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## Background

- Obtaining a diagnosis for a child with a developmental disability (DD) is often challenging and for children with autism spectrum disorder (ASD), may be even more difficult (Nissenbaum, Tollefson, & Reese, 2002).
- Current literature suggests that parents' experiences of the diagnostic process have been largely negative (Mansell & Morris, 2004; Osborne & Reed, 2008; Siklos & Kerns, 2005).
- To date, there has not been a large-scale cross-Canada study of the experiences of parents with the diagnostic process.

## Research Questions

1. Is there a difference between the reported experiences based on:
  - child characteristics (diagnosis of DD vs ASD)?
  - demographics (SES, geographic location, immigration status)?
2. What are the experiences of Canadian parents with the diagnostic process?

## Method

- Over 500 agencies who serve youth with DD were contacted all across Canada and asked to circulate our invitation flyer to parents and other family caregivers.
- Inclusion criteria: children needed to have a diagnosis of an Intellectual Disability and/or ASD.
- This nationwide survey asked parents about their children's physical health, behavior and mental health, social participation and wellbeing. The survey also contained questions asking parents about the positive and negative impacts of raising a child with DD.
- Questions specific to the diagnostic process were examined both qualitatively and quantitatively.
- The Barratt Simplified Measure of Social Status (Barratt, 2006) based on Hollingshead's scale (1975) was used to calculate socioeconomic (SES) scores

## Participants



### Parent characteristics:

- N = 208 parents
- 91.5% biological mothers
- 84.9% reported English or French as their first language

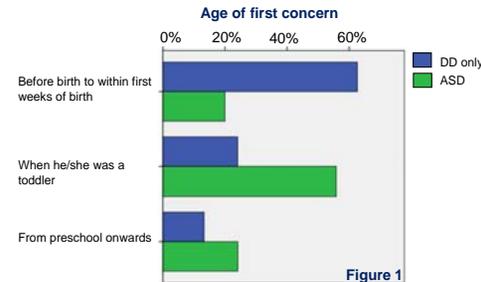
### Child characteristics:

- N = 208
- 71.6% boys
- age 4-19, M = 11 years
- n = 122 (58.7% in ASD (+DD) group)
- n = 86 (41.3% in DD group)

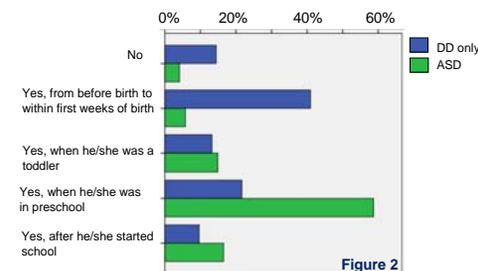
## Results

### Quantitative Results

1. Based on the data collected, differences were found between parents with children DD and ASD. No significant differences were found in parent experiences based on community size, country of birth or Barratt SES scores.



### Has your child received a clear diagnosis by a professional or multiple professionals?



- ASD groups were more likely to report a later age of first concern when compared to DD groups ( $\chi^2(2, 203) = 38.34, p < 0.001, V = 0.44$ ). See Figure 1.
- ASD groups were also more likely to receive a clear diagnosis at a later age ( $\chi^2(4, 204) = 53.85, p < 0.001, V = 0.51$ ). However, DD groups were more likely to not have a clear diagnosis. See Figure 2.

### Qualitative Results

2. Parents were asked to answer the following open-ended question:

**Please add anything else about the process of getting a clear diagnosis for your child.**

Waiting Times

- Frustration
  - Multiple Doctors/Tests
- "Getting a diagnosis took too long- so many hoops to jump through and long waiting lists."
- "It took 5.5 years to get as many of the pieces as we have now, but he is scheduled for further testing this summer."

Parent-Professional Relationship

- Positive
  - Early communication
  - Collaboration
  - Negative
  - Lack of knowledge from Professionals
  - Disrespect
- "We were given as much information as the doctors had in a timely manner. Although it is a difficult process, we were informed all along the way and were cared for in a sensitive, caring but informative way."
- "We saw our pediatrician who connected us with the developmental doctor who diagnosed us. The two worked nicely together."
- "I asked my family doctor about possible Asperger's. His answer...What's Asperger's again? "
- "It took 5 years to find a doctor who would listen to my concerns that there was something wrong with my child. From the day of birth to age 5 was a battle. "

## Discussion

### 1) Parents of children with ASD

- Parents of children with ASD were likely to report a later age of first concern as well as a later age of diagnosis. However, the DD group was more likely to report not having a clear diagnosis.
- The ASD group was more likely to find the cause of the diagnosis stressful. Since ASD does not have clear biological markers, the ambiguity of the cause may contribute to parent stress.

### 2) Waiting Times

- Parents of children with DD and/or ASD reported the waiting time to obtain a diagnosis as being a challenge.
- The lengthy waiting time compounded with seeing multiple doctors and undergoing various assessments likely lead many parents to feel frustrated. Many reported that despite the lengthy process, they still have not found a clear diagnosis.

### 3) Parent-Professional Relationship

- Positive Experiences
  - Parents appreciated when doctors kept them updated and informed about their child's diagnosis. They especially appreciated when the doctors prepared them to receive the diagnosis- such as cautioning parents before the assessment about the possibilities.
- Negative Experiences
  - More than half of the parents responded that they had a negative experience with the diagnostic process. Many felt that the professionals did not take their concerns seriously which delayed the diagnosis. Furthermore, many parents answered that they felt that the professional did not have enough knowledge about ASD and/or DDs.

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