The Health Check for Adults with Intellectual and Developmental Disabilities

Multi-stakeholder Engagement to Develop Educational and Practice Resources for Family Physicians.

THE COLLEGE OF FAMILY PHYSICIANS OF CANADA | LE COLLÈGE DES MÉDECINS DE FAMILLE DU CANADA

SURREY PLACE

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Introduction

This report describes the use of qualitative data on barriers and facilitators to the comprehensive Health Check for adults with intellectual and developmental disabilities (IDD) to identify strategies for improved uptake of this guideline recommended intervention. It describes the results of a project by the CFPC MIG Developmental Disabilities, funded by a CPFC MIGs Project Support Grant, April 2023-24.

Background

> *"It's your body, and you have the right to know what's going on,*
> *whether you have a disability or not,*
> *you have the right to know what's going on, just to stay healthy" – person with IDD*

Adults with Intellectual and Developmental Disabilities (e.g., Down syndrome, Autism) experience complex health problems and challenges to accessing primary care. The *Canadian Consensus Guidelines for the Primary Care of Adults with IDD* (2018) provide recommendations on person-centred and proactive care for this population. The Guidelines were developed by family physicians and consider expert and experiential knowledge from patients, caregivers, and service providers next to empirical evidence.

Implementation and uptake of clinical guidelines by family physicians requires a multi-facetted approach, including practice tools and education strategies.

Some tools exist:The Canadian "IDD Health Check" is a medical record template with practice tips to help family physicians accomplish a proactive, comprehensive health assessment of adults with IDD. It is based on international randomized controlled trial evidence and is a main recommendation of, and a tool to implement, the Canadian Consensus Guidelines for the Primary Care of Adults with IDD. The IDD Health Check was revised and adapted for an EMR-based format by family physicians of the CFPC's Developmental Disabilities Member Interest Group (DD MIG), in partnership with the Developmental Disabilities Primary Care Program (DDPCP) of Surrey Place, Toronto, and the eHealth Centre of Excellence.

Canadian patient-oriented tools, to be completed by patients and caregivers to contribute patient-centered data to the Health Check, also are available: "About My Health" and "My Health Care Visit", developed by the Health Care Access Research and Developmental Disabilities (H-CARDD) program at the Centre for Addiction and Mental Health in consultation with patient self-advocates and direct service workers. Both are available on a digital platform connecting patients and providers (OceanMD).

What gaps exist?

System issues and knowledge, skill and attitude gaps have been reported in several studies as barriers to implementing the IDD Health Check. Physicians, patients and caregivers alike experience barriers to the IDD Health Check and primary care. Therefore, an effective implementation requires a multi-stakeholder approach. Little is known about if existing tools support the implementation of health checks in Canada; and the perspectives of Canadian patients with IDD, their family and paid caregivers, developmental service agencies and other knowledge users towards health check implementation is largely unknown.

Anecdotally, we hear stakeholders' frustrations with the lack of uptake of the guideline recommendations. A few examples:

> *"I've had a lifelong of things that I've been told by doctors about why not to take her as a patient"* ***– Caregiver***
>
> *"We need to talk to the College of Physicians in different provinces, to talk to them about how we can make this a priority because it continues…not enough doctors, not enough support workers…Line up everything, we're always in a crisis for everything."* ***– Person with IDD***
>
> *"As an APSW who would be assisting with these medical appointments, and all of that. It's very detrimental to our guys, for sure. The people that I support, they need all the help they can get for all of the information".* ***– Support worker***

What needs to be assessed?

Family physicians', patients', caregivers' and service providers' perspectives on effective dissemination and education strategies for the IDD Health Check and related tools need to be assessed.

Aim

The primary objective is to gather multi-stakeholder input, from patients, caregivers and other service providers, about educational and practice resources for family physicians that will effectively support dissemination and implementation of the IDD Health Check.

The secondary objective is to disseminate the strategies identified among family physicians.

Methods

Participants were recruited through purposeful sampling via Surrey Place social media, newsletters and the CFPC MIG member networks. Data was collected via an online survey and semi-structured interviews in 1-hour online focus groups for 4 stakeholder groups: family physicians, family caregivers, direct support workers, and adults with IDD. Family caregivers, direct support workers and adults with IDD were paid a small honorarium for participation in the focus group ($45 gift card).

Survey and interview design

Survey and interview questions were designed from behaviour change theory (COM-B model) and frameworks (Theoretical Domains Framework). The COM-B model describes that in order for people to change they need to be capable of change, be motivated to change, and have the opportunity to change. The Theoretical Domains Framework (TDF) is an integrative framework developed from a synthesis of psychological theories to help apply theoretical approaches to interventions aimed at behavior change. The TDF presents 14 domains that describe different types of individual barriers and facilitators people might encounter when confronted with a potential behaviour change. (Appendix 1) This process provides a theory- and evidence-based approach to identifying implementation barriers and facilitators and selecting intervention functions and behaviour change strategies to address these barriers and facilitators. For example, if someone is forgetting to book a Health Check, reminders might be an effective strategy to address this barrier, while reluctance to book a Health Check might require persuasion strategies (e.g., evidence of effectiveness).

Prior to the survey and interview design, DD MIG members familiarized themselves with this implementation practice method. Two or three key barriers to the uptake of the IDD Health Check were selected per stakeholder group from research literature and practice experience.

Subsequently, barriers were mapped onto the COM-B and TDF intervention functions (Appendix 1) which generated a list of change strategies. Finally, criteria from the APEASE framework were used to select a few behaviour change strategies to present in the guided discussion as a conversation starter.

Focus groups

Focus group participants were introduced to the target behaviour: conducting or having a comprehensive Health Check for adults with IDD. Barriers to the target behaviour were briefly acknowledged and some qualitative data statements presented, for example a barrier such as "…our Family Doctor did not remind us to get a Health Check" was examined by the group. Participants were then presented with suggestions for change strategies and encouraged to discuss their ideas for intervention content. Potential modes of intervention were brainstormed with APEASE criteria in mind: affordability, practicability, effectiveness, acceptability, safety and equity.

The selected barriers and facilitators discussed by each stakeholder group varied across groups; with an attempt to focus on barriers and facilitators that are most applicable to their stakeholder group. Interview introductions were adapted for each focus group for example, family physicians were presented with more clinical background information about behaviour change theory, while persons with IDD participated in a discussion with plain language summaries, concrete examples and visuals.

All focus groups were recorded via the Zoom platform with participant consent, and verbatim transcripts were produced for analysis.

Analysis

Transcripts of the focus groups and the results of the survey were summarized into recommendations for a behaviour change intervention. Transcripts for each stakeholder group were analyzed by two members of the working group. The identified quotes for strategies were checked for consistency and any disagreements regarding categorization into intervention functions were reconciled.

Ranking of recommendations was conducted collectively by all working group members using the APEASE (Acceptability, Practicability, Effectiveness, Affordability, Spill-over effects, and Equity) framework. Consideration was made for what is practical and acceptable to the MIG and potentially CFPC for future Health Check promotional work.

Results

Participants

Three focus groups were held for family physicians (N=8), two for persons with IDD (N=8), one for caregivers (N=7) and one for Paid Caregivers/Direct Support Workers (N=3).

Survey

A brief, 5 question survey, was circulated online with recruitment materials. Survey results are summarized in Appendix 2. The survey participants (N=19) included direct support professionals/ adult protective services workers (58%) and family physicians (26%) with some responses from caregivers (family members or paid caregivers) and people with IDD.

Focus groups

Focus group transcripts with suggested change strategies and working group APEASE analysis are summarized in appendices 3a-d.

Appendix 3a: Adults with Intellectual Disabilities Focus Group

Appendix 3b: Caregiver Focus Group

Appendix 3c: Family Physician Focus Group

Appendix 3d: Paid Caregiver Focus Group

Summary of recommendations

Results of the survey and focus group transcript analysis were combined into a summary of change strategies, categorized with the COM-B domains (Table 1 - 3).

TABLE 1: Summary of change strategies to increase awareness, knowledge and skills for the Health Check (Capability)

CHANGE STRATEGY: Capability	
Educational materials	• Syndrome specific guidance and pathways for practicing physicians (e.g., Health Watch Tables) • Pediatric to adult care transition handover guidance for developmental pediatricians (e.g., example hand over package information) • Tips for physicians on how to provide reasonable accommodations for patients with intellectual and developmental disabilities and how to communicate with patients with IDD • Curricula for undergraduate and residency programs in medical schools, informed by stakeholders, including people with intellectual and developmental disabilities and caregivers; include compassionate care and trauma-informed care; and ableism • Accessible plain language materials about the Why, How, What of the Health Check: ○ Plain language document ○ YouTube video ○ Social story ○ Easy read document ○ Dramatization/Skit • Adapt primary care tools and educational materials to local/provincial contexts • Instructional videos by physicians for physicians
Work with educational institutions	• Integrate developmental disabilities curriculum into medical undergraduate and residency programs • Support local champions in their advocacy for medical education (e.g., provide example curricula and letters, FAQs) • Include the IDD Health Check in CFPC "required topics" for training
Work with community agencies and organizations	• Work with leaders in community agencies to share information with staff, people with IDD and their caregivers • Make it a standardized practice for staff at developmental agencies • Offer a "Did you know an annual Health Check is recommended?" handout at transition from child to adult care at points where general transition information is already being shared in Developmental Services
Educational sessions	• Include people with intellectual and developmental disabilities as teachers • Continuing Medical Education (CME); Continuing Professional Development (CPD) events through professional associations/organizations • Host webinar or brief lunch hour events for busy professionals • Presentation at professional conferences (e.g., FMF, OADD, Dev peads..) and networks • Presentation at caregiver support organizations • Presentation at self-advocacy organizations • Mandated training for staff at community/DS agencies (paid time)

CHANGE STRATEGY: Capability	
	• Webinars for caregivers at DS community agency wellness programs • Train office staff
Modeling	• Modeling to Family Medicine residents the use of Health Checks in the real-life setting, at Academic Half-Days and in In-Unit presentations • Normalize the practice while the physicians are still early in their formation
Peer-to-peer learning	• E-consultations for family physicians with IDD expert clinicians • Peer support programs at the College of Family Physicians • Hand-over from developmental pediatrician to family physician at transition from child to adult care • Discuss Health Checks within self-advocacy groups
Integrate in meetings	• Share resources and knowledge in regular business/staff meetings at community agencies • Share resources and knowledge with DS leadership
Mass media	• Share in e-newsletters of professional organizations • Share on websites of professional organizations • Social media - campaign with key messages targeted at different stakeholders • Social media - caregiver groups • Social media - famous people or influences

TABLE 2: Summary of change strategies to create buy-in for performing, supporting, or having the Health Check (Motivation)

CHANGE STRATEGY: Motivation	
Framing/persuasive communication	• Family physicians: practice support tool for complex patients; normalize it as part of good comprehensive primary care; chronic disease (condition) management; a standard of care • Persons with IDD: “don’t miss out on good health”, “getting your health checked is your right”; “better to know than not to know; you don’t have to deal with health issues alone” • Support workers: support a client in equitable access to care
Leaders supporting change	• Community/DS leaders to support change • Family physicians as leaders supporting the change
Action planning	• Encourage caregivers/people with IDD to book a Health Check by providing clear “How to” information • A document to bring to the doctor that helps prepare for the visit
Evidence/data; persuasive communication	• Communicate the benefits of a Health Check (e.g., health outcomes, cost-saving)
Early adopters	• Stories of success and benefits, positive experiences
Incentivize	• CME credits for education • Billing code for IDD Health Check

TABLE 3: Summary of change strategies to facilitate and enable the Health Check (Opportunity)

CHANGE STRATEGY: Opportunity	
Payment scheme	• Billing code for IDD Health Check • More time
Environmental restructuring	• Collect information in a pre-visit in advance of doctor's visit, this could be phone/virtual; use an accessible pre-visit questionnaire; via patient engagement platforms (e.g., OceanMD) • Embed the Health Billing code in the Health Check EMR toolbar • Use a team-based approach to performing the Health Check • Integrate Health Check into DS case-management • Accessible exam rooms • Video or phone visits • Plain language communication • Mobile services • Health check tool available in all EMRs • Include IDD Health Checks in their chronic disease management dashboards • Better transportation arrangements • Reminders mailed to people with IDD/caregivers
Social supports	• Encourage support workers to attend the Health Check, with patient consent.
Allocation of funds	• More family physicians

Discussion

This project used a behavior change approach to stakeholder interviews. Few others in disabilities healthcare report on scholarly work designed with this approach. This section first presents lessons learned regarding interview design, lived experiences, and multi-stakeholder perspectives. Second, a few key findings are discussed.

Interview design

For each interview, a few change strategies were pre-selected for discussion considering APEASE criteria (Acceptability, Practicability, Effectiveness, Affordability, Spill-over effects, and Equity) to keep the discussion within the scope of our current project.

A few pre-selected barriers were acknowledged briefly to begin the discussion, after which the interviewer guided the discussion according to the pre-selected change strategies to avoid digressions about further barriers.. However, often barriers are interconnected; If new barriers did arise from the discussion, associated change strategies were explored when there was time to do so.

Occasionally, unclear articulation of the selected barriers and TDF/COMB strategies caused participants to digress in the discussion. For example, “How can we make it easier to have a Health Check?” is a very broad question, and similarly “How can we educate caregivers?” led the discussion through multiple barriers and domains. A better way to phrase the question would have been, “How do we educate the public that many caregivers want Health Checks for their loved ones?” For future work, it is key to keep suggested change strategies within the broad the TDB/COMB intervention functions (education materials, education sessions). This will elicit more unique suggestions for change strategies from the participants.

Awareness of lived experiences

When conducting interviews with stakeholders it is important to be aware of their lived experiences, whether it concerns the experience of the healthcare practitioner, the patient with IDD, or the caregiver. Building rapport at the start of an interview is key, especially with those who have negative healthcare experiences. A pitfall is digressing into a discussion about already explored barriers. This can be avoided by careful interview design supported by the COMB/TDF framework. By clearly stating the purpose of the interview and focusing on pre-selected intervention functions and change strategies there was a feeling of optimism with the participants at the end of a focus-group that something can be done to improve care.

Caregivers were particularly enthusiastic about the focus group discussion and potential opportunities for changes in the future:

> *“ I just wanted to say thank you for giving us this opportunity to provide input. This is really important work and I know [and] everyone on these calls knows the challenges that we have in this sector with our loved ones. I am very excited to see where this goes and happy to continue to participate and provide any feedback, insight, experience as you move along in this journey and hopefully creating something that…you know, you go into your doctors, and your doctor says “has your loved one had a Health Check this year?”* ***- Caregiver***

Similarly paid caregivers also felt encouraged by participating in the discussion and thankful for the opportunity to participate.

> *“I just wanna say thanks for taking the time to implement and try to get this going, because, as an APSW who would be assisting with these medical appointments, and all of that. It's very detrimental to our guys, for sure. The people that I support, they need all the help they can get for all of the information. So, it's fantastic. Thanks.” -**Direct support worker***

Family physicians also felt enlightened by the discussion and hopeful about future work in support of people with IDD.

> *"..Doing such good job in facilitating today's focus group. Your group is doing important work and has developed amazing resources and strategies. Realize that buy-in takes years but is worth it. Good luck and keep with it as your work is certainly making a difference for practitioners and for this special population and their families and caregivers.”*
> ***- Family physician***

Nothing about us, without us / accessible interviews

People with IDD had a strong desire to share their health care experiences but some participants felt confused about the goals of the project. One participant highlighted the importance of conducting the focus groups in an accessible manner, for example, using plain language and enough preparation for the discussion. For future projects it is important to involve people with IDD in the interview design.

> *“I just wanted to take a quick moment to send out a quick little note after I left today's morning meeting/session feeling rather upset and most frustrated. Anyways, I sincerely apologize if I'm the one misunderstanding here, but I really feel as though both participants and advisors aren't being given a fair chance to share and express their feelings and opinions when being asked questions and participating in the focus group, and that the language being used isn't always very clear and/or very understandable for both Participants and Advisors and Self-Advocates to use, and that the language being used seems much more geared towards Facilitators, WITHOUT BEING AWARE AND/OR TAKING INTO ANY CONSIDERATION THAT PEOPLE WITH IDD'S NEED TO HAVE A VERY CLEAR AND CONCISE UNDERSTANDING OF THE LANGUAGE BEING USED. And my understanding from the session this morning is that we were asked about 'What Do Health Checks Mean For You?' And 'What are Something's That Make You Feel Either Uncomfortable and/or Anxious During Health Checks', etc, and so I really thought the idea was to really be sharing some concrete examples about Health Care Checks from our own lived experiences, but*

> *apparently, I, as and advisor/advocate really and completely missed the mark and didn't speak enough of the Facilitators language here, and so would like to join tonight's session from 4:00-5:00 so I could try the group again, if at all possible, please and thank you. Anyhow, I can absolutely assure you all right now, following the last couple of sessions we've had, if I was asked to rank and/or rate things, I would easily give between a .5 to 1 out of 10 here, as I'm really sorry, but facilitators really need to be aware and acknowledge that THERE ARE PEOPLE WITH IDD'S ON THE CALL HERE.*
>
> *All the best, and thanks again"-* ***Person with IDD***

Later the goals of the study were communicated more clearly and a revised presentation was used and the same participant shared:

> *"I just wanted to take a quick moment to send a quick note to say and let everyone know that that was MUCH MUCH BETTER THIS TIME AROUND, and would like to take the time and opportunity to thank all of you for your time today 😎 😎 The only little minor quick thing I would suggest and/or do, is to maybe stop screen-sharing once and/or after questions are being asked to advisors and self-advocates who are participating on the call, so facilitators are able to see who's hands are up, but yeah, other than that, like I said, MUCH MUCH MUCH BETTER THIS TIME AROUND! Well done 😊 😊"* ***-Person with IDD***

Multi-stakeholder perspectives

Within focus groups, stakeholders discussed strategies that apply to other stakeholder groups. For example, caregivers talked about strategies that would help their family member have a health check. Or, physicians would mention strategies tailored to caregivers and supports, and people with IDD mentioned strategies targeted at physicians. Therefore, it is relevant to always include multiple stakeholder perspectives when designing a knowledge translation and implementation strategy for a specific intervention. This approach will increase the likelihood of selecting effective strategies to invest in as a priority.

Findings

It was enlightening to discover that all stakeholders were enthusiastic about supporting the Health Check. Known gaps in knowledge about the Health Check and previously created tools (McNeil et al.) suggested there may be areas for improvement in dissemination. Indeed, the focus group discussions yielded potential high impact strategies for education about the Health Check that will reach all stakeholder groups. Persons with IDD highlighted their lack of participation in teaching health care providers and lack of resources for the education of their peers about the Health Check. Persuasive messaging was also missing from previous attempts to garner support for this intervention. Champions highlighted the need for support including ready access to evidence-based materials, formal curricula and mentorship.

Results that fell outside the scope of this project were still important to note for future advocacy. Notably, more access to family medicine is clearly needed and supports all preventative care measures including the IDD Health Check. The DD MIG will continue to support initiatives that improve access to primary care. Also, fair renumeration for the IDD Health Check does not exist across Canada, having a dedicated billing code with fair renumeration for the time and skills required to complete this intervention is important and the DD MIG will continue to advocate for this in the future.

Capacity building

The methods used in this project created awareness with family physicians about how implementation practice and science can aid in the design of interventions in healthcare. As one DD MIG member described her experience:

> *"This was an illuminating experience for me and the other working group members as we learned more about implementation science. While working on this project (and a few other projects since this started) I have found myself examining barriers and thinking about which change strategies would be most applicable. It is a very different way to approach knowledge translation and program development. I do believe this project has started my professional journey into scholarly work in this area. I am thankful to the other working group members, the MIG and CFPC for the opportunity to learn about this."*- ***Working Group Member***

Limitations

There were some limitations to this study including recruitment challenges, limited resources for repeat focus groups and limited scope of DD MIG and our partners.

Family physicians, with busy practices, were difficult to recruit for focus groups. We did offer 3 smaller groups to make it possible for more family physicians to participate in the discussion. Durbin et al. highlighted the importance of clinic staff in supporting the implementation of health checks; these staff members play an important role in booking appointments and collecting information. However, clinic staff were not included as a stakeholder group due to recruitment challenges. Using a digital platform also limited the number of participants that can be seen "on the screen" during a discussion.

Only data from one 1-hour meeting per stakeholder group and a brief survey were included. There were many more barriers that would have been useful to discuss; if time permitted an additional focus group meeting per stakeholder group may have provided more actionable strategies. We also explored the use of a survey, however limited survey responses were collected, the majority of this analysis was from the focus groups. Other additional methods of data collection and stakeholder engagement might be needed to inform a more complete intervention strategy.

The APEASE analysis focused on actionable change strategies for Health Check implementation within the scope of the DDPCP, CFPC, and DD MIG. There were several change strategies which could potentially have an impact in Health Check Implementation but are outside of the scope of the current project.

Conclusions and next steps

The working group reviewed the results in Table 1: Summary of change strategies to increase awareness, knowledge and skills for the Health Check (Capability), Table 2: Summary of change strategies to create buy-in for performing, supporting, or having the Health Check (Motivation) and Table 3: Summary of change strategies to facilitate and enable the Health Check (Opportunity). For each intervention strategy an APEASE (Acceptability, Practicability, Effectiveness, Affordability, Spill-over effects, and Equity) analysis with respect to the DD MIG and potentially CFPC for future Health Check promotional work.

After this series of focus groups, it is very clear that when designing an intervention strategy, it is important to gather the perspectives of all stakeholders. We did not expect the enthusiasm of the participants to devise actionable changes. Rather than feel disheartened by poor uptake in the past, all parties are looking forward to work ahead for Health Check implementation. First steps include disseminating this message through a plain language summary to DD MIG members and reviewing this report with Surrey Place, DDPCP and CFPC to identify future directions.

The top 10 currently most actionable recommendations for the CFPC IDD MIG are outlined below.

Top 10 Actionable Recommendations:

1. Create **plain language documents, social stories and easy read documents directed towards adults with intellectual disabilities. Materials should include:**
    - Persuasive messaging: “Do you know you should have a yearly Health Check? Persuasive quotes such as “Don’t miss out on good health”, “Getting your health checked is your right”; “Better to know than not to know; you don’t have to deal with health issues alone”.
    - Practical steps: materials highlighting how to book, how to prepare for the visit and what happens during a Health Check. Handouts that come from the family physician are particularly reassuring for caregivers to ensure that Health Checks happen. These handouts/ digital materials could also be used by developmental service agencies and shared with caregiver organizations. Some materials already exist internationally but would need to be adapted for a Canadian context; including local stories of persons with IDD and their families.
    - Plain language: With a focus on visuals and simple text it will be easy to share in multiple languages.

2. Provide **tips for accommodations in primary care for people with IDD.** Persons with IDD expressed a need for further education directed towards health care providers about reasonable accommodations to their care in clinical settings. Resources such as, Communicate CARE from the MacHealth Curriculum of Caring has already been created. Additional materials could easily be created and can be disseminated to practicing family physicians at conferences (CME) and in family medicine resident teaching. Key topics related to accommodation include using a team-based approach to care, accessible exam rooms, use of video/telephone visits, plain language communication, use of pre-visit questionnaires, understanding the role of support people, use of reminders and understanding local supports for transportation. Asynchronous learning, such as webinars would require funding and support for dissemination.

3. **Integrate IDD content in Curricula for undergraduate and family medicine residency programs in medical schools.** People with IDD and their caregivers recognize the lack of knowledge about IDD in health care professionals. Family physicians noted that revision of curriculum is needed to feel competent to deliver care to this population. Integrate important themes in the required learning for undergraduate medical education and family medicine such as person-centred care, compassionate care, trauma-informed care; and ableism. Revisions should be informed by stakeholders, including people with intellectual and developmental disabilities and their caregivers. Materials already exist, for example: Casson et al. describe a curriculum for Canadian family medicine residents to learn and demonstrate competencies in the care of adults with IDD. Also, instructional videos explaining the Communicating CARE curriculum and a video highlighting physical examination skills for family physicians caring for adults with IDD from the MacHealth Curriculum of Caring are currently used by MIG members at institutions that have agreed to adopt the changes. As highlighted by family physicians, further barriers exist with the implementation of new elements to curricula.

4. Include the **IDD Health Check as a priority topic/key feature** for evaluation objectives for Canadian family physicians. Currently, the broader topic of ‘Disability’ is a priority topic with no mention of intellectual disability. Family physicians noted that the priority topics provided opportunities for peer-to-peer learning amoung family medicine residents and were incentives for residency programs to add educational resources about the topic into their curricula. As an example, The Medical Council of Canada has devised an examination objective in the area of IDD as a national standard for students medical licensure in Canada.

5. **A transition toolkit** including a **health transfer tool** to assist with the transfer of care from pediatrics to family physicians already exist but need to be reviewed. Family physicians expressed a desire for further support through modeling from pediatricians. The existing documents do not provide advice about Health Checks. It would also be helpful if it was structured like a Health Check so the family physician could model this. Equitable dissemination of the toolkit among pediatrics as well as family physicians will need to be considered. In practice, these transition documents do appear to benefit a select group of patients with higher complexity that are followed by developmental pediatricians or teams of pediatric specialists. It is possible this transition tool will be helpful to only a select few.

6. **Provide peer support opportunities for family physicians**. This knowledge sharing opportunityexists through our DD MIG (Developmental Disabilities Member Interest Group) but timely practice support and mentorship continues to be lacking. Explore more effective ways to bring DD MIG members together to share information, practice challenges and clinical successes.

7. Create an **infographic** outlining the benefits of Health Checks including known health benefits, cost savings etc. This can be used as a teaching aid/promotional material at conferences for family physicians and/or direct support professionals and meetings with caregiver associations. Both paid caregivers and family caregivers noted that factual information about the benefits of health checks would improve their motivation to seek out Health Checks.

8. Create **point-of-care handouts for caregivers** promoting yearly Health Checks, along with links to existing resources that aid in preparation for Health Checks, such as My Health Care Visit, and a one-page description of what the Health Check should entail. Caregivers highlighted the importance of family physicians, as leaders supporting the Health Check, to provide these handouts to caregivers and patients.

9. **Promote existing materials directed towards developmental service workers** such as the 'Nuts and Bolts Toolkit' containing tools and tips for direct support professionals supporting people with IDD from Health Care Access Research and Developmental Disabilities program (H-CARDD) and Vita Community Living Services. Utilize strategies for dissemination including the use of social media, conferences (such as OADD- Ontario Association of Developmental Disability Conference) and provincial/ regional meetings. This may be difficult, further advice is required to ensure equitable distribution of the materials across the country.

10. Involve people with intellectual disabilities as experts with lived experience in the development of education materials and in education of medical students, family medicine residents, family physicians and developmental service workers. People with IDD were keen to be involved as teachers and self-advocates, ”**Self-advocates should be doing the training**. We have the knowledge about ourselves. They need to listen to us so we can do the training.”

References

Evidence of benefits of Health Checks:

1. Robertson J, Hatton C, Emerson E, et al.. The impact of health checks for people with intellectual disabilities: an updated systematic review of evidence. Res Dev Disabil 2014;35:2450–62.

2. Kennedy N, Kennedy J, Kerr M, Dredge S, Brophy S. Health checks for adults with intellectual disability and association with survival rates: a linked electronic records matched cohort study in Wales, UK. BMJ Open. 2022;12(4):e049441. Published online 2022 Apr 13. doi: 10.1136/bmjopen-2021-049441

3. Janet Durbin, Avra Selick, Ian Casson, Laurie Green, Andrea Perry, Megan Abou Chacra and Yona Lunsky. Improving the quality of primary care for adults with intellectual and developmental disabilities. Value of the periodic health examination. Canadian Family Physician April 2019, 65 (Suppl 1) S66-S72

Multi-strategy approach to guideline implementation:

4. Francke AL, Smit MC, de Veer AJ, Mistiaen P. Factors influencing the implementation of clinical guidelines for health care professionals: A systematic meta-review. BMC Med Inform Decis Mak. 2008 Sep 12;8:38,6947-8-38

5. Mostofian F, Ruban C, Simunovic N, Bhandari M. Changing physician behavior: What works? Am J Manag Care. 2015 Jan;21(1):75-84

6. The Center for Implementation. (2022). StrategEase Tool [Web application]. https://thecenterforimplementation.com/strategease-tool

The experience of people with IDD:

7. Gregson, N., Randle-Phillips, C., & Hillman, S. (2022). People with intellectual disabilities' experiences of primary care health checks, screenings and GP consultations: A systematic review and meta-ethnography. International Journal of Developmental Disabilities, doi:10.1080/20473869.2022.2056402

8. Perry, J., Felce, D., Kerr, M., Bartley, S., Tomlinson, J., & Felce, J. (2014). Contact with primary care: The experience of people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 27(3), 200-211. doi:10.1111/jar.12072

Evidence of barriers to uptake: knowledge and attitude gaps/Evidence of need for educational program for FPs:

9. **McNeil, K., Achenbach, J., Lawson, B., Delahunty-Pike, A., Barber, B., & Diepstra, H. (2024). Towards developing an intervention to support periodic health checks for adults with intellectual and developmental disabilities: Striving for health equity. *Journal of Applied Research in Intellectual Disabilities*, 37(1), e13169. https://doi.org/10.1111/jar.13169**

10. Caltabiano, P., Bailie, J., Laycock, A. *et al.* Identifying barriers and facilitators to primary care practitioners implementing health assessments for people with intellectual disability: a Theoretical Domains Framework-informed scoping review. *Implement Sci Commun* **5**, 39 (2024). https://doi.org/10.1186/s43058-024-00579-8

11. Wilkinson, J., Dreyfus, D., Cerreto, M., & Bokhour, B. (2012). "Sometimes I feel overwhelmed": Educational needs of family physicians caring for people with intellectual disability. Intellectual and Developmental Disabilities, 50(3), 243-250. doi:10.1352/1934-9556-50.3.243
12. Doherty, A. J., Atherton, H., Boland, P., Hastings, R., Hives, L., Hood, K., . . . Chauhan, U. (2020). Barriers and facilitators to primary health care for people with intellectual disabilities and/or autism: An integrative review. BJGP Open, 4(3) doi:10.3399/bjgpopen20X101030
13. Bakker-Van Gijssel, E. J., Olde Hartman, T. C., Lucassen, P. L. B. J., Van Den Driessen Mareeuw, F., Dees, M. K., Assendelft, W. J. J., & Van Schrojenstein Lantman-De Valk, H. M. J. (2017). GPs' opinions of health assessment instruments for people with intellectual disabilities: A qualitative study. British Journal of General Practice, 67(654), e41-e48. doi:10.3399/bjgp16X688585
14. Shooshtari, S., Temple, B., Waldman, C., Abraham, S., Ouellette-Kuntz, H., & Lennox, N. (2017). Stakeholders' perspectives towards the use of the comprehensive health assessment program (CHAP) for adults with intellectual disabilities in Manitoba. *Journal of Applied Research in Intellectual Disabilities*, *30*(4), 672-683. doi:10.1111/jar.12261
15. Lagu T, Haywood C, Reimold K, DeJong C, Sterling RW, Iezzoni LI. I Am Not The Doctor For You': Physicians' Attitudes About Caring For People With Disabilities. Health Affairs 2022;41(10): 1387–95.
16. Burge P, Ouellette-Kuntz H, Isaacs B, Lunsky Y. Medical students' views on training in intellectual disabilities Can Fam Physician 200; 54:568-9.e1-5

Evidence of need for advice from patients, family and paid caregivers and developmental service agencies:

17. Oosterveld-Vlug, M., Oldenkamp, M., Mastebroek, M., & Boeije, H. (2021). What difficulties do people with mild intellectual disabilities experience when seeking medical help from their GP? A qualitative study. *Journal of Applied Research in Intellectual Disabilities*, *34*(1), 178-189. doi:10.1111/jar.12796
18. Coret, A., Boyd, K., Hobbs, K., Zazulak, J., & McConnell, M. (2018). Patient narratives as a teaching tool: A pilot study of first-year medical students and patient educators affected by Intellectual/Developmental disabilities. *Teaching and Learning in Medicine*, *30*(3), 317-327. doi:10.1080/10401334.2017.1398653
19. Boyd, K., Diepstra, H., Hamdani, K. E. Y., & Lunsky, Y. (2018). Consumer inclusion: Experience of patients with intellectual and developmental disabilities informs primary care. *Canadian Family Physician*, *64*, S8-S10.
20. Baumbusch, J., Phinney, A., & Baumbusch, S. (2014). Practising family medicine for adults with intellectual disabilities: Patient perspectives on helpful interactions. *Canadian Family Physician*, *60*(7), e356-e361.
21. Wigham, S., Bourne, J., McKenzie, K., Rowlands, G., Petersen, K., & Hackett, S. (2022). Improving access to primary care and annual health checks for people who have a learning disability: A multistakeholder qualitative study. BMJ Open, 12(12), e065945. Doi:10.1136/bmjopen-2022-065945
22. Potvin, L. A., Fulford, C., Ouellette-Kuntz, H., & Cobigo, V. (2019). What adults with intellectual and developmental disabilities say they need to access annual health examinations: System navigation support and person-centred care. *Canadian Family Physician*, *65*, S47-S52.

IDD Curriculum:

23. Casson I, Abells D, Boyd K, Bradley E, Gemmill M, Grier E, Griffiths J, Hennen B, Loh A, Lunsky Y, Sue K. (2019). Teaching family medicine residents about care of adults with intellectual and developmental disabilities. Can Fam Physician. Apr;65(Suppl 1):S35-S40. PMID: 31023779; PMCID: PMC6501710.

Appendices

Appendix 1: StrategEase Tool

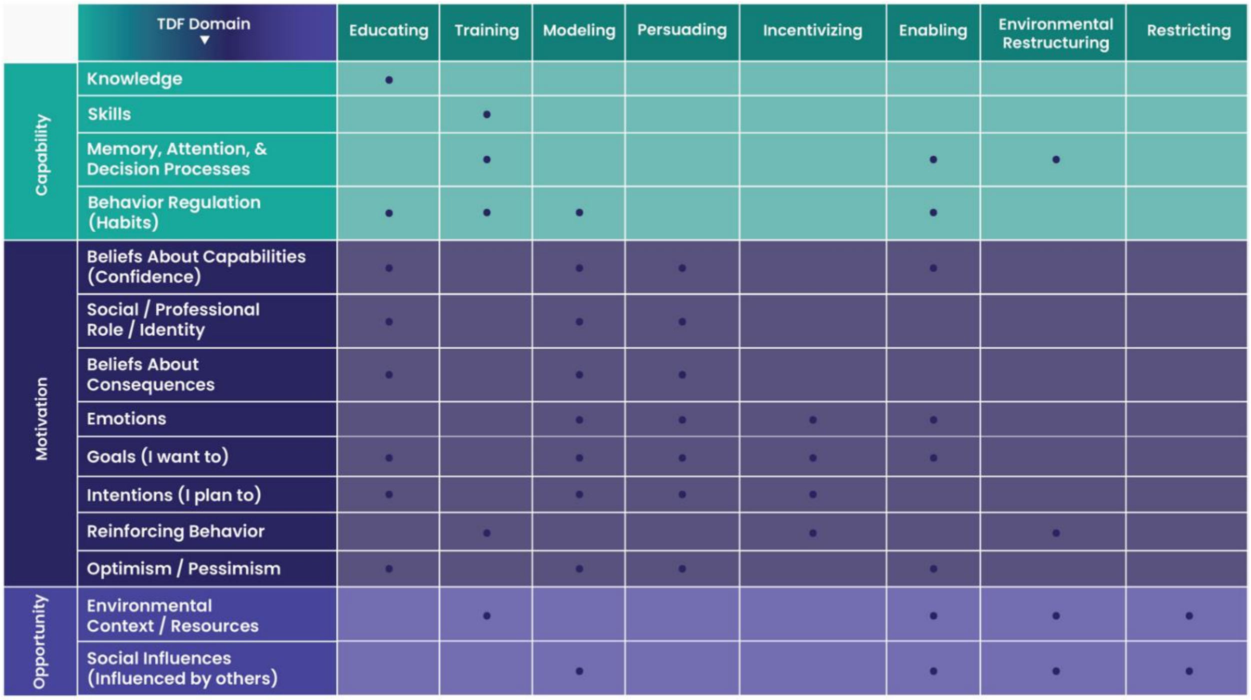
Appendix 2: Survey Results

Appendix 3-d: COMB TDF & quotes per stakeholder group

- Appendix 3a: Adults with Intellectual Disabilities Focus Group
- Appendix 3b: Caregiver Focus Group
- Appendix 3c: Physician Focus Group
- Appendix 3d: Paid Caregiver Focus Group

Appendix 4: Existing Resources and Tools

Appendix 1: StrategEase Behaviour Change Tool



	TDF Domain ▼	Educating	Training	Modeling	Persuading	Incentivizing	Enabling	Environmental Restructuring	Restricting
Capability	Knowledge	●							
	Skills		●						
	Memory, Attention, & Decision Processes		●				●	●	
	Behavior Regulation (Habits)	●	●	●			●		
Motivation	Beliefs About Capabilities (Confidence)	●		●	●		●		
	Social / Professional Role / Identity	●		●	●				
	Beliefs About Consequences	●		●	●				
	Emotions			●	●	●	●		
	Goals (I want to)	●		●	●	●	●		
	Intentions (I plan to)	●		●	●	●			
	Reinforcing Behavior		●			●		●	
	Optimism / Pessimism	●		●	●		●		
Opportunity	Environmental Context / Resources		●				●	●	●
	Social Influences (Influenced by others)			●			●	●	●

Michie, S., Atkins, L., & West, R. (2014). *The behaviour change wheel: A guide to designing interventions.* Silverback Publishing. www.behaviourchangewheel.com

The Center for Implementation

Figure adapted by The Center for Implementation

Table summarizing COM-B (Capability, Motivation, Opportunity) and the TDF (Theoretical Domains Framework) domains and associated intervention functions. For each intervention function on the X axis (Educating, Training etc.) there is a drop-down list of specific change strategies (such as use of educational materials) which was used to inform focus-group transcript analysis.

Appendix 2: Survey Results

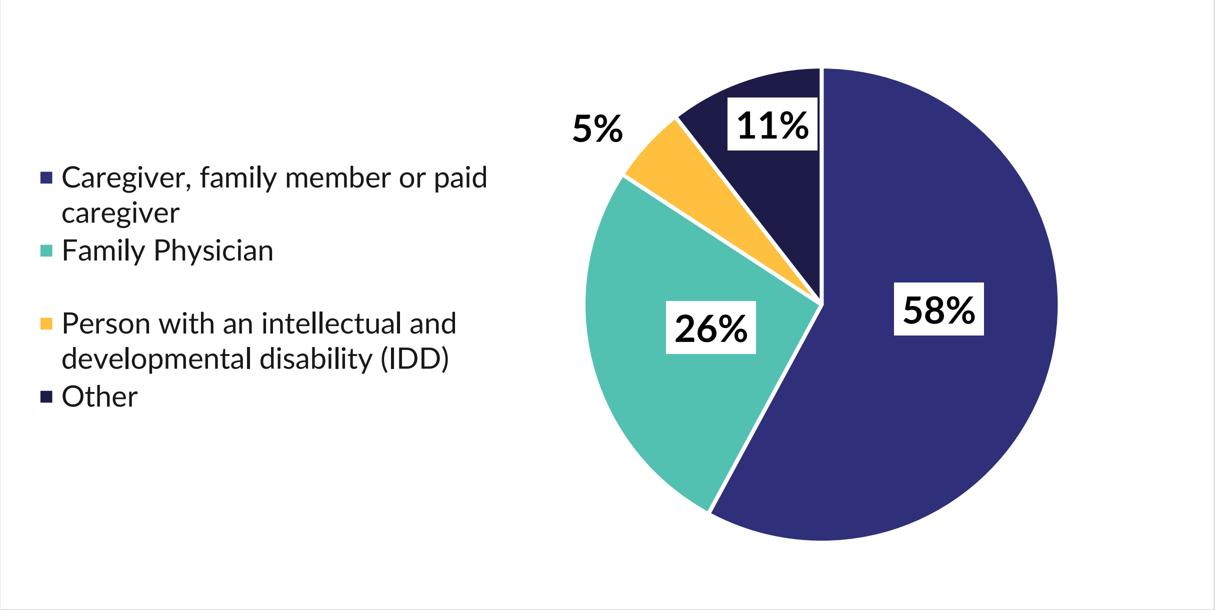


Figure 1. Question 1: I am a…. N=19. Other = Support Network for an Individual, Service Coordinator/ Adult Protective Services Worker

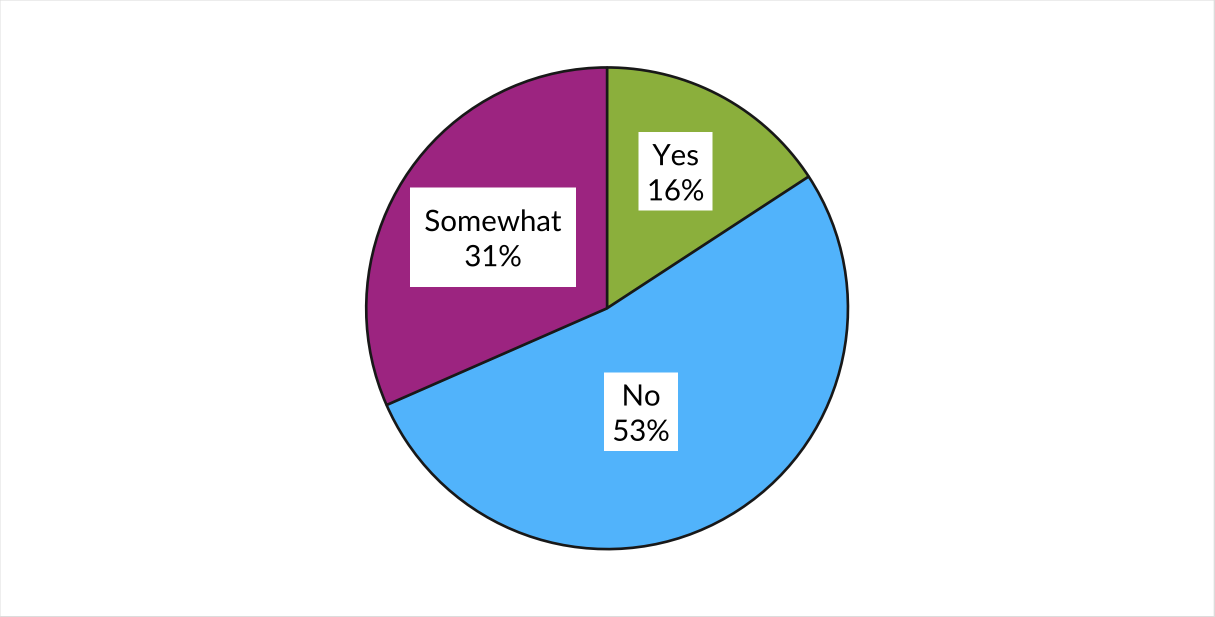


Figure 2. Question 2: Did you previously know what an IDD Health Check is? N=19

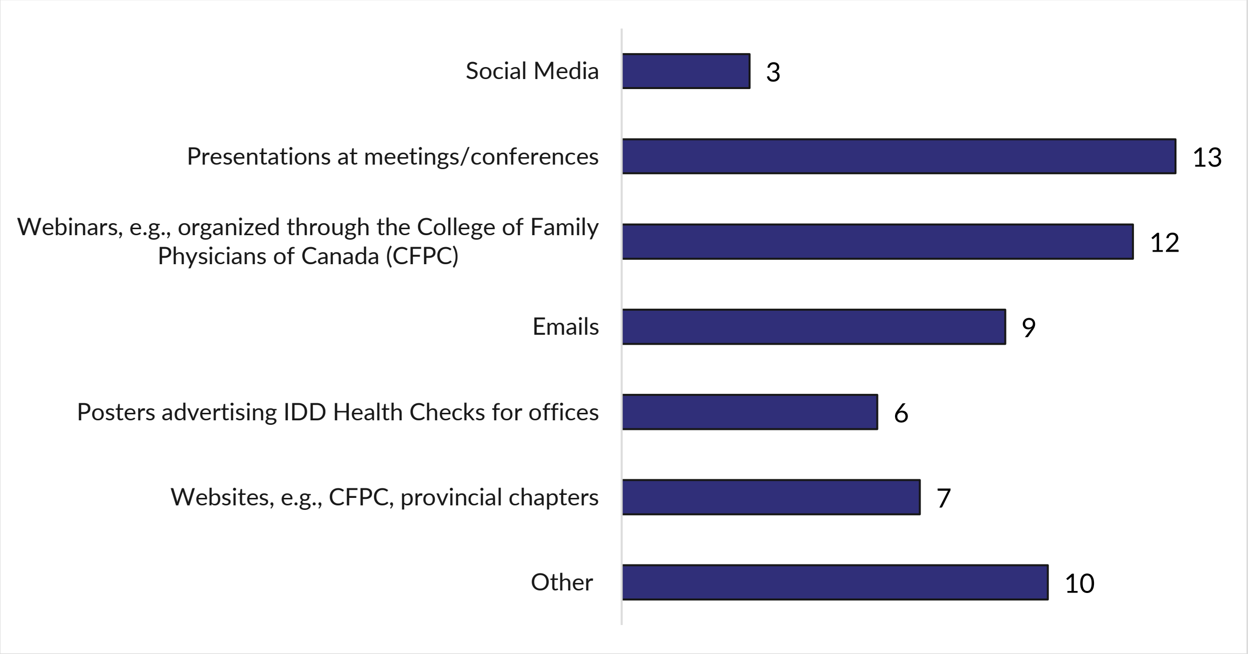


Figure 3. Question 3: What would be the best ways to help family doctors and their colleagues and staff want to learn about and provide health checks?

Other:

Training
"Proper training!! All humans should have the same access to the same medical exams."

"More training in med school"

"right start from medical schol when they are in training."

Environmental Restructuring/ Access
"Have actually access to family doctors."

"My [child] uses a wheelchair so I would need a[n] accessible locaiton to do so."

Education
'An information piece for individuals to give their doctor/nurse"

"it's old school, but direct mail to the doctor's office with key info and "learn more."

"Learn about their local agencies and the supports they provide, to allthem the information before they are in a crisis."

"You have a very challenging job here. I have 6 inboxes to look at after the last patient leaves every work day so messages such as this can get missed in the sruggle to get home before dark…I am later career MD so I NEVER look at social medial. Eamils are easy to ignore or say I'll get back to that later (and then forget to…) Webinars are reasonably effective now that much of CPD is done online."

Advocacy
"Bring it under the attention of the Autism and Disability groups to take to their physician."

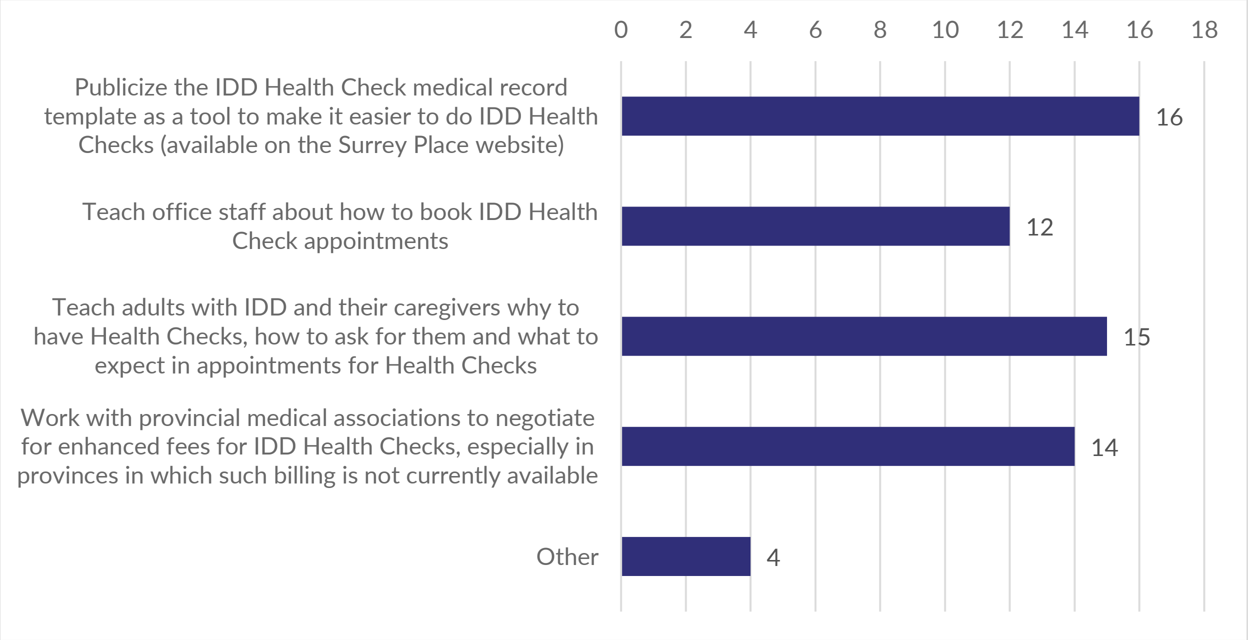


Figure 4. Question 4: What would be the best ways to help make it more feasible for family doctors and their colleagues to provide IDD Health Checks? N= 19

Other:

"Physicians send out yearly reminders to patients requiring IDD health check appointments."

"designate specialty clinics/offices in each regions."

"Imbed it within the DSO."

"Ensure that an easy-to use version of the IDD Health Check medical record template is available for all the different EMRs in Canada."

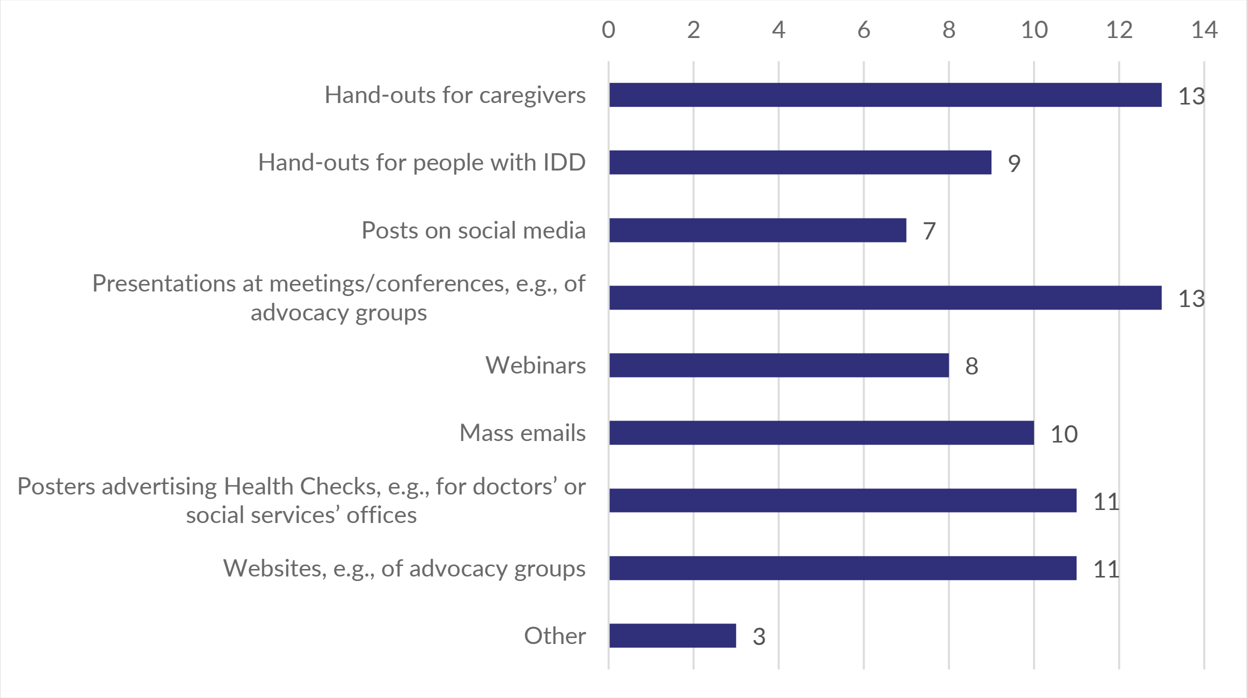


Figure 5. Question 5: What would be the best ways for patients and their caregivers to learn about "IDD Health Checks"? N= 19

Other:

Communication

"Contacting support groups that directly work with families who have members with IDD. I found that our CSW does not forward any type of this information. Get most of our info from advocacy groups and other families with IDD."

"Work with day program providers to create appropriate learning experiences - this worked extremely well for my son's day program when preparing members for Covid vaccine shots (and was done virtually over Zoom)."

"DSO emails/check-ins and also partner with school boards to reach caregivers while individuals are adolescents."

Appendix 3a: Adults with Intellectual and Developmental Disability Focus Group

Summary of findings

Capability

1. Educational materials, co-designed with people with IDD
    a. Easy to share plain language pamphlets explaining what health check is and why it is important
    b. Visuals/posters for public display
2. Mass Media
    a. YouTube videos/ skits explaining health check scenarios
    b. Social media: Facebook, TikTok, Instagram - messages, co-designed with people with IDD
3. Build a coalition/network
    a. Work with the community agencies to share information to people with IDD
    b. Work with caregivers and support workers to share information to people with IDD
4. Work with Educational Institutions/ engage leaders
    a. Work with the CCFP to find pathways to translate knowledge about the PHC into practice, build relationships and find common ground
5. Action Planning:
    a. Health Check preparation tools/communication tools e.g. scripts, lists, pre-visit practice
    b. Learn how to self-advocate at the doctor's office
    c. Bring a document to the doctor that explains the Health Check
6. Peer-to-peer learning:
    a. Discuss health check within advocacy groups
    b. Learn tips from other self-advocates

Motivation

1. **Champions:** Reframe the message in the positive – "Don't miss out on good health". "Healthcare is your right". "Knowledge is power"
2. **Mass Media:** Youtube videos to promote PHCs led by advocacy groups
3. **Patients/Public as active participants:** Reach out to social networks to create a strong message to promote PHCs
4. **Work with educational institutions:** People with IDD to be involved in training healthcare professionals at the post-secondary level

Opportunity

1. Restructure the environment
    a. Accessible exam rooms
    b. Video or phone visits
    c. Mobile services
    d. Provide anxiety reduction strategies
2. Social support
    a. Plain language communication
    b. Allow support workers to attend PHCs and do not send them away without permission from the PWIDD
    c. Be aware of non-verbal cues
    d. Provide explanations and clarification
3. Allocation of resources/funds
    a. More family doctors
    b. Accessible transportation
    c. More time at the doctor's appointment

Analysis

Barrier 1: Lack of awareness/knowledge/understanding and skills for the Health Check

What needs to change: Have a better understanding of the annual Health Check, their importance, and who is eligible. Broaden knowledge mobilization.

COMB/TDF	Intervention Functions (*Presented* / StrategEase list)	Strategies (*presented* / StrategEase list)
Capability – Knowledge	**Educating**	Audit and feedback Capture and share local knowledge Community of Practice (CoP) ***Educational materials*** ***Educational sessions*** Integrating the topic into meetings Knowledge broker ***Mass media***
Capability – Skills Memory, Attention, Decision Processes	**Training** **Enabling** Environmental Restructuring	**Training** Competency -based training Educational materials Educational outreach visits Educational sessions Local opinion leaders Mentorship ***Peer-to-peer learning*** Provide supervision Train-the-trainer ***Work with Educational Institutions*** **Enabling** ***Action Planning*** Allocation of funds ***Build a coalition/network*** Champions Change Payments Schemes/ Structures Community of Practice Data sharing Engage leaders Goal setting

Strategy	Stakeholder Quotations	APEASE
Educational materials	P4:"I think something that would make it easier for people to learn how to take part in a health care check would be to have easy to read materials or easy read pamphlets."	Creation of educational materials requires minimal funding. Existing materials are available but would need to be revised for a Canadian perspective.

	P3:”Make sure the information is given in plain language” P3:”A document showing visual might help” P8:”You can make a poster, and I know [there is a] bulletin board. You can post the poster on the bulletin board, and then people will read and see it.” P6:”a document that you take with you to show your doctor, the different ins and outs about what a health check is involved.”	
Mass media	P8:”To get the word out, yes, yes, social media is very powerful. And not only social media, there’s YouTube.” P4:” I would use or I would start off with social media”. Yes, cause that can be a very good way to get people’s attention” P6:”Doing a skit and what would happen if the different scenarios, and then post it on YouTube and then it can be shared through different social networks.” P8 “So, to get the word out, yes, yes, social media is very powerful. Yeah, there is Twitter, there is Facebook, like *P4* said, there is Tik Tok, and there is Instagram. And not only social media, but there's YouTube.”	Creating videos for YouTube/ X would be costly. This would require
Build a coalition/network	P3:”via DSO outlets, for example I get my information from Surrey place.” “In the community.” “Community agency that knows the people with disability”. P3:”Maybe [via] your caregiver and if you’re not able to live on your own, and if you have a PSW or someone like that who has access to your medical information. You can get information from them.”	
Work with Educational Institutions/ engage leaders	P6 “We need to talk to the College of Physicians in different provinces to talk to them about how we can make this a priority because it continues… not enough doctors, not enough support workers to line up everything. We’re always in a crisis for everything.”	
Action planning	P7:”Sometimes it can help to have like a script set up ahead of time. You can practice what you want to say. And then , if you already know what you’re going to be saying	

	then you have less of a problem finding words to communicate” P4: “have something similar ahead of the actual appointment, so you can have some time to ask any questions …A preparation or pre-visit” P5:”Write down before to come to the health visit…maybe have a list of questions that you want to ask first” P7:”Learning about self-advocacy in general would help because if you’re able to advocate for yourself in some places you can use those skills also at a medical appointment.”	
Peer-to-peer learning	P8:” The advocacy groups they can talk about the health check in the advocacy group with each other….the goup can share suggestions and ideas to make your health check improve” P8: It’s the Advocacy Disability Council at Surrey Place and this is another council, and also can help with the health check”. P7: “I think I’ve learned a lot from other self-advocates, watching what they did.” P7:”If you are able to remember that it’s your health check and your opinions are important, then you might be more likely to speak-up.”	

Barrier 2: lack of motivation to book a health check; anxiety about the health check

What needs to change: Believe PHCs are vital for people who cannot interpret their own body cues. Hold the belief that PHCs increase health equity for adults with IDD

COMB/TDF	**Intervention Functions (*Presented* /** StrategEase list**)**	**Strategies (*Presented* /** StrategEase list**)**
Motivation - Beliefs about consequences	**Educating** Modeling **Persuading**	**Educating** Audit and feedback Capture and share local knowledge Community of Practice (CoP) ***Educational materials*** ***Educational sessions*** ***Integrating the topic into meetings*** Knowledge broker

		Mass media **Persuading** ***Champions*** Engage leaders Facilitation Identify early adopters Implementation coaching Leaders supporting the change Local consensus process ***Mass Media*** Opinion leaders Public demand
Motivation – Emotions	**Modelling** Persuading Incentivizing **Enabling**	**Modeling** Model Change Provide supervision Shadow other experts Simulate change Visit other sites **Enabling** ***Action Planning*** Allocation of funds ***Build a coalition/network*** ***Champions*** Change Payments Schemes/ Structures Community of Practice Data sharing Engage leaders Goal setting

Strategy	**Stakeholder Quotations**	**APEASE**
Champions	P7:"I would let people know that people with developmental disabilities sometimes have more common rates of certain health problems. And that you shouldn't have to deal with these health problems on your own because if you see a doctor there might be something that can be done to make your life easier" P8:"It's not a bad thing to have a health check, because you don't want to be kept in the dark. You want to know if there's something wrong with your health and it's better to know, because once you know what's wrong with your health, then you can seek treatment that the doctor recommends. So it's better to know so you can work on it and improve."	Sharing facts, motivational statements from self-advocates such as "you shouldn't have to dela with these health problems on your own…" are easy to create and share.

	P4: "And what I would say to friends or people in my immediate networks and or surrounding, you know, is yes, I may face challenge more often than others, but look, healthcare is my right. I am allowed to have access to it and I don't want to be denied healthcare either." P1:"Because it's your body, and you have the right to know. You have the right to know what's going on, whether you have a disability or not, you have the right to know what's going on just to stay healthy." [Get a health check, don't miss out on good health] P1:"I like that it's much more positive, and it may, well, it would encourage people to go, because it's not like Oh you're sick! Let's find out that's wrong with you, and let's make you feel as scared as possible. That's not what we want." P4 "When we are talking about advocacy. It is also important to educate healthcare providers that not all disabilities are visible."	
Mass Media	P8: "Advocacy groups can make YouTube video and speak about health checks and how important it is and what to say to your friend and what you can work on."	Creation of a video may be costly. Perhaps possible with appropriate connections to advocacy groups? Representation of a diverse range of Canadian adults with IDD would be important for equity.
Patients/Public as active participants: building a coalition	P4: "And reach out to your own networks and see if you can create something together. If you work together that can be an extra way of sending the message out even stronger."	The DD MIG may not have connections to appropriate networks.
Work with educational institutions	P4: "I think if we had the opportunity to be heard, I think doctors could learn a lot. And healthcare workers could learn a lot. We have a voice. Let us speak." P6: "We need to be the one to train these staff. I mean doctors, nurses, medical professionals, everywhere. I do it right now in the college system….We do the presentation with developmental services workers in the colleges and sometimes in the university…I think we need to develop	People with IDD as teachers to medical professionals has been utilized in some curricula, but is not yet a standard practice. Access to self-advocate networks that can provide support for the adults with IDD who are providing teaching is important. Difficult to implement an equitable program across the country.

	a course to teach as people here to teach…the medical professionals how you're supposed to work together with us; not against us." P7: "Self-advocates should be doing the training. We have the knowledge about ourselves. They need to listen to us so we can do the training."	

Barrier 3: Accessibility and social influences barriers to having a health check

What needs to change: Have collaboration between all stakeholders as a healthcare team. Have better ways to manage healthcare anxiety. Have PHCs recognized as standard of care.

COMB/TDF	**Intervention Functions (Presented / StrategEase list)**	**Strategies (*Presented* / StrategEase list)**
Opportunity – Environmental Context/ Influences	Training **Enabling** **Environmental restructuring** Restricting	**Enabling** Action Planning ***Allocation of funds*** Build a coalition/network Champions Change Payments Schemes/ Structures Community of Practice Data sharing Engage leaders Goal setting **Environmental restructuring** ***Change sites that provide the service*** ***Change the physical environment*** Prompts/Cues Record systems/ reminders Revise professional roles
Opportunity - Social Influences (Influenced by Others)	**Modeling** **Enabling** Environmental restructuring Restricting	**Modeling** Model Change Provide supervision Shadow other experts Simulate change Visit other sites **Enabling** Action Planning ***Allocation of funds*** Build a coalition/network Champions Change Payments Schemes/ Structures Community of Practice Data sharing Engage leaders Goal setting

Strategy	**Stakeholder Quotations**	**APEASE**
Facilitation	P8 "And it's very difficult to come on multiple days because it goes back to the situation of transportation…It is easier if you can provide at least one or two hours to do everything."	Improving transportation is outside the scope of this project, however, being mindful of transportation challenges can

	P6"They might do phone calls, they might do video unless they're (not) trained and have the hardware with their computer that they can do it [and] if they don't then we need to make that available for them to teach them. P2:"also explaining options. For example, I had no idea that you could take a urine cup home with you. I thought I would have to do it in the office, something so simple. "You can take it home", 'Oh okay, really? I didn't know!" should take into consideration that kind of stuff."	assist with accommodations for clinical encounters. Offering virtual care (telephone or video visits) are also reasonable accommodations for many patient encounters. Family physicians should be able to identify ways to make investigations more patient-centred. This is an important teaching point.
Restructure the environment	P3:" More mobile services" P8:"Maybe a phone call or Zoom that the doctor can meet you and talk to you on the phone and see you on the Zoom and then you're in the comfort of your own place, and that would take a lot of tension off." P3:"Make sure the space and the room is accessible" P1 "Even have things at the doctor's office. If someone come in who's anxious have a fidget toy."	Clinical encounters with accessibility as a priority including offering virtual care, when appropriate and providing a physically accessible clinical space are reasonable adjustments that can be made for patients with IDD.
Social support	P4:"Having appropriate support networks when attending healthcare check-ups, because sometimes, when you go in for healthcare checkups, the language that healthcare providers use isn't always easy to understand. So, if you have someone with you there then that's some little extra support which have always been beneficial to me" P7:"Don't send my support person away. I understand they're concerned about privacy but if I come in with a support person ask me if I want them there and then just let my support person be there because I am really nervous about talking to new people or sometimes even talking to people I know. So just let me have my support person in the room, because I will be less anxious, and then I'll likely to be	Recognition of the importance of support networks for people with IDD may challenge physicians who are seeking autonomy for their patients. Teaching should include how to ask if your patient would like a support person to stay with them during the clinical encounter.

	able to tell you how I'm feeling and what I'm thinking" P4:"[Talk to me directly], If we don't understand something, then find language that's accessible to us". P1:" Doing your research in terms if someone comes in and they're anxious, don't always expect them to make eye contact" P4:"Make sure that the language is accessible, as I sort of was saying. Health care talk is not always in English and they often use very big terms. They can be very hard to understand, especially for people with IDD. So use small, easy language that's comprehensible for everyone." P1:"It's important to always use simple and plain language and also make sure that you let them know if I have questions let them know that you need to have the ability to ask questions. So if I need clarification on something, or if you're confused about something, they need to know you understand."	Patient-Centred Care is already highlighted in some curricula but needs to be disseminated further.
Allocation of funds /resources	P8: "It's really hard to make an appointment with the family doctor right now. My family doctor is booking appointments for April. So it's not enough, we need more family doctors in order for people with developmental disabilities to have the opportunity to have frequent health checks." P6: "Not have a time limit". "A half and hour or an hour, because 20 min doesn't go long enough, I say an hour. Then it gives you time to go through all your issues that you're dealing with to get result." P8: "Transportation is an issue. And it's very difficult to come on multiple days because it goes back to the situation of transportation. It's very difficult to get transportation and to reply on transportation. And it's easier if you get provided at least 1 or 2 hours to do everything in one appointment."	Allowing adequate time for clinical encounters, providing resources for patients to have more time with providers. This is an additional barrier that could be discussed further. For example, family physicians may have difficulty with renumeration for long visits. Billing codes with fair renumeration for IDD Health Check have been used in parts of Canada but not in all provinces/ territories.

Strategies for physicians/ accommodations:

P7:"It's hard for me to have medical stuff done because I have medical trauma, and that is really common in people with developmental disabilities. And so, first of all some ***compassion from the doctor*** *is really necessary. I don't want to be shamed for maybe not coming in sooner because just making the appointment was hard enough because it's really worrisome for me. It is hard to get diagnosed with health problems even at the emergency department, when they find out that you're autistic and have anxiety because they think you're just making it up. It took me a long time to get actually diagnosed with a real physical health problem that they didn't believe me about. So it starts back with doctor's* ***training to learn that they can't dismiss somebody*** *on the basis of developmental disability of mental health stuff."*

Educational sessions:

*P7:"****Self-advocates should be doing the training****. We have the knowledge about ourselves. They need to listen to us so we can do the training."*

P6:"So, having us at the table and stuff, and speaking with and doing the presentation to these medical professionals would be very useful, because then they can in their beginning of their studies and ongoing studies, they will hear from us…."

P6:"I think we need to develop a course to teach as people here…teach these medical professionals how we can make things, how you're supposed to work together with us [and] not against us."

P4:" I agree on the advocacy very very much. I think if we had the opportunity to be heard. I think doctors could learn a lot. We have a voice, let us speak,"

P3:"More education to health care teams, about how they could help make a health check a more positive experience for people".

P4:"It's also important to educate healthcare providers that not all disabilities are visible".

Quote Highlights:

P3: "It's your body, and you have the right to know what's going on, whether you have a disability or not, you have the right to know what's going on, just to stay healthy"

P6:"We need to talk to the College of Physicians in different provinces, to talk to them about how we can make this a priority because it continues…not enough doctors, not enough support workers…Line up everything, we're always in a crisis for everything.

Appendix 3b: Caregiver Focus Group

Summary of findings

Motivation Goals "I want my loved one to have health checks" and help caregivers confidently ask for health checks. To reduce anxiety or reluctance for caregivers who want to ask for a health check for their loved ones. Strategies explored included educating, persuading and enabling.

1) Data sharing
    a. Communicate evidence/data of the <u>benefits</u> of a IDD health check
    b. Communicate that an annual/periodic health check is an evidence-based guideline recommended practice for people with IDD
    c. Communicate that the IDD Health Check falls within best practice for physicians
2) Action planning
    a. Encourage caregivers to ask the doctor for an annual health check for the person with IDD
3) Early adopters
    a. Share stories of success from family and person with IDD

Capability Increase knowledge, skills and awareness of health checks amongst caregivers.

1) Educational materials for caregivers
    a. Caregiver pamphlet/brief document including: "caregivers want health checks", what a health check entails, what you need to do, why it is important for people with IDD.
    b. A flyer or handout that a family physician can deliver to caregivers/developmental service agencies about the importance of health checks
    c. Communicate a "did you know" at point of transition to adult care, alerting caregivers to the recommended health check.
    d. Work with organizations where general transition information is being shared (e.g., Developmental Services Ontario, Passport coordinators)
2) Educational sessions for caregivers
    e. Offer information sessions for caregivers about the why, what and how of the IDD Heath Check through community agencies serving persons with IDD (e.g., within agency's caregiver wellness programs)
    f. Offer information sessions for caregivers about the why, what and how of the IDD Heath Check at caregiver organizations (e.g., Ontario Caregivers Organization; Canadian Centre for Caregiver Excellence)
3) Mass media
    g. Social media geared toward caregivers (Facebook, Instagram)
        i. use influencers or famous people with IDD/caregivers to increase reach
        ii. targeted sharing in caregiver groups
4) Reminders
    h. Send reminders in the mail, that can be brought to the family physicians's office)

Analysis

Facilitator 1a: Motivation- Goals ("I want to…"): "I think this is a great idea, I want to make sure my love one gets an annual health check"

This discussion also brought about discussion about a **barrier: "Caregivers do not know about Health Checks"- Barrier- Capability**. (discussed separately below)

COMB/TDF	**Intervention Functions (Presented/** StrategEase list**)**	**Strategies (*presented /* StrategEase list)**
Motivation Beliefs about capabilities Beliefs about consequences Social role/identity **Goals (I want to)** Opportunity – social influences	**Educating** Modeling **Enabling** **Persuading** **Restructuring the environment**	**Educating** Audit and feedback Capture and share local knowledge Community of Practice (CoP) ***Educational materials*** ***Educational sessions*** ***Integrating the topic into meetings*** Knowledge broker Mass media **Persuading** Public demand Opinion leaders ***Champions*** ***Engage leaders*** Facilitation ***Identify early adopters*** Implementation coaching Leaders supporting the change Local consensus process Mass media **Enabling** Goal setting Action planning Allocation of funds Build a coalition/network ***Champions*** Change payment schemes or structures Community of Practice (CoP) ***Data sharing*** ***Engage leaders*** ***Social support*** Implementation coaching Involve executive boards Leaders supporting the change Opinion leaders

		Patients/public as active participants Problem solving ***Restructure the environment*** Self-monitoring of behavior

Barrier 1b: Lack of knowledge/ lack of awareness about the IDD health check and how to prepare for it with a loved one

Barrier- Capability

:"It would be enough for me to just share the knowledge that is considered best practice for people with IDD to have a health check once a year… For me, that would be enough of a way to convince me that its appropriate to ask for it because now I'm aware of it, the health outcomes will be better for the patient by having it."

"For people like my daughter, it's to convince the caregiver, just the facts. You know, then you got it on your agenda, you'll just do it once a year or however often you are supposed to do it."

What needs to change: Caregivers need to understand what a Health Check is and how to prepare for a Health Check

COMB/TDF	**Intervention Functions**	**Strategies (Presented / StrategEase list)**
Capability - Knowledge	Education	Audit and feedback Capture and share local knowledge Community of Practice (CoP) ***Educational materials*** ***Educational sessions*** ***Integrating the topic into meetings*** Knowledge broker Mass media
Capability - Skills	Training	Competency-based training Work with educational institutions Train-the-trainer ***Educational materials*** Educational outreach visit ***Educational sessions*** ***Local opinion leaders*** Mentorship Peer-to-peer learning Provide supervision

Barrier 2: "Our family doctor did not remind us to do a health check".

Motivation- Social Professional Role (It is not my responsibility to remember about health checks or to initiate them)-

C7: "If it is an annual health check, it will also be helpful if we can have an annual reminder from mail and we can bring it to the family doctor."

What needs to change: Caregivers need to feel confident that it is within their role, as caregivers, to ask for a Health Check for their loved one.

COMB/TDF	**Intervention Functions (*Presented* / StrategEase list)**	**Strategies (*Presented* / StrategEase list)**
Motivation – bBeliefs about capabilities Beliefs about consequences **Social role/identity** Goals (I want to)	**Educating** **Modeling** Enabling **Persuading** **Restructuring the environment**	**Education** ***Educational materials*** ***Educational sessions*** **Persuading** Public demand Opinion leaders ***Champions*** ***Engage leaders*** Facilitation ***Identify early adopters*** Implementation coaching ***Leaders supporting the change*** Local consensus process Mass media **Enabling** Goal setting Action planning Allocation of funds Build a coalition/network ***Champions*** Change payment schemes or structures Community of Practice (CoP) Data sharing ***Engage leaders*** ***Social support*** Implementation coaching Involve executive boards Leaders supporting the change Opinion leaders Patients/public as active participants Problem solving ***Restructure the environment*** Self-monitoring of behavior

Strategy	Stakeholder Quotations	APEASE
Education materials	C4:"I wonder if for a caregiver who might be reluctant to take their child or person supported for a health check, maybe something like your experience as a neurotypical person going to the doctor, like what you need to do, why you need to go to the doctors, and why its even more important for someone with IDD to go to the doctor. And provide some, not high level statistical information, like things that will convince you that its important." "for me, sharing a story of a person with IDD who benefited from the health check is more effective than others from my perspective. Because when we explain something the people, or that man, that boy, that girl he has benefited from it, then he is very happy sharing his story, his real-life story, it's helpful I think." (?) C5:"For people like my daughter, it's to convince the caregiver which is just something that is just the facts: for those that cannot identify issues going on with them , this is what a health check is, this is what it gets, this is how long it takes, not what it gets, but this is what it ENTAILS, this is how long it takes, just the facts. You know, then you got it on your agenda, you'll just do it once a year or however often you are supposed to do it." C6:"It would be enough for me to just share the knowledge that is considered best practice for people with IDD to have a health check once a year. Get that word out there, and then beneath that "ask your doctor, if you haven't had a health check this year, ask your doctor. Every person with an IDD should have a health check every year, ask your doctor for one. For me, that would be enough of a way to convince me that its appropriate to ask for it because now I'm aware of it, the health outcomes will be better for the patient by having it. It's just	Suitable for our MIG to create educational materials, including handouts, stories and quotes from family doctors. These are relatively inexpensive (but would require some funding to create) and within our area of expertise., We will have challenges ensuring equitable distribution of the materials across the country and into marginalized communities and communities without MIG members who are involved in IDD. We should be mindful of potential barriers such as language and literacy level. Providing the materials to all family physicians would improve access, we would need to partner with the College of Family Practice for options to do this.

	knowing its advised and the asking for one if you haven't had one in a year." C3:"Quotes from family physicians would show me as a caregiver that they are aware of it. Encouraging caregivers to enquire and act upon."	
Role/identity	C5:"It would be great to have a handout or something that said – this is for somebody with IDD, they should always have dental appointments once every six months, eyes once every two years, a health check…you know and have it so that it would written down so they know it's their responsibility, that this is something to add."	Handouts are within our scope. Dissemination would need to be equitable.
Social support/influences	C3:"If I knew that the physicians knew about this, it would be so much easier to communicate for me to go out there and feel "oh doctors know about this, I'll bring my sister….I've had a lifelong of things that I've been told by doctors about why not take her as a patient".	Doctors as leaders supporting the change. It would require education and materials provided to family doctors. Creating a handout for doctors to provide to patients would be easy to do. The challenge would be getting the handout into the hands of Family doctors.
Educational Materials – content/format (knowledge)	<u>Materials for caregivers</u> C5: "the parameters of what it would involve is important"…"to know what it is, what it entails.." C6: "…I think there should be a little bit of education or awareness information made available to caregivers to speak about this and what the health check is and why they're important, and why they are recommended for the population of intellectual disabilities vs not recommended for the general population." C2:"I think for caregivers a pamphlet would be beneficial. The more information the better"	

Educational materials – dissemination (awareness)	C6: "There a lot of places and instances where I could see receiving a "did you know" as part of transition you should schedule an annual health check for the person you care providing care to. If you registered for DSO for example, that could come from DSO at the time you start to register or prepare for transition to adulthood. For caregivers to adults already, maybe there is an annual communication that you get from DSO related to funding, or supports, or services and it could be included with that." C2:" I was going to say through Passport as well. Like through the Passport coordinator, through the DSO." C2:"I think also disseminating that information to different agencies, agencies where there is day programs, agencies where there is residential care, not just agencies that are transfer payment agencies, I know that are a lot of smaller agencies that don't get information shared down to them." C2:" through social media. There's a lot of caregivers that are involved in different groups whether that is through Facebook or Instagram or whatever, and sharing information through there." C3:" My sister is 65. I am very involved with her and I have never heard of a health check before. I don't understand if this is coming from family services, like a government agency, or from physicians, like should the College of Family Physicians know about this or is this more family services?" Where does it start?" C4:"would this information also be shared with physicians? Because I'm not sure physicians know this. His [son] general physician, I don't know if he would know to do this." C2:"famous people can get the word out, …They have a big following so I you can get	

	someone, I think in every way, in anyway, get the information out there' C6:"Another way to share this information is through Caregivers Organizations such as Ontario Caregivers Organization and Canadian Centre for Caregiver Excellence"	
Educational sessions	C1:"Education sessions about how to ask for health checks" C6: " I like the idea of including it in information sessions for caregivers." C2: "I know there is a lot of agencies, that have sessions specifically for caregivers…a caregiver wellness program where we have information sessions, so trying to get into those and get a spot on the roster to be able to share that information." C4:"I would definitely make time for that. I think it's so important, you know, knowledge/understanding what is there, what's available. I don't think again that it is well known and part of the work you're doing here."	This will be more labour intensive, will require collaboration with a broad range of caregivers in order to be truly representative. We have the expertise to create a curriculum for education sessions but limited reach for meeting with agencies across the country.

Strategy	Stakeholder Quotations	APEASE
Educational Materials – content/format (knowledge)	Materials for caregivers C5: "the parameters of what it would involve is important"…"to know what it is, what it entails.." C6: "…I think there should be a little bit of education or awareness information made available to caregivers to speak about this and what the health check is and why they're important, and why they are recommended for the population of intellectual disabilities vs not recommended for the general population." C2:"I think for caregivers a pamphlet would be beneficial. The more information the better"	Handouts directed towards caregivers explaining what a health check should contain. Easy to create with some funding.

Educational materials – dissemination (awareness)	C6: “There a lot of places and instances where I could see receiving a “did you know” as part of transition you should schedule an annual health check for the person you care providing care to. If you registered for DSO for example, that could come from DSO at the time you start to register or prepare for transition to adulthood. For caregivers to adults already, maybe there is an annual communication that you get from DSO related to funding, or supports, or services and it could be included with that.” C2:” I was going to say through Passport as well. Like through the Passport coordinator, through the DSO.” C2:”I think also disseminating that information to different agencies, agencies where there is day programs, agencies where there is residential care, not just agencies that are transfer payment agencies, I know that are a lot of smaller agencies that don’t get information shared down to them.” C2:” through social media. There’s a lot of caregivers that are involved in different groups whether that is through Facebook or Instagram or whatever, and sharing information through there.” C3:” My sister is 65. I am very involved with her and I have never heard of a health check before. I don’t understand if this is coming from family services, like a government agency, or from physicians, like should the College of Family Physicians know about this or is this more family services?” Where does it start?” C4:”would this information also be shared with physicians? Because I’m not sure physicians know this. His [son] general physician, I don’t know if he would know to do this.”	

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Strategies suggested by caregivers for people with IDD:

Materials for people with IDD:
C5: "I think just a card, because a pamphlet is a lot" [on format of information for person with IDD]

C5: "You have to be specific, so if you're gonna be specific on everything like a full book, she's gonna loose her focus. So, even just on sentence, or two at the most, with a picture, that's fine." [on information for person with IDD]

Incentivizing for people with IDD (reward)
C5:"you gonna have to be specific. So even just a sentence, or two at the most, with a picture that's fine. Even if you had the ability to check it off that you've done it. That would be great."

Modeling for people with IDD:
C1:" role playing or model something like this, [it would] teach me and also my son that this the way." .."I am the doctor and you are the patient and if we do several times, maybe it works."[how to..]

C2:"I noticed that when I was taking my brother to appointments that I was doing a lot of training with him myself, like so this is his appointment, so he is the advocate. When we walk in he's able to say "my name is x and I have an appointment at" and hands his health card over. "

C4:"sometimes it's helpful to go through a story. My son would never do a role play, it's just not gonna happen. But if you keep going through a social story with him so he starts to understand that this is gonna happen, like you have that ability to keep reinforcing it....".

Family physicians as leaders supporting the change:
C5:"It would be great to have a handout or something that said – this is for somebody with IDD, they should always have dental appointments once every six months, eyes once every two years, a health check…you know and have it so that it would written down so they know it's their responsibility, that this is something to add."

C3 :"Quotes from family physicians would show me as a caregiver that they are aware of it. Encouraging caregivers to enquire and act upon."

Educate: family physicians
C2:"There certainly needs to be a lot of training for physicians"

C4:"would this information also be shared with physicians? Because I'm not sure physicians know this. His [son] general physician, I don't know if he would know to do this."

Quote Highlights

C4:" I just wanted to say thank you for giving us this opportunity to provide input. This is really important work and I know [and] everyone on these calls knows the challenges that we have in this sector with our loved ones. I am very excited to see where this goes and happy to continue to participate and provide any feedback, insight, experience as you move along in this journey and hopefully creating something that…you know, you go into your doctors, and your doctor says "has your loved one had a health check this year?"

Appendix 3c: Family Physician Focus Group

Summary of findings

Capability Increasing knowledge/awareness

1) Work with educational institutions to integrate IDD content into medical education curriculum (undergrad and post-grad)
    a. Develop example curriculum materials
        i. Seek input from DD MIG about residency curriculum requirements
        ii. Update existing 2014 competency-based residency curriculum (Surrey Place)
        iii. Connect with Queens University or UofT regarding undergrad curriculum examples
    b. Identify local/provincial champions for advocacy with medical schools
    c. Share example curriculum materials with local champions and on DDPCP/Surrey Place website
    d. Develop and share other materials that support local champions in their advocacy efforts (example letters, FAQs etc)
        i. Ask those who were successful in their advocacy for advice on what worked well, or what was needed
2) Educational materials
    a. Consider more syndrome specific materials and pathways for family physicians
        i. DDPCP to update and reformat Health Watch Tables
    b. Develop educational materials for developmental pediatricians (hand-over template, tips, presentation examples)
        i. Connect with TAY Surrey Place/St Michael's hospital pilot clinical for report template and tips
    c. Develop educational materials for paid caregivers, DS workers (Pre-Health Check information collection)
        i. Connect with HCARDD about Nuts and Bolts Toolkit pilot
    d. Develop educational materials for family caregivers (Pre-Health Check information collection)'
        i. Connect with HCARDD about Family Matters Toolkit pilot
3) Educational sessions CPD/CME events
    a. Identify brief CME events at national and provincial level
        i. CFPC Mike Allen's program (?), webinar series MIG, lunch hour events
    b. Ensure that any CME content is adapted to local provincial context
        i. Develop example presentations/slide deck(s) and share on DDPCP website
        ii. Work with provincial champions to adapt content to local context
    c. CPD at Family Medicine Forum and provincial primary care conferences
    d. Co-design and co-teach with people with developmental disabilities
4) "Mass media"
    a. CFPC e-news
    b. CFPC website, provincial colleges websites: share tools information, e.g., tools included in OCFP resource list.

Capability Increasing skills

1) Peer-to-peer learning
    a. Work with developmental pediatricians on hand-over to adult care
        i. Seek educational opportunities with developmental pediatricians, educate on transition/hand-over
    b. Facilitate and promote e-Consults with those who have experience in supporting patients with IDD
    c. Peer support programs at the College
    d. Complement primary care toolkit with instructional videos by physicians experienced in supporting patients with IDD

Motivation/Buy In

1) Payment Schemes
    a. Billing codes
        i. Develop and share materials that support local champions in their advocacy efforts (example letters, FAQs etc)
        ii. Ask those who were successful in their advocacy for advice on what worked well, or what was needed
        iii. Share "how to advocate for billing code" via DDPCP website (?)
    b. Team-based approach
        i. Advocate for team-based resources (e.g., nursing support)
2) Reframe messaging around the IDD Health Check
    a. This is part of comprehensive primary care – normalize it
    b. Don't use the word "annual" Health Check, name it comprehensive review
    c. Leverage uniqueness of few complex patients, rather than presenting it as a population intervention
    d. Focus on "solution/support" for those few complex patients, rather than population prevention message

Opportunity

1) Billing codes, embed in EMR toolbar
2) Pre-Health Check information collection methods
3) Develop team-based approach such that the Health Check visit takes less time
    a. Develop pre-Health Check questionnaires

Analysis

Barrier 1: Lack of awareness of IDD Health Check; Lack of skills to complete the Health Check

What needs to change: Family physicians need to be aware of the Health Check, what it should include and have the clinical skills to complete the intervention.

COMB/TDF	**Intervention Functions (Presented /** StrategEase list)	**Strategies (Presented/** StrategEase**)**
Capability - Knowledge	Educating	***Use mass media*** ***Use a "knowledge broker"*** ***Do educational sessions*** ***Present at staff meetings, rounds***

		Share knowledge from pilot projects Audit and feedback ***Capture and share local knowledge*** ***Community of Practice (CoP)*** ***Educational materials*** ***Educational sessions*** Integrating the topic into staff meetings Knowledge broker Mass media
Capability – Skills Motivation – Beliefs about capabilities	Training	***Offer training to increase skills or confidence in doing a Health Check*** Competency based training ***Work with educational institutions*** Train-the-trainer ***Educational materials*** Educational outreach visit ***Educational sessions*** Local opinion leaders ***Mentorship*** ***Peer-to-peer learning*** Provide supervision

Focus group 1: FP1, FP2, FP3

Strategy	**Stakeholder Quotations**	**APEASE**
Work with educational institutions; Disseminate education materials to medical schools, both undergrad and post grad, including residency training;	FP 1: I know that they will say, ‘Oh, there's too much in the curriculum,’ but this is I don't know, they must already be doing some sort of talk about this, even if it's just to make people aware that this is where you go [to] get your information on it then it is there. FP1: It's very hard, because every medical school is different and the same with the Residency programs. They're all different. FP2: So, I think I would say about that having gone through this recently, is that we, as Med students and residents, tend to have your like cheat sheets or cheat books or user compilation of top resources, sort of books, and every school	Working with educational institution considered important, but might be difficult Resource compilation that students use – can be hard to find where to share. Need student participation to create.

“Mass media” CPD - email blasts/newsletters;	often publishes them themselves. Sometimes it's like a group of med students who are editing. It's like Toronto notes, it's like the most formal version. FP2: that's the kind of place for Med students [where] the curriculum may not be the same, but a lot of us are using the same resources. And a lot of them are student edited and so, they are like tricky to figure out like there's not one central person, it's not a society or the college who is overseeing them. A lot of them are just disseminated because people want resources that are accessible. FP5: embed this in the CFPC’s Training Guide. That it needs to be one of the... it's no longer 99 topics, but it used to be 99 topics...the required teaching topics for trainees in the college of family medicine programs. So, as they're when they're in the residencies. I don't think they're getting a lot of IDD, and to be fair in a lot of practices there isn't any, so they wouldn't see it. But if it's part of their required training, then at least they would have a textbook knowledge of it, even if they don't have a practical knowledge. FP2: I would say, just on that note a lot of them are electronic resources as well. And so, I think now that I'm practicing and in residency, I started subscribing to a lot of these. But there's continuing professional development newsletters that come out because nobody can figure out all that. There are so many places to go for these resources. ...But let's say, U of T has a continuing professional development that sends out sort of summary articles and that kind of thing, another one that I like, let me see, I'm trying to remember what it's called. I can actually give you a specific example. The College of Family Physicians has one called Peer, I can't remember what it stands for, [I think] practice, empower something, but it's tools for practice and so, every couple of weeks they just send out an email, and	Target e-news letters to share information – seems very feasible. Connect with CFPC regarding various channels.

	somebody has had a clinical question they write a bottom line, and then they kind of give you their summary of the evidence. And I find those incredibly digestible FP2: I would say, I really like these email blasts… I can send you one of the ones that I'm looking at. I just pull it up on my email to remind myself what it is. But the headlines are clinical question bottom line and then evidence. It's all bullet points context, and then they give you references like I had to scroll twice to get to the bottom. So really brief [and] really well summarized.	
"Mass media" - CFPC website	FP1: you're talking about Surrey Place, yes, that's a good place for your website. But I think you want to link to national organizations if you can as well.	It is easy to share on national websites such as CPFC – actively reach out to ask toolkit to be shared in other resource lists. We would need more connections to reach provincial chapter websites.
Developmental pediatricians; Canadian Pediatric Society [= peer-to-peer learning during handover pediatric to adult]	FP1: I wonder if you should also reach out to developmental pediatricians because, as these developmental pediatricians are turning care over as their juvenile patients [or] clients graduate from them if they are aware and buy into all this, it makes it easier for them, and they don't feel so badly turning things over. And the Canadian Pediatric Society, …. I see them as perhaps being a help to you too, just as far as them being able to sort of help with their transitions.	Education of developmental Pediatricians about existing resources for transition to adult care. Existing resources need to be revised to include more information about Health Checks. We would need to find out how to work with Pediatric Societies to present/ how to share info.
Educational sessions	FP1: When you talk about educational sessions, I mean, we've always presented at CFPC, at Family Medicine Forum, we've sometimes presented at the Pediatrics Annual meeting.	Present at FMF and other conferences
Skills training	FP2: I think, increasing awareness that these exist like if we're increasing awareness that they exist at all, then that's how I would want to find out about it. Yeah, incorporating whether you feel confident, I think certainly some of these have some practical tips for you, but I don't know. I mean in terms of actually	Mentoring/shadowing in practice – seems not realistic for many family docs

	being able to shadow somebody that's just like not a realistic part of my schedule right now. So that's a pretty tough. I would find that a tough one. FP7: … it impresses me that several of these strategies can be incorporated simultaneously by advancing an IDD curriculum within Family Medicine Residency programs…. And I think, although I'm not teaching as a full-time preceptor anymore, I think that for those who do simply making it part of their practice and modeling the use of it for their residence would be a very effective strategy, and perhaps in a way, the most important one. Because you're getting family docs in their formative years then, you can normalize the practice for them.	Modeling by preceptors in family medicine residency programs is ideal and has been accomplished in a few family medicine programs. The challenge would be for local family practice teaching units to have teachers who are competent in this area.
Present at staff meetings and rounds	FP2: the only place that I've ever seen anybody have staff rounds is that an academic center because residents are forced to do that as part of our training. Otherwise, people sometimes will informally send out an email if they find something helpful or interesting. But to date at most clinics, I've worked at so far in FOE's or CHC's, people are meeting about… staff meetings are based around logistics or finances or management, or flow between who's seeing which patients that kind of stuff, and not so much actual medical information or improving practice information. I don't know if that's universal for sure, but definitely, hugely dependent. So, it'd be hard to say, 'we're gonna have a targeted campaign for like rounds' because I don't think most clinics would do that on a regular basis.	Context dependent – academic setting versus single practice; Staff meetings share different type of information – not the right setting for educational programming about health checks.

Focus group 2: FP4, FP5, FP6,

Strategy	Stakeholder Quotations	APEASE
Peer-to-peer learning / mentoring: e-consult availability for family doctors	FP4: I might get it. I mean, if I have something I'm not familiar with, I want a bit of hand holding at the start and what about eConsult? I look at the eConsult in our region. They're all developmental	E-consults for peer-to-peer support. How to identify the champions? How to facilitate e-Consults being offered; How to advertise availability of expert E-

	pediatricians and this and that, there's no primary care family practice developmental disabilities on offer there. Okay, if somebody want to get into that, it's $200 an hour that you get for answering eConsult's, plus you can send an attachment or reference this health check to the family doctor [and] say, 'hey, start with this, get back to me' and sort of have a few eConsult sessions to follow through. FP4: As it turns out, I kind of got a bit pushy when the pediatrician was discharging my son, and so they found somebody who is interested in developmental disabilities on the internal medicine side, that means university. So now my son sees him in consultation but once a year, and this really helps our family doctor have the confidence to say, 'oh, yeah, I can handle this,' or 'I kind of feel I've got this backup if I need to group things.' So, it's been a nice bridge FP4: if you look at the scope of family medicine, and what family medicine is supposed to do now consider the specialty you can handle this. Yeah, I might need some extra help but you can get there. There's lots of ways of doing that.	consults? Currently econsultation is limited in Ontario by billing challenges due to payment models.
Educational sessions	FP4: What about Family Medicine Forum? I haven't attended for a bunch of years but are there things like that where I know this takes time and effort but if you're in an academic institution, maybe you get a bit of a bonus or some recognition if you're part of that.	As this physician highlighted, does not reach all family doctors, but these presentations do connect with academic institutions which could improve Health Check implementation.
Peer-to-peer learning / mentoring: Developmental Pediatricians /Transition pediatric to adults	FP4: Well, my son was under the care of a pediatrician until he aged out and he had a good family doctor all along the way, really good and still does. But the family doctor felt just a bit intimidated about managing the whole thing, even the thyroid issue. So, I think, just developing that confidence and knowing that it's okay and have this kind of health check guidance is going to be very, very helpful.	Working with developmental pediatricians – seems a straightforward and direct way of information sharing, but how to get buy in at Peads site for this?

	FP5: the other piece I would suggest, just coming off what *FP4* mentioned about the transitions is the Health Quality Ontario has a transition in care guideline that I was actually part of as well. [It was] on transitioning patients from the pediatric system to the adult system and I would say, a lot of the principles that are there translate very well for people with complex medical to people with developmental disabilities as well. So, leveraging that may make a difference. FP5: I had to get people to care so it might be out there but there was no motivation. It was like, 'oh, well, your family doctor can handle this.' No, my family doctor was not able to handle it. FP6: But getting the Family Doc familiar with the individual moving them through that pathway. There's no reason they can't be working as a team. And then, between 18 and 25, maybe that's pediatrician can be a resource because they've had a longitudinal relationship, and they can be a resource for a few years or [they say] 'I'm not quite sure what to do with this', and maybe the pediatrician doesn't know either. But at least they have some expertise with the IDD part. So again, it's talking about, how could we build a team around an individual and maybe potentially leverage someone that already knows them with somebody who doesn't know them and that might create some capacity for me if they didn't have a pediatrician, and I happened to care for them because I'm rural.	

Strategies suggested by family doctors

Curriculum Development/ Challenges:

FP 1: "I know that they will say, 'Oh, there's too much in the curriculum,' but this is I don't know, they must already be doing some sort of talk about this."

FP1: "It's very hard, because every medical school is different and the same with the Residency programs."

How to Connect with residents/ family physicians:

FP2: " ...cheat sheets or cheat books or user compilation of top resources, sort of books, and every school often publishes them themselves. Sometimes it's like a group of med students who are editing. It's like Toronto notes, it's like the most formal version."

FP2:" ...there's continuing professional development newsletters that come out"

FP2: "The College of Family Physicians has one called Peer, I can't remember what it stands for, [I think] practice, empower something, but it's tools for practice and so, every couple of weeks they just send out an email, and somebody has had a clinical question they write a bottom line, and then they kind of give you their summary of the evidence. And I find those incredibly digestible"

FP1: "I think you want to link to national organizations"

FP1:" When you talk about educational sessions, I mean, we've always presented at CFPC, at Family Medicine Forum, we've sometimes presented at the Pediatrics Annual meeting."

FP2: "But to date at most clinics, I've worked at so far in FOE's or CHC's, people are meeting about... staff meetings are based around logistics or finances or management, or flow between who's seeing which patients that kind of stuff, and not so much actual medical information or improving practice information."

Supporting/mentoring family physicians:

FP4: "I might get it. I mean, if I have something I'm not familiar with, I want a bit of hand holding at the start and what about eConsult?"

FP2: "I mean in terms of actually being able to shadow somebody that's just like not a realistic part of my schedule right now. So that's a pretty tough."

FP4: "plus you can send an attachment or reference this health check to the family doctor [and] say, 'hey, start with this, get back to me' and sort of have a few eConsult sessions to follow through."

Transitions as a point of intervention:

FP5: "the other piece I would suggest, just coming off what FP4 mentioned about the transitions is the Health Quality Ontario has a transition in care guideline"

FP6: "And then, between 18 and 25, maybe that's pediatrician can be a resource because they've had a longitudinal relationship, and they can be a resource for a few years or [they say] 'I'm not quite sure what to do with this', and maybe the pediatrician doesn't know either. But at least they have some expertise with the IDD part. So again, it's talking about, how could we build a team around an individual"

Appendix 3d: Paid Caregiver (Developmental Service Workers/ Support Workers) Focus Group

Summary of findings

Capability Increasing knowledge, skills, awareness

1. Educational materials
    a. Adapt clinical support tools to local settings and promote at provincial level
        i. DDPCP to encourage adaptations and share examples of adaptations (e.g., BC primary care team; VanderBilt IDD Toolkit)
        ii. Work with provincial champions/leaders to adapt content to local contexts and province specific processes or rules
2. Educational sessions
    a. Develop training program for agencies to sign up for
    b. Develop competency-based training
    c. Engage leaders
3. Educational outreach visits
4. Train-the-trainer
5. Integration of the topic into meetings
    a. Share information with leadership to pass along to agencies in regular business meetings for DS agencies
    b. Share information at professional associations (OADD APSO, APSW network), registries and annual conferences
    c. Share information with program coordinator network (province wide or regional)
6. Leaders supporting the change

Motivation

1. Educational sessions
    a. Mandated training at agencies (paid time)
2. Educational materials
    a. Explain why it is important for people with IDD to have a Health Check in plain language 2-pager
    b. Provide data and evidence background information
3. Mass media
    a. Advocacy campaign to convey the message about equity and rights to accommodations for patients with IDD
4. Stories
    a. Communicate stories that illustrate the benefits of the tools (in terms of resource efficiency)

Opportunity

1. Environmental restructuring
    a. Integrate "health" better into the case management task or role; case managers have a relation with the person with IDD and opportunities to bring up health topic

Analysis

Focus group 1: P1, P2, P3.

Barrier 1: Lack of knowledge/awareness about the IDD Health Check.

What needs to change: Paid caregivers (Developmental Service Workers) need to be aware of the annual Health Check, what is involved in a Health Check and how to access Health Checks for their clients.

COMB/TDF	Intervention Functions (*Presented* / StrategEase list)	Strategies (selected / StrategEase list)
Capability	Education	Audit and feedback ***Capture and share local knowledge*** Community of Practice (CoP) ***Educational materials*** ***Educational sessions*** ***Integrating the topic into meetings*** Knowledge broker Mass media

Strategy	Stakeholder Quotations	APEASE
Educational materials – adapt to context Work with provincial champions/experts	DSW2:"teaching the information to the caregivers and supports I think you need, and when not just provincially (Ontario), so each province has different DSOs, they don't have DSO, they have, I don't know what it's called in Saskatchewan. But so those references, those all need to be kind of tweaked right?" "If you had like provincial people, so someone from each province to add input into their area, and what criteria that they follow, cause every province is different.." DSW1: I will say this apologetically, but I think Surrey Place needs to brand themselves "better" in the sense of being outside the province of Ontario. The acronyms are different from province to province and region, so I would just be mindful of those. I think that developing contacts that can share that information is important… Jest a scattered response.	It may be difficult for us to develop the correct connections to governmental services for adults with IDD across the country Surrey Place is not known nationally- many materials are Ontario-focused. Materials should be broad enough for use across Canada. Having local champions who can then take our tools and update within a local context for their needs.

Educational sessions Train the trainer	DSW2:”..if those agencies were given the tools or the training then, once the training is available to them… or the information and resources that could get passed along during orientation for the new staff and the new hires you could, you know, implement it within the agencies and make like special, I don’t like to call them special learners, but like special leaders, I guess, for each and just connect with those main contact to pass the message along.”	Providing training for developmental serve workers is likely outside the scope of this project. This would require connections. We are not familiar with current curriculum for developmental service workers. Some virtual examples do exist including the Nuts-and-Bolts website.
Integrating the topic in meetings Educational outreach sessions Train the trainer Mandatory training Engage leaders	DSW1:”We have, we call them PC network meetings…. It can be on a province wide basis, or a regional basis, that they come in and we do instruction and just, you know, there is a plethora of things we discuss at these. Providing that sort of information in that kind of context would probably be the most useful, because I think you’re directing it towards the people who make decisions and they can direct others to actually, enact it out. We often have gut speakers”. [PC = program coordinators?] … ”I think it would be a very welcomed resource. I think it’s somewhat an unmet, undiscussed issue until it often, you know, often times things escalate by the time I’m aware of them. So, I think being able to disseminate that information at that level would be probably most useful.” DSW2:” ..within regular business meetings where all staff are attending that would be something where we could present, to show, to provide the information, to assist everybody in the knowledge of all of it.” DSW2:”..as coordinators, or ASPW as some of use are called, we have the APSO, and it is a network of APSW throughout Ontario. And it’s a registry, it registered, and we’re all part of this, and there’s regular yearly conference. That would be something you could touch from Windsor to all the way to Timmins and the North.”	We could present some of our materials and PC network/ provincial or regional developmental service meetings (especially if virtual). Guest speakers are common. Presentations at business meetings at individual developmental service agencies may be difficult for us to implement.

	DSW1: I think that the "disability network" needs to champion the tools, I think there is far too much noise for GP's to add this to their already overwhelmed practices. DSW1: "I think in person is also better than visual as you get more attention, everybody's more attentive to what's going on so, anyway." DSW2:"We've al just done conscious care and support through UofT. Our agency decided that everybody in our agency needs to learn it. We all did the program. Whether you're working or not, you got paid for the time, and you did the program. So, we just boom ,like a mass training, get everybody trained."	In Ontario, focus training towards APSWs. Consider attending their annual conference. This is an appealing opportunity, we are concerned that this is Ontario-focused, it is possible to find similar opportunities in other provinces/ territories? Virtual training is much easier to develop and share but there is a desire for in-person workshops/ training for developmental service workers. Consider creating a "mass training" - virtual training module that can be used for developmental service agency staff. We would need to first learn about existing curriculum for DS staff. It will be difficult to make this broad enough to share across the country but specific enough to local contexts that staff are interested and engaged.
Environmental restructuring	DSW3:" I think the case management piece that comes often with the work can actually help leverage to support the health pieces (knowing the patient and relationship over time, entry to conversation)	Direct Support workers are key members of the team, can help support health checks.
Marketing	DSW 1: I mean to be quite honest I stumbled upon Surrey Place accidentally one day while I was looking for resources,	A focus on dissemination of our existing tools, considering developmental services.

	for I mainly do a lot of behavioral issues, and providing a guidance in that aspect and working with psychiatrists and very inadvertently stumbled upon your tools. And I'm just thinking like it's a shame, it's really a shame, because I think you have such great materials. I would think everybody in disability sector should be utilizing them. So, I think some of this is a marketing aspect, right.	

Dissemination:

DSW1 "I always feel like every time I stumble on your tools and I use them. I feel like, how does the whole world not know about this, right? And I feel like, Oh, my gosh. I don't know [because] I'm not a marketing person, but I know that, I think, keeping your trademark on there actually lends to your credibility. So, I wouldn't neutralize it in that sense, because I feel [for] me that brand recognition, 'Oh, it comes from Surrey Place', I don't even question the credibility, so I would hang on to that, I think, making it a bit more neutral, just maybe in terms of how [Ontario focused content]… I mean to be quite honest I stumbled upon Surrey Place accidentally one day while I was looking for resources, for I mainly do a lot of behavioral issues, and providing a guidance in that aspect and working with psychiatrists and very inadvertently stumbled upon your tools. And I'm just thinking like ***it's a shame, it's really a shame, because I think you have such great materials. I would think everybody in disability sector should be utilizing them. So, I think some of this is a marketing aspect,*** *right."*

Barrier 2: Reluctance to ask for Health Check, sometimes based on negative previous experiences in primary care. Motivation- Pessimism

Also highlighted a **Facilitator- Motivation- Goals "I want to"**

Facilitator: DSW2:"I think most agencies do recognize this as a huge concern. So I can't imagine there would not be buy in by most…"

What needs to change: Paid caregivers (Direct Support Workers) need to overcome pessimistic attitudes towards the Health Check despite previous challenges in medical settings.

COMB/TDF	Intervention Functions	Strategies (selected / StrategEase list)
Motivation- Goals "I want to" and Pessimism	**Educating** Modeling Enabling **Persuading** Restructuring the environment	**Educating** Audit and feedback ***Capture and share local knowledge*** Community of Practice (CoP) ***Educational materials*** ***Educational sessions*** ***Integrating the topic into meetings*** Knowledge broker Mass media **Persuading** Public demand Opinion leaders ***Champions*** ***Engage leaders*** Facilitation Identify early adopters Implementation coaching Leaders supporting the change Local consensus process Mass media

Strategy	Stakeholder Quotations	APEASE
Educational materials	DSW3:"..the why and perhaps language as, if there's research out there about language to use around just why this is important, why this subset would be really important for but also this language we could use with clients, so it could be like a relatively straightforward kind of 1-2 pager….Like that reminder of why this is important, and then you can certainly have links to articles that might be good to say there's actually research backing this up."	Clear information about why Health checks are important (brief 1-2 page document) would be easy to create.

Mass media	DSW1:"I think you need to almost like hit this kind of "public announcement"...sort of maybe a campaign on a smaller level, but you know through social media, right?. That kind of self-advocating or public service type announcements." DSW1:" continuing to put your name out there, put your message out there, talk about it, I think you guys are at the forefront of disability services in Canada. So go with that right? I think that's a great way to disseminate your message and just create that public awareness." DSW1:"I think that if you put out there that people with IDD need more care from physicians, from wherever, I think that's really important, because I think that being missed....say for example, supported employment is huge in the disability network, they've done so well, it's a great issue, so many people know about it. But in healthcare I don't think there's that same kind of advocacy or just awareness. I think if there's a way to kind of created [this] through social media then you know just that increases awareness."	Using social media for a "public announcement" is possible. This may leave out certain areas of the country that do not have strong connections with DDPCP or our MIG.
Educational sessions	DSW2:"I was also thinking about the Ontario Association for Developmental Disability (OADD). I'm not sure what the other associations are in other provinces, but I'm sure they're similar. All the DS sectors, every DS agency is invited and that's a good way also to target the information out there."	OADD- Ontario Association of Developmental Disability is a good local example of a conference for direct support workers. We would need to consider other conference in other provinces/ territories.
Champions	DSW1:"I think creating efficiencies by using your tools is so important and I think that having a voice to champion that....you connecting you guys and his [champion psychiatrist] influence is very profound, and not just in this province."	Consider using physician champions, local champions to promote the Health Check.
Stories	DSW1:" I think stories does cause, that' always the connection between us intellectually understanding something and us practically being able to use that...I think gathering stories is huge, and we certainly know at the end of the day everybody is resource dependent. We	

	have to talk about that…how much it really does create wins for everybody when we're not, you know misappropriating or misusing resources, whether they're medicl or behavioural or social services..".	
Facilitation/Enabling standardize the process	DSW1:"I think presenting it as a standardized procedure for those providing disability supports can ensure that the information is directed to those who need to and can facilitate the outcomes." DSW3:" Just say.. this is what we do and it might be just good around resource sharing and etc. that it just might just shed more knowledge and information about this is what we do, and ideally, as if there was a standard process, I wonder if there is value in that, and just working with the agency.	

Quotes Highlight:

DSW 2: "I just wanna say thanks for taking the time to implement and try to get this going, because, as an APSW who would be assisting with these medical appointments, and all of that. It's very detrimental to our guys, for sure. The people that I support, they need all the help they can get for all of the information. So, it's fantastic. Thanks".

DSW 1: "I mean to be quite honest I stumbled upon Surrey Place accidentally one day while I was looking for resources, for I mainly do a lot of behavioral issues, and providing a guidance in that aspect and working with psychiatrists and very inadvertently stumbled upon your tools. And I'm just thinking like it's a shame, it's really a shame, because I think you have such great materials. I would think everybody in disability sector should be utilizing them. So, I think some of this is a marketing aspect, right."

DSW1: "I kind of trumpet the hidden treasure of the resources, they are desperately needed."

Appendix 4: *Existing tools/materials*

Health check point of care tools for family physicians:

1. **IDD Health Check Preventative Care Checklist:** A pdf and EMR-based format of the IDD Health Check by family physicians of the CFPC's Developmental Disabilities Member Interest Group (DD MIG), in partnership with the Developmental Disabilities Primary Care Program (DDPCP) of Surrey Place, Toronto, and the eHealth Centre of Excellence (available in March 2023). Available online at: https://ddprimarycare.surreyplace.ca/tools-2/general-health/preventive-care-checklist/
2. A form from a toolkit designed for transition from pediatric to adult health care for patients with IDD. This tool needs revision to include the Health Check. Available online at: https://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/09/2.5-TAY-Transition-Transfer-Tool.pdf

Curriculum resources:

3. Curriculum of caring from the AMX Phoenix Project and McMaster University. This suite of resources is designed to aid health care providers with the care of people with IDD. Available in it's entirety at: https://machealth.ca/programs/curriculum_of_caring/

- A summary of communication skills "Communicate C.A.R.E." Available online at:
  - https://ddprimarycare.surreyplace.ca/tools-2/general-health/communicating-effectively/
  - https://machealth.ca/programs/curriculum_of_caring/m/mediagallery/2210
- A video of physical examination, "Keys to Success when examining patients with developmental disabilities" Available online at: https://machealth.ca/programs/curriculum_of_caring/m/mediagallery/2204'

4. Medical Council of Canada Examination objective for medical students completing their medical degree in Canada, "Adults with Developmental Disabilities" (https://mcc.ca/objectives/medical-expert/adults-with-developmental-disabilities/

Continuing professional education

5. CFPC Learn: Family Medicine Rounds Series,: IDD Health Check. -A podcast by DD MIG members explaining the rationale for the IDD Health Check and an outline of how to perform a health check for family physicians. Available online at: https://cfpclearn.ca/podcast/fm-rounds-12/

Caregiver resources:

6. The Nuts and Bolts Toolkit- A toolkit containing tools and tips for direct support professionals supporting people with IDD from H-CARDD and Vita Community Living Services. Available online at: https://nutsandbolts.ddtoolkits.com/

Persons with IDD resources:

7. My Health Care Visit- A tool for people with IDD to complete with their health care providers to prepare for a clinic visit and to summaries the visit. Available as an eform in the Ocean communication platform and can also be accessed online at: https://ddprimarycare.surreyplace.ca/tools-2/general-health/todays-visit/
8. About My Health- A summary of past medical history and social history that people with IDD and their support network can complete and share with healthcare providers. Available online at: https://ddprimarycare.surreyplace.ca/wp-content/uploads/2021/03/5.1-About-My-Health-new.pdf