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Formative evaluation report of the Intellectual Disability and Mental Health Hubs (the Hubs)

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Abbreviations and meanings

3DN	Department of Developmental Disability Neuropsychiatry at UNSW Sydney
ASD	Autism spectrum disorder
CALD	Culturally and Linguistically Diverse
Consumer	Person with intellectual disability and mental health. They may or may not use the Hubs.
DCJ	NSW Department of Communities and Justice
Hubs	Hub for children and adolescents at Sydney Children's Hospital Network (SCHN MHID Hub) and Hub for adults at Sydney Local Health District (SIDMHOS)
ID	Intellectual Disability
IDMH	Intellectual Disability Mental Health
KPI	Key performance indicators
LHD	Local Health District
MDS	Minimum dataset
MH	Mental Health
Ministry	NSW Ministry of Health
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NSW	New South Wales
Participant	Person with intellectual disability and mental health who used the Hubs
RFP	IDMH NDIS Residual Functions Program
SCHN	Sydney Children's Hospital Network
SCHN MHID Hub	Sydney Children's Hospitals Network Mental Health and Intellectual Disability Hub
SIDMHOS	Statewide Intellectual Disability Mental Health Outreach Service
SLHD	Sydney Local Health District
SPRC	Social Policy Research Centre
UNSW Sydney	University of New South Wales

Short summary

Two new statewide Hubs aim to support better access of services for people with both intellectual disability and mental health needs. The statewide Intellectual Disability and Mental Health (IDMH) Hubs were established by the NSW Ministry of Health (the Ministry). The Hubs work with people with IDMH, their families and carers, and their service providers. The Hubs also deliver activities to build capacity in the health workforce and among other interested professionals, so they can better support people with IDMH.

The Ministry commissioned the Social Policy Research Centre (SPRC) and Department of Developmental Disability Neuropsychiatry (3DN) at UNSW Sydney to evaluate the Hubs. This is the interim report of the evaluation. Its purpose is to inform the further practice of the Hubs.

The report presents findings from the first round of interviews and focus groups from May to July 2021. Sixty-one (61) people attended the interviews – Hub providers, other health professionals and workers, and people with IDMH and their carers.

The fieldwork indicates that the Hubs achieved success across many of the intended outcomes. Hub participants, families and carers and service providers were mostly positive about their experiences with the Hub processes and services. Success was limited by Hub resources, a shortage of services and coordination activities at local and state levels, and hesitancy from relevant services to use Hub support.

Some questions have arisen from the Hub experience so far that could stimulate reflection, refinement and communication. These include:

- how to facilitate access to mental health, disability and other health and social services before, during and after contact with the Hubs
- how to better include Hub participants in their Hub assessment and advice, and in providing training for service providers
- how to manage timely support as more people and providers become aware of and use the Hubs
- how to prioritise support to locations of greatest need, where fewer general and specialist services may be available, such as some regional LHDs
- how to resolve implementation tensions between different aims of the Hubs, particularly between specialist support and capacity building
- how to further build research capacity within the Hubs
- how to improve collaboration between the Hubs, LHDs and NDIS providers
- how to encourage greater involvement from LHDs, NDIS providers and other service staff in Hub capacity building
- how to communicate effectively to people and providers how the Hubs work.

Executive summary

Two new statewide Hubs aim to support better access of services to people with both intellectual disability and mental health issues. The Hubs were established by the NSW Ministry of Health (the Ministry). The two Hubs are a:

- Hub for children and adolescents – Sydney Children's Hospitals Network Mental Health and Intellectual Disability Hub (SCHN MHID Hub)
- Hub for adults – Statewide Intellectual Disability Mental Health Outreach Service (SIDMHOS).

The Hubs work with people with intellectual disability who have mental health needs. The Hubs also deliver activities to build capacity in the health workforce and among other interested professionals, so they can better support people with intellectual disability and mental health issues (**Section 1**).

The Ministry commissioned the Social Policy Research Centre (SPRC) and Department of Developmental Disability Neuropsychiatry (3DN) at UNSW Sydney to evaluate the Hubs. The evaluation runs from September 2020 to November 2023. It aims to assess the outcomes of the Hub model and the effectiveness of the service processes. The evaluation uses a mixed-method design, including both quantitative and qualitative data.

This is the interim report of the evaluation. It contains findings from the first round of interviews and focus groups with staff and users of the Hubs and other people involved. SPRC researchers spoke to 61 people from May to July 2021. The people were:

- Hub participants – people with intellectual disability and mental health issues (IDMH) who use the Hubs
- families and carers of Hub participants
- Hub staff – clinicians, practitioners, managers
- service providers using the Hubs – who referred to the Hubs or attended Hub training
- stakeholders – involved in governance, advocacy or policy (**Section 2**).

The fieldwork indicates that the Hubs achieved success across many of the intended outcomes. Hub participants, families and carers and service providers were mostly positive about their experiences with the Hub processes and services. Success was limited by Hub resources, by a shortage of services and coordination activities at local and state levels, and by hesitancy from relevant services to embrace IDMH support.

Findings about Hub activities and outcomes are summarised below. The findings have implications that could stimulate reflection for the continuing work of the Hubs.

Hub activities

The Hub activities were advice, assessment, data, training and supervision, partnerships and research (**Section 3**).

Advice

The Hubs offered specialist advice to people supporting the person with intellectual disability and mental health. These supporters included primary health clinicians such as GPs and paediatricians, disability support services, and families and carers. Advice was rarely given directly to Hub participants.

The Hubs also offered some consultation to clinicians to discuss consumers who had not been formally referred to the Hub. Some Hub staff said time for consultations was limited due to their other tasks (**3.1**).

Assessment

Assessments involved 2 steps. First, Hub specialists reviewed the participant's medical and social histories. Second, the Hubs arranged a consultation meeting, or conference, with clinicians, family or carers and direct service providers of the Hub participant.

It seemed that Hub participants rarely attended meetings. Reasons the Hubs gave were that the Hubs' focus was on supporting health professionals, families and carers and that the process of the meetings might not be suitable or accessible for the participants (**3.2**).

Data

At the time of this report, 4 new data tools were being designed by the evaluation team and the Hubs together. The Hubs and the Ministry were collaborating to make the tools meaningful. The aims of the tools were to assess Hub activities and effectiveness and to improve data availability about people with IDMH.

- IDMH Hub Minimum Data Set (MDS) – to collect information about the Hub participants and about Hub services
- Workforce capacity survey in IDMH services – to evaluate the impact of the Hubs on the broad capacity of the service providers who referred to the Hubs
- LHD data dashboard – to gather hospital and other health data about LHD consumers with intellectual disability

- Key performance indicators (KPIs) – to track access to mental health services for people with intellectual disability.

Further, at the time of this report, the Hubs were collecting feedback from Hub users, including participants and service providers (**3.3**).

Training and supervision

The Hubs gave training to service providers in various formats: webinars, workshops and written resources. Psychiatrists in training had the opportunity to work at the Hubs.

Clinical supervision to mental health clinicians was related to individual cases. Clinicians said they found this useful. Some Hub staff said that time for clinical supervision was limited (**3.4**).

Partnerships and promotion

Hub training seemed to be widely promoted within the sector. Some service providers asked for clearer information about the training content and more notice. Many interviewees noted the potential to develop partnerships in the Hubs' training activities. They suggested drawing on the expertise of intellectual disability services, consumers and families and carers to train mental health staff.

Hub services for participants were not consistently promoted across the state. Most people in the interviews who used the Hubs found out about them by chance. This may indicate some people might be excluded from using the Hubs because they do not know about them or they cannot access information about them. Some Hub staff agreed further promotion would increase demand, which would then naturally require addressing referral criteria and resource allocation.

Partnerships with disability and other health providers emerged while the Hubs were working together with them in relation to Hub participants. Wider system-level partnerships were less obvious. Barriers to partnership that interviewees identified were that there were too many NDIS providers, and that providers had little funding for partnership activities. Interviewees had also observed little collaboration in public health systems, especially between paediatrics and children and young people's mental health services. The Ministry promotes system-wide change through the IDMH initiatives, including supporting the advisory group (**3.5**).

Research

While clinical support and capacity building were the primary aims of the Hubs, research was a secondary activity. The interviews and focus groups indicate the Hubs were involved in some research, using their limited time and resources. There

was internal research, such as audits of referrals and satisfaction surveys of Hub users. More formal research included evaluation of a training program. Both Hubs employed practitioners who contributed to academic research. The Hubs found and distributed new, relevant research to their professional networks and to families and carers of Hub participants (**3.6**).

Hub outcomes

There were Hub outcomes were for participants and their families and carers, for providers of intellectual disability and mental health services and for the mental health and disability service systems (**Section 4**).

Outcomes for Hub participants and their families and carers (4.1)

Wellbeing

The preliminary findings in this report indicate that the Hub activities improve the wellbeing of many Hub participants, their families and carers. Reasons for success were the Hubs' multi-disciplinary teams and the intensive, expert and collaborative intervention that the Hubs offered.

As a result, families and carers felt more understood, involved and consulted than before contacting the Hubs. In the future, the Hubs might work even more directly with participants and involve them more in meetings. This would need adjustment of meeting processes including time and ways of communicating (**4.1.1**).

Access

According to the fieldwork findings, access to mental health services improved for many Hub participants because of the knowledge and advocacy of Hub staff. Action on referrals to the Hubs was quick. For many Hub participants, this was their first access to psychiatric and other mental health services. Some families received, and appreciated, second opinions and different mental health expertise to what they had before.

The Hubs also improved access for people with intellectual disability and mental health issues to other services, such as disability, housing and physical health support.

A few barriers to access were mentioned. The physical space of the Hubs in a hospital setting may be confronting for some participants and families if face to face meetings are held there. Interviewees suggested flexibility about location when participants are in the meeting, such as a community health centre used by the Adult

Hub. The location of both statewide Hubs in Sydney appeared to not be a barrier when telehealth became widely accepted.

There seemed to be ongoing barriers to accessing mental health support before and after Hub involvement. These barriers included a shortage and the cost of private psychiatrists specialising in ID; and that people with intellectual disability were often not able to access relevant public mental health services. Adjustments to the Hubs' referral criteria to take account of these restrictions and systemwide IDMH initiatives from the Ministry could assist with overcoming these barriers (**4.1.2**).

Treatment

Many families and carers found Hub advice about changing medication and behaviour management helpful. Some service providers and external stakeholders expressed concerns about medication changes if the Hub was seeing a person only for a short time. However, the referral criteria to the Hubs included the ongoing involvement of a clinician or health team who could implement recommendations, including about medications (**4.1.3**).

NDIS

There was evidence that the Hubs improved the mental health support from NDIS providers who supported Hub participants. NDIS providers also reported that the Hubs had improved relationships between NSW Health and NDIS, through working with professionals from both sides.

Many interviewees said the Hubs did not have the capacity to engage with NDIS-funded providers at a statewide level. They felt that structural changes and agreements were needed to improve collaboration between the NDIA (National Disability Insurance Agency), NDIS-funded providers and NSW Health (**4.1.4**).

Outcomes for providers of intellectual disability and mental health services (4.2)

Capacity

Service providers who made referrals to the Hubs said the Hubs increased their capacity to support people with intellectual disability and mental health issues, usually through working with them on individual cases. Interviewees said this was especially important in LHDs and populations with little or no access to clinical IDMH support.

A few providers felt the Hubs substituted for their care of the participant and did not build capacity of the referring clinician.

Many providers found the Hub training useful and relevant to building their capacity.

Suggestions to further improve provider capacity were:

- short-term work placements of mainstream mental health workers into Hub roles
- nominate 'intellectual disability champions' in community mental health teams
- paid local IDMH positions
- continued capacity building by the Ministry.

Professionals outside mental health services, including paediatricians and disability support workers, reported increased confidence to work with or treat people with intellectual disability and mental health. Some clinical providers saw the Hubs as a new safety net to review their use of psychotropic medications and other treatments (**4.2.1**).

Exposure

As the Hubs supported participants to access appropriate support, the Hubs were increasing the exposure of mental health clinicians to people with intellectual disability.

Providers gave many examples of how increased exposure had changed their attitudes and their practice towards people with intellectual disability. Some providers said misconceptions about people with intellectual disability were the main barrier to appropriate service provision (**4.2.2**).

Coordination

Many people said the Hubs were bringing together different people involved in a person's wellbeing, including families and carers, service providers and schools. They said the Hubs might also help to forge potential new service pathways for the flow of consumers in mental health and disability support. But they said this potential was limited by current gaps in service types and uncertain pathways.

The fieldwork indicated other barriers to the effectiveness of Hub coordination activities. These included the limited resources of the Hubs, reluctance from some mental health services to engage with the Hubs and participants with intellectual disability, and difficulties coordinating with an NDIS system with many providers. The Ministry is addressing some of these systemwide barriers.

A few stakeholders suggested that the Hubs expand their multi-disciplinary teams to include or collaborate with physical health practitioners and with domestic violence, multi-cultural and Aboriginal services (**4.2.3**).

Training

Most service providers who had used the Hub educational programs and resources found them useful and relevant. They especially liked discussion about complex cases because they could see how the training was relevant to their work.

Most providers liked the online format, which gave them flexibility to participate. Other providers asked for more after-hours options so they could participate more often.

Service providers generally liked the resources that were available through the Hubs. Some said it was difficult to encourage colleagues to use the resources because some mental health staff did not see how IDMH resources were relevant to their responsibilities (**4.2.4**).

Specialist support

The fieldwork indicates that specialist support from the Hubs to mental health and other referring clinicians occurred ad hoc. Specialist support was generally about individual cases and short-term. Service providers appreciated the support, especially those from non-metro areas and without specialist IDMH staff.

The Hubs said they had insufficient resources to offer ongoing specialist support to mental health clinicians for particular cases after their engagement with the Hub ended (**4.2.5**).

Outcomes for the mental health and disability service systems (4.3)

Data

Several types of data are collected by the Hubs, the LHDs and the evaluators. Findings from the data will be in the final evaluation report (**4.3.1**).

IDMH as a specialty practice area

Service providers and stakeholders saw benefits and disadvantages to IDMH as a specialty practice area. Most thought that some level of ongoing specialist support would be needed for people with intellectual disability and mental health issues. Others saw specialty practice as an essential temporary measure until mainstream mental health and disability services were better equipped to support this cohort (**4.3.2**).

Consumer flow

People in the fieldwork mentioned several barriers to improved flow of consumers through mental health services:

- limited staff and bed capacity of mental health services to support consumers
- practices that exclude people with intellectual disability or autism from some mental health services
- difficulties for young people to transition to adequate adult mental health services
- shortage of suitable housing and accommodation support for consumers in mental health inpatient care.

The Hub teams said they were addressing resistance to consumer flow case by case. They said it also needed structural level change before most people with intellectual disability and mental health would be fully included and supported (**4.3.3**).

Implications

Questions arise from the Hub experience so far (**Section 5**). They could stimulate reflection, refinement and communication about:

1. How to facilitate access to mental health, disability and other health and social services before, during and after contact with the Hubs. This includes discussions about

    a. which support is given or organised by the Hubs or by collaboration with local or state services

    b. how to support local services to increase IDMH capacity by learning through working together with a Hub participant

    c. how to identify and resolve gaps in mental health, disability and other service support.

2. How to better include Hub participants in their Hub assessment and advice, and in providing training for service providers.

3. How to manage timely support as more people and providers become aware of and use the Hubs.

4. How to achieve equitable access in locations of greatest need, where fewer general and specialist services may be available, such as some regional LHDs. Options to identify such locations might include using Ministry mapping of current IDMH strengths and gaps.

5. How to resolve implementation tensions between the two major aims of the Hubs (specialist support and capacity building). Assessing current practice would be a first step. Options might include using Hub data to map how budgets are distributed between specialist support and capacity building.

6. How to further build research capacity within the Hubs, and in collaboration with external agencies engaged in research in intellectual disability mental health.
7. How to improve collaboration between the Hubs, LHDs, NDIS providers and other services at the state and local levels. Collaboration includes professional and organisational relationships, consumer pathways and formal agreements.
8. How to encourage greater involvement from LHDs, NDIS providers and other service staff in Hub capacity building. Options to consider include:
    a. support the use of current resources and training;
    b. work placements between the Hubs, LHDs and NDIS providers;
    c. flexible training, such as after hours;
    d. targeted and accessible versions of information about training and its content for all service providers and people who use the Hubs.
9. How to communicate to service providers about how the Hubs work, so that they are reassured about monitoring the progress of the participant, continuity of support and transition in and out of support from the Hubs. They also need information about how the advice and case work fits with the other activities of the Hubs so that they understand the dual aims of the service.

1 Introduction

IDMH Hubs

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). The NSW Ministry of Health (the Ministry) wants to address this gap. It established 2 Statewide Tertiary Intellectual Disability and Mental Health Hubs (the Hubs). The Hubs aim to support better access and availability of services to people living with both intellectual disability and mental health issues. The 2 Hubs are:

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

The Hubs offer multi-disciplinary support for people with complex, co-occurring intellectual disability and mental health issues. They each have multi-disciplinary teams.[1]

The Hubs work with people with intellectual disability who have a diagnosed mental illness and others who may have mental health issues that affect their ability to function. The Hubs also deliver activities to build capacity in the health workforce and among other interested professionals, so they can better support people with intellectual disability and mental health issues.

Funding is ongoing, and initial funding agreements run from March 2019 to March 2024.

Hub evaluation

The Ministry commissioned the Social Policy Research Centre (SPRC) and Department of Developmental Disability Neuropsychiatry (3DN) at UNSW Sydney to evaluate the Hubs from September 2020 to November 2023. The evaluation assesses the outcomes of the Hub model as well as the effectiveness of the service processes. It aims to inform the future development of the Hubs. The evaluation plan (Purcal et al 2021) outlines how the SPRC and 3DN evaluate the Hubs. The plan is refined with stakeholders throughout the evaluation.

[1] Team composition changes over time. At the time of the interviews, the teams consisted of: Children's Hub - Psychiatrist, clinical psychologist, health service manager, occupational therapist, social worker. Adult Hub - Psychiatrist, clinical nurse consultant, clinical psychologist, registrar psychiatrist.

This is an interim report of the evaluation. It contains findings from the first round of qualitative fieldwork. The findings have implications for the continuing work of the Hubs. Quantitative results will be available in the next report.

2 Evaluation methods

The evaluation uses a mixed-method design. This means the evaluators collect and analyse information from a range of sources and include both quantitative and qualitative data. The evaluators then compare the information against the program logic to assess the effectiveness and outcomes of the Hubs.

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 program users 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. The Hub program logic is in **Appendix A**.

The evaluation methods are:

- co-design of the evaluation approach, methods and reporting
- analysis of program documents from the Hubs
- qualitative interviews and focus groups with Hub stakeholders (2 rounds)
- quantitative Hub program data from the Hub management (2 rounds)
- linked participant outcome data across NSW Health
- NSW mental health workforce capacity survey (2 rounds)
- LHD capacity survey.

More detail about the evaluation approach and methods is in the evaluation plan (Purcal et al 2021).

This interim report is based on the first round of qualitative interviews and focus groups with stakeholders of both Hubs. These stakeholders were:

- Hub participants – people with intellectual disability and mental health who use the Hubs
- families and carers of Hub participants
- Hub staff – clinicians, practitioners, managers
- service providers using the Hubs – who referred to the Hubs or attended Hub training
- stakeholders – involved in governance, advocacy or policy.

The sample for the interviews and focus groups is in **Table 1**. SPRC spoke to 61 people from May to July 2021. Two people sent written responses to the interview questions. Hub staff, service providers and stakeholders were larger samples than anticipated. There were fewer interviews than intended with Hub participants, families and carers. This could be partly because the Hubs were relatively new at the

time. The evaluators are working with the Hubs to increase the sample of consumers, family and carers for the second round of interviews in 2023.

Table 1 Sample for interviews and focus groups round 1, 2021

Participant group	Number of participants			Total participants
	Interviews	Focus groups	Written responses	
Hub participants	2		1	3
Families and carers of Hub participants	6		1	7
Hub staff		12		12
Service providers using the Hubs	11	5		16
Stakeholders	1	22		23
Total	20	39	2	61

SPRC did most interviews and focus groups via video or telephone. This was due to COVID-19 restrictions, participant preferences or their location outside Sydney. Interviews and focus groups with 14 people were done face to face before the Sydney lockdown, with Covid-safe precautions.

Details of the interview, recruitment and consent processes are in the evaluation plan (Purcal et al 2021).

The findings of the interviews and focus groups are in Sections 3 and 4. The structure of the findings is based on the Hub program logic, **Appendix A**. Items in the program logic were combined under summary headings, and they were mapped against previous work by 3DN (3DN 2014 and 2016). This gave us 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 intellectual disability and mental health. The mapping against 3DN work is in **Appendix B.** Composite case studies about Hub participants, families and carers are in **Appendix C**.

The two Hubs were not evaluated separately, and this report does not compare the two Hubs with each other. The program is statewide, where both Hubs have the same aims and offer similar services to different age groups. The evaluation intends to inform the further implementation of the statewide Hubs program.

3 Hub activities

This section summarises findings about Hub activities. This includes the way the Hubs worked and the factors that helped them to work well. The activities reported in this section align with the program logic and 3DN analysis frameworks, **Appendix B**.

Linda, Hub Participant

Linda lives in supported accommodation. She enjoys talking with people and doing activities with her housemates and carers. Linda's favourite things to do include going out to dinner with her friends and boyfriend, playing soccer and riding around her neighbourhood on her bicycle. About 6 months ago, Linda began to feel sad and frustrated and was having trouble sleeping. She was also having trouble connecting with her carers and explaining her feelings to them. She no longer wanted to go to any of her social activities and even felt too tired to have a chat with her housemates. Linda's carers took her to the Hub, and the psychiatrist changed her medications. They discussed with Linda and her carers about some new strategies to help support Linda. Linda began to feel a bit better and had less trouble sleeping. Although she still had difficult days, Linda has been able to have a laugh with her friends and has enjoyed riding her bike again. **Appendix C**

3.1 Advice

The program logic refers to advice in the following Hub activities:

- offer advice to support the care of people with intellectual disability in mainstream mental health settings
- improve access to specialist IDMH services

The Hubs offered specialist advice to people supporting the person with intellectual disability and mental health. These supporters included mental health clinicians, primary health clinicians like GPs and paediatricians, NDIS and other service providers, and families and carers. Hubs staff said advice was tailored to each person's circumstances. For example, it might be recommendations to change medication or how to manage behaviour. The advice might also be how and where to find other support, including specialist IDMH services.

The Hubs offered advice directly and via a report. Staff said the advice was aimed at improving the mental health and wellbeing of the Hub participants and their family or carers. Staff said it could also contribute to building the capacity of people who worked and lived with a person, like service providers and families.

> The role of a clinical psychologist, which is 'talking therapy' in its traditional form, changes [in the Hub] to one of helping the carers, the families, the support team understand behaviour and so … it is more about supporting the support workers and the NDIS supports that are already in place – Hub staff

The Hubs also offered some consultation to clinicians to discuss consumers who had not been formally referred to the Hub. The Hubs said time and staff for consultations were limited due to their other tasks.

Advice was rarely given directly to the Hub participants with intellectual disability. Reasons included that the Hubs' primary focus was on supporting health professionals working with people with ID. The Hubs also considered how the person might experience being part of a meeting. The Hubs stated that they did respect patient centred care and that they included Hub participants as much as possible. One Hub was developing Easy Read materials.

3.2 Assessment

The program logic includes assessment as the Hub activity to:

- provide clinical assessment and care recommendations for the complex care of people with intellectual disability and mental health needs.

Hub clinicians reported that their assessment process was comprehensive. This was made possible through the Hubs' multi-disciplinary approach. This approach involved several specialists, including from psychiatry, psychology, social work and occupational therapy.

Hub staff reported that the first step in the assessment process was reviewing the participant's medical and social histories. This involved tracing medications, doctors and diagnoses over time, and reviewing past assessments. The second step was usually a consultation meeting, or conference, with clinicians, family or carers and direct service providers of the Hub participant.

> I generally do some research on the patient for about two weeks before the conference, so that might be contacting every Local Health District that they've been involved in to get their documentation – Hub staff

> [the conference] is a two-hour holistic comprehensive assessment – Hub staff

The Hubs used the information from the review and the conference to develop their recommendations. Hub staff reported that they looked beyond behaviour and diagnosis. They also considered the cultural background and support networks of the participant in the assessment process.

The Hubs offered some flexibility around how conferences were held, either in person or remotely. Video-conferencing made access to the Hubs more equitable, particularly with rural and remote referrals. One service provider suggested that the Hubs might consider assessments at the participant's home. They thought that Hub staff might miss important contextual information by conducting consultation meetings at the Hub sites.

The Hub teams and families and carers indicated that Hub participants rarely attended meetings, and rarely received advice directly (3.1).

> Most of [the conferences] to date, the person hasn't been involved in that conference, just because it's a very difficult space for some people to be part of and it's not always necessary to the person. We can get information from people who know the person well rather than us having to get that information ourselves – Hub staff

Hubs prepared a report about the assessment and Hub recommendations for providers and families. Staff from one Hub said they were aiming to produce an Easy Read version of the report to make it more accessible to Hub participants.

Stakeholders held a strong impression that assessment was all that the Hubs did. Some stakeholders saw the Hubs' value in providing a one-off assessment as limited, due to the long-term nature of the Hub participants' needs.

> One-off assessment has value, but it has limited value. These families are not dealing with a short-term, transient problem. They're dealing with problems that go on for years and years – Stakeholder

Hub staff reported that they did more than one assessment with a participant when they needed to. Staff said they stayed involved until the participant was well supported by the disability and mental health system.

3.3 Data

The Hub data activities from the program logic are:

- develop IDMH data dashboard
- develop statewide IDMH key performance indicators (KPIs)

Four key activities were underway to collect data related to the Hubs.

3.3.1 IDMH Hub Minimum Data Set

The Hubs designed the IDMH Hub Minimum Data Set (MDS) in collaboration with the Ministry and the evaluation team. This data collection aims to collect consistent information about the Hub participants, for example:

- communication needs
- severity of intellectual disability
- behaviours of concern
- risk to self and others
- treatment and service access history.

The MDS will track the participants through the Hub services.

It also aims to quantify the capacity building activities of the Hubs, including i) type of activity, ii) how many people participated, iii) their professional background.

These data are important because they are not routinely captured by NSW Health through the existing reporting mechanisms.

The data captured through the MDS will be used to:

- assess the size of Hub wait lists and the length of wait times
- understand the characteristics of Hub participants
- assist with interpreting the results from the data linkage for the evaluation
- quantify the capacity building activities of the Hubs.

The data collection commenced in May 2021. Analysis of the data will be included in the final evaluation report.

In addition to the MDS, Hub staff in the fieldwork said that they increasingly sought feedback from Hub users. Some satisfaction surveys and interviews were taking place about the experiences of Hub participants and service providers using the Hubs.

3.3.2 Workforce capacity survey

The evaluation team, in collaboration with the Hubs and the Ministry, was designing a survey to evaluate the impact of the Hubs on service providers who referred to the Hubs. Data collection was due to begin in October 2021.

3.3.3 LHD data dashboard

Interviewees noted that there were insufficient real-time data about people with co-occurring intellectual disability and mental health issues. They said this made adequate system responses difficult. Stakeholders and service providers suggested that data on the number of people with intellectual disability and mental health who presented at emergency departments would be helpful. Many interviewees in different roles noted the importance of more data for psychiatrists.

> We don't have a clear, consistent way of recording people with intellectual disability coming into health systems, full stop – Hub staff

To address these data gaps, the Ministry was developing a data dashboard that could be accessed by NSW Health staff to view data by service, LHD and statewide. This would include regularly refreshed data about consumers with intellectual disability accessing mental health care in NSW Health services.

3.3.4 Key performance indicators

Key performance indicators (KPIs) were being developed by the Ministry to track access to mental health services for people with intellectual disability. A few stakeholders said it was important that KPIs were based on participant outcomes rather than Hub outputs. They said the KPIs should link directly to the Hubs' role.

Hub providers hoped that the collection and publication of meaningful KPI data would help to show the impact of the Hub services.

3.4 Training and supervision

The Hub program logic refers to training and supervision in the following points:

- produce educational programs and resources – for example Kids Webinar Series and Project ECHO
- clinical supervision and training

Both Hubs produced **training** webinars for service providers. Webinar sessions were attended by a range of professionals working with people with intellectual disability. The sessions typically began with a talk and ended with a case discussion. The Hubs also ran open Zoom conferences and workshops, and training sessions for specific teams. They also created and collected a range of resources about intellectual disability and mental health, which they distributed to relevant service providers.

Some service providers saw the opportunity for psychiatry registrars to work in the Hubs as an important area of training. They said it would help develop IDMH expertise in the medical community.

The Hubs offered some clinical **supervision** to mental health clinicians. This largely happened on an ad hoc basis about an individual case rather than as a general arrangement. Providers found it useful.

> Although it wasn't like a formal supervision as such, [the Hub staff] felt very accessible during that period of when they did the assessment and did the

> joint team meeting with our team's psychiatrist, consultant psychiatrist, our manager – Service provider

Hub staff indicated that the capacity of the Hubs to give clinical supervision was limited.

3.5 Partnerships and promotion

Partnerships are represented in the Hub program logic as the following Hub activities:

- promote Hub services
- develop relationships and partnerships with: LHD inpatient and community mental health services, NSW Health and private care providers, NDIA.

The Hub training appeared to be widely **promoted** in the mental health sector, but less so in related sectors like disability and allied health. In the interviews, most service providers and stakeholders were aware of it. Some said they would like clearer information in the promotional material about what the training included, as this may encourage more clinicians to attend. Others found they needed more notice to make the time in their schedule to attend.

> … the advertising for that gets to me really late – Stakeholder

Many interviewees noted the potential to develop partnerships through participating in the Hubs' training activities, especially through drawing on the expertise of intellectual disability services, consumers and families and carers to train mental health staff.

There seemed to be some general promotion of Hub services, including the Hub launch, promoting the service in LHDs and sending information to a mailing list of behaviour support practitioners. In the interviews, many service providers and families said they found out about the Hubs though previous relationships or chance, for example when talking to a colleague or friend. The risk seems that some people, providers or groups might be excluded from using the Hubs because they do not know about them. Some stakeholders pointed out that information about the Hubs in various languages and formats – such as print and online, Easy English and Plain English – was needed to allow families and carers from diverse backgrounds to find out about the Hubs. Hub staff reported that the Hubs were increasing their reach across the state.

Some Hub staff were wary about promoting the Hubs any further. They were unsure whether the funding and capacity of the Hubs would be adequate for the potential higher demand that promotion might bring.

The Hub teams reported that they were working to build **relationships** with primary health services, LHDs and disability and mental health service providers. Partnerships were evident when working with individual Hub participants. Wider system-level partnerships were less obvious. Hub staff and stakeholders said it was difficult to collaborate at a systems level with NDIS providers. There were many NDIS providers to engage with, and providers had little funding to participate in networking activities.

Hub teams, providers and stakeholders were concerned about limited collaboration with and between different specialities in public health systems, especially between paediatrics and children and young people's mental health services. The Ministry promotes system-wide change through the IDMH initiatives, including supporting the advisory group.

3.6 Research

The Hub program logic refers to research as:

- leadership and participation in research activities regarding the mental health needs of people with intellectual disability.

While clinical support and capacity building were the primary aims of the Hubs, research was a secondary activity. The interviews and focus groups indicate the Hubs were involved in some research.

There was internal research, such as audits of referrals and satisfaction surveys of Hub users. More formal research included evaluation of a training program. Both Hubs employed practitioners who contributed to academic research. The Hubs found and distributed new, relevant research to their professional networks and to families and carers of Hub participants. Hub staff said they would like more time and resources to be involved in a range of research projects, potentially including evaluating their own services, research into IDMH interventions and literature reviews of evidenced based practice.

4 Hub outcomes

Hub outcomes are the impacts that the Hub activities had, or what the Hubs achieved and what the reasons for success were. The outcomes reported in this section align with the program logic and 3DN analysis frameworks, **Appendix B**. SPRC examined outcomes for Hub participants, providers and the wider system.

Jason, Hub Participant

Jason is 13 years old. He was diagnosed with ADHD and ASD at the age of three. Jason enjoys playing with his sensory toys and listening to the sounds they make. Until last year, Jason had difficulty communicating and had multiple 'outbursts' each day at home, often damaging property. At school Jason sometimes hit students and teachers and could not concentrate in class. His parents sought help, going to multiple doctors over the years, but could not find suitable medication and therapies for Jason. Last year they took him to the Hub. Hub staff changed Jason's medication, suggested behavioural strategies and reassured his parents. Since the Hub intervention, Jason has had less outbursts and appears to be more in control of his behaviour. He has learned some new skills, including using the bathroom independently. Although still difficult, Jason is finding it a bit easier to communicate with his parents and teachers and to connect and play with his peers at school. **Appendix C**

4.1 Outcomes for Hub participants, families and carers

4.1.1 Wellbeing

The program logic lists as one of the intended Hub outcomes:

- improved wellbeing of people with intellectual disability, their families and carers

Hub participants, carers and service providers gave examples of how the Hubs had improved the wellbeing of people with intellectual disability, their families and carers. For example, they remarked on positive changes to the participant's life due to revised medications and helpful strategies to better manage behaviour at home. Family and carers said their own wellbeing and health had also improved.

> So we've seen a real transformation in my son. His language has come on immensely; his behaviour ... He's like a different child – Family or carer

> The other thing [the Hub helped with was] around behavioural strategies, and what to expect, and how best to sort of manage that. So I felt like we got a lot out of that as well – Family or carer

> It was remarkable the difference … Honestly like at one point they took away one medication and put him on a new one, and it was like his brain was actually calm for the first time in his life – Family or carer

Many providers, families and carers said wellbeing improved because of the Hubs' multi-disciplinary team approach and their intensive, expert and collaborative service provision.

> It was severe parental exhaustion because of the constant problematic behaviours, and so the therapy for the parents and some plans around that and what not. [The Hubs] have done really good work … sometimes you need that, another lens and angle and … really high-level, complex expertise – Service provider

> … there was a massive change in [name]'s behaviour where it was more controlled… So that was a real lifesaver for me … The relief! – Family or carer

The Hub teams appeared to have strong recovery-oriented and trauma-informed approaches to their practice. They saw improving lives as the end goal, and Hub staff described inclusive practices in working with Hub participants, families and carers. As a result, families and carers felt more understood, involved and consulted than before contacting the Hubs.

> There's empathy there, there's understanding, there's a real desire to help and an actual motivation to find a way to do that – Family or carer

> I wasn't just a faceless attachment to this [person] that they were going to fix and I'd just be sort of notified later. It was very much a collaborative effort – Family or carer

> Quality of life is the main outcome – Hub staff

There is opportunity for the Hubs to work even more directly with participants and to support their involvement in the process.

4.1.2 Access

There are 2 access-related outcomes in the Hub program logic:

- improved access to local and specialist mental health care for people with intellectual disability
- timely access to NSW MH services and programs based on clinical need.

The fieldwork indicates that access to mental health services improved for some Hub participants because of the knowledge and advocacy of Hub staff. The Hubs also improved access for people with intellectual disability and mental health challenges to other services, such as disability, housing and physical health support.

The Hubs responded to referrals based on risk and need. Service providers and carers praised the referral process, saying they did not experience a waiting period.

Hubs used their knowledge to find timely access to specialist IDMH services. According to service providers and Hub staff, the participants often had not received timely mental health support until they engaged with the Hubs. For many Hub participants, the Hub was their first access to psychiatric and other mental health services.

> We were calling up people all across the state trying to find suitable support for this person, and people were just like, look our waitlist is two years… there was nowhere for this person to get the support that they deserved… [The Hub staff] were fantastic, they were very quick in how they responded to the referral – Service provider

When accessing the Hubs, some families wanted and received second opinions and mental health expertise that was different to their previous contacts.

> It was good to get another viewpoint in the way to move forward with [our daughter] – Family or carer

> The private psychiatrist who they saw told them that there was nothing that could be done with this boy. So I think that was kind of the hopelessness the family was having. But … we were able to put the formulation together, which the family was able to understand, and the family was very relieved to know that something could be done – Hub staff

In addition, the Hubs could also assist people with intellectual disability and mental health issues to access other services such as disability and physical health support. For example, they assisted families to apply for NDIS support or helped Hub participants to undertake screening or tests related to a physical condition.

> So often we recommend things around doctors' visits or accessing services like eyesight or hearing checks. And a number of our referrers have fed back to us that there has been increased access to health care services – Hub staff

Hub staff and many providers and stakeholders found that the increased use and acceptance of telehealth made access easier for people in rural and remote areas. They said this was important since both Hubs were located in Sydney. They suggested to think about how to address inequity in access to telehealth, for example because people lacked the necessary equipment or had not been given the knowledge to use telehealth.

Hub participants, families and carers spoke about access issues for Hub participants to assessment conferences or other case discussions (**Section 3.2**). One of the barriers to access was that the Hubs were located in hospitals. Interviewees said hospitals were environments that might be uncomfortable or unwelcoming spaces for participants and families. At worst, hospitals might be places of previous trauma, particularly for people from marginalised groups. Some meetings were held in community mental health centres. Interviewees suggested there needed to be more flexibility and choice in deciding where assessments were conducted.

> So having really a culturally safe space and environment and that time to build trust and rapport … around service provision. I think [sometimes] we are very fixed in our ways and expect people to fit in with that, but being more flexible and sort of offering a service that fits with people rather than expecting people to fit with us is the way to break down those accessibility barriers – Stakeholder

Stakeholders, providers, Hub staff and families and carers mentioned barriers to accessing mental health support before and after Hub involvement. These barriers included a shortage of affordable psychiatrists; and that people with intellectual disability were often not able to access relevant public mental health services.

> We have tried every single possibility to engage with the local [ ] mental health services. And I think most, if not all of my [clients] have tried that first and when we failed, this is when we referred to the Mental Health Hub ... So I think there is already quite a significant expectation from the [families or carers] who are literally desperate and those [clients] really need to see psychiatrists … and they would need to [continue to see] psychiatrists – Service provider

4.1.3 Treatment

The program logic states that an intended Hub outcome is:

- improved use of treatments including psychotropic medication and behaviour support plans.

Medication review was part of the Hub service, and often the Hub recommendations included changes to medication. To ensure this was effective, the referral criteria to the Hubs included the ongoing involvement of a clinician or health team who could implement recommendations.

Many Hub participants, families and carers gave examples of where changes in medication had helped (**Section 4.1.1, Appendix C**). Some service providers and stakeholders raised concerns about whether medication should be changed if the Hub was seeing a person only for a short time.

Hub clinicians stressed that recommendations about medication were only a small part of their treatment advice.

> The family came to me and said, “Can you suggest some medication?” and I said, “Look, I don’t just talk about the medication. I do a whole comprehensive assessment.” So we do a whole family assessment – Hub staff

The Hubs’ holistic approach seemed to increase family and carers’ capacity to be involved in their family member’s treatment and support. Carers spoke about helpful advice they had received for managing at home (**Section 4.1.1**).

> [The Hub staff said:] “I want you to try a chill out zone in his room rather than it being a timeout. It’s a chill out.” And it’s just looking at how to set things up, or how to manage things, or trying different strategies with him … sort of understanding where he was at with his emotional development and understanding where we were with what we were trying, and being able to adapt that and … give us a sort of tailored strategic approach to managing it – Family or carer

4.1.4 NDIS

Hubs intend to achieve, according to the program logic:

- improved and stable service provision from NDIS funded providers.

Many NDIS providers participated in Hub training. There was evidence in the fieldwork that the Hubs improved the services of NDIS providers connected with the Hub participants. This led to better outcomes for these participants and their carers and families. For example, advice from the Hubs helped NDIS accommodation providers to support people to regulate their emotions and better manage social interactions within households. One example was recounted in the interviews, where the Hub recommendations did not reach the frontline staff who worked directly with the particpant.

NDIS providers also reported that the Hubs had improved relationships between NSW Health and NDIS, through working with professionals from both sides.

> I feel like overall, it is a really helpful step forward in bridging that gap between Health and NDIS – Service provider

There was little evidence in the fieldwork that the Hubs were improving and stabilising more generally the service provision from NDIS-funded providers for NDIS participants. Many interviewees pointed to the vast number of NDIS providers, high turnover of staff and lack of funding for NDIS providers to participate in networking activities (**Section 3.5**). The interviewees said these conditions made capacity building on a large scale difficult. They said the Hubs did not have the capacity to

engage with NDIS-funded providers at a statewide level. Most Hub fieldwork interviewees felt that statewide agreements were needed to improve collaboration between the NDIA, NDIS-funded providers and NSW Health.

4.2 Outcomes for disability and mental health service providers

4.2.1 Capacity

The Hub program logic refers to capacity for service providers as:

- increased capacity of health services to meet the mental health needs of people with intellectual disability
- improved confidence and skills of mainstream mental health staff in working with people with intellectual disability

Service providers who had made referrals to the Hubs said the Hubs had increased their **capacity** through working with them supporting a particular person. This was especially important in LHDs and populations where there was little or no access to clinical IDMH support.

> I think the impact they've had, not only for the [participants], but also on us. I think a big part of that has been also preparing and also advising and a bit of education of us through very comprehensive [advice]. That has been a very important part because we know the expectation is that the Mental Health Hub is not going to become a primary care provider, and we need to [know how to work with the person], and the recommendations are also formulated that way – Service provider

> It gave us the expertise to really have a longitudinal look at this person's interaction with the health care system over a long period – Service provider

Some providers said that after working together to support a person, they were able to use the Hub tools with other consumers, so the capacity building became longer term. On the other hand, a few providers felt the Hubs took over the care of the participants, which did not build capacity of the referring clinician.

The Hubs built capacity with individual practitioners and through group or online work such as case consultation, team training and online education programs (**Section 3.4**). Many interviewees reflected on the value of having various methods of capacity building.

> I think the beauty of it is having that multi-level approach … to build the confidence of people dealing with this population, you know, they can go to one of the webinars or do the online on-demand webinar – Hub staff

Many providers found the Hub training useful and relevant to building their capacity to work with people with intellectual disability and mental health issues.

The impact of the Hubs on provider capacity differed by the location and by what other resources the providers had. Rural providers and providers without specialist IDMH staff were more likely to say the Hubs enhanced their capacity. Health clinicians with well-resourced and interdisciplinary teams were less reliant on Hubs for capacity building.

To build capacity in the mental health workforce further, fieldwork interviewees suggested:

- short-term work placements of mainstream mental health workers to Hub roles nominate ‘intellectual disability champions’ in community mental health teams.
- that the Ministry set training expectations for mental health practitioners to learn to work with people with intellectual disability.

> While I think there is value in that capacity building on a case by case basis [in the Hubs] … I think any broader capacity building activity probably needs to be backed up by a message from the Ministry, and the Mental Health Branch, saying this is now also an expectation for your services, and we’re going to resource it appropriately – Hub staff

The Hubs also increased the capacity of professionals outside mental health services, including paediatricians and disability support workers. Some of these providers reported increased confidence to work with or treat people with intellectual disability and mental health. After being involved with the Hubs, some also said they thought differently about mental illness and medication use. For example, some said they had learnt about potential benefits of non-mediation approaches.

Some clinical providers saw the Hubs as a new safety net to review their use of psychotropic medications and other treatments when this was not their specialisation – for example paediatricians.

> So from my perspective it’s really reassuring to know that when things are really tricky that I’ve got somewhere to go. And I think my biggest frustration, concern in my role has been when things were beyond my capacity, I didn’t have somewhere to go. And now I do, so I think from a patient safety perspective I think that’s really important – Service provider

Some providers said that the previous IDMH Residual Functions Program (RFP) had increased staff capacity and confidence to work with people with intellectual disability and mental health challenges. They were concerned that this expertise was not yet embedded in their services. They said that without the local RFP positions and resources, they expected they would lose the local expertise to work with people with intellectual disability and mental health issues. They saw local expertise as an

important channel to coordinate individual support with the Hubs and to support Hub capacity building of local mainstream staff.

4.2.2 Exposure

According to the program logic, the Hubs are meant to achieve:

- increased mental health clinician exposure to working with people with intellectual disability.

The Hubs increased exposure of mental health clinicians to working with people with intellectual disability, as they supported people with intellectual disability to access mental health services.

Providers gave many examples of how increased exposure had changed their attitudes and their practice towards people with intellectual disability. Some providers saw misconceptions about people with intellectual disability as the main barrier to appropriate service provision.

> I have more of an appreciation of the struggles [of consumers] but a bit more awareness of the fact that people can make a lot of progress too – Service provider

4.2.3 Coordination

The Hub program logic mentions coordination as:

- increased coordination and engagement across health and disability providers to facilitate integrated care
- improved patient flow through acute, subacute, rehabilitation and community mental health services due to integrated care planning.

Service providers said that the Hubs were a positive step towards holistic service delivery for people with co-occurring intellectual disability and mental health issues. Many interviewees in the fieldwork reported that the Hubs brought together the different people involved in a participant's wellbeing, including families and carers, service providers and schools. Several interviewees described the Hubs as 'translating' between the different professional languages used by health services, mental health and disability sectors and families and carers. They said the translating helped to engage and coordinate separate systems that often operated in their own siloes.

> I think some of the best cases we've had is where there's been this marriage of the interplay of all of our services and expertise to get the [Hub participant] where they need to be – Hub staff

Some providers said that one of the benefits of the Hubs was that LHDs might forge potential new service pathways for the flow of consumers through mental health services. They said the potential was limited by current gaps in services and uncertain pathways. These included the limited resources of the Hubs, reluctance from some mental health services to engage with the Hubs and participants with intellectual disability, and difficulties coordinating with an NDIS system with many providers.

The fieldwork indicates some structural limits to the effectiveness of Hub coordination activities. Most stakeholders found that the expectations on the Hubs for coordination were unrealistic given they were 'just two small services in one big state'. Hub staff and stakeholders said it was difficult to collaborate at a statewide level with NDIS providers, as there were so many organisations. Hub staff, providers and stakeholders spoke about poor collaboration with and between different specialities in public health systems – for example they said Paediatrics and Children and Young People's Mental Health were not well engaged in integrated care. They said the Hubs made some progress with access to children and young people's mental health services and adult mental health services. The Ministry was addressing some of these structural barriers, and the Hubs suggested they would need Ministry assistance at the statewide level to support significant change.

A few stakeholders suggested that the Hubs expand their multi-disciplinary teams to include or collaborate with physical health practitioners and with domestic violence, multi-cultural and Aboriginal services.

4.2.4 Training

The training outcome is mentioned in the Hub program logic as:

- improved access to targeted education and training in intellectual disability for mental health clinicians.

Most service providers who had used the Hub educational programs and resources found them useful and relevant. They also said that the training offered an opportunity for interdisciplinary partnership building and collaboration.

Most providers liked the online format, as it allowed them more flexibility to participate. Many saw the engagement with other providers as an important feature of the training. They found training that included discussion about complex cases most useful because it was concrete, and because providers could see how the training was relevant to their work.

> I did find the opportunity to discuss complex cases in the space with other professionals highly valuable – Stakeholder

A few providers had not accessed the training as often as they would have liked because of their tight work schedule. Some suggested that more after-hours options would be useful.

Some providers suggested that the Hubs offer more opportunities for mental health staff to learn from people on the ground – disability support services, people with intellectual disability and their families and carers.

Service providers generally liked the resources that were available through the Hubs. Some said it was difficult to encourage colleagues to use the resources because some mental health staff did not see how IDMH resources were relevant to their responsibilities.

Some service providers said the resources were too complex for disability support workers who may not have basic mental health knowledge, but others disagreed.

4.2.5 Specialist support

The program logic intends that Hubs improve:

- access to specialist support for MH clinicians.

The fieldwork indicates that specialist support from the Hubs to mental health and other referring clinicians occurred ad hoc. It was generally about individual cases and short-term. Service providers appreciated the opportunity (**Section 3.4**).

As discussed in **Section 4.2.1**, rural providers and providers without specialist IDMH staff were more likely to access the Hubs for specialist support.

The Hub staff said they had insufficient resources to offer ongoing support to mental health clinicians.

4.3 Outcomes for the mental health and disability service systems

4.3.1 Data

The Hub program logic lists as an intended outcome:

- improved data on the service usage, prevalence and access to care for people with intellectual disability.

Data is being collected by the Hubs, the LHDs and the evaluators (**Section 3.3**). Findings from the data will be in the final evaluation report.

4.3.2 IDMH as a specialty practice area

The Hub program logic asks as an outcome of the Hub program:

- development of IDMH as an area of specialty practice.

Service providers and stakeholders saw benefits and disadvantages to IDMH as a specialty practice area. Most people thought that some level of ongoing specialist support would be needed for people with intellectual disability and mental health challenges. Others saw specialty practice as an essential temporary measure until mainstream mental health and disability services were better equipped to support this cohort.

> [The Hubs] are providing a great service, but I'd like to actually see that you could have something like an intellectual disability mental health specialist in each district who works with that bridging between [the Hubs], Community Health and the hospitals. (Service provider)

Many people in the fieldwork were concerned that the availability of specialist IDMH care might present a disincentive for mainstream services to work with people with intellectual disability and mental health.

> I think it allows mental health services to go over and they sit in that box, and it takes us away from disability inclusion. – Stakeholder

Some service providers said that the opportunity for psychiatry registrars to work in the Hubs would help develop IDMH expertise in the medical community (**Section 3.4**).

4.3.3 Consumer flow

The Hub program logic includes the aim for Hubs to achieve:

- improved patient flow of people with intellectual disability through acute, subacute, rehabilitation and community mental health services (removing bed blocks)

NSW health policy states that everyone who needs it is entitled to access public mental health services. Service providers said that in reality many people with intellectual disability and autism spectrum disorder (ASD) were excluded from many child and adult mental health services. Many referrals to the Hubs came from non-mental health specialist clinicians rather than from mental health services.

Some stakeholders and service providers said the practice of exclusion stemmed from limited capacity of mental health services. They said past practice had been to exclude people with intellectual disability and mental health with the assumption that

disability services would support them. Some LHD mental health services had not yet transitioned to offering support to people with both mental health and intellectual disability support needs.

Hub staff said it was difficult to set up sustainable support from mental health services when they explicitly excluded people with intellectual disability or ASD in their practice. General clinicians could sometimes fill that gap with support from the Hubs, but they did not have psychiatric training (**Section 3.2**).

Some providers observed a barrier for young people, whose mental health may have been managed by a paediatrician. When they grew up, they found it difficult to transition to adult mental health support due to the shortage of available services.

A few providers mentioned another challenge for consumer flow. They said DCJ (NSW Department of Communities and Justice) or NDIS sometimes referred people to mental health services when they did not have alternative suitable housing for them. This practice might block the mental health system even when the person did not have a mental health disorder.

The Hub teams said they were addressing resistance within mental health services case by case. They said structural level change was also needed before people with intellectual disability and mental health would be fully included and supported. They said one of their functions was to improve the capacity of Children and Young People's Mental Health and adult mental health services to overcome some of the practice barriers.

Rani, Family carer

Rani has four children, two with developmental disabilities, and is also a carer for her husband Tej, who has multiple sclerosis. She described feeling overwhelmed with caring for her family and juggling her full-time job.

Of particular concern for Rani was an escalation of disruptive and sometimes violent behaviour from her 11-year-old son, Sanjay. This had made engaging with and supporting the rest of the family even more challenging. Rani had visited many doctors over the years seeking help for Sanjay. Some doctors had suggested to Rani that her parenting methods were the cause of Sanjay's behaviour. This made Rani feel inadequate as a parent.

Rani was referred by Sanjay's paediatrician to the Hub earlier this year. At the Hub, Rani felt an immediate sense of reassurance and understanding. It was the first service in which she felt listened to and supported. She felt that the doctors at the Hub displayed a deep level of care and empathy for not only Sanjay, but for herself as a carer. They suggested strategies that helped her strengthen her own

mental health while also caring for her son and her family. Rani now feels supported in her role as a mother and a carer. She is hopeful for the future as Sanjay transitions into high school. She is now able to spend more time on her hobbies and on strengthening her relationships with her other children.

Appendix C

5 Summary and implications

The purpose of this report is to assess Hub activities and outcomes so far and to inform the further implementation of the Hubs. The fieldwork findings in the earlier sections indicate that the Hubs achieved success across many intended outcomes. Hub participants, families and carers and service providers were mostly positive about their experiences with the Hub processes and services.

Access to mental health services seemed to improve for many Hub participants because of the knowledge and advocacy of Hub staff. Action on referrals to the Hubs was quick. Service providers and family and carers appreciated the comprehensive assessments and advice from the Hubs. Many families and carers found Hub advice about changing medication and behaviour management helpful. They said it improved the participant's and family's life. It also built the capacity and the confidence of service providers to support people with intellectual disability and mental health issues.

Hub training and supervision services were widely used within the mental health sector. They seemed useful for practitioners. Some strengths were the group discussions about particular cases and the online format.

Partnerships with disability and health providers emerged while working together about Hub participants. NDIS providers also reported that the Hubs had improved relationships between NSW Health and NDIS, through working with professionals from both sides.

The findings in the earlier sections give rise to questions for the continuing work of the Hubs. The implications summarised below can inform refinements to the Hub design, implementation and communication to all people and organisations involved with the Hubs and with people with intellectual disability and mental health issues. These include LHDs, NDIS providers, other health and social service providers, families and consumers. Discussions need to include who is responsible for implementing any changes, where the resources might come from and who should be involved.

Questions arise from the Hub experience so far. They could stimulate reflection, refinement and communication about:

1. How to facilitate access to mental health, disability and other health and social services before, during and after contact with the Hubs. This includes discussions about

   a. which support is given or organised by the Hubs or by collaboration with local or state services

   b. how to support local services to increase IDMH capacity by learning through working together with a Hubs participant

   c. how to identify and resolve gaps in mental health, disability and other service support.

2. How to better include Hub participants in their Hub assessment and advice, and in the training for service providers.

3. How to manage timely support as more people and providers become aware of and use the Hubs.

4. How to achieve equitable access in locations of greatest need, where fewer general and specialist services are available, such as some regional LHDs. Options to identify such locations might include using Ministry mapping of current IDMH strengths and gaps.

5. How to resolve implementation tensions between the aims of the Hubs (specialist support and capacity building). Assessing current practice would be a first step. Options might include using Hub data to map how budgets are distributed between specialist support and capacity building.

6. How to further build research capacity within the hubs, and in collaboration with external agencies engaged in research in intellectual disability mental health.

7. How to improve collaboration between the Hubs, LHDs, NDIS providers and other services at the state and local levels. Collaboration includes professional and organisational relationships, consumer pathways and formal agreements.

8. How to encourage greater involvement from LHDs, NDIS providers and other service staff in Hub capacity building. Options to consider include how to encourage their use of current resources and training; work placements between the Hubs, LHDs and NDIS providers; flexible training, such as after hours; targeted and accessible versions of information about training and its content for all service providers and people who use the Hubs.

9. How to communicate to service providers about how the Hubs work, so that they are reassured about monitoring the progress of the participant, continuity of support and transition in and out of support from the Hubs. They also need information about how the advice and case work fits with the other activities of the Hubs so that they understand the dual aims of the service.

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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 (Activities)			Outcomes – short to medium term		
	For participants	**For providers**	**For the system**	**For participants**	**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 needs	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 Report structure by program logic and 3DN frameworks

Report section	Sub-headings	Program logic	3DN Guide and Core Competency Framework
Hub activities (includes process and facilitating factors – what happened and why?)	1. Advice	Offer advice to support the care of people with ID in mainstream mental health settings Improve access to specialist IDMH services	Guiding Principles to underpin Hub activities (they also map to approaches to service provision in the 3DN framework): Rights / Inclusion / Person-centred approach / Promoting independence / Recovery oriented practice / Evidence based Access to specialised IDMH services
	2. Assessment	Provide clinical assessment and care recommendations for the complex care of people with ID and mental health needs	Rights / Inclusion / Person-centred approach / Promoting independence / Recovery oriented practice / Evidence based
	3. Data	Develop IDMH Data dashboard Develop statewide IDMH KPI	Evidence based
	4. Training	Produce educational programs and resources- Kids Webinar Series and Project ECHO Clinical supervision and training	Training and education for professionals Training and education for professionals
	5. Partnerships	Promote Hub services Develop relationships and partnerships with: • LHD inpatient and community mental health services • NSW Health and private care providers • NDIA	Partnership, collaboration and integration

	6. Research	Leadership and participation in research activities regarding the mental health needs of people with ID	Quality improvement and professional development Research, quality improvement and professional development
Hub outcomes a) for participants	1. Wellbeing	Improved wellbeing of people with ID and their families	Promoting independence Recovery oriented practice
	2. Access	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	Inclusion Adaptation of clinical approach Access to mental health services Access to specialised IDMH services
	3. Treatment	Improved use of treatments including psychotropic medication and behaviour support plans	Responsible, safe, ethical practice Adaptation of clinical approach Person-centred Multidisciplinary Mental health interventions and care planning
	4. NDIS	Improved and stable service provision from NDIS funded providers	
b) for providers	1. Capacity	Increased capacity of health services to meet the mental health needs of people with ID Improved confidence and skills of mainstream mental health staff in working with people with ID	Core Competencies - Working with people with intellectual disability: Responsible, safe, ethical practice / Recovery focus / Meeting diverse needs / Communication / Partnership, collaboration and integration - Clinical Competencies: Common clinical competencies / Intake / Assessment / Mental health interventions and care planning / Transfer of care

	2. Exposure	Increased mental health clinician exposure to working with people with ID	Access to mental health services Partnership, collaboration and integration
	3. Coordination	Increased coordination and engagement across health and disability providers to facilitate integrated care Improved patient flow through acute, subacute, rehabilitation and community mental health services due to integrated care planning	Multidisciplinary approach and interagency collaboration Partnership, collaboration and integration Identification of care pathways
	4. Training	Improved access to targeted education and training in ID for mental health clinicians	Training and education for professionals Research, quality improvement and professional development
	5. Specialist support	Access to specialist support for mental health clinicians	Access to specialised IDMH services
c) for the system	1. Data	Improved data on the service usage, prevalence and access to care for people with ID	Data collection and evaluation Inclusion in policy development
	2. IDMH as a specialty practice area	Development of IDMH as an area of specialty practice	Access to specialised IDMH services Training and education for professionals Research, quality improvement and professional development
	3. Patient flow	Improved **patient flow** through acute, subacute, rehabilitation and community mental health services (removing bed blocks)	Access to specialised IDMH services Identification of care pathways

Appendix C Composite case studies

Composite case studies have been written from multiple stories in the fieldwork data to protect privacy and confidentiality.

Linda, Hub Participant

Linda lives in supported accommodation. She enjoys talking with people and doing activities with her housemates and carers. Linda's favourite things to do include going out to dinner with her friends and boyfriend, playing soccer and riding around her neighbourhood on her bicycle. About 6 months ago, Linda began to feel sad and frustrated and was having trouble sleeping. She was also having trouble connecting with her carers and explaining her feelings to them. She no longer wanted to go to any of her social activities and even felt too tired to have a chat with her housemates. Linda's carers took her to the Hub, and the psychiatrist changed her medications. They discussed with Linda and her carers about some new strategies to help support Linda. Linda began to feel a bit better and had less trouble sleeping. Although she still had difficult days, Linda has been able to have a laugh with her friends and has enjoyed riding her bike again.

Jason, Hub Participant

Jason is 13 years old. He was diagnosed with ADHD and ASD at the age of three. Jason enjoys playing with his sensory toys and listening to the sounds they make. Until last year, Jason had difficulty communicating and had multiple 'outbursts' each day at home, often damaging property. At school Jason sometimes hit students and teachers and could not concentrate in class. His parents sought help, going to multiple doctors over the years, but could not find suitable medication and therapies for Jason. Last year they took him to the Hub. Hub staff changed Jason's medication, suggested behavioural strategies and reassured his parents. Since the Hub intervention, Jason has had less outbursts and appears to be more in control of his behaviour. He has learned some new skills, including using the bathroom independently. Although still difficult, Jason is finding it a bit easier to communicate with his parents and teachers and to connect and play with his peers at school.

Rani, Family carer

Rani has four children, two with developmental disabilities, and is also a carer for her husband Tej, who has multiple sclerosis. She described feeling overwhelmed with caring for her family and juggling her full-time job.

Of particular concern for Rani was an escalation of disruptive and sometimes violent behaviour from her 11-year-old son, Sanjay. This had made engaging with and supporting the rest of the family even more challenging. Rani had visited many

doctors over the years seeking help for Sanjay. Some doctors had suggested to Rani that her parenting methods were the cause of Sanjay's behaviour. This made Rani feel inadequate as a parent.

Rani was referred by Sanjay's paediatrician to the Hub earlier this year. At the Hub, Rani felt an immediate sense of reassurance and understanding. It was the first service in which she felt listened to and supported. She felt that the doctors at the Hub displayed a deep level of care and empathy for not only Sanjay, but for herself as a carer. They suggested strategies that helped her strengthen her own mental health while also caring for her son and her family. Rani now feels supported in her role as a mother and a carer. She is hopeful for the future as Sanjay transitions into high school. She is now able to spend more time on her hobbies and on strengthening her relationships with her other children.