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Background

- Children and youth with **severe DD** may have a wide range of diagnoses and are often termed “hard-to-serve” or as having “complex needs”.
- Despite their high need for services, many authors report that **these needs are often left unmet** (Douma, Dekker, & Koot, 2006).
- Understanding **their needs, service utilization and barriers to access** within the Canadian health context, is of critical importance for families, service providers, and policy makers.

Purpose of the Present Study

- The aim of the current study is to examine:
- The **need for and use of health and mental health services** among Canadian children and youth with severe DD.
 - Various health and mental health service areas will be reported.
 - When service needs are unmet, an examination of parental **perceptions of the barriers to service use** are examined.

Sample

- 79 parents** of Canadian children and youth with severe DD aged **9 to 16 years** ($M = 12.68$, $SD = 2.13$).
 - Gender:** 67.1% boys; 32.9% girls
 - Primary Diagnosis:** Autism (50.7%), Intellectual Disability (20.3%)
 - Support Level (SIB-R):** Limited (29.1%), Pervasive (21.5%), Extensive (20.3%)
 - Concurrent disabilities:** 1 (36.7%), 2 (48.1%), 3 (11.4%) and 4 (3.8%)
- Caregiver Information**
 - Gender:** 5.1% fathers and 93.7% mothers
 - Age:** 29 to 57 years ($M = 43.22$, $SD = 5.83$)
 - First language:** English (81%)
 - Marital Status:** Married/common law (77.2%), **Highest Education:** College/university (48.1%), **Employment:** Full-time (34.2%)
 - Location:** Urban (39.2%)
 - Distribution by Province:** Ontario (55.7%), British Columbia (20.3%), Saskatchewan (11.4%), Alberta (6.3%), Manitoba (3.8%), Quebec (1.3%), Prince Edward Island (1.3%)



Measure

- Online health survey; 3 parts (each 30-45 minutes to complete)

Results

Medical Conditions (>25% of sample have current needs)

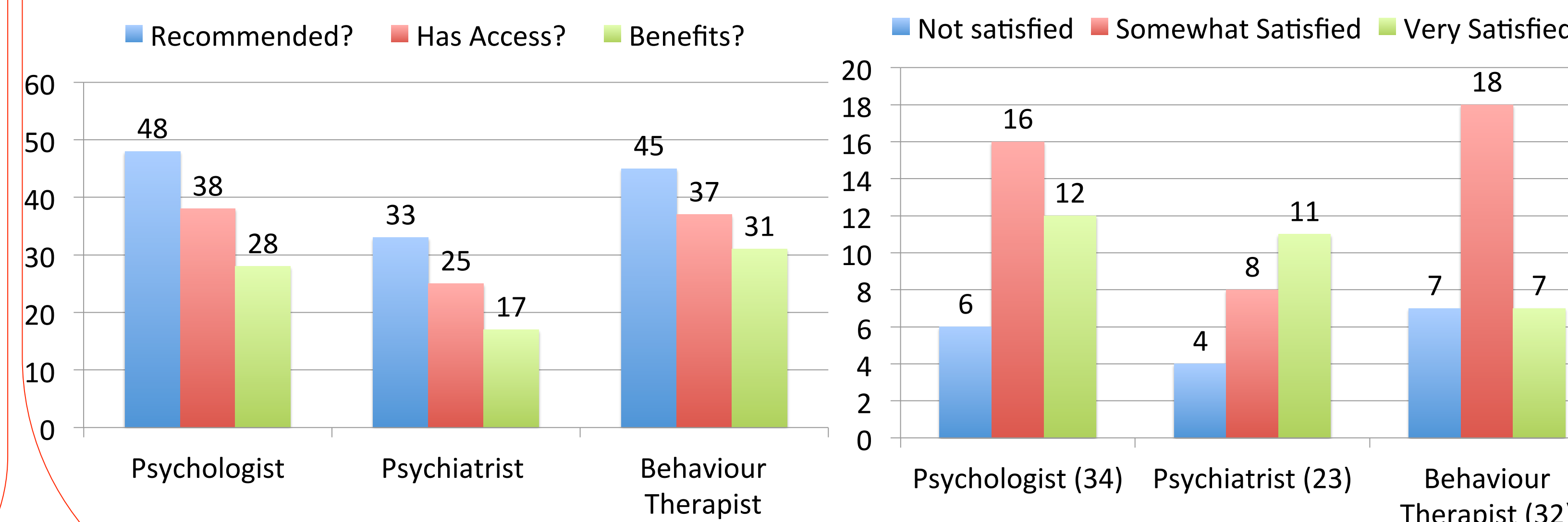
Health Problem	Never	Past	Current	No Help	Has Help
Visual Problems (N=75)	62.7%	5.3%	32.0%	20.8%	79.2%
Dental Problems (N=74)	29.7%	32.4%	37.8%	14.3%	85.7%
Stomach/GI (N=72)	36.1%	33.3%	30.6%	31.8%	68.2%
Kidney/Bladder/Urine (N=71)	57.5%	16.9%	25.4%	27.8%	72.2%
Growth Problems (N=75)	66.7%	2.7%	30.7%	43.5%	56.5%
Allergies (N=72)	62.5%	6.9%	30.6%	31.8%	68.2%
Feeding Problems (N=74)	47.3%	17.6%	35.1%	57.7%	42.3%

How Well Service Needs are Met

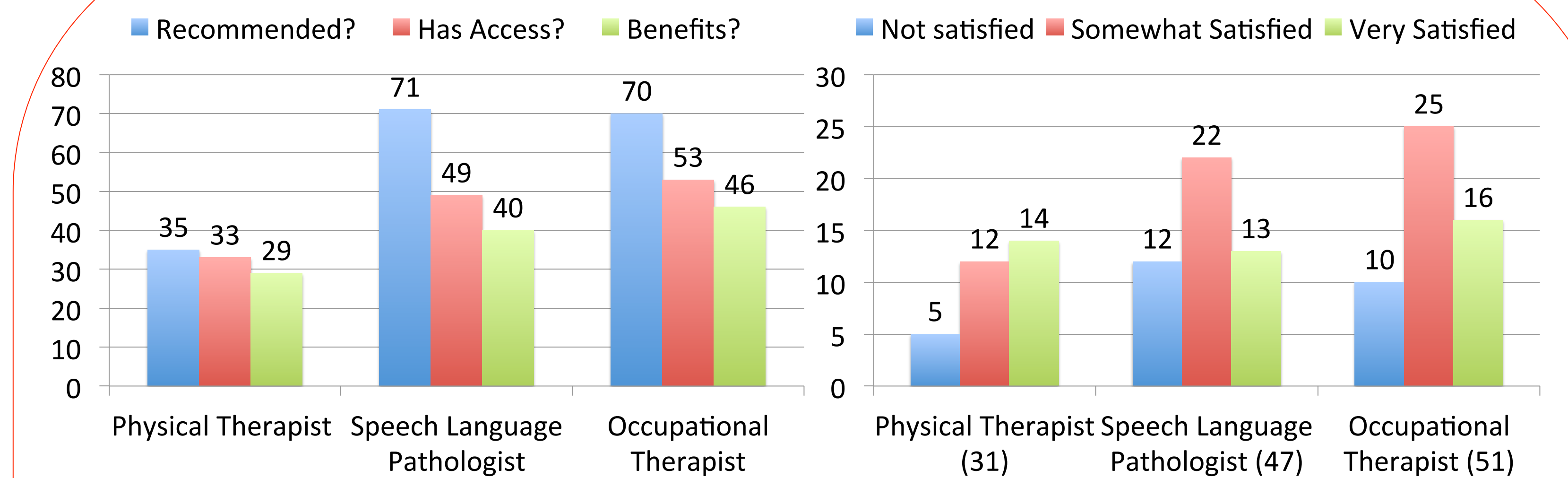
Health Provider	Always	Sometimes	Does Not
Pediatrician (N=56)	25.0%	30.4%	14.3%
Emergency Room (N=50)	21.4%	32.1%	8.9%
Hospital Admission (N=37)	14.3%	21.4%	10.7%
Dentist (N=67)	41.8%	20.9%	4.5%
Developmental Pediatrician (N=27)	33.3%	25.9%	11.1%
Neurologist (N=42)	25.0%	16.7%	16.7%
GI Specialist (N=11)	36.4%	18.2%	27.3%
Endocrinologist (N=10)	20.0%	10.0%	50.0%
Chiropractor (N=13)	53.8%	7.7%	30.8%
Naturopath (N=15)	20.0%	33.3%	26.7%
Homeopath (N=8)	12.5%	12.5%	37.5%
Other (N=12)	25.0%	8.3%	0.0%

Access to **Primary Care:** 96% who responded (3 did not). Those who don't, use “walk-in” or ER

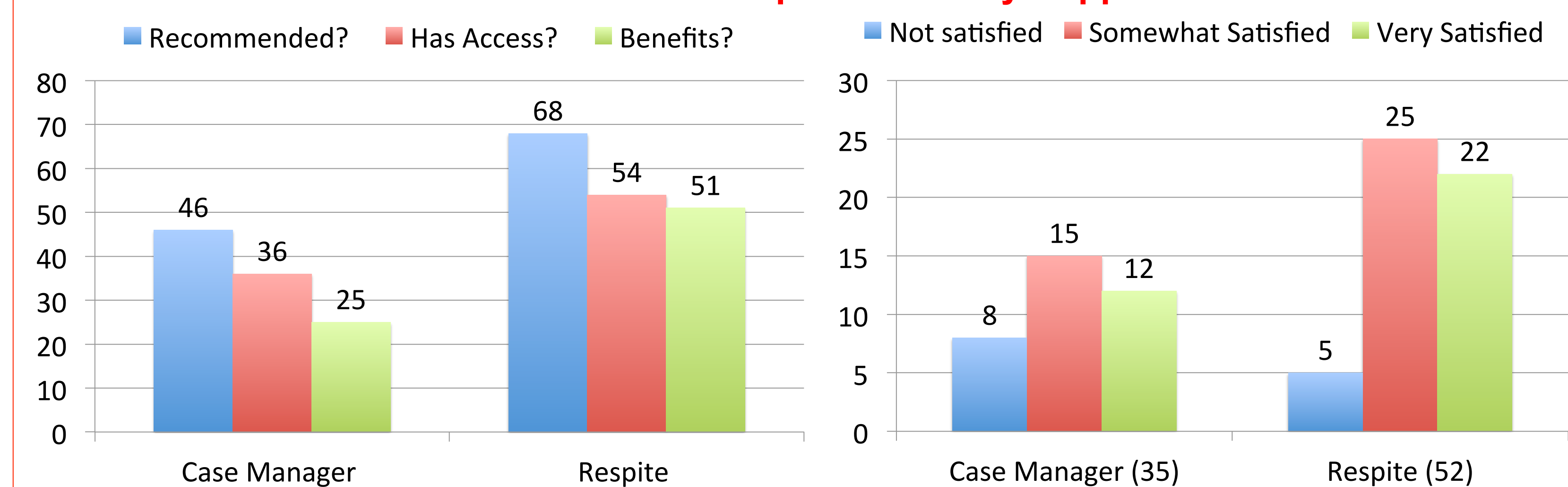
Numbers of Participants - Mental Health Services



Numbers of Participants - Allied Disciplines



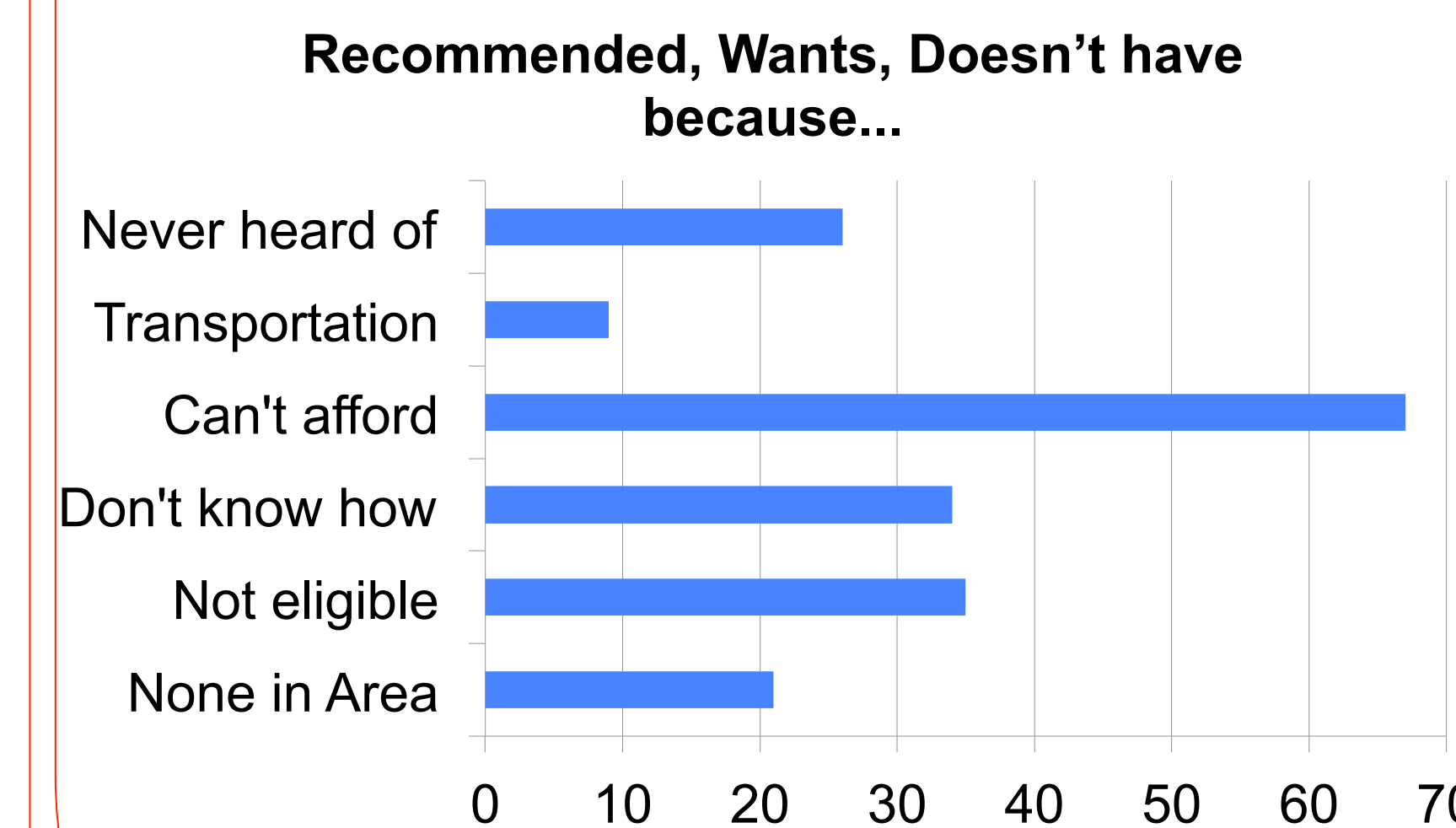
Numbers of Participants - Family Support



- Consistent pattern; more recommended, fewer who utilize, and even fewer who feel that their child benefits

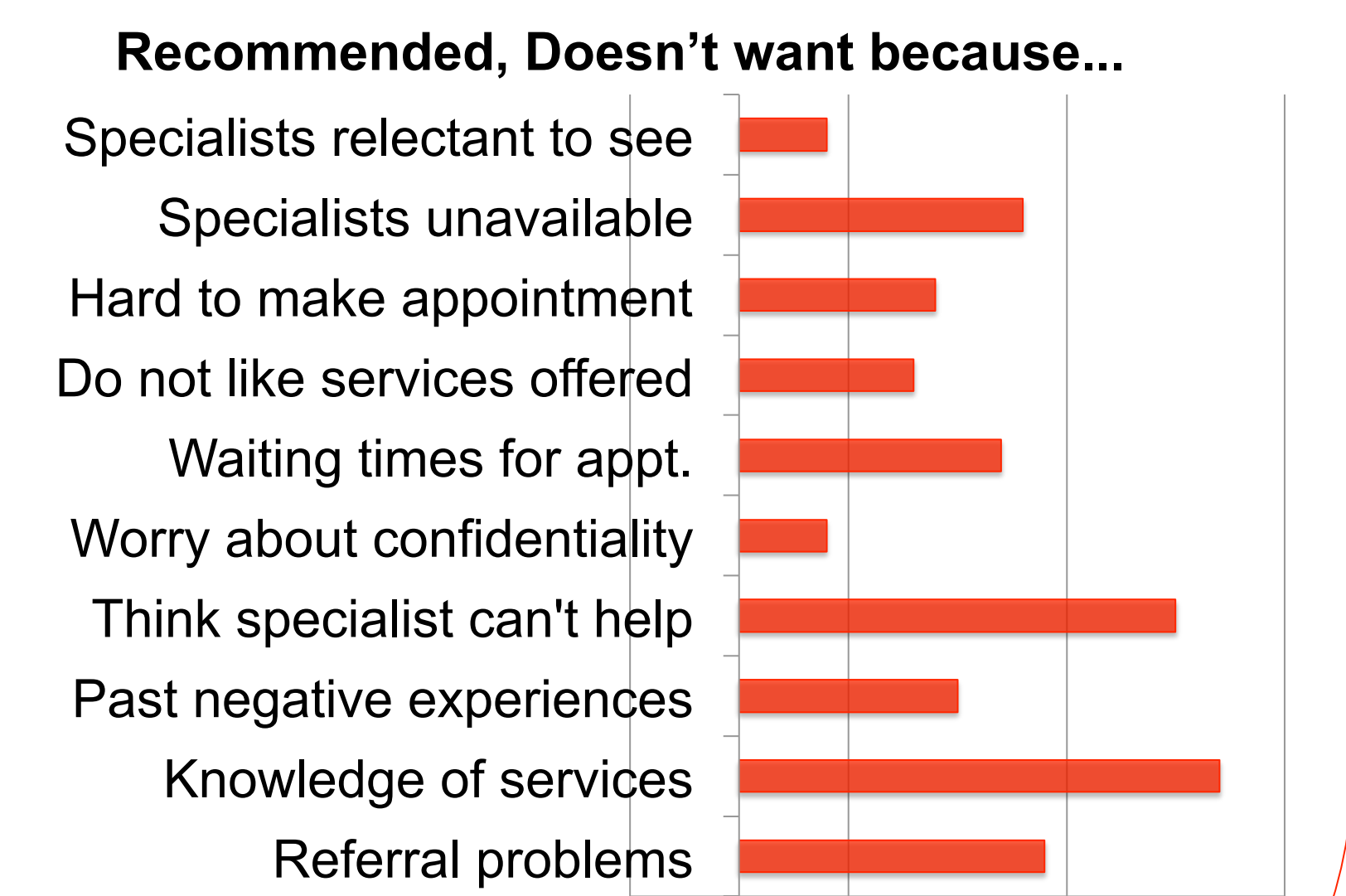
- Parents are generally satisfied by their child's mental health supports

Barriers to Access



- Financial need is high for those who need, but don't have services
- Lack of knowledge and belief that specialist couldn't help are two frequent barriers for those who don't need

Reasons for Not Pursuing



Discussion

- Children and youth with severe DD are an underserved population when it comes to needing health and mental health services; almost all children have a primary care physician; feeding issues have the highest unmet needs
- Those with mental health supports are generally satisfied, but those without supports identified barriers to access while some have decided not to pursue for several reasons
- Limitations:** Survey bias, mostly mothers living married or common-law with post secondary education; sample representativeness
- The knowledge gained from this study can inform service providers and policy makers to improve the health and wellbeing for these Canadian children

Acknowledgments: Thank you to all the parents for completing the Survey!

Data for this study were collected as part of the CIHR Team: GO4KIDDS: Great Outcomes for Kids Impacted by Severe Developmental Disabilities, Nominated Principal Investigator: Adrienne Perry, York University. (www.go4kidds.ca)