Evaluation Plan of the Intellectual Disability and Mental Health Hubs (the Hubs)

Christiane Purcal, Janelle Weise, Karen R Fisher, Peri O'Shea, Julian Trollor, Preeyaporn Srasuebkul

Prepared for: NSW Ministry of Health

March 2021

Research Team
Karen R Fisher (Chief Investigator), Christiane Purcal, Peri O'Shea, BJ Newton, Julian Trollor, Janelle Weise, Preeyaporn Srasuebkul, Rachel Spencer, Erin Forrester, Katielee Simpson, Vicky Xu, Sunny Hemraj

For further information:
Professor Karen R Fisher, karen.fisher@unsw.edu.au, +61 2 9385 7800

Social Policy Research Centre
UNSW Sydney NSW 2052 Australia
T +61 2 9385 7800
F +61 2 9385 7838
E sprc@unsw.edu.au
W www.arts.unsw.edu.au/sprc

© UNSW Australia 2021

The Social Policy Research Centre is based in the Faculty of Arts, Design & Architecture at UNSW Sydney. This report is an output of the Intellectual Disability and Mental Health Hubs (IDMH Hubs) Evaluation research project, funded by NSW Ministry of Health.

Suggested citation:

Purcal, C., Weise, J., Fisher, KR., O'Shea, P., Trollor, J., Srasuebkul, P. (2021), *Evaluation plan of the Intellectual Disability and Mental Health Hubs (IDMH Hubs)*. Sydney: UNSW Social Policy Research Centre.

Contents

Summary of the evaluation plan 1
1 IDMH Hubs 5
2 Evaluation approach 7
3 Methods 9
3.1 Program documentation 11
3.2 Qualitative interviews and focus groups 12
3.2.1 Recruitment 14
3.2.2 Consent 16
3.3 Quantitative Hub program data 17
3.4 Linked participant outcome data across NSW Health 17
3.5 NSW health workforce capacity survey 18
3.6 LHD capacity survey 19
3.7 Inclusive and culturally sensitive approaches 19
3.8 Data analysis 20
3.9 Timeline 21
4 Quality assurance processes 24
4.1 Governance 24
4.2 Communication plan 24
4.3 Ethics 26
4.4 Risk management 26
4.5 Reporting and data storage 28
References 30
Appendix A Program logic for IDMH Hubs 31
Appendix B Support for people taking part in interviews 32

Tables

Table 1 Methods and sampling framework 11
Table 2 Project timeline 22
Table 3 Communication plan 25
Table 4 Risks and mitigation strategies 27

Abbreviations

3DN	Department of Developmental Disability Neuropsychiatry at UNSW Sydney
AH&MRC	Aboriginal Health and Medical Research Council
CALD	Culturally and Linguistically Diverse
CHeReL	Centre for Health Record Linkage
HREC	Human Research Ethics Committee
ID	Intellectual Disability
IDMH	Intellectual Disability Mental Health
LHD	Local Health District
MH	Mental Health
Ministry	NSW Ministry of Health
NDIS	National Disability Insurance Scheme
NSW	New South Wales
P&HSREC	NSW Population and Health Services Research Ethics Committee
SCCS	Self-controlled case series
SCHN	Sydney Children's Hospital Network
SLHD	Sydney Local Health District
SPRC	Social Policy Research Centre
UNSW Sydney	University of New South Wales

Terms

Co-design	Collaborative, shared approach to design. Including end service users and other people with lived experience to work alongside people with professional experience
Concrete reference tools	Tools that help people to understand what we are asking them. An example is picture cards. The tools can help everyone stay on topic and facilitate conversation
Data linkage	Joining together data about each person from several sources
Families or family members and carers	The family members or significant others of participants. This group may include legal guardians and friends of the participants
Hubs (or Program or Hub Program)	Short for: The Statewide Tertiary Intellectual Disability and Mental Health Hubs
Mixed method	Using different methods of data collection and analysis. For example in this evaluation, qualitative and quantitative methods and co-design are used
Participant	Person with Intellectual disability and mental health challenges who accesses Hub services
Participatory research design	Program participants and other people with lived experiences of intellectual disability and/or mental health challenges are involved in the design process
Peer-based research	Service users and other people with similar lived experiences are involved in the design, implementation and review of the research
Program or Hub Program (or Hubs)	Short for: The Statewide Tertiary Intellectual Disability and Mental Health Hubs
Program logic	A document that lists the Program activities and intended outcomes and shows the relationships between the Program inputs, activities, outputs and outcomes
Qualitative methods	Collection of detailed information from some stakeholders. This information is obtained through talking to people and also through other methods such as using photos or stories
Quantitative methods	Collection or analysis of data that can be counted. This is called quantitative data
Service providers	Includes Hub clinical managers and staff, other mental health and health clinicians referring to or receiving advice from the Hubs, existing service providers of participants such as case managers, community mental health providers, Aboriginal and CALD support services, disability service providers, disability advocates and others as identified in the co-design

Summary of the evaluation plan

The Statewide Tertiary Intellectual Disability and Mental Health Hubs (called ‘the Hubs’ for short) are a NSW Ministry of Health (Ministry) Program.

The Hubs aim to develop services to better support people who experience both mental health issues and intellectual disability. The Hubs offer direct support to participants. The Hubs also offer training and advice to health professionals.

There are 2 Hubs:

- a Hub for **children and adolescents** at Sydney Children’s Hospital Network (SCHN)
- a Hub for **adults** at Sydney Local Health District (SLHD).

Evaluation of the Hubs

The Social Policy Research Centre (SPRC) at UNSW Sydney will evaluate the Hubs together with 3DN at UNSW Sydney. The evaluation commenced in September 2020 and runs until November 2023.

This evaluation plan outlines how the SPRC and 3DN will evaluate the Hubs.

The evaluation will assess the outcomes of the Hub model. The evaluation will also assess how efficient and effective the service processes are. This means it will look at how the Hubs were established and how they are working now. The evaluation will look to see how successfully the Hubs follow their intended structure and activities. We will not conduct an economic evaluation.

The evaluation objectives (or aims) are to:

1. Assess the effectiveness of the Hub services in meeting program objectives
2. Examine the benefits, outcomes and innovation arising from the Hubs
3. Identify critical factors/service elements contributing to the greatest outcomes
4. Identify opportunities to improve service quality and effectiveness
5. Inform NSW decision-making about future policy directions for the Hubs
6. Provide recommendations for further development and sustainability of the Hubs as a service component of the Intellectual Disability and Mental Health (IDMH) Network.

Evaluation methods

The evaluation will use a mixed method approach. A mixed method approach collects different types of data and uses different methods of data collection and analysis. The mixed method approach that will be used in this evaluation includes:

- Co-design of research methods
- Analysis of qualitative data from interviews
- Analysis of quantitative data collected by program providers, data linkage and surveys.

The co-design of research methods process will aim to improve the evaluation approach and methodology – or how the evaluators will do their work. The co-design process will involve collaboration between:

- NSW Health – including NSW Health epidemiologists, Centre for Aboriginal Health and ID Health Team
- the IDMH Advisory Group members – mental health and intellectual disability peak bodies, community organisations including NSW Council for Intellectual Disability (CID) and Carers NSW, Aboriginal advisors, and advisors on children, people from culturally and linguistically diverse (CALD) backgrounds and people in the criminal justice system
- researchers with lived experience of mental illness and intellectual disability in the evaluation team
- named expert advisors for: mental health and lived experience, intellectual disability, mental health clinical advice, Aboriginal and Torres Strait Islander people, children, young people, families, CALD participants
- Aboriginal LHD Health Workers, as well as Aboriginal Health Units of the Hub LHDs and local Aboriginal and CALD organisations as appropriate, in the Hub sites.

Qualitative data collection involves talking to people in interviews or focus groups about their experiences of the Hubs. We will take the recommended actions to protect people from COVID-19 during the interviews and focus groups.

Quantitative data collection involves obtaining anonymous health data of Hubs participants from various data sets within the Ministry. It also includes surveys with health professionals who have used the Hubs. We will analyse the quantitative data to see how well the Hubs are working. The evaluation does not include an external comparison group. Instead we will compare outcomes for Hub participants and service providers before and after they use the Hubs.

Analysis: The data collected will be measured against the program logic and evaluation aims to assess the effectiveness and outcomes of the Hubs. We will present the findings in relation to contextual evidence, that means considering the wider service system for potential participants.

The program logic lists the Hub activities and intended outcomes. The evaluators use the program logic to measure how the Hubs are working in relation to their intended aims. The draft Hubs program logic can be found in Appendix A.

The evaluation includes **ethical, inclusive and culturally sensitive approaches** to data collection and analysis. Details about these approaches can be found in Section 3.7 of this plan.

Details of the data sources, collection and analysis are in Section 3 of this plan.

Timeline

The evaluation will be conducted in three stages:

- Phase 1: Project set-up, co-design, ethics submissions and Evaluation Plan (September – December 2020)
- Phase 2: 1st round of qualitative and quantitative program data collection and a Formative Evaluation Report (January – August 2021)
- Phase 3: 2nd round of fieldwork and program data collection, linked data, surveys and final analysis for the Summative Evaluation Report (September 2021 – November 2023).

Table 2 in Section 3.9 of this plan shows the evaluation timeline.

Quality assurance

The Project Governance will be managed and overseen through:

- **Meetings and reports** between SPRC, 3DN and the Mental Health Branch in the Ministry.
- An **IDMH Advisory Group**, which will include people with lived experience of intellectual disability and mental health challenges, relevant policy sections in the Ministry, and representatives from several LHDs, mental health and intellectual disability peak bodies and community organisations.
- The **IDMH Hubs** joint meetings, which occur every 3 months.
- Advice will be sought on culturally appropriate and trauma-informed methodology regarding participants from **Aboriginal and Torres Strait Islander** and **culturally and linguistically diverse (CALD)** backgrounds. This advice will come from: Aboriginal and Torres Strait Islander and CALD

members of the evaluation team; expert advisors from the SPRC; and, regarding Aboriginal participants, the Centre for Aboriginal Health at NSW Health.

The Communication plan for the evaluation is provided in Table 3 in Section 4.2.

Ethics applications will ensure voluntary participation and confidentiality in the qualitative and quantitative research. The applications will include strategies to minimise the risk of psychological harm and trauma to Hub participants. Details of the ethics process are provided in Section 4.3.

Risk management strategies are provided in

Table **4** in Section 4.4 of this plan.

The final evaluation **report**, including easier-to-read and short video versions, will be published on the SPRC website, with approval from the Ministry.

1 IDMH Hubs

People with intellectual disability are more likely to have poor health outcomes when compared to Australians in general. For example people with intellectual disability may have more physical and mental health problems and experience multiple health problems at the same time. People with intellectual disability also have a shorter life expectancy than people who do not have an intellectual disability.

People with intellectual disability are also more likely to have mental health challenges. Studies show, however, that people with intellectual disability can find it difficult to access appropriate mental health care when they need it (Cvejic et al. 2018; Weise et al 2020).

To address this service gap, the NSW Government committed $4.4 million over 4 years from financial year 2018-2019 to support better access and availability of services to people living with both intellectual disability and mental health conditions. Two Statewide Tertiary Intellectual Disability and Mental Health Hubs (the Hubs) were established as part of this funding:

- a Hub for children and adolescents at Sydney Children's Hospital Network (SCHN)
- a Hub for adults at Sydney Local Health District (SLHD).

The Hubs offer multi-disciplinary support for people with complex, co-occurring intellectual disability and mental health challenges. The Hubs work with people who have a diagnosed mental illness and others who may have mental health that might affect their ability to function. The Hubs also deliver activities to build capacity in the health workforce and among other interested professionals to support people with intellectual disability and mental health issues. Funding is ongoing, and initial funding agreements run from March 2019 to March 2024.

Program Logic

The Program Logic is a document that lists the Program activities and intended outcomes. The Program Logic shows how program inputs, activities and outputs, process outcomes and outcomes for participants fit together. The evaluators use a program logic to measure how the program is going. The Program Logic for the Hubs was developed with the Ministry and will be refined during the evaluation. The Hub Program Logic is in Appendix A.

Evaluation of the Hubs

The NSW Ministry of Health (the Ministry) commissioned the Social Policy Research Centre (SPRC) at UNSW Sydney to evaluate the Hubs. The SPRC will conduct the

evaluation together with the Department of Developmental Disability Neuropsychiatry (3DN) at UNSW Sydney.

This evaluation plan outlines how the SPRC and 3DN will evaluate the Hubs. It presents the planned approach, methodology and quality assurance processes for the evaluation. This plan will be refined with stakeholders during the initial phase of the evaluation.

2 Evaluation approach

This project is a summative outcome evaluation of the Hubs. The evaluation assesses the outcomes of the Hub model as well as the effectiveness of the service processes.

The evaluation objectives are to:

1. Assess the effectiveness of the services in meeting the Hub objectives
2. Examine the benefits, outcomes and innovation arising from the Hubs
3. Identify critical factors/service elements contributing to the greatest outcomes
4. Identify opportunities to improve service quality and effectiveness
5. Inform NSW decision-making about future policy directions for the Hubs
6. Provide recommendations for further development and sustainability of the Hubs as a service component of the Intellectual Disability and Mental Health Network.

The evaluation commenced in September 2020 and runs until November 2023.

The evaluation adopts a mixed-method research design. This means we will collect and analyse information from a breadth of sources and include both quantitative and qualitative data. We will then triangulate the information against an evaluation framework to assess the effectiveness and outcomes of the Hubs. We will not conduct an economic evaluation.

The evaluation does not include an external comparison group. Instead, we will compare health and wellbeing of Hub participants before, during and after they get services from the Hubs (**Section 3.8**). We will also compare service provider attitudes and skills before and after they engage with the Hubs.

We acknowledge that the Hubs operate in a wider system and are linked to other services and policies. For example, there are specialist ID health teams and NDIS residual functions services as well as continuous changes to the NDIS. The evaluation will not be able to determine exactly whether and how much any other services or policies contributed to impacts of the Hubs.

The evaluation includes ethical, inclusive and culturally relevant approaches to research. This is particularly important as the Hubs support marginalised population groups – people with intellectual disability and mental illness, including children and young people, Aboriginal and Torres Strait Islanders and people from culturally and linguistically diverse (CALD) backgrounds. The qualitative data collection uses participatory research design, including peer-based research methods, research

team members with lived experience and relevant expertise from key evaluation stakeholders.

3 Methods

The evaluation uses a mixed-method design as described above in **Section 2**. The evaluation incorporates information from a wide range of qualitative and quantitative sources. The information (or data) collected will be analysed against the program logic and evaluation objectives to assess the effectiveness and outcomes of the Hubs.

Co-design

Details of the methods will be refined through **co-design**. The co-design process improves the evaluation approach, methodology and reporting, or how the evaluation will do things. The co-design process includes collaboration of:

- the research team from SPRC and 3DN, including researchers with lived experience of mental illness and intellectual disability
- the Ministry – including NSW Health epidemiologists, Centre for Aboriginal Health and others
- the IDMH Advisory Group members – mental health and intellectual disability peak bodies and community organisations including NSW Council for Intellectual Disability (CID)
- named expert advisors for: mental health and lived experience, intellectual disability, mental health clinical advice, children, young people, families, CALD participants, Aboriginal and Torres Strait Islander people.

These stakeholders collaborate via meetings and e-mails. Contact will be in larger or smaller groups, depending on the task. The co-design will initially build on information from the Ministry about the Hub implementation and participants as at September 2020. It will explore synergies and efficiencies with two concurrent evaluations of related programs – the IDMH NDIS Residual Functions Program and the ID Health Teams. The co-design will initially:

- develop the evaluation questions
- refine the research methods (peer-based, inclusive methods)
- develop a program logic
- review data sources and content for the quantitative program data and data linkage
- finalise the sampling framework (Table 1)
- finalise fieldwork protocols
- engage stakeholders in the fieldwork sites (clinical managers and staff involved in the Hubs, other community mental health services, disability

service providers) to build critical fieldwork relationships early in the evaluation.

Co-design will then continue throughout the evaluation (**Section 3.7**). For example, it will be used to adjust methodologies for second-round data collection or in response to first-round findings. It will also occur through feedback on report drafts.

Data sources

We will collect and analyse 6 data sources:

1. **Program documentation** from the Hubs
2. **Qualitative interviews and focus groups** with Hub stakeholders including participants, families and carers, frontline staff, managers, referring practitioners and organisations and other Hub stakeholders
3. **Quantitative Hub program data** transferred from the Hub management (SLHD and SCHN) to monitor implementation, outputs, capacity building activities and outcomes
4. **Linked participant outcome data across NSW Health** to measure the Hubs' impact on participant outcomes
5. **NSW mental health workforce capacity survey** to measure the impact of the Hubs on mental health professionals
6. **LHD capacity survey** to measure the impact of the Hubs on service provision.

Each data source and the method to collect it is described below.

The data collection and analysis will use inclusive and culturally sensitive approaches as described in **Section 3.7**. The evaluation will be done in three phases as described in **Section 3.9**.

There will be 2 rounds of interviews and focus groups, of Hub data analysis and of the workforce survey. This is so we can measure the functioning and the impact of the Hubs over time. We will summarise the findings of the first round of data collection in the Formative Evaluation Report, also called Interim Report (**Section 3.9**). The Hub stakeholders may consider those findings and use them to change how the Hubs work. By the second round of interviews and focus groups, we can see whether Hubs processes and services have evolved.

Sampling framework

Table 1 summarises the sampling framework. The table outlines: the data collection method, how much data will be collected (sample size), where the data will be collected from and what the timeframe is for collection.

Table 1 Methods and sampling framework

Method	Sample sizes per round	Data source	Timeframe
Review of program **documentation**	Both Hubs	Available documentation from both Hubs	Phases 1 to 3
Qualitative interviews with **participants**	Up to 10 participants per Hub = total up to 20 participants	**Fieldwork** at 2 Hubs (face to face, phone, video)	Phases 2 and 3
Qualitative interviews with **families and carers** (matched to participants)	Total up to 10 family members or carers across both Hubs	**Fieldwork** at 2 Hubs	Phases 2 and 3
Qualitative interviews and focus groups with **service providers**	Approximately 5 interviews/focus groups per Hub = approximately 10 in total	**Fieldwork** at 2 Hubs	Phases 2 and 3
Qualitative interviews and focus groups with **other stakeholders**	6 -12 representatives across the program	Focus groups, individual interviews where required	Phases 2 and 3
Quantitative Hub **program data**	All Hub participants	Available program and participant outcome data from both Hubs	Phases 2 and 3
Workforce capacity data	All consenting health professionals who have made a referral to a Hub	Online workforce capacity survey	Phase 3
Linked **participant outcome** data	All Hub participants (we will seek a waiver of consent from Ethics)	Available data linkage content through Centre for Health Record Linkage (CHeReL) or the Ministry	Phase 3
Local health district **capacity** data	All consenting Directors whose services have accessed the Hubs	Online survey	Phase 3

3.1 Program documentation

The evaluation will review program documentation from the 2 Hubs and the Ministry, as available. The documents may include Expressions of Interest from the Hubs when they applied for funding to NSW Health, and progress reports once the Hubs had started. We will determine during the co-design phase what types of program documentation might be available.

The Ministry will send the program documentation to the SPRC to analyse against the program logic. The review will provide a baseline for understanding the Hubs and their implementation. The review will inform the evaluation methodology. Progress reports may indicate how the Hubs evolve over time and whether evaluation findings from the first round of data analysis are being included.

3.2 Qualitative interviews and focus groups

The evaluators will conduct interviews and focus groups with Hub stakeholders including:

- **participants** at both Hubs – we aim to include a broad range of participants. We will aim to have diversity in gender, cultural background, location and mental health and intellectual disability status. Given the focus of the 2 Hubs on different age groups, we will include adults and young people aged 14 and above with parental/guardian consent
- **families and carers** of participants at both Hubs – matched to the participants we interview. This group may include legal guardians and friends of the participants
- **service providers** at both Hubs– may include Hub clinical managers and staff, other mental health and health clinicians referring to or receiving advice from the Hubs, existing service providers of participants such as case managers, community mental health providers, Aboriginal and CALD support services, disability service providers, disability advocates and others as identified in the co-design
- **other stakeholders** – from the Ministry, program partners in the Hub sites, mental health and intellectual disability peak bodies, youth support services, community organisations and others as identified in the co-design.

The fieldwork sites are the 2 Hubs. In addition, we will conduct interviews and focus groups with other, state-wide stakeholders face-to-face in Sydney, or by phone or video.

Research experience and relevant literature[1] suggest that the sample sizes in **Table 1** are enough to allow the evaluators to capture the views and experiences of a wide range of participants. The sample size will also be adequate to reach theoretical saturation. Theoretical Saturation is when no new findings appear and all themes and concepts are well developed.

[1] Crouch, M. & McKenzie, H. (2006). The logic of small samples in interview-based qualitative research. *Social Science Information*, 45(4), 483-499. DOI: 10.1177/0539018406069584

Qualitative data collection will assess Hub activities, satisfaction, outcomes and innovation arising from the Hubs as well as opportunities to improve service quality and effectiveness. The Hubs have a dual focus on participant assessment and building capacity in the health workforce and broader professions. Many Hub **participants** will have limited contact with the Hubs. Therefore participants may not be able to talk about their experience of the Hub service. Instead they may talk about changes to their mental health, function and quality of life, which may have occurred because of the Hubs.

The number of families and carers who are available for interviews might differ between the Hubs. In the children and adolescent Hub, most parents or guardians will be involved in the service. The adult Hub finds that many participants do not have a family member or carer involved. If one is involved, we will ask them about their direct experience of the service (if they have direct experience) or about their impression of the experience of the person they care for.

We will speak to participants face-to-face unless they have other preferences. With participant permission, **families and carers** will be interviewed face-to-face during the site visits, alternatively by phone or video. The interviews are about people's experience of the Hubs rather than personal stories. However, the topics in the interviews could still raise distress or anxiety in the participants. To reduce this risk, participants and families may access support before, during and after the interviews (details in **Appendix B**).

Service providers will be interviewed individually, in small groups or post-visit by phone or video. Similarly, **other stakeholders** such as Ministry staff, mental health and intellectual disability peak bodies and community organisations and referring partners will be invited to individual interviews or small focus groups. This will depend on their preferences and what is practical and allowed. All interviews and focus groups outside of Sydney will be done remotely.

All interviews and focus groups will be semi-structured. Semi-structured means that the interviewer (person asking the questions) will flexibly use a list of suggested questions. The interviewee (person being interviewed) can respond to the questions or they can just tell their story. We will develop lists of questions during the co-design phase.

The first round of interviews will be in March to May 2021 and the second round in February to April 2023. We use a flexible and **inclusive** approach to conduct research with people with intellectual disability and mental illness. A range of accessible methods will be available, including:

- standard interviews
- observation

- informal discussion
- storytelling and photo stories
- group activities
- written or documented responses.

Interviews will be conducted with easier to read questions and the use of 'Concrete Reference Tools' such as picture cards. We will adapt the interviews to the person's communication needs and preferences. This includes intellectual disability and sensory impairment such as sight and hearing.

Interviewers include the university researchers who are trained in these methods and the Lived Experience Researchers (also called peer researchers) with intellectual disability and/or mental health challenges. Interviewers will also be supported by evaluation advisors from Aboriginal and Torres Strait Islander and from Culturally and Linguistically Diverse (CALD) backgrounds. We will engage interpreters where appropriate.

In response to the COVID-19 pandemic, we have developed strategies to help protect interview participants and researchers during fieldwork. These strategies include social distancing and hygiene measures consistent with the current health advice. Where participants and service providers prefer, we will conduct interviews remotely.

All interview data will be confidential (**Section 4.5**).

3.2.1 Recruitment

How people will be invited to participate in interviews and focus groups will be decided during the co-design phase of the evaluation. This will ensure that the process fits with the Hub services, the participant group and the fieldwork locations.

We suggest that the recruitment process be similar to other evaluations the evaluators have done which included people with intellectual disability and mental illness. This process is described below.

Recruitment of Hub participants: Participants will be invited by service providers to share their experience.

Possible approaches include:

- Hub staff place recruitment flyer in waiting area at the Hub
- Hub staff verbally introduce the study to current participants during a consultation, and to past participants by appropriate contact method, e.g. phone, letter, e-mail.

If a participant is interested, Hub staff will ask whether they agree to being contacted by the researcher. If so, Hub staff will ascertain the appropriate method of contacting the participant, e.g. telephone, letter, email.

- Hub staff forward recruitment flyer to service providers across NSW (e.g. clinicians) who have referred participants to the Hubs or have consulted the Hubs about particular participants. The service provider can then forward the recruitment flyer to the participant or verbally introduce the study to the participant.
  If a participant is interested, the service provider will ask whether they agree to being contacted by the researcher. If so, the service provider will advise on the appropriate method of contacting the participant, e.g. telephone, letter, email.

Recruitment of family members: Family members and carers will be invited by the participants they care for. The invitation will be given verbally or through the recruitment flyer.

- **Step 1 Recruitment of family members and carers:** During the interviews with participants, the researcher will ask whether the participant has a **family member or carer** we could also talk to (we will check with Hub staff first if that is alright).

- **Step 2 Recruitment of family members:** If the participant agrees, the participant will contact the family member or carer and invite them to participate; if they agree, participant or the family member will contact the SPRC directly or ask the participant or service provider to forward their contact details to the SPRC.

Recruitment of service providers and other stakeholders: Service provider managers in the fieldwork sites will identify suitable staff for the interviews and ask them if they would like to participate. The invitation can be verbal, by e-mail or through forwarding the information and consent form. SPRC will ask the managers to select a mix of staff who vary in position, background and experience. Other stakeholders will be invited by the Ministry to participate. The sample will be determined during the co-design process.

Who will be invited to participate:

All people in the interviews and focus groups will be 14 years or older to minimise ethical risks. This follows ethics requirements of the National Health and Medical Research Council (NHMRC). Younger children will not be invited to an interview. Children 14 years and older might be invited if it is ethically safe for them to do so. This will be decided with the child and their parent or guardian.

We aim to get a full picture of outcomes and experiences of the Program. Therefore, service providers will try to identify **participants** who receive different kinds of Hub support now or have received it in the past. Hub support may include a single case discussion or assessment, or a small number of consultations. Service providers will also consider any other selection criteria as agreed in the co-design to gain diversity in the sample. For example: the aim is to interview a broad range of participants of different sex, age, cultural background, location and mental health and intellectual disability. At the interview, we will collect demographic data from participants and information about other support they may receive, for example from the NDIS.

Family members and carers will be identified through nomination by the participant during or after the interview (as described above).

Service providers and **other stakeholders** will be identified through discussions with site managers and subject to criteria decided upon in the co-design process.

3.2.2 Consent

Taking part in the interviews or focus groups is voluntary. All people must be freely able to give their consent to take part. For program participants aged under 18 years and for people under guardianship, a parent or guardian must also give consent.

Consent processes and forms will be finalised during the co-design phase. In previous evaluations, we used the processes described below. Any changes for this evaluation will consider the particulars of the Hubs, the participant group and the fieldwork locations.

The **consent process for participants** will involve the following steps:

1. SPRC will produce information material and consent forms about the evaluation designed in an accessible way for participants and/or their parents and guardians, as appropriate. These will be designed with advice from service providers about appropriate media, length and wording. For example, we will provide Easy Read versions of the consent forms, which will include pictures.
2. Service providers will talk through the information material and what the evaluation involves with participants and their guardians, if appropriate
3. Researchers will collect informed consent from participants before the interviews. Participants can give consent through signing the consent form, speaking or other means of communication.

The **consent process for families and carers** of participants will involve the following steps:

1. SPRC will produce information material and consent forms about the evaluation designed in an accessible way for families and carers, with advice from service providers about appropriate media, length and wording
2. Participants (or service providers on behalf of the participant) forward the information sheet to the family member nominated by the participant
3. Researchers will collect informed consent from family members before the interviews.

The **consent process for service providers and other stakeholders** will involve the following steps:

1. SPRC will produce information sheets and consent forms about the evaluation
2. The Ministry or service providers forward the information sheet to nominated people
3. Researchers will collect informed consent from service providers and other stakeholders before the interviews/focus groups.

3.3 Quantitative Hub program data

The evaluators will analyse quantitative Program data collected by the Hubs and transferred by the Ministry to the evaluators. The analysis aims to assess the effectiveness of Hub implementation and outputs. We will determine during the co-design phase what types of program data might be available. All data about participants will be confidential. Names and other details that might identify a person will be removed or changed (or de-identified) before being sent to the evaluators.

3.4 Linked participant outcome data across NSW Health

We will link existing NSW health data for participants in the Hubs. This means joining data about each person from several sources, for example hospitals and GPs. The linkage aims to determine the impact that the Hubs have had on how often participants use health services and on participants' health outcomes. We propose two options. One of them will be chosen in consultation with the Ministry during the co-design phase.

Option 1: NSW Health links and analyses administrative health data for participants of the Hubs

OR

Option 2: We request a linkage through Centre for Health Record Linkage (CHeReL) of administrative health data for participants of the Hubs. For this

option we would work with the Ministry to have this linkage prioritised for completion by September 2022.

Approach to linkage for option 2: We will request a linkage through CHeReL for data from the NSW Admitted Patient Data Collection, NSW Ambulatory Mental Health and NSW Emergency Department Data Collection, NSW Ambulance data, and the Registry of Births, Deaths and Marriages for participants. The linkage will include data from at least 1 year prior to the participants' first engagement with the Hubs until September 2022. Due to the delay of data being available to CheReL, a linkage in March 2023 will allow us to access data until September 2022.

Any issues around data privacy will be addressed during the ethics application process.

3.5 NSW health workforce capacity survey

The evaluation aims to measure the impact of the Hubs on health professionals who have referred to the Hubs. We will explore the workforce's cultural background, their attitudes, knowledge, skills and confidence towards working with people with an intellectual disability, and what learning or development they gained from the Hubs.

To collect this data, we will use the workforce capacity survey tool developed and published by Weise and Trollor (https://www.tandfonline.com/doi/full/10.3109/13668250.2017.1310825).

We will ask the Hubs to invite all health professionals who have referred to their service to undertake an online survey, at 2 points in time – at referral (the baseline survey) and post, or after, engagement with the Hub (the post survey). Each person who refers to the Hubs will be asked to complete the baseline survey once. If a person refers more than one time, we will ask them to complete the post survey after each time they re-engage with the service. This is important as the type of Hub service will vary based on the needs of each person being referred.

An email invitation to take part in the survey will be sent to a person when they refer to the Hubs.

- If they consent to participate, they will be invited to complete the online baseline survey. We will setup an automated system to send referrers the post survey 3 months after they complete the baseline survey. OR

- If they consent and have previously completed the baseline survey, we will send them an email thanking them for agreeing to participate again and explain that we will send them the post survey in 3 months.

We will confirm details of the methodology during the co-design.

Data collection will run from October 2021 to March 2023.

3.6 LHD capacity survey

The evaluation will also aim to measure the impact of the Hubs on LHD service provision. To this end we will do an online consultation with LHD directors whose services have accessed the Hubs. The tool will explore capacity building at a district, service and workforce level. We will ask the Hubs to invite LHD directors whose services have accessed the Hubs to undertake the survey, which will be conducted in April 2023.

3.7 Inclusive and culturally sensitive approaches

The interviews and focus groups will follow the principles of ethical conduct in evaluation research, including:

- Use data collection methods that are ethical, preferred by stakeholders (where possible/feasible), and disability inclusive
- Reduce respondent burden, using mechanisms preferred by Hub managers and staff (e.g. surveys, phone, small groups)
- Design flexible methods, in particular for the changing health context under COVID-19
- Maximise diversity of respondents by including Hub participants and support services in non-metro NSW.

Lived experience: SPRC will recruit and support people with lived experience of mental illness and intellectual disability to contribute to all stages of the evaluation, from design through data collection to analysis and reporting.

During the co-design process we will refine the qualitative data collection and peer research methods with input from expert advisors for mental health, intellectual disability, Aboriginal and Torres Strait Islander people, people from CALD backgrounds and people with experience and expertise of the criminal justice system.

Our fieldwork protocols will contain inclusive and culturally appropriate recruitment strategies, safety protocols and sensitive research practices, as outlined in **Section 3.2**. Depending on their preferences, lived experience researchers will also be involved in the fieldwork itself, data analysis and commenting on draft reports.

The lived experience research is organised by the research team’s mental health peer researcher. NSW Council for Intellectual Disability (CID) will support lived experience researchers with intellectual disability.

Aboriginal and Torres Strait Islander expertise will be sought from local Aboriginal organisations and the Hub and LHD workers in the fieldwork sites. We will build on local contacts, or on the relationships we have developed through previous evaluations to partner with local Aboriginal organisations.

In addition, the SPRC evaluation team includes an academic Aboriginal and Torres Strait Islander advisor, and one of the lived experience researchers recruited for the evaluation identifies as Aboriginal. The Centre for Aboriginal Health (CAH) at NSW Health will also provide expert advice.

Similarly, we will seek **CALD expertise** from Hub workers. Details will be determined through co-design when preparing fieldwork. The evaluators will also draw on the expertise of the SPRC CALD advisors.

Lived experience and expertise of the **criminal justice system** will be organised during the co-design phase.

3.8 Data analysis

Data analysis processes will be finalised during the co-design phase of the evaluation. We suggest using previous work by 3DN as an **analytical framework** to measure how the Hubs have enhanced the capacity of NSW health services to meet the mental health needs of people with ID and mental ill-health (3DN 2014 and 2016). The work consists of:

- a Guide that articulates the role that each service has in delivering accessible mental health services to people with intellectual disability
- a Framework that identifies the attributes required of the mental health workforce when working with people with intellectual disability.

The data from the **interviews** and focus groups will be thematically analysed against the evaluation questions and the analysis framework as determined in the co-design phase. This means the evaluators will look at how the interview responses fit with the questions that the evaluation aims to answer and with the framework. The interview and focus group data will be examined and sorted into themes using analysis software called NVivo.

For the **linkage** data we will compare the Hub participants with the evaluators' existing linked data set of people with intellectual disability and co-occurring mental illness in NSW. This will help understand the demographic, health and health service use profile of the Hub participants, and how it is similar or different to people with intellectual disability living in NSW. If there are enough Hub participants, we will break down the findings by age, gender, living situation or cultural background, or by the type of Hub service received.

To assess whether there are changes in health service usage in people who are accessing the Hubs we will use the self-controlled case series (SCCS) method with two steps.

- Step One: For each Hub, if there are enough participants, we will conduct a SCCS to compare health service usage patterns of each participant before and after joining the Hub. Where possible we will also compare health outcomes before and after joining the Hub.

- Step Two: Using Hub level data from both Hubs, the approach is the same as in step one, however, to estimate impact of the Hub in each location, we will use the SCCS method and include time factors for each location in the model.

The data from both **surveys** will be analysed together with the quantitative Hub **program** data to assess the impact and effectiveness of Hub activities. This will include age-appropriate outcome measures collected by the Hubs as part of service delivery.

For the **workforce survey data**, we will use descriptive analyses and linear mixed model analysis. Linear mixed model analysis is a type of quantitative data analysis that will let us test whether there was any significant change in workforce capacity after accounting for the relationships within and between survey respondents. For example, the analysis can account for differences in the respondents' professional background, previous work experience with people with intellectual disability, and education completed in the area of intellectual disability mental health.

For the **LHD capacity survey**, we will use descriptive analysis for quantitative answers and thematic analysis for qualitative answers to understand the impact of the Hubs.

We will present all findings in relation to contextual evidence, that means considering the wider service system for potential participants.

3.9 Timeline

The evaluation will be conducted in three phases:

- Phase 1: Project set-up, co-design, ethics submissions and Evaluation Plan (September-December 2020)
- Phase 2: 1st round fieldwork and program data collection and Formative Evaluation Report (Interim Report) (January-August 2021)
- Phase 3: 2nd round fieldwork and program data collection, linked data, surveys and final analysis for the Summative Evaluation Report (September 2021-November 2023)

Detail is provided in **Table 2** below. If any issues should impact on timeframes during the evaluation, the Ministry and SPRC together will manage variations to the evaluation timeline. Potential issues may relate to resourcing at the Hubs or the Ministry, or to COVID-19.

Table 2 Project timeline

Evaluation tasks and processes	**Date**
Phase 1	***Sep-Dec 2020***
Project start	Sep
Initial meeting	Sep
Decide communication plan	Sep
Review quantitative data sources	Sep
Collect and review program documentation	Sep-Nov
Initial co-design process: • Develop evaluation questions • Refine research methodology incl. peer methodologies • Develop program logic • Select fieldwork sites • Review data sources • Finalise sampling framework • Finalise fieldwork protocols	Sep-Dec
Ethics applications	Sept-Dec
Engage key contacts and stakeholders in the Hub and LHD fieldwork sites	Sept-Nov
Recruit and train peer researchers	Sept-Nov
Deliverable 1: Ethics submitted for approvals **Deliverable 2: Evaluation Plan**	**December 2020**
Phase 2	***Jan-Aug 2021***
1st round fieldwork in 2 Hubs and LHD/s with participants, family, staff, providers	Mar-May
1st round focus groups/interviews with other key stakeholders	Mar-May
Qualitative data analysis (interviews, focus groups)	May-Jul
1st round quantitative data analysis (program data)	May-Jul
Deliverable 3: Formative Evaluation Report (Interim Report)	**Draft 31 July, Final 31 August 2021**
Phase 3	***Sep 2021 – Nov 2023***
Workforce survey (data collection and analysis)	Oct 2021 - Mar 2023

Evaluation tasks and processes	**Date**
2nd round fieldwork in 2 Hubs and LHD/s with participants, family, staff, providers	Feb-Apr 2023
2nd round focus groups/interviews with other key stakeholders	Feb-Apr 2023
Quantitative data analysis (program and linked outcome data)	Apr-Jun 2023
LHD capacity survey (data collection and analysis)	Apr-June 2023
Qualitative data analysis (interviews, focus groups)	May-Jun 2023
Triangulation of qualitative and quantitative data	Jul 2023
Deliverable 4: Draft Summative Evaluation Report	**31 July 2023**
Deliverable 5: Final Summative Evaluation Report	**30 November 2023**
Project end	30 Nov 2023

4 Quality assurance processes

4.1 Governance

This project will be managed and overseen through the following mechanisms.

SPRC and 3DN will report to the **Mental Health Branch**, NSW Ministry of Health. Monthly project meetings have been agreed to, and the frequency can be adjusted in consultation with the Ministry as needed. Meetings include updates on evaluation progress and findings and any potential variations to the project scope, budget or deliverables.

The Ministry's **IDMH Advisory Group** will advise on evaluation design and methodology, comment on deliverables and provide general evaluation guidance. Members include people with lived experience of intellectual disability and mental health challenges, relevant policy sections in the Ministry, representatives from several LHDs, mental health and intellectual disability peak bodies and community organisations.

The **IDMH Hubs** have a joint meeting every 3 months. They will provide feedback to the evaluators on methodology and findings, and they will act on the 1st round findings of the evaluation. These findings are called formative because they influence how the program operates while the evaluation is still going on.

SPRC and 3DN will attend meetings of the IDMH Advisory Group and the IDMH Hubs. We will present evaluation progress and findings as required and appropriate.

Mental Health Branch will also engage with Centre for Aboriginal Health for Aboriginal and Torres Strait Islander input.

SPRC will seek advice from a representative group for CALD mental health participants.

4.2 Communication plan

Table 3 summarises the communication plan for the evaluation. It aims to ensure that all stakeholders are engaged and confident in the evaluation and informed about its progress. SPRC will communicate the final evaluation findings to all stakeholders in various appropriate formats in November 2023.

Table 3 Communication plan

Stakeholder type	Communication point or method	Times
Hub participants	Introduction of evaluation by Hubs	Mar 2021
	Interviews	Mar-May 2021, Feb-Apr 2023
	Feedback about evaluation findings (full public report and accessible versions such as short reports, easy read and film)	Nov 2023
Families of Hub participants	Participants/Hubs contact families	Mar 2021
	Interviews	Mar-May 2021, Feb-Apr 2023
	Feedback about evaluation findings (full public report and accessible versions)	Nov 2023
Hub and other service providers	Fieldwork	Mar-May 2021, Feb-Apr 2023
	Online surveys	Oct 2021-Mar 2023, April-June 2023
	Feedback about evaluation progress and findings: through representation on governance groups, evaluation reports and direct communication from the Ministry	From Sep 2020
Other stakeholders	Interviews and focus groups (after the Ministry has informed stakeholders about the evaluation and they have agreed to participate)	Mar-May 2021, Feb-Apr 2023
	Feedback about evaluation findings (full public report and accessible versions)	Nov 2023
Peer researchers	Advice on fieldwork methodology and interview recruitment processes	From Oct 2020
	Fieldwork	Mar-May 2021, Feb-Apr 2023
	Contributing to analysis in evaluation reports	Nov 2020, Jul 2021, Jul-Nov 2023
Aboriginal and CALD advisors	Advice on evaluation design, methodology and analysis	From Oct 2020
	Feedback on reports	Nov 2020, Jul 2021, Jul-Nov 2023

4.3 Ethics

This evaluation requires several ethics approvals. Applications will include strategies to minimise the risk of psychological harm and trauma to Hubs participants. The applications will ensure voluntary participation and confidentiality in the qualitative and quantitative research.

Ethics approval will be sought from the following ethics committees:

- **UNSW Human Research Ethics Committee (HREC)**, which will provide approval for the qualitative data collection
- **Aboriginal Health and Medical Research Council (AH&MRC) Human Research Ethics Committee (HREC)**, which will provide ethics clearance for Aboriginal and Torres Strait Islander involvement in the evaluation
- **NSW Population and Health Services Research Ethics Committee (P&HSREC)**, which will provide ethics approval for the program data and linked outcomes data
- **A Local Health District (LHD) Human Research Ethics Committee (HREC) – to be determined –** which will be the lead HREC for the qualitative fieldwork in the Hubs and the LHD/s
- **LHD Research Governance Offices in the fieldwork sites**, for Site Specific Approvals (SSAs) for qualitative fieldwork.

The research will adhere to the requirements outlined in the UNSW Code of Conduct and align with best-practice principles in the NSW Government Evaluation Framework, for example communicating evaluation results to various audiences.

4.4 Risk management

Table **4** outlines some of the challenges that could arise over the course of the evaluation, their potential consequences, their likelihood and mitigation strategies. The table will be refined during co-design, and risks will be monitored and addressed during the evaluation.

Table 4 Risks and mitigation strategies

Risks	Likelihood	Impact on evaluation & stakeholders	Risk management response
Evaluator cannot effectively engage with sufficient stakeholders from different target groups dispersed across different locations.	High	High	Early communication with stakeholders to engage them in the evaluation process and to identify how to best involve them in interviews and gain access to program and other data. Peer methods to build trust and quality working relationships with participants and families. Evaluation experience with stakeholders and data holders (Ministry, InforMH, community service providers) will avoid and resolve engagement problems. Communicate progress to stakeholders throughout the project. Tele/video conferencing for dispersed organisational stakeholders.
Only limited data available in the early stages of the evaluation.	High	Low	Evaluation design so that early stages do not require access to Hub outcome data.
Delay in data access from Ministry/SLHD/ SCHN and low data quality including data linkage	High	High	Early communication with stakeholders and CHeReL to identify how to access program data. Transparency in how the data will be used and to address concerns about sharing data. Two strategies for linking participant outcomes data to mitigate the risk of delay in accessing linked data. Past experience with LHDs/SHNs to access resources and their staff members' research participation about intellectual disability mental health.
Ethics approval processes not finalised within short time frame allocated.	Medium	High	Team is highly experienced with relevant ethics committees; and strong record obtaining ethics approvals for similar projects.
Multiple overlapping advisory processes may produce contradictory advice.	Medium	High	Team is highly experienced in coordinating such processes and managing disagreements, if any arise, for example through regular communication with all stakeholders (4.2).

Submission of deliverables may be delayed.	Low	Medium	Solid project management and risk management protocols, detailed communication protocols.
Evaluation provides insufficient critical analysis of the Hub service model, and does not produce useful and actionable recommendations.	Low	High	Team renowned for rigorous research governed by university standards that produces comprehensive and useful policy guidance to inform program improvement and decisions. Mixed-method approach from various data sources compensates for data limitations, and findings will be linked to actionable recommendations.
Evaluation activities interfere with the delivery of services to participants	Low	Medium	Evaluation design with focus on Hub data reduces impact on service providers and participants. Demands will be kept to a workable limit to minimise clinician burden.
Participant data protocols are breached.	Low	Medium	Experienced managing sensitive data, systematic data collection and storage methods. All personal data will be confidential, with access limited to evaluators for analysis.
Engagement of participants and families in the project is not effective	Low	High	Experience engaging participants, family members and service staff. Successful recruitment documentation and approaches for people with mental illness and ID. Experience working with formal guardians and family. Self-controlled case series (SCCS) method to allow for small sample sizes.
The evaluation methodology is inappropriate	Low	Low	Mixed methods design and strong team to reduce this possibility. Leading Australian experts in intellectual disability/mental health, evaluation and peer methodologies.

4.5 Reporting and data storage

The final evaluation report will be published, with approval from the Ministry, on the SPRC website. In addition, accessible versions of the report will be created with input from the Ministry and project advisors, who will suggest suitable formats for audiences with various communication needs. Formats may include an Easy Read version of the report and short videos with added Auslan. All versions of the report will be published, with approval from the Ministry, on the SPRC website. The Ministry may also publish the reports on its own website, or link from it to the SPRC website.

The Executive Summary will be made available to all evaluation participants who indicate on the consent form that they wish to receive it.

The study findings will also be published in peer-reviewed journal articles and presented at national and international conferences. All data will be reported in such a way that no evaluation participant is identifiable.

Any data collected during this evaluation will be stored, in accordance with ethics and University requirements, for a period of seven years. Data will be stored in a de-identified form on a secure server, with access limited to the research team.

All data will be kept confidential. Only the research team will see the data. No-one else will be able to identify people who took part in interviews or focus groups, or who were participants of the Hubs. For example, when interview transcripts are edited and checked, any identifying names, locations or circumstances will be erased or changed. Transcripts and participant contact details will be kept separate, so it is impossible to match transcripts to any individual. Further, in any publication and/or presentation of the findings, the information provided by the interviewees will be used in such a way that they will not be individually identifiable. Any quote extracted from the interviews will be edited to remove any names or identifying information.

References

3DN (Department of Developmental Disability Neuropsychiatry) (2014) *Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers.* Sydney: University of New South Wales Sydney.

3DN (Department of Developmental Disability Neuropsychiatry) (2016). *The Intellectual Disability Mental Health Core Competency Framework: A Manual for Mental Health Professionals*. Sydney: UNSW Sydney

Cvejic, R., Eagleson, C., Weise, J., Trollor, J. (2018) A scoping study of the need for a tertiary intellectual disability mental health service in New South Wales. Department of Developmental Disability Neuropsychiatry UNSW, Sydney.

Weise, J., Cvejic, R., Eagleson, C. & Trollor, J. (2020) A Scoping Study of a Tertiary Intellectual Disability Mental Health Service: A Family Member and Support Person Perspective, Journal of Mental Health Research in Intellectual Disabilities, 10.1080/19315864.2020.1753268

Appendix A Program logic for IDMH Hubs

Program aim: To give multidisciplinary support for people with complex co-occurring ID and MH care needs, and build capacity in the health workforce to work more effectively with people living with intellectual disability and co-occurring mental illness, and with their families and carers

Inputs	Outputs			Outcomes – short to medium term		
	For consumers	For providers	For the system	For consumers	For providers	For the system
Sydney Children's Hospitals Network Mental Health and Intellectual Disability Hub (SCHN MHID Hub): 1.8 FTE **Statewide Intellectual Disability Mental Health Outreach Service (SIDMHOS):** 3.42 FTE **Ministry of Health:** • Program Management • Mental Health Community Data collection • Policy directive and guidance (e.g IDMH Strategic Plan) • IDMH Advisory Group	Offer **advice to support the care** of people with ID in mainstream mental health settings Provide **clinical assessment and care recommendations** for the complex care of people with ID and mental health problems	Develop **relationships and partnerships** with: • LHD inpatient and community mental health services • NSW Health and private care providers • NDIA Deliver **educational programs** and resources – e.g. Kids Webinar Series and Project ECHO Deliver clinical supervision and **training** by specialist staff to mainstream mental health staff Leadership and participation in **research** activities regarding the mental health needs of people with ID (additional to evaluation)	Develop **IDMH Data dashboard** including **MDS** Develop **statewide IDMH KPIs** **Promote** Hub services and IDMH care **Improve access** to specialist IDMH services	Improved **wellbeing** of people with ID and their families Improved **access** to local and specialist mental health care for people with ID **Timely access** to NSW mental health services and programs based on clinical need More appropriate use of **treatments** including psychotropic medication and behaviour support Improved and **stable service provision** from NDIS funded providers	Increased **capacity** of health services to meet the mental health needs of people with ID Access to s**pecialist** support for mental health clinicians Improved **patient flow** through acute, subacute, rehabilitation and community mental health services Increased **coordination** and engagement across health and disability providers to facilitate integrated care Improved access to targeted **education and training** in ID for mental health clinicians Increased mental health clinician **exposure** to working with people w. ID Improved **confidence and skills** of mainstream mental health staff in working with people w. ID	Improved **patient flow** through acute, subacute, rehabilitation and community mental health services (removing bed blocks) Development of IDMH as an area of **specialty practice** Improved **data** on the service usage, prevalence and access to care for people with ID

Appendix B Support for people taking part in interviews

The minimisation strategies outlined below are well established and have been repeatedly used by researchers in similar evaluations.

Risks for people with lived experiences of mental illness and intellectual disability and their family members

The interviews focus on people's experience of the Hubs and not personal stories, but the topics discussed in the interviews could still create distress or anxiety in the participants. To reduce the risk of participants being reminded of anxiety or grief about mental illness or intellectual disability, the research team is adopting three strategies.

1. Strategies to reduce risk of psychological harm during recruitment:

In the early stage of recruitment, researchers and service providers will establish with participants:

- Preference for a phone or face-to-face interview
- Location of interview
- Whether they would like a support person to attend
- The key areas of focus
- Which researcher will interview them
- Any supporting information they may find helpful

2. Strategies to reduce risk of psychological harm during the interview:
    - The interviews will be conducted with experienced researchers who have lived experience of intellectual disability and/or mental health challenges. Depending on the preference of the interviewee, the peer researcher will attend or co-conduct the interview, or be there to provide support.
    - Participants will be reminded that they can stop or take breaks throughout the interview. This may include getting a cup of water or tea/coffee, having a smoke or stretching their legs.
    - The interviewers will remind participants that they are free to stop at any time to ask for support or completely end the interview.
3. Strategies to reduce risk of psychological harm at the end of the interview:
    - At the end of the interview, participants will be reminded that if they need someone to talk to that they can call Lifeline Australia (13 11 14) whose number will be included on the

information sheet. The participant will also be contacted by the researcher 24 hours after the interview to ensure that no additional support is required.

Risks for service providers and other stakeholders

The risk for service providers and other stakeholders is limited, but during the interviews or focus groups participants may be reminded of anxiety or grief about mental illness or intellectual disabilities. The participant is free to end the interview or leave the focus group at any time. A phone number for the Mental Health Line (1800 011 511) will be provided on their consent form.