through autism societies and autism association across Canada. The researcher asked the society/associations to send out recruitment e-mails to their membership.
- This study was conducted over a 6- month period, commencing in April 2013. It followed a non-experimental survey research design (Kalaian, 2008) and aimed to collect information to validate themes associated with a study examining the experiences of parents of individuals diagnosed with ASD and individuals with a diagnosis of ASD and co-occurring depression and/or anxiety.

- The participants were asked to answer open ended questions regarding their experiences and to complete demographic information. The questions were not specific to the themes as the researcher did not want to bias the participants.

# Methodology

- The researcher used Fluid Surveys and the informed consent was presented as the first page that participants viewed.
- The participants were required to acknowledge that they have read and agreed to participate.
- The on-line survey company, *Fluid Surveys*, hosted the survey (and is located in the Canada and as such is subject to Canadian laws).

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# Methodology

- The data was analyzed using thematic analysis as outlined by (Colaizi, 1978). Thematic analysis is a method used to identify, analyze and report patterns or themes. The aim was to organize and describe the data collected in the study.

# Survey questions

- 1. Describe your/your child's educational experiences ? For example were you educated in an inclusive classroom, a regular education classroom with pull out support, or a special education classroom?
- 2. What was the most significant challenge you've experienced as it relates to you/your child's diagnosis of autism spectrum disorder ? Please describe these experiences.

# Survey questions

- 3. In what ways have the characteristic of Autism Spectrum Disorder affected your/your child's school experiences? Please describe these experiences.
- 4. What things would you like to have teachers, school administrators and other school staff to understand better with respect to Autism Spectrum Disorders?

# Survey questions

- 5. Describe your best school experience for yourself or your child. Describe what was different about that experience that makes it the best experience?
- 6. Describe any relationship experiences you may have had with teachers, school staff or classmates that have negatively impacted you? Please share any information you are comfortable sharing.
- 7. Describe how your individual learning and sensory needs were addressed with your/your child's classroom and school community?

# Current presentation

- This presentation will present the demographic information and the thematic analysis from one of the seven questions asked during this survey:
  - 2. What was the most significant challenge you've experienced as it relates to you/your child's diagnosis of autism spectrum disorder? Please describe these experiences.

# Demographics

- **Appendix B**
- **Demographic Questionnaire**
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- In which province do you reside?
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- Are you a parent/caregiver of a child diagnosed with ASD? Yes—No
- Are you an individual diagnosed with ASD \_\_\_\_\_
- If yes, please indicate your age/ your child's age \_\_\_\_\_
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- If yes, does your child have any addition diagnoses? Please list.

# Demographic

Respondent	Percentage	Count	Partially Completed
Parent/caregiver	83%	68	20* (88)
Individual	17%	8	10* (18)
			Total Number 106

\*The partially completed surveys that contained responses to any of the questions were included in the analysis.

# Demographic (parents/caregivers)

Province	Percentage	Count
Alberta	9%	8
British Columbia	9%	8
Manitoba	1.13%	1
New Brunswick	12.5%	11
Newfoundland and Lab	9%	8
Northwest Territories	2.27%	2
Nova Scotia	7.95%	7
Ontario	36.36%	32
PEI	2.27%	2
Quebec	1.13%	1
Yukon	1.13%	1
Not identified	7.9%	7

# Demographic: Individuals

Province		Percentage
Alberta	3	16.6%
British Columbia	1	5.5%
Ontario	8	44.4%
Quebec	1	5.5%
Not identified	5	27%

# Theme 1: The individual

- The first theme was within Child/Individual characteristics; social, sensory, behavioral and learning.

# Quotes

- “Difficulty with social situations in non-structured times, difficulty with transitions and is misunderstood and gets into trouble everyday for behavior, has been suspended” (P2)
- “Challenges with emotional regulation, disorganized, unable to keep track of things, loses things, overly sensitive to environment (catastrophic reaction to sounds, being touched, not being able to read social situations=gets bullied and made fun of)” (P4)

# Quotes

- “An extreme flight risk, everywhere we go, she wants to run off” (P5)
- “Her aloofness made her seem ‘mean’ and ‘unfriendly’, she disliked circle time and having people sit close to her” (P7)
- “He had such a hard time fitting in with his peers. He is a gentle guy and gets teased a lot. He is fearful and scared” ) (P.8)

# Quotes

- “Emotional regulation and getting back under control after a disappointment, meltdown..”(p.9)
- “My son has significant communication, fine motor difficulties” (P. 10)
- “Sensory issues play a big part of keeping regulated, focused, he does not like to do anything that involves fine motor” (P.12)

# Quotes

- “lack of social interaction ability with peers, (Asperger’s) lack of play with other kids, social isolation” (P. 14)
- “Difficulty with social situations (conversation, making and retaining friends, inclusion, etc.), challenges with transitions, challenges with persistent, difficult behavior such as perseverating, sensory challenges and sensitivities, learning difficulties i.e. reading & following materials on the board, intrusive thoughts.....”(P17)

## Theme 2: Within Family`

- The second theme was within Family, marital stress, stress on other family members, extended family acceptance and interference, and the isolation of families as a result of the diagnosis.

# Quotes

- “lack of privacy for the family in that he was identified at an early age and a plethora of professional visited our doorstep daily, for years, the added burden of doing wife-work, initiating the diagnosis against my husband’s wishes, initiating and organizing treatments, enacting the treatments, meeting with professionals daily, IPP meetings, school meetings, play date orchestration with willing families and peers, in some way, shape or forms teaching my son all day everyday in ways most parents are not called upon to do with such intensity” (P.64)

# Quotes

- “dealing with the sadness of loss of expectations for him to have a life we envisioned. Relief that we knew what was wrong. Self-blame that I somehow caused him to have this problem” (P.18)
- “Family found it hard to understand and/or accept. Some still do not accept the diagnosis. Some do not know how to relate to my son.” (P. 25)

# Theme 3: Public Services

- The third theme within Public Service, included getting an initial diagnosis, finding qualified professionals (including doctors and dentists), long waitlists for services, lack of guidance provided in the treatment of ASD, and the expense associated with using private services

# Quotes

- From a parents of a child aged 5.5
- “Initially getting a diagnosis was a major issue. The doctor would not listen to me that there was an issue. We didn’t get a diagnosis until he was 5 years old and we were unable to get early intervention...” (P. 28)
- “I find doctors and dentists also lack an understanding of the special needs of ASD kids” (P. 25)

# Quotes

- “Getting an initial diagnosis, then looking for help...feeling overwhelmed by the massive amount of information on-line, all the “cure” and controversy, division between the medical and naturopathic/alternative treatments options. Feeling isolated from family and friends while trying to figure out how to handle our child” (P. 44)

# Quotes

- “I literally had to research on the internet to determine for myself which specialists and then get an autism diagnosis” (P. 49)
- “Having to pay for a year of therapy out of pocket because of an arbitrary age deadline for provincially funded services (missed by 8 days). That has now been corrected in NB but too late for us.” (P.21)

- “Not knowing what to do in the beginning....getting overwhelmed by “cures” on the internet. It would be great if there were a doctor or other professionals who specialize in autism that parents could go to for periodic check-ups...as you would with other illnesses...eventually you end up winging it and hoping you are on the right track” (P. 21)

# Theme 4: Within Community

- The fourth theme is within Community, access to recreation, access to community groups (for example going to church), obtaining appropriate child care, and attending community events.

- “Going out with both my kids-twins one with autism and one with sensory issues.”
- “Other parents of [my child’s] classmates have not always been as understanding (P. 25)

# quotes

- “lack of before and after school special needs care, resulting in our dependence on social assistance” (P. 20)
- “Social isolations for the family, it’s so hard to go to social functions, church, etc. even visiting our family” (P.22)

# Quotes

- “My child has issues with transitions and public events. We have gone from being very involved in the community to being housebound or we “divide and conquer”(P. 27)
- “In the community things like soccer leagues, swimming lessons are difficult as there are not usually accommodations for special needs” (P. 25).

# Theme 5: Within School

- The final theme, within school, suggested a lack of teacher knowledge about autism, school staff's difficulty dealing with behavior associated with autism, understanding the unique learning and sensory difficulties are cited as issues.
- Bullying was raised by a couple of families for this question but it is a more dominant theme for other questions used in the survey.

# Quotes to support the theme

- “The teacher did not want to learn about ASD or work with us” (P2)
- “The principal admits lack of knowledge and does not know how to deal well with situations, we have witnessed the principal yelling at our son, 3 inches from his face, all because of her misunderstanding. She apologized. We lost our suspension appeals all because the trustees felt our son was smart and should know better” (P2)

# quotes

- “We had to advocate for inclusive bussing in order to travel to and from school with friends and family. Numerous consultative supports have been provided, we have always encouraged services to be offered in class. School staff sometimes have a limited knowledge on how to adapt the curriculum and assess with his physical and communication challenges. Many meetings and advocacy roles have been necessary and difficult for family members”(P16)

# quotes

- “Difficulty with transition, challenges with persistent, difficult behaviors such as perseverating, sensory challenges...learning difficulties i.e. reading & following material on a board...self-stimulating behavior, talking to hands, making noises, talking to self etc.” (p. 17)

# quotes

- “despite hours and hours of meetings, professionals from (Name of organization) to drill home to the school what our son needs to succeed at school, he ended up being forgotten and only received sporadic assistance when ‘remembered’ or when it was so extreme, it was obvious he was struggling and failing. For example he has severe fine motor delays and only when he became so frustrated in a test would they remember that he was allowed either more time in a separate room to finish or give answers orally” (P 25)

- “also resources at school, once provided were not fully appropriate. The EAS (Educational Assistant Staff) while nice and dedicated, have NO AUTISM TRAINING (even though the bulk of their kids with special needs have autism spectrum disorders). And teachers, even the good ones, know next to nothing about autism” (P26)

# quotes

- “They denied him services in the X (Name of Program) from the Y (Name of School) so it is impossible for a parents with a kid with autism to get a real job because of the timings, and the constant phone call from school to come and pick up my kid. The used to call me quite often, at one point they used to call me everyday (I have it documented) to pick him up, but they didn’t see a pattern...I could go on the whole night”

- “Getting adequate supports at school for educational issues. Transitioning from grade to grade, from elementary to junior high. Teachers lack knowledge about autism” (P.55)
- “Bullying was not dealt with properly”. (P. 42)
- “Little education on behalf of the school staff in sensory and behavioral needs, adapting learning styles and using different tools to facilitate learning styles. Lack of allowing outside professionals to assist in the school setting” (P. 24)

# What's next

- Research into teacher's knowledge of autism-ethics approval and now waiting on School Board ethics
- Currently putting together a cross country team to investigate the family school relationships and hope to develop mentoring programs for teachers and in-services for parents.