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Evaluating the impact of a national brain health education course for older adults with intellectual and developmental disabilities and caregivers: Brain Health-IDD Program protocol

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ABSTRACT

Introduction Adults with intellectual and/or developmental disabilities (IDD) experience higher rates of age-related health concerns, including dementia, than adults without disabilities. Despite this, current efforts to support brain health in ageing have often excluded this population. To address this gap, we will codesign, codeliver and evaluate a national virtual brain health education programme, Brain Health-IDD, for ageing individuals with IDD, family caregivers and health and social care providers.

Methods and analysis This study will evaluate the Brain Health-IDD Program, an interactive virtual psychoeducation course codesigned and coled by an interdisciplinary team of clinicians and people with lived experience. Three participant groups will be recruited from across Canada: adults with IDD, aged 40 years and older; family caregivers who have a family member with IDD aged 40 years and older or who are themselves aged 60 years and older; and health or social service providers who support adults with IDD aged 40 years and older. Outcomes will be measured at baseline, postcourse and 3-month follow-up. Data will be collected through structured surveys, including both closed and open-ended questions, and focus group interviews.

Primary outcomes are participation, satisfaction and changes in knowledge and self-efficacy related to brain health among the three participant groups. Secondary outcomes for both adults with IDD and family caregivers include changes in health-related behaviours (social connections, sleep hygiene and physical activity), physical health, mental wellbeing, resilience and whether cognitive screening is initiated for adults with IDD and for caregivers. For health and social service providers, secondary outcomes include changes in brain health promotion practices and whether cognitive screening for older adults with IDD is initiated.

Analysis of open-text survey responses and qualitative data from focus group interviews will explore the experiences of participants with the Brain Health-IDD Program.

Ethics and dissemination Institutional ethics approval was obtained from the Centre for Addiction and Mental Health Research Ethics Board. Programme findings and resources will be shared with advocacy groups, disability agencies, family caregiver organisations, clinicians and policymakers in the fields of disability, health and ageing at the provincial, national and international levels.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ A key strength is the codesign and codelivery of the Brain Health-IDD Program in partnership with older adults with intellectual and/or developmental disabilities (IDD), and older family caregivers.
⇒ Rather than focus on only one group, this intervention study is delivering parallel interventions to the three key audiences who would benefit (ageing adults with IDD, family caregivers and health and social service providers).
⇒ Another strength is the inclusion of a follow-up time point for data collection.
⇒ Recruitment is limited to those who have access to technology and reliable internet.

INTRODUCTION

Adults with intellectual and/or developmental disabilities (IDD) are living longer than ever before and, as a result, are

experiencing a myriad of age-related issues that impact their overall health and wellbeing.[1–4] They also experience age-related health concerns at a younger age than those without disabilities. Dementia, a common diagnosis among adults with IDD, can manifest clinically as early as 40 years of age in Down syndrome, whose risk of Alzheimer's disease is three to five times greater than in the general population.[5] Increased risk of dementia is not only true for adults with Down syndrome, but has also been reported in autistic adults[6] and adults with intellectual disabilities who do not have Down syndrome.[7–11]

Multiple biological, psychological and social factors contribute to the elevated risk of dementia observed among adults with IDD. Several modifiable risk factors for dementia identified in the Livingston model[12] occur more frequently in people with IDD. Like other marginalised groups, adults with IDD face the health effects of stress and discrimination, often referred to as 'weathering', which may contribute to lower levels of cognitive reserve than other adults.[13] Additionally, adverse lifestyle factors such as poor sleep quality and high rates of sedentary behaviour, further elevate their vulnerability and risk for cognitive symptoms of dementia compared with adults of the same age without IDD.[14] Adults with IDD are also at risk for physical health issues as they age, including mobility challenges, bone loss, sensory impairments (eg, vision/hearing), and multimorbidity (eg, living with multiple chronic conditions such as type II diabetes, hypertension, chronic obstructive pulmonary disease and cardiovascular disease).[1 4 15 16] In addition to these physical health challenges, adults with IDD are likely to experience poor mental health as they age, including anxiety and depression, compounded by grief and loss.[17 18] Moreover, severe social isolation is common, particularly following the death of their ageing parents.[19–21] Together, these mental and physical health conditions can also increase their risk of dementia.[12]

The challenges of 'ageing well' impact not only people with IDD but also their family caregivers (parents, siblings and other relatives), and the paid health and social service providers who support them.[20 22] Family caregivers, particularly parents who have been 'perpetual caregivers', struggle to continue providing care as they navigate the physical, mental and social aspects of ageing.[23 24] So many decades of caregiving can impact caregiver physical and mental health directly, but can also lead to isolation, reduced income and fewer opportunities to engage in activities that promote brain health.[25 26] As parents face age-related changes, caregiving responsibilities can fall to siblings, who may feel ill-equipped to take on caregiving responsibilities for several reasons, including geography, social distance and work. These new responsibilities can be additive as siblings may also have their own caregiving responsibilities for their partners or children.[20 23 27]

To comprehensively support adults with IDD as they age, health and social service providers must work together. There are many requirements for achieving this level of collaboration, with one being the need for developing expertise in the unique issues related to health and ageing affecting this population.[22 28 29] However, providers in both health and social services report feeling ill-equipped to meet the needs of ageing adults with IDD as neither system is designed to address both age-related health and developmental concerns.[22 28] In contrast to the general population, the health trajectory of ageing adults with IDD is largely dependent on the knowledge, skills and capacity of their healthcare team, paid staff and family caregivers. Therefore, interventions to promote healthy ageing and brain health for this population need to be cross-sectoral, tailored and inclusive, involving the individual, along with family, healthcare providers and paid support staff.

It is critically important to rapidly identify and address the unmet health and social support needs of ageing adults with IDD and their family caregivers.[30] There is evidence that educational programmes focused on brain health are beneficial in the general population.[31 32] However, despite greater risks, these broader brain health and dementia awareness efforts continue to exclude adults with IDD, and the people who care for them.[29] Together with promoting early screening for dementia,[33] we believe that IDD-specific brain health educational efforts can help people with IDD, family caregivers and service providers to improve the health and life trajectories of both ageing adults with IDD and their ageing caregivers. Achieving these outcomes requires collaboration between people with disabilities, their families and health and social care providers.

This study builds on the foundational work of our team, including scientists, clinicians, adults with IDD and family caregivers, who codesigned, codelivered and evaluated virtual education programmes that addressed health concerns for people with IDD and family caregivers during the pandemic across Canada.[34] The Brain Health-IDD courses are modelled after Extension for Community Healthcare Outcomes, a virtual education framework used around the world to support healthcare providers and build communities of practice. Using videoconferencing, course participants ('spokes') join regular sessions with specialist teams ('hubs') to learn together and share knowledge.[35]

This protocol paper outlines the codesign, implementation and evaluation of Brain Health-IDD, a national virtual brain health education programme focused on brain health for ageing individuals (40 years and older) who identify as having IDD, family caregivers 60 years and older, or those of any age caring for an adult with IDD 40 years and older, and the health and social service providers who support them.

RESEARCH OBJECTIVES

Primary objectives

1. Evaluate the extent of participation and satisfaction with the Brain Health-IDD Program among ageing

Table 1 Course topics

People with IDD	Service providers	Family caregivers
Introduction to brain health	Introduction to brain health	Introduction to brain health
Nutrition	Physical health	Prioritising physical health
Sleep	Dementia	Supporting your cognitive health
Mental health and regulation	Mental health	Prioritising mental health
Movement	Finding the balance	Navigating change and building resilience
Putting it all together and social connections	Putting it all together and moving forward	Putting it all together and moving forward
Dementia and caregiving		

adults with IDD, family caregivers and health and social service providers.
2. Evaluate changes in knowledge and self-efficacy regarding brain health, including identification and management of health-related ageing concerns, across all three participant groups following participation in the Brain Health-IDD Program.

Secondary objectives

1. For adults with IDD and family caregivers:
   a. Evaluate changes in health behaviours related to social connections, sleep hygiene and physical activity, and whether cognitive screening for adults with IDD and caregivers is initiated following participation in the Brain Health-IDD Program.
   b. Evaluate changes in physical health, mental wellbeing and resilience following participation in the Brain Health-IDD Program.
2. For health and social care providers:
   a. Explore what activities providers have initiated to promote brain health among adults with IDD whom they support, including initiating cognitive screening following participation in the Brain Health-IDD Program.

METHODS AND ANALYSIS

Intervention description

The Brain Health-IDD Program has been codesigned by older people with IDD, older family caregivers, clinicians and scientists. Each programme is delivered weekly over Zoom for 90 min in six sessions (family caregivers, service providers) or seven sessions (people with IDD). Sessions were set at 90 min to ensure sufficient time to cover the curriculum while maintaining participant engagement. This format has been used successfully in prior education programmes without attrition.[34] Each session follows a similar structure combining didactic teaching (content codesigned and codelivered) with case-based examples and discussions. The topics focus on aspects of brain health found to be important to prevent dementia (see table 1 for course topics and figure 1 for programme framework).

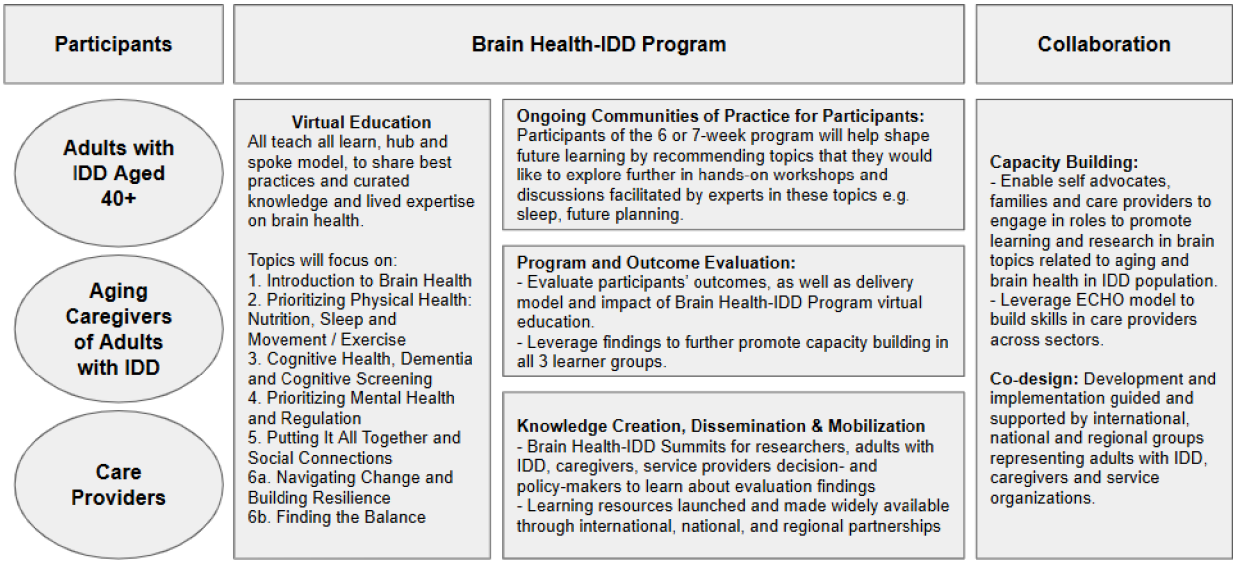

Figure 1 Brain Health-IDD Program framework. ECHO, Extension for Community Healthcare Outcomes; IDD, intellectual and developmental disabilities.

Study design

The evaluation of Brain Health-IDD employs a mixed-methods pre-post evaluation design with two components: (1) survey evaluations, and (2) participant focus groups. We are using an explanatory sequential mixed-methods design in this research, using the focus groups to help explain our survey findings and delve deeper into the experiences of participants in the programme.[36 37]

Over a 2-year period, we will recruit four cohorts of each of the three participant groups (adults with IDD, family caregivers and service providers). All course participants will complete survey questionnaires at three time points: baseline (Time 1–0 weeks), postcourse (Time 2–8 weeks) and follow-up (Time 3–18 weeks). Surveys will evaluate course impact, including participation, satisfaction, knowledge, self-efficacy and changes in health behaviours/performance, physical health, mental well-being and resilience. Additionally, focus groups will explore participant experiences with the codesigned and codelivered programme.

Participants

The target three populations are adults with IDD, family caregivers and health and social service providers. Eligibility criteria are as follows:

- Adults with IDD must be 40 years of age or older.
- Diagnoses of IDD include intellectual disability, autism and genetic conditions strongly associated with IDD such as Down syndrome or Fragile X syndrome. Diagnoses are based on self-report and participants also identify the disability agency who provides them with support.
- Family caregivers must either be caring for a family member with IDD who is 40 years of age or older, or be 60 years of age or older themselves.
- Health and social service providers must work in IDD services, health services, ageing home care, or long-term care, and provide care to one or more individuals with IDD who are 40 years of age or older.

In addition, all participants are required to be able to understand and communicate in English, live in Canada and engage in online learning independently or with limited support.

Individuals are excluded from participation if they meet the following criteria:

- Unable to provide informed consent to participate.
- Lack the technology required to participate in the virtual course, such as internet access, a telephone, a tablet, a smartphone or a computer.

Outcomes

Study outcomes (see online supplemental appendix A) have been designed to align with the programme's goals (see figure 1). Measures were selected based on: (1) relevance based on input from lived experience advisors and clinicians, (2) prior studies focused on older adults with IDD and their caregivers and (3) feasibility (eg, time/effort/comprehension). Prior to measures finalisation, they were piloted with the team members with IDD, family caregivers and clinicians. Changes were made based on their feedback.

Participants will rate their experience with the Brain Health-IDD Program across the first four of seven levels of Moore's Evaluation Framework[38] used in previous research[17 38]: participation/retention (level 1); satisfaction (level 2); knowledge/learning (level 3); competence/self-efficacy (level 4).

Primary outcomes

1. Participation and satisfaction (study objective 1): Participation will be operationalised as the mean and median number of sessions attended per participant and the percentage of participants who attended over 50%, 66% and 100% of sessions. Satisfaction (ie, session format, content, group discussion, sense of group support and ease of using technology) will be rated on a 5-point Likert scale included in the survey (3-point Likert scale for participants with IDD), in addition to open-ended survey items related to course satisfaction at Time 2. Satisfaction items are based on prior studies completed by members of the research team.[39–41]
2. Knowledge and self-efficacy (study objective 2): Knowledge and self-efficacy will be evaluated at all three time points through self-report of health competencies, using a validated 100-point visual analogue scale (VAS) from 0 (not confident at all) to 100 (very confident). These questions and VAS were modified from a previous measure[40] and used successfully to demonstrate change in prior studies of people with IDD, families and service providers and completed by members of the research team.[39–41]

Secondary outcomes

3. Health behaviours/performance (study objective 3): Participants with IDD will rate their health behaviours at baseline and follow-up using items from the survey protocol of the Intellectual Disability Supplement to the Irish Longitudinal Study on Aging (IDS-TILDA),[4] measuring sleep quality, physical activity and leisure and social participation. Family caregivers will rate their own health behaviours at baseline and follow-up, as well as report on their family member's health behaviours. At post and follow-up, they will report on whether they have completed or plan to complete a dementia screening questionnaire introduced as part of the programme, the National Task Group-Early Dementia Screen for Dementia Tool (NTG-EDSD) for participants with IDD[42] or Cogniciti Brain Health Assessment for caregivers,[43] and if so, provide feedback on that experience. At post and follow-up, service providers will describe in an open-ended format on the survey any changes they have made, or intend to make, in their practice with older adults with IDD to improve sleep quality, physical and leisure activity, social participation, overall health and/or NTG-EDSD completion.

4. Physical health, mental wellbeing and resilience (study objective 4): Physical health of participants with IDD will be measured using items (eg, overall health, fatigue, pain) from the survey protocol of the IDS-TILDA programme,[4] which are consistent with constructs used in the international longitudinal ageing research programmes. Family caregivers will also provide this information about themselves. These measures will be completed as part of the survey at baseline and follow-up. Mental wellbeing will be measured using the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS), which has been adapted for adults with IDD[44 45] and was sensitive to change in our most recent evaluation of adults with IDD[41] and of family caregivers,[39] and will be administered at all three time points. The 7-item short version of the WEMWBS will be administered to service providers at the three time points. Resilience will be measured with the Brief Resilience Scale at all three time points, using a six-item 5-point Likert scale for family caregivers[46] and a simplified adaptation for adults with IDD.

Sample size

To determine the sample size required for each course, an a priori power analysis was conducted using G-Power 3.1 (α=0.05, power=0.95), based on previous studies to estimate the effect size.[39–41] Minimum sample sizes were determined to be 38 for the adults with IDD course (f=0.26), 133 for the family caregiver course (f=0.14) and 103 for the social service providers course (f=0.16). Accounting for potential dropout and attrition, the four synchronous programme cycles will aim to recruit a total of 60–80 adults with IDD (maximum of 20 per cycle), 200–300 family caregivers (maximum of 75 per cycle) and 200–300 health and social service providers (maximum of 75 per cycle) from across Canada.

Recruitment

Recruitment materials, prepared jointly with self-advocate and family advisors, will be shared on the study website, the Health Care Access Research and Developmental Disabilities (www.hcardd.ca) monthly national newsletter with over 2500 subscribers, and forwarded by email through partner and collaborator organisations. In addition to recruitment flyers, tailored recruitment videos for both people with IDD and family caregivers will be used to provide an engaging study overview. People can discuss the study with research staff through email, text, videoconference or phone, and access materials about the study either online or on paper.

Data collection

People interested in participating in the study will complete an Expression of Interest Form online using Research Electronic Data Capture (REDCap) electronic data capture tools hosted at the Centre for Addiction and Mental Health (CAMH). REDCap is a secure, web-based software platform designed to support data capture for research studies.[47] Alternatively, they can complete the form by phone with assistance from research staff. Adults with IDD, family caregivers and service providers will be contacted by telephone to discuss the study and confirm eligibility.

Eligible family caregivers and service providers will complete consent online through REDCap, directing them to baseline surveys (Week 0), including demographic information (eg, gender, race, location). Post-course (Week 7 or 8) and follow-up (Week 20 or 21) surveys will be completed similarly and will include repeated measures and qualitative reflection questions. Surveys will take approximately 40–50 min for adults with IDD and family caregivers, and 20–30 min for service providers. Flexible data collection methods will be offered to support individuals with low digital literacy; consent and surveys can also be completed by telephone or on paper if needed.

Adults with IDD will participate in an informed consent discussion and complete surveys in the format of a structured interview with the study's research coordinator. The survey will be shown onscreen, and the research coordinator will record participants' responses to the survey questions. This method, which has been successfully used previously,[41] allows participants who can read to type or speak their responses, and those who do not read to have questions read aloud and explained. If needed, the informed consent discussion and survey will be completed over two sessions. Participants may also choose to have a support person present during these discussions/interviews.

Participants will receive an honourarium of an e-gift card based on the number of surveys completed (pre, post and follow-up). Adults with IDD and family caregivers will receive $75 for completing all three surveys, $50 for two, and $25 for one. Service providers will receive $50, $30 or $15, respectively. The higher amounts for adults with IDD and family caregivers reflect the greater completion time required. Participants who withdraw early will receive the amount corresponding to the number of surveys completed.

To further explore course experiences, three focus groups of approximately 8–12 participants will be held virtually with adults with IDD, family caregivers and service providers who completed at least three sessions of the course. Eligible participants will be identified through the follow-up survey, where they can indicate their interest in participating. If more than 12 individuals from a participant group express interest, participants will be selected to ensure broad representation across factors such as geographic region, age and gender. The virtual focus groups will be recorded, transcribed verbatim and anonymised. Focus group participants will receive an honourarium in the form of a $30 e-gift card. Information power, the extent to which a sample of participants share the information needed to answer the research question[48] will be used as a strategy to decide whether additional focus groups will need to be held.

Data analysis

Qualitative and quantitative findings will be analysed independently and then synthesised at the end of the study to provide a comprehensive understanding of participants' experiences with virtual learning, their knowledge and self-efficacy related to brain health (their own or the person they support), and health impacts.

Quantitative analysis: Descriptive statistics will be used to describe the sociodemographic and clinical profiles of participants. Demographic information, including socioeconomic status, ethnicity, age, gender, geographic location, type of disability, family caregiver role, living situation and level of support provided, will be collected in the baseline questionnaire. This will allow for subanalyses of key groups, if sample size permits (eg, ageing siblings or people with Down syndrome). For continuous variables, means and SD or medians (IQRs) will be presented. For categorical variables, proportions will be presented.

Recruitment rates, attendance and satisfaction will be analysed descriptively, measuring frequencies, means and SD or medians (IQRs).

We will use mixed-effects modelling to measure change related to knowledge and self-efficacy, health behaviours, physical health, mental wellbeing and resilience across time. Unstructured covariance matrices will be used so that any variance and/or covariance will be uniquely fit to the data. This modelling will both allow for the detection of change in the outcomes while controlling for covariates such as participant age. Where possible, we will stratify analyses by participant gender, participant age group, role of family member participant (parent/sibling), to explore demographic differences in changes in outcomes.

Qualitative analysis: Qualitative analysis will be led by NB, TV, YL and MC. Survey open-text responses will be analysed using descriptive content analysis.[49] Thematic analysis will be the primary analytic strategy for the focus groups.[50] Both analyses will focus on types of benefits and challenges experienced through the programme and explore changes in participants' views on brain health following participation.

Data integration: Quantitative and qualitative findings will be triangulated to offer a comprehensive understanding of participant experiences. Results will be presented in joint displays to help synthesise findings from both approaches and provide a comprehensive overview of the final results.

Data management

Quantitative and qualitative data will be de-identified by removing identifying information as needed. A data monitoring committee is not needed because participation involves minimal risk. Study investigators and team members will meet frequently to review accrued data, data confidentiality, Research Ethics Board (REB) guidelines, and adherence to protocol design, recruitment and participant feedback. At the end of the study, all data will continue to be securely stored in compliance with institutional and regulatory requirements.

PATIENT AND PUBLIC INVOLVEMENT (PPI)

Patient and public involvement (PPI) is central to our approach in this study. We have taken numerous steps to involve people with IDD, family caregivers, community groups, service managers and clinicians in ageing, health and social care in codesigning and codelivering the Brain Health-IDD Program. The research team has longstanding connections to clinical practice and psychoeducation with this population, leading to strong and trusting relationships with people with IDD, family caregivers and service providers. They contributed to the overall study design and course content development and will play a key role in programme delivery and evaluation. All caregivers and people with IDD in advisory roles have and will continue to be compensated for their time.

PPI stage 1: pre-application consultation

This project builds on a prior study involving people with IDD, family caregivers, clinicians and researchers, focused on capacity-building in healthcare for this population during the COVID-19 pandemic.[34] Feedback from that programme, particularly from older participants and family caregivers of older individuals, informed the development of the current project. Members of the previous programme were invited to be part of the current project, and over several months, team members met with additional people with lived experience of disability and/or caregiving to shape the research design and review the application. Project advisors, including people with IDD and family caregivers, were compensated for their time in helping to shape the proposal.

PPI stage 2: development of the Brain Health-IDD Program and resources

Each of the three course groups, composed of scientists, clinicians, family caregivers and people with IDD, met weekly over three months to plan the three parallel courses and to finalise the study outcome measures. Designated staff provided liaison support to team members with lived experience, ensuring they understood the content and felt prepared for each meeting. To support full participation, individual discussions were held to identify access needs and meeting preferences.

PPI stage 3: Brain Health-IDD delivery

During course delivery, team members will meet weekly to debrief, reflect and refine the sessions. More in-depth debriefing on both team process and course content will occur after each cycle, and in preparation for the next. Any changes made to course content and teaching/facilitation strategies, along with the reasons for doing so, will be documented. After the first cycle of courses, team member and participant feedback, along with satisfaction data, will be reviewed and modifications to course content and delivery will be made. In addition, quarterly virtual meetings with break-out sessions will be held to share information among all team members, including those with lived experience.

PPI stage 4: analysis, interpretation and knowledge dissemination

Each of the three course delivery teams will collaborate with lead scientists to analyse and interpret their programme findings and will also describe their coproduction experience. Group leaders will also work with lead scientists to develop accessible knowledge products (videos and easy-read summaries) of key findings.

PPI outcomes

We will report on PPI using the Guidance for Reporting Involvement of Patients and Public (GRIPP2) Checklist.[51] Our work is consistent with recommendations reported in the literature for working with people with intellectual disabilities,[52] with neurodivergent people[53] and family caregivers.[54]

We will document the number of meetings and the types of accommodations provided to team members at each stage of the study, as well as changes made to improve accessibility over time.

ETHICS AND DISSEMINATION

Both the quantitative and qualitative arms of the study have been reviewed and approved by the Centre for Addiction and Mental Health REB (REB number 010–2024). Data collection commenced in April 2024 and is expected to continue until April 2026. Informed consent will be obtained from all participants by the research staff. Study data will be kept confidential and de-identified, and all study files will be maintained on a password-protected secure server. Any protocol modifications will be communicated to the REB for approval.

This protocol takes into account the guiding principles concerning the rights of people with lived experience. The study recognises the importance of supporting individuals with lived experience, particularly those with IDD, and addresses ethical concerns related to inclusivity, autonomy and respect for their voices in the research process. We will actively engage people with lived experience in decision-making processes, ensuring that their insights help guide the development of programme strategies.

To contribute to capacity building and knowledge mobilisation, results from this initiative will be submitted for publication in peer-reviewed scientific journals. Key findings will also be published in non-academic reports targeted to our partners and community stakeholders, as well as through videos and easy-read documents, and presentations at knowledge summits and academic conferences. A synthesised version of the results will be developed as a practical resource for people with IDD and their families.

All resources included in the Brain Health-IDD courses will be available on the programme website for public access once the study is complete. Some instructional content will also be video recorded and made available to individuals outside of the study. These videos will be posted on the H-CARDD YouTube channel (7700 subscribers) and can be accessed through the Brain Health-IDD website. To scale and spread components of these programmes, we have partnered with key policymakers and end users in several provinces and at the national level. These partners will be invited to attend quarterly meetings with our team and annual Brain Health-IDD summits, where we will present study findings. We will meet with partners before dissemination to explore strategies for the uptake and sustainability of the programme.

STUDY STATUS

Recruitment began in March 2024 at the Centre for Addiction and Mental Health. The study is anticipated to finish recruitment by November 2025 and data collection by April 2026. Full-length protocol is available on request.

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Contributors YL, NB, MC and AT designed the study and the other authors collaborated in the design of the study. LSJ provided statistical expertise. YL, NB, MC and AT prepared the initial draft of the manuscript and revised the manuscript. All authors read and provided feedback on the revised manuscript and approved the final manuscript. YL is the guarantor of the contributorship statement.

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Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting or dissemination plans of this research. Refer to the Methods and analysis section and the Patient and Public Involvement section for further details.

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