

Appendix

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A capstone project submitted to the Faculty of Graduate Studies of the University of Manitoba in partial fulfillment of the requirements for the degree of
MASTER OF PHYSICIAN ASSISTANT STUDIES

Master of Physician Assistant Studies, University of Manitoba, Winnipeg, MB
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Appendix A. Study Questionnaire

A Survey Study Exploring the Perceived Communication Barriers and Facilitators Between Primary Care Providers and Patients with Intellectual Developmental Disabilities Questionnaire

Survey Monkey Link: <https://www.surveymonkey.com/r/GFM9HL8>

Consent Disclosure

“A Survey Study Exploring the Perceived Communication Barriers and Facilitators Between Primary Care Providers and Patients with Intellectual Developmental Disabilities.” Master of Physician Assistant Studies (MPAS), Rady Faculty of Health Sciences, University of Manitoba.

Thank-you for accessing this survey. This study is conducted by a group of researchers from the University of Manitoba. The objective of this survey is to investigate the perceived communication barriers and facilitators between primary care providers and patients with intellectual developmental disabilities (IDD) from primary healthcare professionals’ perspectives.

Your feedback will be collected through an online survey which will ask you a series of questions about challenges and facilitators you have experienced while communicating with patients with IDD. Your response to these questions will be recorded using a 5 point Likert scale and you will also have the opportunities to provide additional comments and feedback related to this subject during the survey. The survey should take about 10-15 minutes to complete.

Your participation on this on-line survey is completely voluntary. You are not required to provide any personal information such as your name, address or telephone number, and you don’t have to answer any questions you don’t want to.

Confidentiality

Your survey responses are confidential. The survey system will not record your email address or IP (Internet protocol) address. This survey is done through SurveyMonkey. Any demographic information provided in the survey will also be kept anonymous and confidential. All virtual data collected is stored in secured UM network drives or password-protected cloud drives.

If you agree to participate in the survey, please note that you must complete the survey in one sitting. Also, please note that when you submit your response. You will not be able to withdraw them as we cannot link the survey responses back to you.

Information gathered in this research study will be presented in public forums in an aggregated and anonymized fashion at the Physician Assistant student capstone project presentation for academic and research purposes. This data may be shared with other researchers in the future through academic publications or presentations to help address research questions in this field.

Your participation is important to us and will help us better understand the communication challenges and facilitators encountered by providers while interacting with patients with IDD. Ultimately, these insights may inform future health policies and resource allocations aimed at better supporting patients with IDDs, thereby fostering improvements in their quality of life and long-term health. Therefore, we truly appreciate your time and participation.

If you have any questions about this survey study, please do not hesitate to contact Sarah Zhu (Primary Investigator) Physician Assistant student; zhus4@myumanitoba.ca.

This study has been approved by the University of Manitoba Health Research Ethics Board.

I Consent to participate in this survey.

- Yes No

Section 1: Participant Demographics

- **What gender do you identify as?**
 - woman
 - man
 - non-binary/Trans/Gender Diverse
 - Or please specify: _____
 - Prefer not to answer
- **What is your age?**
 - < 18 years old

- 18-30 years old
- 30-45 years old
- 45-60 years old
- 60+ years old
- Prefer not to answer
- **What is your occupation? _____**
- **How many years of practice do you have? _____**
- **What is the setting/type of the primary care clinic you work in?**
 - Fee-For-Service (FFS)
 - Interprofessional Team Demonstration Initiative (ITDI)
 - Winnipeg Regional Health Authority (WRHA) Primary Care
 - Community Health Clinic/Community Health Agency Centers
 - Teaching/Academic Clinic
 - Others (please specify): _____
 - Prefer not to answer
- **Does your clinic have a walk-in clinic portion attached?**
 - yes
 - no
 - Prefer not to answer
- **How many patients with IDD are in your panel?**
 - Less than 5
 - 5-10
 - 10-15
 - 15-20
 - More than 20
 - Prefer not to answer
- **What is the highest degree or level of education you have completed?**
 - High school
 - Bachelor's Degree

- Master's Degree
- Ph.D. or higher
- Prefer not to answer
- **What is your current employment status?**
 - Full time
 - Part time
 - Casual
 - Other: _____ (please specify)
- **What is your race/ethnicity?**
 - Caucasian
 - Black or African Canadian
 - Latino, Hispanic or Spanish Origin
 - Asian
 - Pacific Islander
 - Indigenous
 - Two or More
 - Other/Unknown
 - Prefer not to answer
- **How many languages do you speak? Please specify: _____**

Section 2: Exploring Barriers to Communications with Patients with IDD

Reflecting on your most recent month of working with patients with IDD, please rate the importance of the following barriers in **preventing** you from having effective communications with your patients. As you rate the importance of each barrier, consider both the **magnitude of the barrier and its frequency**.

Barriers related to Patient-level Factors

Very Unimportant Barrier	Somewhat Unimportant Barrier	Neither Important nor Unimportant Barrier	Somewhat Important Barrier	Very Important Barrier
a) Difficulty understanding the information provided				
1	2	3	4	5
b) Level of Health Literacy				
1	2	3	4	5
c) Cognitive Impairments				
1	2	3	4	5
d) Physical distance or remote challenges in communicating with patients				
1	2	3	4	5
e) Fear, stigma, negative patient expectations surrounding standard screening measures (e.g. mammography, blood test) and/or treatment plans				
1	2	3	4	5
f) Language Barriers				
1	2	3	4	5
g) Lack of family, caregivers or alternative or augmentative communication (AAC) involvement in health decision making process				
1	2	3	4	5
h) impaired patient autonomy or lack of involvement of patient in the decision making process				
1	2	3	4	5

Barriers Related to Family and/or Caregivers and/or Supporters

Very Unimportant Barrier	Somewhat Unimportant Barrier	Neither Important nor Unimportant Barrier	Somewhat Important Barrier	Very Important Barrier
a) Cultural and/or Linguistic Barriers				
1	2	3	4	5
b) Difficulty understanding the complex medical terminology, treatment options, and healthcare procedures				
1	2	3	4	5
c) Lack of time and effort/energy to effectively communicate with healthcare providers to ensure patients' healthcare needs are met				
1	2	3	4	5

Barriers Related to Roles of Healthcare Professionals/ Teams

Very Unimportant Barrier	Somewhat Unimportant Barrier	Neither Important nor Unimportant Barrier	Somewhat Important Barrier	Very Important Barrier
a) Insufficient space and time for communication and collaboration with patients and supporters (e.g. additional patient education time)				
1	2	3	4	5
b) Lack of training and professional skills in effectively communicating with patients with IDD's or their supporters				
1	2	3	4	5
c) Lack of coordination, communication, and teamwork among healthcare team members				
1	2	3	4	5
d) Lack of experiences in caring for adults with IDD's				
1	2	3	4	5
e) Disconnect/Ineffective communication between clinical staff and community health services				
1	2	3	4	5
e) Inadequate awareness of patient's preferred methods of communication or sensory needs				
1	2	3	4	5
f) Disconnect between administration and frontline healthcare staff				
1	2	3	4	5
g) Insufficient professional knowledge about medical issues related to disabilities, where to refer patients, chronic disease management in adults with IDD's				
1	2	3	4	5

Other Barriers

Very Unimportant Barrier	Somewhat Unimportant Barrier	Neither Important nor Unimportant Barrier	Somewhat Important Barrier	Very Important Barrier
a) Other Barrier:				
1	2	3	4	5
b) Other Barrier:				
1	2	3	4	5
c) Other Barrier:				
1	2	3	4	5
d) Other Barrier:				
1	2	3	4	5

Section 3: Exploring Facilitators to Communications with Patients with IDD

Reflecting on your most recent month of working with patients with IDD, please rate the importance of the following factors in **facilitating** you in communicating with patients during health visits. As you rate the importance of each facilitator, consider both the **magnitude of the facilitator and its frequency**.

Facilitators Related to Patient-level Factors

Very Unimportant Facilitator	Somewhat Unimportant Facilitator	Neither Important nor Unimportant Facilitator	Somewhat Important Facilitator	Very Important Facilitator
a) Involvement of supporters such as caregivers, substitute decision makers or translators				
1	2	3	4	5
b) Adoption of alternative or augmentative communication methods (e.g. telemedicine, patient passports, online translators)				
1	2	3	4	5
c) Communication carried out in patients' preferred methods of communication (e.g. written instead of verbal)				
1	2	3	4	5
d) Use of Visual Aids				
1	2	3	4	5

Facilitators Related to Family and/or Caregivers and/or Supporters

Very Unimportant Facilitator	Somewhat Unimportant Facilitator	Neither Important nor Unimportant Facilitator	Somewhat Important Facilitator	Very Important Facilitator
a) Interpretation and Translation				
1	2	3	4	5
b) Emotional Support				
1	2	3	4	5
c) Advocate for the healthcare needs and preferences of individuals with IDD's				
d) Provide Feedback and Actively Follow-up with the healthcare team regarding patient's status				
1	2	3	4	5

Facilitators Related to Roles of Healthcare Professionals/ Teams

Very Unimportant Facilitator	Somewhat Unimportant Facilitator	Neither Important nor Unimportant Facilitator	Somewhat Important Facilitator	Very Important Facilitator
a) Collaboration with patient's caregivers and support networks				
1	2	3	4	5
b) Use of clear and simple language				
1	2	3	4	5
c) Allocating time for additional patient education				
1	2	3	4	5
d) Active Listening				
1	2	3	4	5
e) Use of other communication aids and/or technologies to facilitate communication with patients				
1	2	3	4	5
f) Collaboration within interprofessional team				
1	2	3	4	5
g) Training and Education on communication strategies and best practices for interacting with patients with IDD's				
1	2	3	4	5

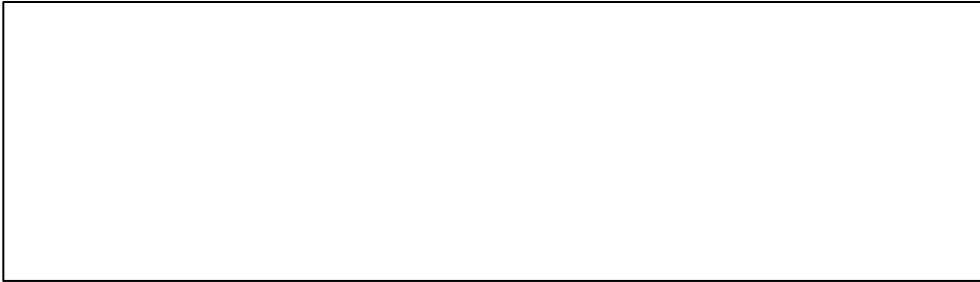
Other Facilitators

Very Unimportant Facilitator	Somewhat Unimportant Facilitator	Neither Important nor Unimportant Facilitator	Somewhat Important Facilitator	Very Important Facilitator
a) Other Facilitator:				
1	2	3	4	5
b) Other Facilitator:				
1	2	3	4	5
c) Other Facilitator:				
1	2	3	4	5
d) Other Facilitator:				
1	2	3	4	5

Section 4: Moving forward

1. Reflecting on the barriers which you rated as **Somewhat Important** and **Very Important** in Section 2, what specific suggestions do you have about ways to overcome these barriers and make it easier for health care providers to effectively communicate with their patients?

2. What is currently working well to promote and facilitate communication between healthcare providers and patients and their family members/caregivers?

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Participant Feedback

- Any additional Feedback?

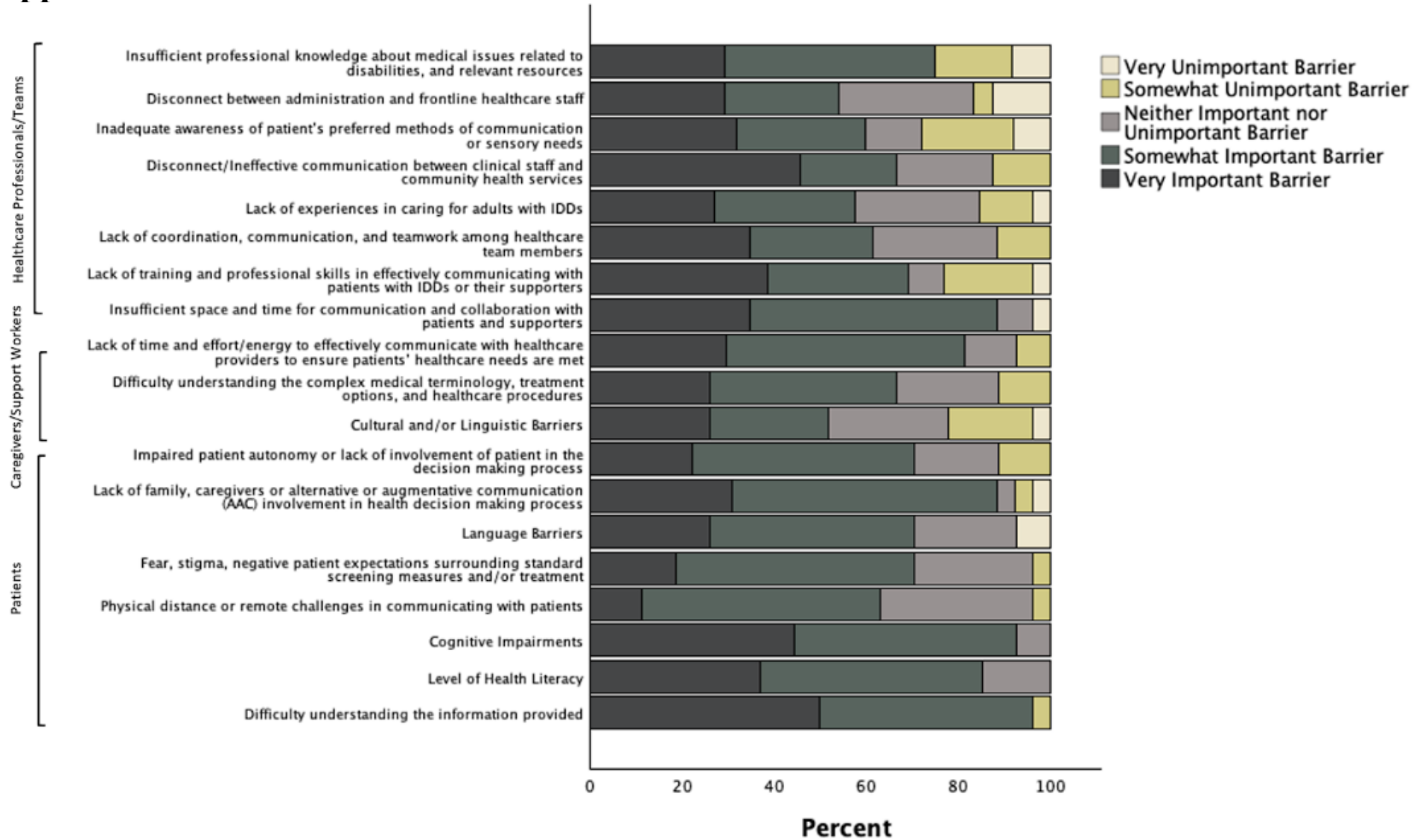
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Thank you for your participation in this survey!

Appendix B.

	Male	Female	Others (non-binary/trans/gender diverse)							
Gender	7 (25.9%)	19 (70.4%)	1 (3.7%)							
Age	18-30 4 (14.8%)	30-45 12 (44.4%)	45-60 10 (37.0%)	60+ 1 (3.7%)						
Occupation	Occupational Therapist 1 (3.7%)	Physician 9 (33.3%)	Registered Nurse 3 (11.1%)	Physician Assistant 5 (18.5%)	Community Support Worker/Mental Health Worker 1 (3.7%)	Physiotherapist 3 (11.1%)	Medical Office Assistance/Supervisor 3 (11.1%)	Dietician 1 (3.7%)	Social Worker 1 (3.7%)	
Years of Practice	< 5 6 (22.2%)	5-10 9 (33.3%)	11-20 6 (22.2%)	21-30 4 (14.8%)	>30 2 (7.4%)					
Setting/type of the primary care clinic	Winnipeg Regional Health Authority (WRHA) Primary Care 15 (55.6%)	Fee-For-Service (FFS) 6 (22.2%)	Community Health Clinic/Community Health Agency Centers 4 (14.8%)	Interprofessional Team Demonstration Initiative (ITDI) 1 (3.7%)	Others 1 (3.7%)					
Walk-in clinic portion attached?	Yes 15 (55.6%)	No 11 (40.7%)	Prefer not to answer 1 (3.7%)							
# of patients with IDD's in your panel	<5 3 (12.0%)	5-10 6 (24.0%)	10-15 4 (16.0%)	>20 8 (32.0%)	Prefer not to answer 4 (16.0%)					
Education	High school 2 (7.4%)	Bachelor 8 (29.6%)	Master's Degree 10 (37.0%)	Ph.D or higher 5 (18.5%)	Prefer not to answer 2 (7.4%)					
Employment Status	Full Time 21 (77.8%)	Part Time 5 (18.5%)	Other 1 (3.7%)							
Race/Ethnicity	Caucasian 18 (66.7%)	Asian 3 (11.1%)	Black or African Canadian 2 (7.4%)	Indigenous 2 (7.4%)	Two or more 1 (3.7%)		Prefer not to answer 1 (3.7%)			
Languages spoken	1 13 (48.1%)	2 12 (44.4%)	3 or more 2 (7.4%)							

Appendix C.



Appendix D.

