

Barriers and Facilitators to Accessing Services for Youth with Disabilities and their Families

Brittany Finlay¹, Dercia Materula¹, Krystle Wittevrongel¹, Michèle L. Hébert^{1,3}, Kathleen O'Grady⁴, Lucyna M. Lach², David Nicholas³, Jennifer Zwicker^{1, 5}
¹School of Public Policy, University of Calgary; ²School of Social Work, McGill University; ³Faculty of Social Work, University of Calgary; ⁴Simone de Beauvoir Institute, Concordia University; ⁵Faculty of Kinesiology, University of Calgary.



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Background

- Government disability programs provide support to individuals with disabilities to improve their health equity by addressing the socioeconomic barriers that they face.
- To date, little is known about utilization of disability programs at the Federal and provincial/territorial levels among youth with disabilities and their families.

Aim & Research Questions

- **Aim:** To understand how youth with disabilities and their families interact with the government disability system in Canada.
- **Research Questions:**
 1. To what extent are disability programs accessed by this population?
 2. What factors influence the ability of this population to access disability programs?

Mixed-Methods Approach

Sequential Explanatory Design

Population of Interest

- Parents of young people (0-30 years) with disabilities
- Young people (18-30 years) with disabilities
- Individuals from all provinces/territories

Snowball and convenience sampling on Facebook

Phase #1: Online Survey

- Questions: demographic, disability, accessing disability programs
- Respondents indicated interest in interview

End of survey: respondents indicate interest for phase #2

Maximum variation sampling

Phase #2: Phone Interviews

- Semi-structured
- Participants elaborated on survey responses and discussed experiences accessing services

Results

Demographic Characteristics	Study Phase		Demographic Characteristics	Study Phase	
	Survey (n=531)	Interview (n=84)		Survey (n=531)	Interview (n=84)
Participant Type, n (%)			Indigenous, n (%)	31 (5.8%)	11 (13.3%)
Parent or Caregiver	513 (96.6%)	80 (95.2%)	Province or Territory, n (%)		
Person with NDD	18 (3.4%)	4 (4.8%)	Alberta	79 (14.9%)	10 (11.9%)
Gender, n (%)			British Columbia	67 (12.6%)	10 (11.9%)
Male	45 (8.5%)	6 (7.1%)	Manitoba	35 (6.6%)	10 (11.9%)
Female	476 (89.6%)	78 (92.9%)	New Brunswick	26 (4.9%)	7 (8.3%)
Other	5 (0.9%)	0 (0.0%)	Newfoundland	7 (1.3%)	1 (1.2%)
Age, mean years (range)	41.5 (18-70)	41.6 (24-60)	Northwest Territories	3 (0.6%)	1 (1.2%)
Disability Diagnosis, n (%) *			Nova Scotia	17 (3.2%)	2 (2.4%)
ADHD	26 (4.9%)	2 (2.4%)	Nunavut	1 (0.2%)	0 (0.0%)
ASD	151 (28.4%)	25 (29.8%)	Ontario	187 (35.2%)	15 (17.9%)
CP	25 (4.7%)	3 (3.6%)	Prince Edward Island	3 (0.6%)	1 (1.2%)
Down Syndrome	12 (2.3%)	0 (0.0%)	Quebec	57 (10.7%)	15 (17.9%)
FASD	24 (4.5%)	3 (3.6%)	Saskatchewan	46 (8.7%)	11 (13.1%)
>1 Disability Diagnosis	230 (43.3%)	45 (53.6%)	Yukon	1 (0.2%)	1 (1.2%)
Intellectual Disability	9 (1.7%)	1 (1.2%)	Community Type, n (%)		
Angelman Syndrome	7 (1.3%)	3 (3.6%)	Urban	454 (85.5%)	72 (85.7%)
Other Diagnosis**	46 (8.7%)	2 (2.4%)	Rural	70 (13.2%)	12 (14.3%)

Table 1. Characteristics of Study Participants. This table summarizes demographic characteristics of participants in both phases of the study. *For parents/caregivers, disability diagnosis represents the diagnosis the child they care for has received. **Includes 19 diagnoses that were indicated on the surveys of less than one percent of participants.

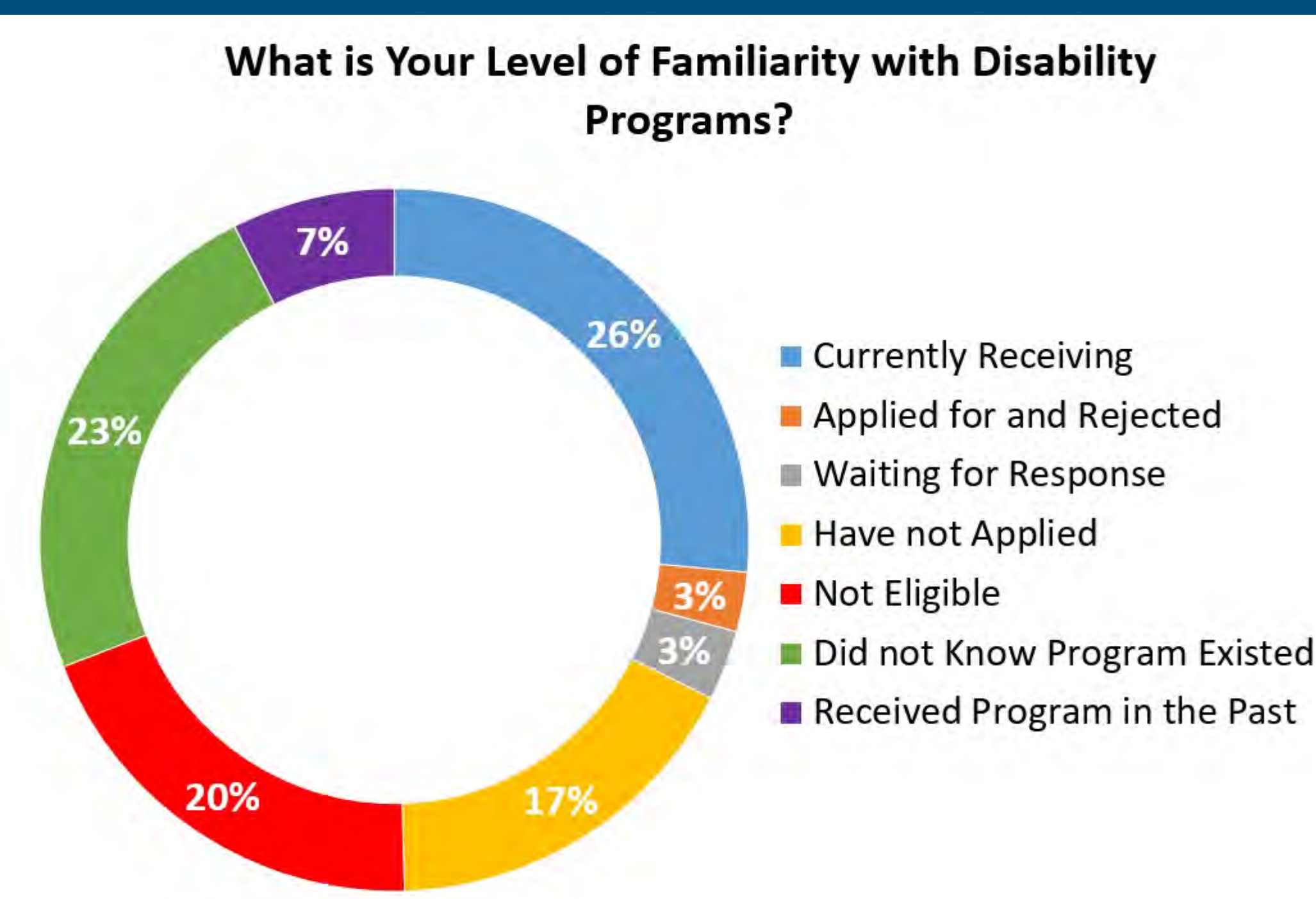


Figure 2. Level of Familiarity with Disability Programs. This figure summarizes survey responses to the above question across all participants and all disability programs.

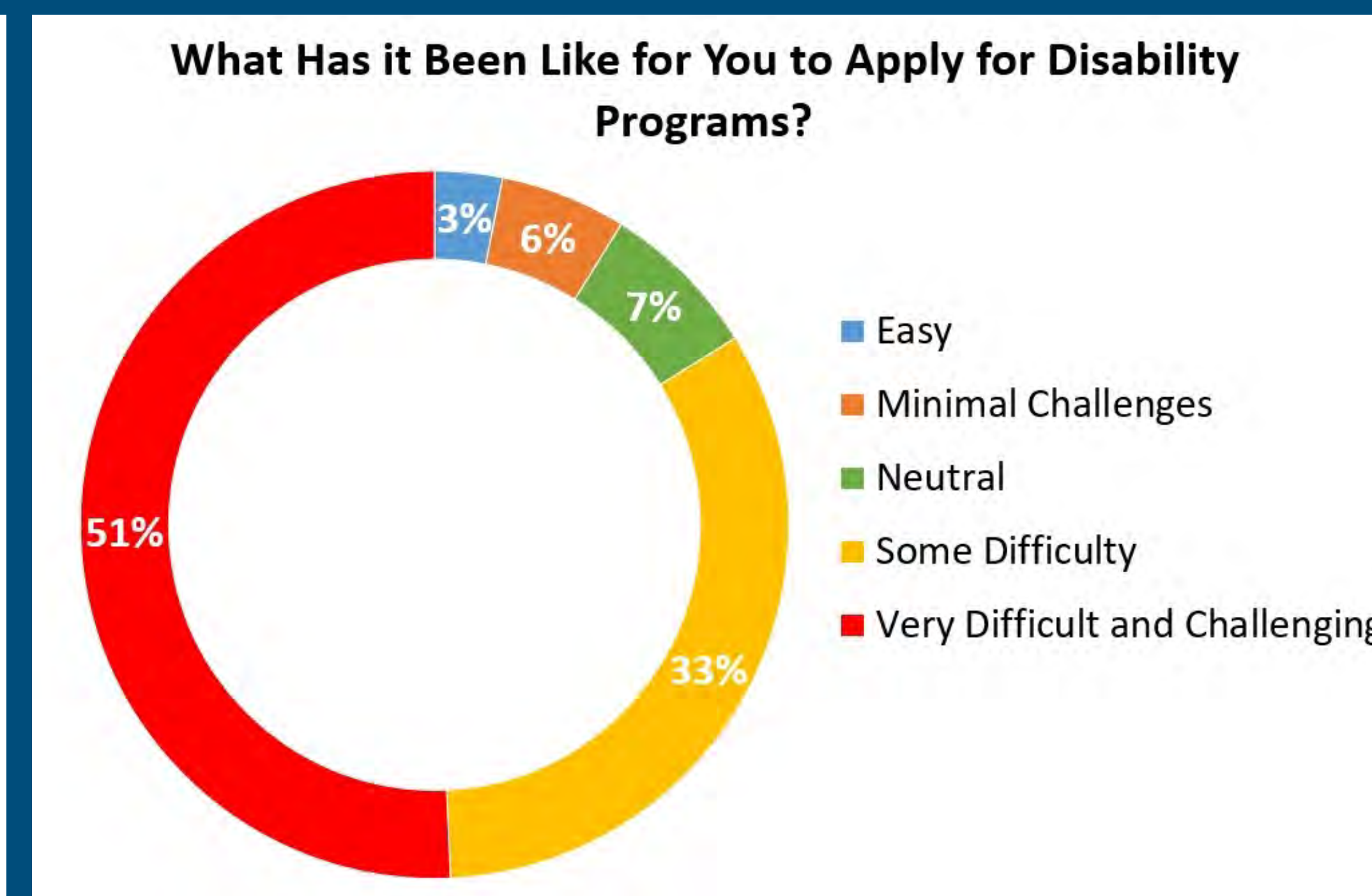


Figure 3. Experiences Applying for Disability Programs. This figure summarizes survey responses to the above question across all survey participants.

Factors Impacting Access to Disability Programs

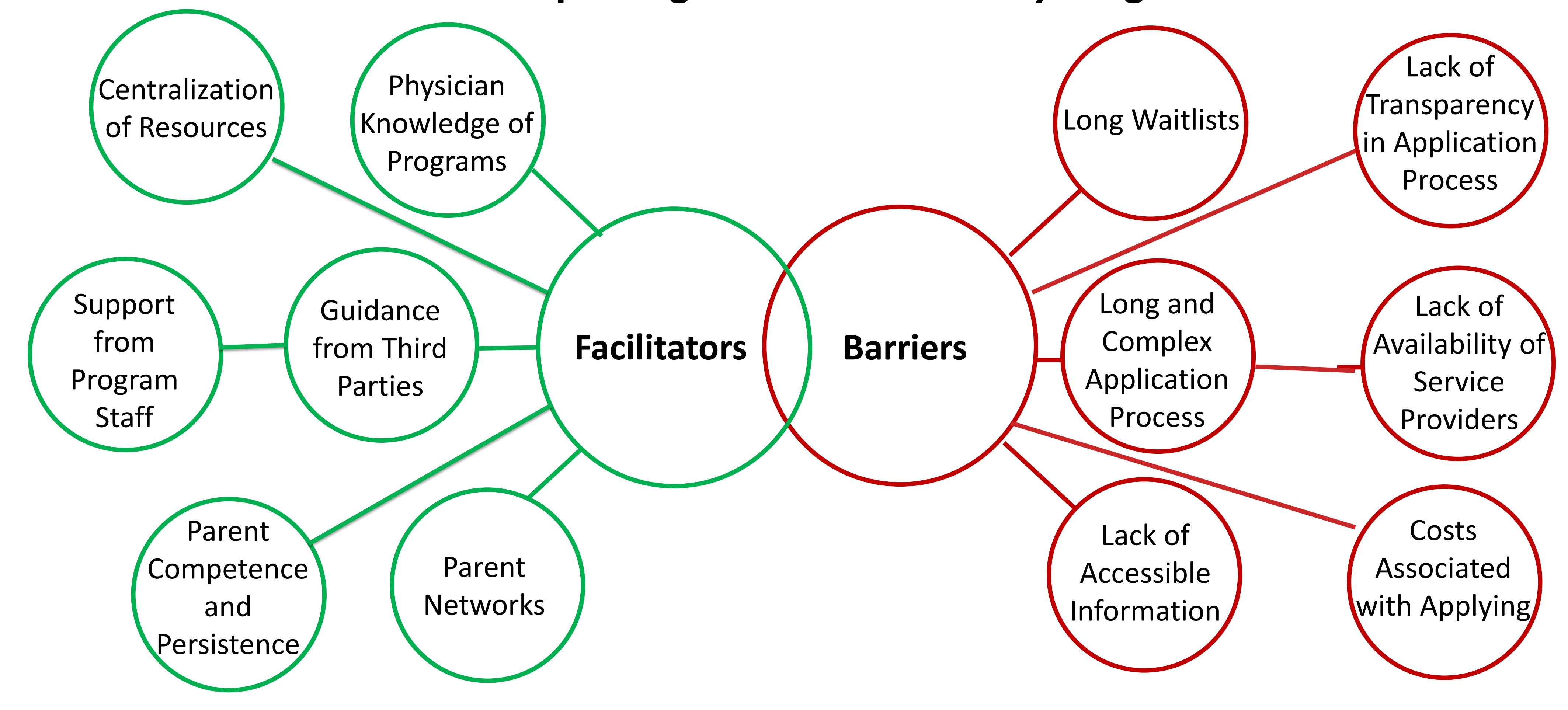


Figure 4. Factors Influencing Program Access. This figure summarizes some of the facilitators and barriers to accessing disability programs, as identified by participants of qualitative interviews.

Demographic Characteristics	Study Phase	
	Survey (n=531)	Interview (n=84)
Total Household Income, n (%)		
<\$30,000	76 (14.3%)	12 (14.3%)
\$30,000-\$59,999	112 (21.1%)	22 (26.2%)
\$60,000-\$90,000	105 (19.8%)	16 (19.0%)
>\$90,000	213 (40.1%)	30 (35.7%)

Key Takeaways

- **Utilization of Disability Programs is Relatively Low**
 - Survey participants indicate only 33% of the time that they are currently receiving or have received a given program
- **Application Process for Disability Programs is Challenging**
 - 84% of survey participants indicated that they have some level of difficulty applying for disability programs.
- **A Number of Facilitators and Barriers to Program Access Exist in Canada**
 - Some factors are related to individual characteristics of participants, while others are related to the current system of providing disability services

Limitations

- Survey recruitment through Facebook may have introduced selection bias
 - It is possible that the viewpoints of individuals less engaged in Facebook may have been missed
- Participants were not required to respond to every question in the online survey, resulting in a small amount of missing survey data
- Qualitative interviews relied on participant recall of experiences accessing programs

Conclusion

- This study provides key insight into the functioning of the current system of providing disability programs from the perspective of youth with disabilities and their families
- Future work will examine how findings can be translated into recommendations for policy change that can improve program access for this population