

GO4KIDDS & York University

Background

- GO4KIDDS is a Canadian team project exploring the health, well-being, and social inclusion of children with severe developmental disabilities (DD) and their parents
- The diagnostic process can be difficult and time-consuming for a child with DD and his/her parents
- Diagnosis may be delayed and complicated as a function of:
 - Socioeconomic status (SES; Slone, 1998)
 - Community size (Rosenberg, Daniels, Law, Law, & Kauffman, 2009)
 - Child's age at diagnosis
 - Child's cohort (Newschaffer, Falb, & Gurney, 2005)
 - Parents' immigrant status or country of origin

Research Questions

Are parents' experiences of the diagnostic process a function of:

1. SES - expect lower → more difficult
2. Community size – expect rural → more difficult
3. Child's age at diagnosis – expect older age → more difficult
4. Child's cohort – expect older cohorts → more difficult
5. Parents' immigration status – expect immigrants → more difficult

Participants

- N = 152
- Caregivers of children with DD: 138 mothers, 8 fathers, 5 other (step parent, grand parent, etc.), 1 missing info
 - 25% immigrants, 75% Canadian-born
- Children: 108 males, 43 females, 1 missing gender information
 - 4-19 years of age ($M = 11.1$, $SD = 3.5$)
 - 61 DD, 91 DD+ASD

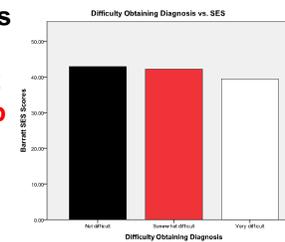
Measures

- GO4KIDDS Basic and Extended Surveys
 - **Difficulty obtaining diagnosis** → 3 categories: No clear diagnosis/very difficult, somewhat difficult, not too difficult/not difficult at all
 - **SES** → calculated using education and occupation (Barratt, 2006)
 - **Community size** → remote/rural, suburban, or urban area of Canada
 - **Child's age at time of diagnosis** → prenatal/at birth, toddler, preschool, or school age
 - **Child's cohort** → year of birth: 1991-1997, 1998-2001, 2002+
 - **Caregivers' immigration status** → immigrant vs. Canadian-born

Results

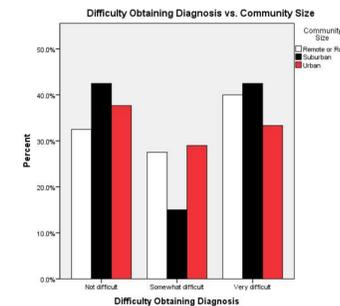
1. Difficulty obtaining diagnosis vs. SES

Results from an ANOVA **did not show a significant relationship** between difficulty obtaining a diagnosis and SES scores ($F(2, 157) = 1.39, ns$)



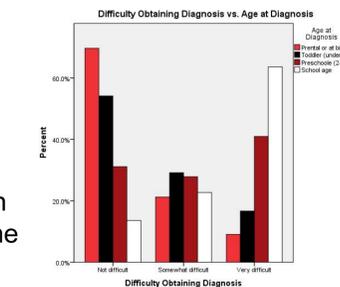
2. Difficulty obtaining diagnosis vs. community size

Results from a chi-square test **did not show a significant difference** in difficulty obtaining a diagnosis based on geographical area ($X^2 = 3.34, ns$)



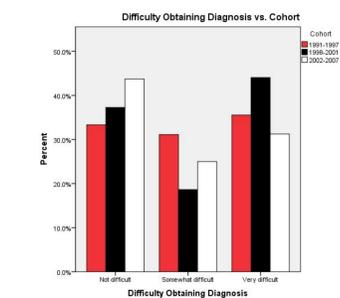
3. Difficulty obtaining diagnosis vs. age at diagnosis

Results from a chi-square test showed a **significant difference** in difficulty obtaining diagnosis based on the age of the child at the time of diagnosis ($X^2 = 28.68, p < .001$)



4. Difficulty obtaining diagnosis vs. cohort

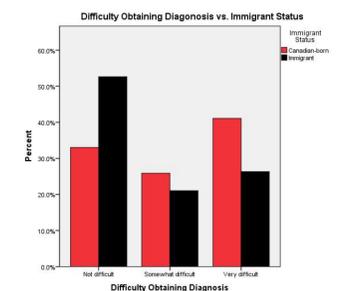
Results from a chi-square test **did not show a significant difference** in difficulty obtaining diagnosis based on the child's cohort ($X^2 = 3.55, ns$)



Results (continued)

5. Difficulty obtaining diagnosis vs. immigrant status

Results from a chi-square test **did not show a significant difference** in difficulty obtaining diagnosis based on the parents' immigrant status ($X^2 = 4.99, ns$)



Discussion

- SES** → results suggest that parents do not differ in their perceived difficulty of obtaining their child's diagnosis as a function of SES, which is encouraging
- Community size** → families living in diverse community sizes are comparable in their level of difficulty in obtaining a diagnosis for their child with DD, also encouraging
- Age at Diagnosis** → the older the child was at diagnosis, the more difficulty parents reported during the process, which makes sense, as the longer the process, the more frustration parents are likely to experience (child factors not controlled)
- Child's cohort** → no clear cohort effect that makes the diagnostic process more difficult at one time over another, although most recent cohort (born after 2002) more likely to have least difficulty
- Parents' Immigrant status** → Canadian-born and immigrant parents report similar levels of difficulty during the diagnostic process

Limitations and Future Research

- Sample, though large and from across Canada, may not be representative re SES, immigrant status (all did online survey)
- Difficulty of diagnostic process was measured only in a crude way
- Does not examine differences as function of specific diagnosis (e.g. ASD, genetic disorders)
- Does not take into account services and supports used during diagnostic process, which may have served to influence perceived difficulty of process and possibly affect group differences
- Future studies should look at other variables that may impact parents' experience

Acknowledgments

The authors would like to thank all the families who have completed the Basic and Extended Surveys that were used for this study.

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