

Background

- The diagnostic process can be difficult for parents of children with Developmental Disabilities (DD).
 - It may be complex, difficult to accept or understand, involve many professionals, and result in a significant amount of stress (Selfe, 2002).
- The experience of parents of children diagnosed with Autism Spectrum Disorder (ASD) may be different from that of parents of children with other DDs, possibly because of the somewhat ambiguous nature of the early symptoms.
- In Canada, parents of children with ASD:
 - See an average of 4.5 professionals over a period of 3 years
 - Often express dissatisfaction with the long time required to obtain a diagnosis, i.e. from when parents first express concern to when their child is actually formally diagnosed (Siklos & Kerns, 2007).
- It is likely that parents of children with other DDs of a medical or genetic basis diagnosed at birth (e.g., Down syndrome) may be less ambiguous, leading to a quicker, and less stressful diagnostic process.

Purpose and Research Questions

- To investigate parents' experience of the diagnostic process in families of children with ASD and DD:
 - Is there a difference between the experiences of parents of children with ASD compared to children with DD in general?
 - Do parents of children with ASD report more difficulty during the diagnostic process than parents of children with DD?
 - Does the age when parents first became concerned differ between the two groups?
 - Does the age when parents first became concerned differ from the actual age of formal diagnosis?
 - Does the parents' experience of the diagnostic process differ based on the severity of the child's DD?
 - Which professionals were involved in the diagnostic process?
 - Do parents agree with the diagnosis given to their child?

Method

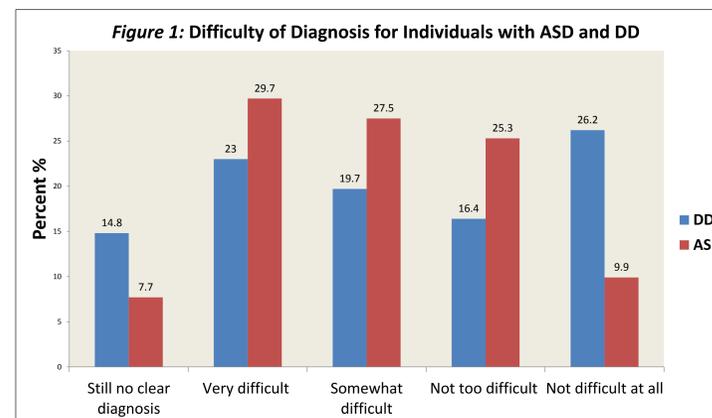
- Data collected through GO4KIDDS online survey examining the general health, well-being and social inclusion of children with DD and their parents
- Questions specific to the diagnostic process were considered

Participants:

- N=152 parents (93% mothers) from across Canada
- Children: 71% boys; age 4-19, M=11 years
- N=91 (60%) in ASD group (ASD + DD)
- N=61 (40%) in DD (no autism) group
- Many of the children also have: genetic or other syndromes, physical disabilities and disorders, sensory system limitations, problem behavior, etc.
- Gender ratio equal in DD group; more boys than girls in the ASD group (6.5:1)

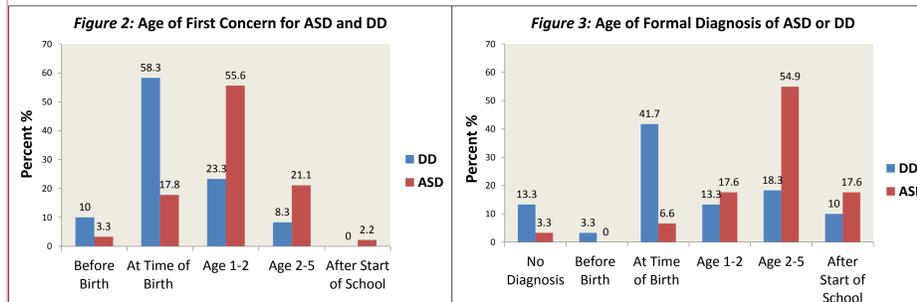
Results

- There was a difference between the experiences of parents of children with ASD compared to children with DD in general.
 - Parent ratings of difficulty of diagnosis differed between parents of children with ASD versus DD ($\chi^2=10.51, p=.033$). As seen in Figure 1:
 - DD group more likely to have no difficulty at all; also more who still had no clear diagnosis
 - ASD group more likely to have very or somewhat difficult experience; but also higher % in the not too difficult category



- Parent ratings of age of first concern and age of formal diagnosis differed between parents of children with ASD versus DD ($\chi^2=33.85, p<.001$; $\chi^2=43.54, p<.001$). See Figures 2 and 3.
- Parents of children with DD were more likely to have concerns at birth, and more likely to receive a formal diagnosis also at the time of birth.

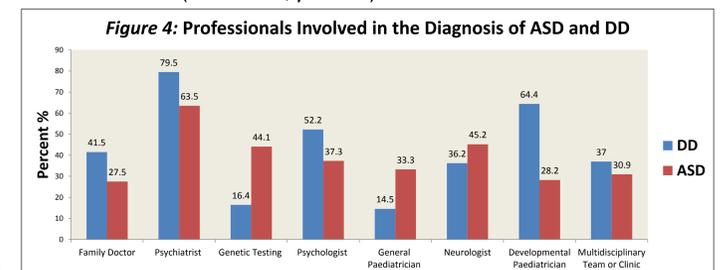
Parents of children with ASD were more likely to first show concern when their child was between the ages of 1 and 2, while they were most likely to receive a formal diagnosis between the ages of 2 and 5.



- When the sample was categorized based on severity (i.e. mild/moderate versus severe/profound) there were no differences found for difficulty of diagnosis, age of first concern, or age of formal diagnosis.

Results (cont)

- There were differences in which professionals were involved in the diagnostic process of children with ASD as compared to children with DD:
 - The ASD group was more likely to have had genetic testing done during the diagnostic process ($\chi^2=10.82, p=.001$).
 - The DD group was *less* likely to have had a general paediatrician involved ($\chi^2=5.84, p=.016$), and they were *more* likely to have had a developmental paediatrician involved ($\chi^2=14.86, p<.001$).



- The majority of parents indicated that they agreed with their child's diagnosis (Yes=138, No=8).

Discussion

- Parents of children with ASD have more difficulty obtaining a diagnosis than parents of children with DD (as expected).
- DD group were more likely to report no difficulty at all with diagnosis (e.g., Down syndrome), but were also more likely to have no clear diagnosis, which may reflect that many DDs have no known etiology
- DD group more likely to be first concerned at birth; ASD group as toddlers
- ASD group showed a longer latency between age of first concern and age of diagnosis
- Severity was not related to difficulty in diagnosis (but measure of severity was crude and missing some data)
- Range of professionals involved in diagnosis – highest % was psychiatrist (surprisingly) – only about 1/3 of children were diagnosed by multidisciplinary clinic (best practice)
- DD group more likely to have developmental paediatrician
- ASD group more likely to have had genetic testing done

Limitations and Future Research

- Sample, though quite large and Canada-wide, may not be representative
- Difficulty of diagnostic process was measured only in a crude way
- Future studies should look at other variables that may impact parents' experience, role of various professionals, timing and delays in more nuanced way

Acknowledgments

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