Intellectual Disability and Mental Health Hubs Evaluation

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

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Research Team
Karen R Fisher (Chief Investigator), Christiane Purcal, Peri O'Shea, BJ Newton, Julian Trollor, Janelle Weise, Preeyaporn Srasuebkul, Errin Forrester, Katielee Simpson, Vicky Xu, Justen Thomas, Pamela Darling, Rachel Spencer, Yasmin Edwards, Kathleen Reedy, Rosie Pether, Winnie Feng

For further information:
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
www.unsw.edu.au/arts-design-architecture/our-research/research-centres-institutes/social-policy-research-centre

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Contents

List of tables

Abbreviations and meanings

3DN	Department of Developmental Disability Neuropsychiatry at UNSW Sydney
ASD	Autism spectrum disorder
CALD	Culturally and Linguistically Diverse
CAMHS	Child and Adolescent Mental Health Services
Carer	Carers, family members and friends of people with intellectual disability and mental health challenges (unpaid)
Consumer	Person with intellectual or developmental disability and mental health needs. They may or may not use the Hubs.
DCJ	NSW Department of Communities and Justice
Family	Family members and carers of people with intellectual disability and mental health challenges
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 services	Intellectual Disability Mental Health services
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
Specialty networks	Sydney Children's Hospitals Network and Justice Health and Forensic Mental Health
NSW	New South Wales
Participant	Person with intellectual disability and mental health challenges who used the Hubs
Person with disability or person with intellectual disability:	in this report, short for person with intellectual or developmental disability and mental health needs
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. 'Child Hub'

SIDMHOS	Statewide Intellectual Disability Mental Health Outreach Service. ‘Adult Hub’
SLHD	Sydney Local Health District
SPRC	Social Policy Research Centre
UNSW Sydney	University of New South Wales

UNSW SYDNEY

SPRC
Social Policy Research Centre

Evaluation of Statewide Intellectual Disability Mental Health Hubs

Easy read summary

Easy Read

Contents

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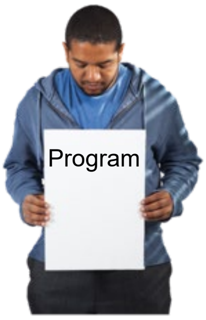
Part 1

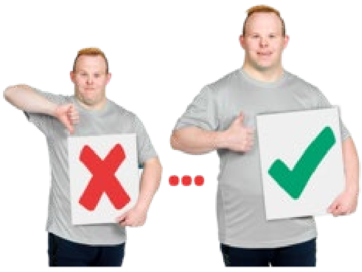
About this report



This report is about a program for people with both intellectual disability and mental health needs.

The program is called the Statewide Intellectual Disability Mental Health Hubs.

We say the **Hubs** for short.



This report is about what the Hubs:

- Are doing well
- Could do better.

The report has 4 parts:
Part 1 is about this report and the Hubs
Part 2 is about what we found by talking with people
Part 3 is about what the Hubs should do next
Part 4 is about the evaluation

You can read all parts or just parts you are interested in.

About the Hubs

Hubs help services support people with intellectual disabilities and mental health needs.

NSW Health pays for the Hubs.

NSW Health is part of the NSW Government.

Hubs started in 2020.

What the Hubs do

Hubs talk to people about how they can have a better life

Hubs train health and disability workers and give them advice.

There are 2 Hubs

1 for children and young people

1 for adults

Hubs are for people and services from all over NSW (New South Wales).

Part 2

What Hubs did well with people and families

Hubs helped people and their families feel happier and healthier.

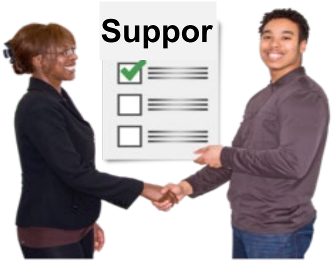
Hubs helped people get other support services.

Hubs helped people with better medication and behaviour support.

Hubs helped people get more support from **NDIS** (National Disability Insurance Scheme).

Hubs helped people not go to hospital emergency as much.

What Hubs did well with services



Hubs helped **services** give better support to people.

Services are organisations or workers that support people.

Hubs helped services to better understand intellectual disability and mental health.

Hubs helped services to work better with people with intellectual disability and mental health needs.

Hubs helped services to work together more.

Part 3

What the Hubs can do next

Make sure Hubs meet the needs of people

- from all parts of NSW

- from all cultures

- who are Aboriginal

- with all kinds of intellectual disability and mental health needs.

Hubs can also

Help people get appointments with specialist doctors and support services.

Make sure services know how to get information and training from the Hubs.

Include people with intellectual disability and mental health needs as trainers for services.

Make it easier to find out information about the Hubs.

NSW Government could help all the services work better together.

These services could be

- Hubs
- Mental health services
- NDIS
- Disability services
- Schools

Part 4

How we did the evaluation

We talked to people with intellectual disability and mental health needs who used the Hubs.

They are the Hub **participants**.

We talked to their families.

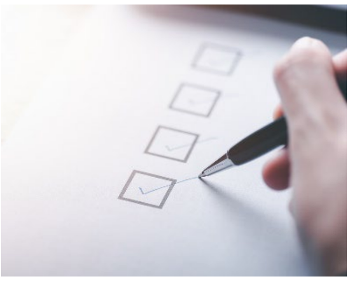
We talked to services who worked at the Hubs or had advice from the Hubs.

We talked to people in government about the Hubs.

We talked to many people 2 times over 3 years.

We wanted to see what things changed.

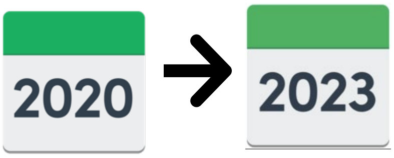
We did surveys with health workers.



We did surveys with families.

We used other information about Hub participants.

About the evaluation



The evaluation started in 2020 and finished in 2023.

Researchers were from 2 organisations:

SPRC
Social Policy Research Centre

The Social Policy Research Centre

It is called **SPRC** for short.

3DN

Department of Developmental Disability Neuropsychiatry.

It is called **3DN** for short.

Researchers are people who find things out.

Peer researchers are people with intellectual disability or mental health needs in the research team.

Peer researchers made the research better because they know what it is like to have intellectual disability or mental illness.

More information

More information about the evaluation is on the SPRC website.

www.unsw.edu.au/research/sprc/our-projects/evaluation-the-hubs

You can click this link

Evaluation of the Intellectual Disability and Mental Health Hubs (IDMH Hubs) | Arts, Design & Architecture - UNSW Sydney

Short summary

Two statewide Hubs aim to improve access to services for people who have intellectual or developmental disability and mental health needs. The Statewide Intellectual Disability and Mental Health Hubs (the Hubs) were established by the NSW Ministry of Health (the Ministry). The Hubs work short-term with people with intellectual disability and mental health needs (Hub participants), their family members and carers (families), and their service providers. The Hubs also deliver activities to build capacity in the health and disability workforces and other relevant professionals, so they can better support people with disability.

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 used mixed methods with i) 2 rounds of qualitative interviews, ii) linked administrative health data on health care usage and outcomes for Hub participants, iii) Hub capacity building activities, iv) a survey of Local Health Districts, and v) a satisfaction survey of Hub participants, their support networks and referrers.

The Hubs achieved success across a range of intended outcomes. The Hubs facilitated access to community mental health services and mental health professionals. The Hubs may have contributed to fewer emergency department presentations for participants. In the main, Hub participants, families and service providers were positive about their experiences with the Hub processes and services. This included the range of capacity building activities that reached across disciplines and sectors. Limitations included Hub resources, a shortage of disability and mental health services and coordination at local and state levels, and by hesitation and lack of familiarity from some services that underutilised IDMH support.

Implications of the findings for the Ministry and the Hubs were across 7 areas:

1. Hub assessments and advice to professionals
2. Participant and family engagement
3. Capacity building, training and supervision
4. Promoting services and specialist support
5. Access to services and consumer flow
6. Partnerships to support Hub participants
7. Data, research and evaluation.

Executive summary

Two new statewide Hubs aim to support better access of services to people who have intellectual or developmental disability and mental health needs. The Hubs were established by the NSW Ministry of Health (the Ministry). The two Hubs are:

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

The Hubs work short-term with people with intellectual disability who have mental health needs and with their families. The Hubs also deliver activities to build capacity in the health workforce and among other relevant professionals, so they can better support people (**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 was from September 2020 to November 2023. It assessed the outcomes of the Hubs and the effectiveness of the service processes. The evaluation used a mixed-method design, including quantitative and qualitative data. This is the final report of the evaluation.

The qualitative findings are from two rounds of individual and group interviews conducted in 2021 and 2023. 142 responses were collected through interviews and written feedback. These responses were from:

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

The quantitative findings include data from 386 Hub participants, 13 representatives from 8 local health districts/networks, 18 referrers to the Hubs, and 15 families of Hub participants.

Results

The research indicates that the Hubs achieved success across a range of intended outcomes. The Hubs facilitated access to mainstream and specialist community mental health services and mental health professionals. The findings also demonstrate that the Hubs may have contributed to fewer emergency department presentations for participants. In the main, Hub participants, families and service providers were positive about their experiences with the Hub processes and services. This included the range of capacity building activities that reached across disciplines and across sectors. Referrers also reported being likely to recommend the Hubs to their colleagues. Limitations included Hub resources, a shortage of disability and mental health services and coordination activities at local and state levels, and by hesitation and lack of familiarity leading to some services underutilising 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. Implications are listed in **Section 5.**

Hub activities

The Hub activities included advice and assessment, training and supervision, partnerships, promotion, data and research. The first of these activities involved support for individual Hub participants. The remainder of the activities were about capacity building of IDMH services and building infrastructure for the effectiveness of the Hubs (**Section 3**).

Referrals

The Hubs became better known over time as more service providers and families used them. Word of mouth was how most people found out about the Hubs, including referrers, professionals, participants and families. Service providers and families praised the referral process, with minimal waiting periods. The Hubs responded to referrals based on risk and need. Strategies to manage referrals were to triage, offer different levels of service, and allocate within the team (Section 3.1).

Advice

The Hubs offered specialist advice to people and professionals who supported Hub participants. Initially the Hubs focused on support for professionals, including GPs, paediatricians and mental health and disability support services. Over time, the Hubs also gave direct advice to more families and Hub participants through their assessment and treatment plans. A strength of the Hubs was the quality of the staff.

The Hubs offered consultation to clinicians to discuss people who had not been formally referred to the Hubs. Consultation increased as the Hubs became better known and as more professionals developed a relationship with the Hubs.

Over time, the Hubs became flexible about how long they remained engaged with a person's case, consistent with the aims of the Hubs. They followed up, conducted reviews and continued to offer advice if necessary (Section **3.2**).

Access

Equitable access for participants to the Hubs continued to develop. The Hub processes became more inclusive of people from rural areas, culturally and linguistically diverse communities and Indigenous people (Section 3.3).

Assessment

When a referral to the Hubs resulted in an assessment, the Hubs took a holistic approach. The multidisciplinary team reviewed the person's medical and social histories and met with clinicians, the participant and family, and direct service providers of the Hub participant.

Recommendations from an assessment included linking with services for long term support, medication changes and strategies for communication and to manage behaviour (Section 3.4).

Training and supervision

Training and supervision included educational programs, resources and clinical supervision. These capacity building activities were popular and reached a wide range of professionals, mainly in mental health, and other health, disability and education sectors. The training emphasised holistic care.

The impact of the training was strong, with training participants saying it improved their practice. Participants said they appreciated the general information, and case discussions and clinical supervision, which were particularly useful for problem solving. They suggested training for specific disciplines and more information about the training to reach a wider range of professionals.

Resources and training for participants and families were also starting to become available (Section **3.5**).

Partnerships and promotion

The Hubs built partnerships to promote their activities and to collaborate with relevant services, such as in health, mental health, disability and education, when supporting Hub participants.

Promotion of the capacity building activities reached a wide range of professionals across the relevant sectors (health, mental health, education and disability). Many professionals, families and participants continued to be unaware of opportunities or how and when to seek support from the Hubs, according to the evaluation data.

The Hubs increased the number and quality of the partnerships they built with other services. Initial partnerships developed from cooperating about individual cases. These partnerships with the Hubs now extend to engagement about improving service systems, including with the LHDs (Local Health Districts), Specialty networks (Sydney Children's Hospitals Network and Justice Health and Forensic Mental Health) and NDIS (National Disability Insurance Scheme) providers (Section **3.6**).

Data

Data development activities are underway to inform improvements to service access for people with intellectual disability and mental health needs.

The IDMH Hub Minimum Data Set (MDS) aimed to collect consistent information about the Hub participants and activities, to track participants through the Hub services and to quantify the capacity building activities of the Hubs.

The LHD data dashboard (Mental Health in the Community) had recent data about consumers (people with intellectual disability and mental health needs) accessing mental health care in NSW Health services. The dashboard can be accessed by NSW Health staff to inform local and system responses. At September 2023, the LHD data Dashboard was not available and was undergoing changes arising from updates in Ministry of Health data warehousing (Section 3.7).

Research

The Hubs distributed relevant research evidence as part of the capacity building activities. Hub staff initiated and participated in research about clinical and capacity building activities. Future opportunities to expand research activities and evaluate the Hubs would inform statewide and national practice improvement (Section 3.8).

Hub outcomes

The Hubs improved outcomes for participants and their families, for providers of intellectual disability and mental health services, and for the mental health and disability service systems. Many Hub participants felt they had a better life, many families felt involved and consulted, and many stakeholders appreciated the holistic approach taken by the Hubs (Section **4**).

Outcomes for Hub participants and their families

The Hubs improved the wellbeing of most Hub participants and families who were interviewed. The linked data were insufficient to demonstrate significant change as measured with the Health of the Nation Outcome Scales (HoNOS) and the Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA).[1] The samples were too small and the three month follow up period used in this study may be too short. The Hubs could use outcome measures to track the wellbeing of participants during and after contact with the Hubs.

Access to mental health services improved overall for Hub participants. Families and service providers reported satisfaction with the way Hubs linked the person with psychiatrists, local mental health services, physical health services and support for the family.

Positive treatment outcomes were achieved through a combination of medication reviews and behaviour support implemented by the local support and families.

Access to NDIS services was an outcome area that improved through recommendations in the assessment report, supporting the NDIS application process, finding suitable NDIS providers and Hub training with NDIS providers (Section **4.1**).

Outcomes for providers of mental health and disability services

The combined approach of individual participant support, training and resources improved the capacity of mental health and disability providers to deliver quality support to people with intellectual disability and mental health needs. The impact varied by location and local resources.

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[1] The Child Hub noted that the HoNOSCA is not suitable for this population and the Children's Global Assessment Scale (CGAS) is a better measure.

When mental health clinicians worked with people with disability, this exposure changed their attitudes and confidence and gave them a framework to address any added complexity.

Coordination between professionals for integrated care was developing, based on the holistic service approach. Hubs facilitated engagement and coordination by translating between different professions.

The Hubs offered education and training to mental health clinicians through online formats. The mental health clinicians said the training changed their practice. They suggested more training options were needed to encourage colleagues to participate, such as recognition of training and more afterhours options.

Professionals used specialist support from the Hubs for individual referrals, particularly when they had fewer local resources. Local IDMH positions were also important so they could coordinate specialised support from the Hubs and promote Hub capacity building to local mainstream staff, according to local and Hub staff. (Section **4.2**).

Outcomes for the mental health and disability service systems

Intellectual disability and mental health as a specialty practice area was developing. Stakeholders said specialists in this area would continue to be needed in the Hubs and in local mainstream services.

New pathways for people with intellectual disability and mental health needs were emerging as the capacity of mainstream providers increased. They relied on the Hubs to support individual participants and deliver training and resources to develop this capacity. Consumer flow in mainstream services was improving but this was an ongoing process owing to a history of access barriers and exclusion criteria, a shortage of mainstream services and discontinuity in transition from children to adult services.

Effective systems change requires participation and influence from policy makers and practitioners across the systems, not just the Hubs themselves. Building effective partnerships for systems change was more challenging for the Hubs, compared to direct support and capacity building with professionals (Section **4.3).**

Implications

Implications of the findings for the Ministry and the Hubs are detailed in Section **5**:

1. Hub assessments and advice to professionals
2. Participant and family engagement
3. Capacity building, training and supervision
4. Promoting services and specialist support
5. Access to services and consumer flow
6. Partnerships to support Hub participants
7. Data, research and evaluation.

1 Introduction

1.1 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. The Ministry established 2 Statewide Tertiary Intellectual Disability and Mental Health Hubs (the Hubs). The Hubs support better access and availability of services to people with both intellectual disability and mental health needs. The 2 Hubs are:

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

The Hubs offer short-term multi-disciplinary support for people with complex, co-occurring intellectual disability or developmental disability and mental health needs. They each have multi-disciplinary teams.[2]

The Hubs work primarily with people with intellectual disability who have a diagnosed mental illness or 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.

Initial funding agreements for the Hubs ran from March 2019 to March 2024, and funding was ongoing at the time of this report.

Information about the Hubs is on their websites:

- Statewide Intellectual Disability Mental Health Outreach Service (SIDMHOS) (nsw.gov.au), Adult Hub: https://www.slhd.nsw.gov.au/MentalHealth/SIDMHOS.html

- Sydney Children's Hospitals Network Mental Health Intellectual Disability Hub, Child Hub: https://www.schn.health.nsw.gov.au/find-a-service/health-medical-services/mental-health-services/sch-chw-mhid

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[2] Team composition changes over time. At the time of the interviews, the teams consisted of: Child Hub - Psychiatrist, clinical psychologist, health service manager, occupational therapist, social worker. Adult Hub – Two psychiatrists, clinical nurse consultant, clinical psychologist, psychologist (forensic), psychiatry registrar.

1.2 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. The evaluation ran from September 2020 to November 2023. It assessed the outcomes of the Hub model as well as the effectiveness of the service processes. It aimed to inform the future development of the Hubs.

The evaluation plan (Purcal et al 2021a) outlines how the evaluation was conducted. The plan was refined with stakeholders throughout the evaluation. The interim report of the evaluation (Purcal et al 2021b) contains findings from the first round of qualitative fieldwork. The findings had implications for the continuing work of the Hubs.

This final evaluation report combines the findings from 2 rounds of qualitative fieldwork and available program documents, and the findings from the quantitative methods: surveys with referrers, families, LHD and Network staff and analysis of data about the program and the participants.

Section 2 of this report is an overview of the evaluation methods and presents the study samples. The evaluation findings 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 (2014 and 2016). This gave us an analytical framework to measure how the Hubs enhanced the capacity of NSW health services to meet the mental health needs of people with intellectual and developmental disability. The mapping against 3DN work is in **Appendix B**. Composite case studies about Hub participants and families are in **Appendix C.** The case studies illustrate the journey of Hub participants and the services that the Hubs provided. Each case study was composed from multiple stories in the fieldwork data to protect privacy and confidentiality. **Appendix D** presents detail about the evaluation methods**. Appendix E**, **Appendix F**, **Appendix G** and **Appendix H** contain the findings of the quantitative methods.

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 informs the further implementation of the statewide Hubs program.

Implications from the analysis are written in the first section in which they are relevant. The implications are not repeated when they are also relevant to later sections. All implications are collated in Section **5**.

2 Evaluation approach and samples

This was a formative evaluation. It means that the evaluation presented analysis during the length of the evaluation as the Hubs developed over time. We summarised initial findings in the Interim Report, so that the Hubs and the Ministry could consider the findings and use them to improve the Hub processes. The evaluation involved two rounds of qualitative data collection (interviews) and analysis of several years of quantitative data about how consumers accessed health services (consumer outcomes) as well as several surveys. This allowed the evaluation to measure the processes and impact of the Hubs over time.

The evaluation used a mixed-method design. This means the evaluators collected and analysed information from a range of sources and included both quantitative and qualitative data. The evaluators then compared the information against the program logic to assess the effectiveness and outcomes of the Hubs. The program logic is a document listing the program activities and intended outcomes (**Appendix A**). It was developed with the Ministry.

The evaluation methods were (**Appendix D**):

- co-design of the evaluation approach, methods and reporting
- analysis of program documents from the Hubs
- qualitative interviews with Hub stakeholders, both individually and in groups (2 rounds, in 2021 and 2023), including written responses to the interview questions
- linked administrative and outcomes data for Hub participants
- workforce capacity survey for health professionals who referred to the Hubs
- Local Health District capacity survey
- Satisfaction survey of Hub participants, families and referrers.

Appendix D describes how the data were analysed and their limitations.

2.1 Interviews

We conducted 2 rounds of interviews with stakeholders of both Hubs. The Hub stakeholders were:

- Hub participants – people with intellectual disability and mental health needs who used the Hubs
- Families – family members and carers of Hub participants
- Hub staff – clinicians, practitioners, and managers

- Service providers – who used the Hubs, either by referring to the Hubs or attending Hub training
- Statewide stakeholders – involved in governance, advocacy or policy.

The sample of participants is in **Table** . Overall, 142 people participated over 2 data collection periods: 1) from May to July 2021; 2) February to June 2023. People participated in individual or group interviews or provided a written response, depending on the respondents’ preference or capacity.

Hub staff and service providers were larger samples than anticipated. There were fewer interviews than intended with Hub participants. During the first round of fieldwork, the Hubs were relatively new and had limited engagement with participants. The evaluators worked with the Hubs to increase the sample for the second round of fieldwork in 2023. This resulted in twice the number of families and almost twice the number of participants compared to the first round of interviews. Nevertheless, more interviews with Hub participants would have strengthened the evaluation. Some reasons for the low participation rate might be:

- the Hubs’ contact was often with the service providers, family or support service rather than the participant themselves
- most participants of the Child Hub could not be interviewed for ethical reasons as they were aged under 16
- face-to-face interview options were limited due to Covid-19 (mainly in the first round) and due to evaluation funding constraints, which limited travel outside Sydney.

Quotes from participants are prioritised in the report when they were available, but few participants spoke directly about the Hubs and their support. Mainly, their experiences with the Hubs were relayed by their families. They are illustrated in the composite case studies of participants throughout the findings sections **3** and **4** and collated in **Appendix C**.

Table 2.1: Qualitative data sample, Round 1, 2021 and Round 2, 2023

		Number of responses			
Participant group	**Round**	**Interviews**	**Focus groups**	**Written responses**	**Totals**
Hub participants	Round 1	2	0	1	3
	Round 2	5	0	0	5
	Total	**7**	**0**	**1**	8
Families	Round 1	6	0	1	7
	Round 2	14	0	0	14
	Total	**20**	**0**	**1**	**21**
Hub staff	Round 1	0	12	0	12
	Round 2	2	14	0	16
	Total	**2**	**26**	**0**	**28**
Service providers using Hubs	Round 1	11	5	0	16
	Round 2	7	14	10	31
	Total	**18**	**19**	**10**	**47**
Stakeholders	Round 1	1	22	0	23
	Round 2	5	9	1	15
	Total	**6**	**31**	**1**	**38**
All Participants	**Round 1**	**20**	**39**	**2**	**61**
	Round 2	**33**	**37**	**11**	**81**
	Total	**53**	**76**	**13**	**142**

2.2 Program data and surveys

2.2.1 Linked data study

The linkage study included 386 Hubs participants (220 for the Child Hub and 166 for the Adult Hub). This linkage included data from the NSW Admitted Patient Data Collection, NSW Ambulatory Mental Health (including Hubs data), NSW Emergency Department Data Collection, NSW Mental Health Outcomes Collection, NSW Registry of Births Deaths and Marriages and the Hubs minimum data collection (**Appendix E**). The profile of participants is in **Table 3.1**.

2.2.2 Local Health District capacity survey

A total of 13 representatives from 8 local health districts/networks participated in the capacity building survey. Demographic information is not presented to protect anonymity (**Appendix G**).

2.2.3 Satisfaction survey

15 people who supported a person to access the Hubs completed the satisfaction survey (**Appendix H**). All were female, and they were aged between 25-55+ years old. Just over half accessed the Adult Hub (53.3%), with the remainder having accessed the Child Hub.

18 people who made referrals to the Hubs completed the satisfaction survey. Half of the referrers were in urban areas, and half were from a regional/rural/remote area. One-third of them (6 referrers or 33.3%) made a referral to the Child Hub, and the remainder referred to the Adult Hub.

2.3 Limitations

The limitations of the evaluation and the methods included that we were unable to analyse the data collected from the workforce capacity survey because an inadequate number of people participated in the pre and post surveys. However, we were able to incorporate the questions about workforce capacity into the second round of qualitative work and the local health district capacity building survey.

The Hubs were establishing during the linked data period (1 year prior and 3 months post). The 3 months post may not reflect change now that the Hubs are more established.

Further research and evaluation will be important to follow up about further longitudinal outcomes, refinements to the Hubs and capacity of IDMH services.

3 Hub activities

This section summarises findings about the Hub activities. The information includes the way the Hubs worked and the factors that helped them to work well. The outcomes from these activities are in Section **4**. The activities reported in this section align with the program logic and 3DN analysis frameworks in **Appendix B**. Findings are based on all data sources as available for each activity's topic.

The Hub activities included responding to referrals, advice, assessment, data, training and supervision, partnerships and promotion, data development and research. The first of these activities involved support for individual Hub participants. The remainder of the activities were about capacity building of the sector and infrastructure for the effectiveness of the Hubs.

Case study: Scott and Barbara

Scott was 16 years old with diagnoses of ADHD, intellectual disability and Autism Spectrum Disorder. Barbara was his mother. Scott's behaviour was sometimes dangerous and abusive to Barbara. She was home-schooling Scott, after he was expelled for aggressive behaviour towards other students.

Barbara often felt that nobody understood how challenging caring for Scott was and that people were judging her. She often judged herself as a bad parent.

When Barbara sought support to help manage Scott's behaviour, she had difficulty finding appropriate, affordable mental health services who would see Scott. Luckily one of the mental health staff at the hospital knew about the Hubs. They made some calls and organised support to refer Scott and Barbara to the Hub.

When Barbara and Scott met with the Hub, Barbara felt she was listened to and that her role as a parent and a carer was understood. This contrasted with many past encounters with services, when she had felt invisible or judged.

The Hub reviewed and changed Scott's medication, helped Barbara to get Scott more NDIS support, including respite, occupational therapy and one-on-one support. The Hub also connected Barbara to a group of parents of children and young people with disabilities, which helped Barbara to feel less isolated.

Since going to the Hub, Scott was no longer as aggressive at home, and he was trialling a two day a week return to school. Barbara had a bit more time to do things she enjoyed and had a deep appreciation of the challenges she had faced and overcome providing support to Scott. She felt confident to stand up for herself and educate people who 'do not get it'. She no longer felt like a bad parent.

3.1 Referrals to the Hubs

Summary

The Hubs became better known over time as more service providers and families used them. Word of mouth was how most people found out about the Hubs, including referrers, professionals, participants and families.

Service providers and families praised the referral process, with minimal waiting periods. The Hubs responded to referrals based on risk and need. Strategies to manage referrals were to triage, offer different levels of service, and allocate within the team.

How people found out about the Hubs continued to change as the Hubs developed. First contact with the Hubs for professionals, participants and families usually resulted in a referral, advice (Section 3.2), access (Section 3.3) or an assessment (Section **3.4**). A strength of the Hubs was the quality of the staff. They were knowledgeable, compassionate, strong communicators, transparent and friendly, according to the referrers and families in the satisfaction survey (**Appendix H**). A consideration for the Hubs will be how to continue to foster the high quality of the Hub teams as demands on their time increase.

3.1.1 Profile of Hub participants

The profile of Hub participants from the linked data (**Appendix E**) demonstrated diversity across age and culture.

Table 3.1: Demographics of participants in the Hubs

Variable	Category	Child Hub n=220 (%)	Adult Hub n=166 (%)	Total n=386 (%)
Sex	Female	40 (18.2)	71 (42.8)	111 (28.8)
	Male	172 (78.2)	90 (54.2)	262 (67.9)
	Missing	8 (3.6)	5 (3.0)	13 (3.4)
Indigenous status	Indigenous	25 (11.4)	21 (12.7)	46 (11.9)
	Non-Indigenous	183 (83.2)	134 (80.7)	317 (82.1)
	Missing	12 (5.5)	11 (6.6)	23 (6.0)
Born in Australia	No	14 (6.4)	16 (9.6)	30 (7.8)
	Yes	198 (90.0)	145 (87.3)	343 (88.9)
	Missing	8 (3.6)	5 (3.0)	13 (3.4)
Living situation	With family	165 (75.0)	67 (40.4)	232 (60.1)
	Out of home care	22 (10.0)	N/A	
	Supported independent living	0 (0.0)	74 (44.6)	74 (19.2)
	Other *	8 (3.6)	25 (15.1)	33 (8.5)
	Unknown	25 (11.4)	0 (0.0)	25 (6.5)
Have an intellectual disability	No	95 (43.2)	20 (12.0)	115 (29.8)
	Yes	125 (56.8)	146 (88.0)	271 (70.2)
Severity of intellectual disability (n=271)	Mild	25 (20.0)	53 (36.3)	78 (28.8)
	Moderate	45 (36.0)	59 (40.4)	104 (38.4)
	Severe	33 (26.4)	29 (19.9)	62 (22.9)
	Profound	8 (6.4)	5 (3.4)	13 (4.8)
	Other	14 (11.2)	0 (0.0)	14 (5.2)
Have Autism	No	33 (15.0)	98 (59.0)	131 (33.9)
	Yes	187 (85.0)	68 (41.0)	255 (66.1)
NDIS Recipient	Yes	160 (72.7)	142 (85.5)	302 (78.2)
	No	60 (27.3)	24 (14.5)	84 (21.8)

Source: Data linkage from NSW Admitted Patient Data Collection, NSW Ambulatory Mental Health, NSW Emergency Department Data Collection, NSW Mental Health Outcomes Collection, NSW Registry of Births Deaths and Marriages and the Hubs minimum data collection - Note: *e.g. homeless, hospital, residential aged care, independent

The Hub participant ages ranged from 2 to 79 years with a mean age of 22 years (SD = 15.0). For the Child Hub, participant ages ranged from 2 to 18 years with a mean age of 12 years (SD = 3.0), and for the Adult Hub, ages ranged from 18 to 79 years with a mean age of 34 years (SD = 15.0).

Most participants across the Hubs were male (67.9%). Most children lived with family (75.0%) and adults lived in supported accommodation (44.6%) or family (40.4%) (Table 3.1). Participants who identified as Indigenous (11.9%) were overrepresented and participants born overseas (7.8%) were underrepresented. Most participants received NDIS funded support (78.2%), and most used verbal forms of communication (71.5%).

Most (n=271, 70.2%) Hub participants identified as having an intellectual disability, with a relatively even distribution of participants identifying as having a mild, moderate, or severe/profound levels of disability. Most Child Hub participants also identified as autistic (n=187, 85.0%), while less than half (n=68, 41.0%) of Adult Hub participants did. Multiple potential explanations for this difference include, but not limited to, the broader pre-existing focus of child services on autism, under-recognition of autism in adult populations and divergent referral patterns. The Ministry and the Hubs could further explore the reasons for this difference to consider the implications on future Hub delivery.

The primary mental health diagnoses varied across the Hubs. For the Adult Hub the top two primary mental health diagnoses were i) schizophrenia, schizotypal and delusional disorders (n=44), and ii) depression (n=34). For the Child Hub the top primary diagnoses were attention deficit hyperactivity disorder (n-95) and anxiety (n=30).

3.1.2 Finding out about the Hubs

Information about the Hubs was on the NSW Health website and on other websites dedicated to intellectual disability mental health. Word of mouth was the way many providers and most families said they found out about the Hubs. Usually this was by someone who knew a practitioner at the Hubs or had used the Hubs before. Some service providers found the Hubs incidentally while searching the internet for services for their consumers.

Knowledge of the Hubs increased during the evaluation, as reflected in the increased referral numbers (**Appendix E**). The referrals implied that the Hubs were becoming better known over time as more service providers and families used them. The Hub training and promotion activities also increased the profile of the Hubs (Sections **3.5**, **3.6**).

> Compared to [fieldwork round 1], we're much more known than we were, and people do know what we can offer. (Hub staff)

Knowledge gaps about the Hubs remained by the end of the evaluation. These gaps disadvantaged people who were not connected to someone who knew about the Hubs. The many families who did make the connection, valued finding the Hubs after long searches.

> If I wasn't persistent, and I was only persistent because the crisis continued, I just would have given up. (Family)

Some service providers and statewide stakeholders observed that NDIS providers often did not know about the Hubs nor about service pathways for people they worked with who had mental health needs.

> We're finding that people are being … left in the emergency department by NDIS providers, they're not sure [what to do], so they come into the mental health unit and then we have a really long length of stay and sometimes not the best treatment for the individual. (Statewide stakeholder)

Service providers who found the Hubs by chance wished that others in their field or location were also informed, particularly in large non-metropolitan areas.

> How we discovered the Hub sort of felt a little accidental and I can't remember how we even stumbled across it to refer this family. So me, as an [practitioner] knowing about the Hub has changed how I might work with people because I now know that it exists. So I guess it's about now how we then get that information out to others up in the [rural] region to understand that the Hub exists as a possible referral for families. I'm not really sure even if our CAMHS services are fully across its potential. (Service provider)

3.1.3 Referral criteria and response

The Hubs responded to referrals based on risk and need. Service providers and families praised the referral process, with minimal waiting periods. Referrers to the Hubs reported being satisfied with the referral process (**Appendix H**).

The criteria developed for who was eligible to access the Hubs during the evaluation period. In the first round of fieldwork, the evaluation identified there was a focus that the person needed to be out of hospital, have a psychiatrist, a diagnosed mental illness and a clinical support network around them. Feedback from service providers, stakeholders and families raised equity issues in these referral criteria. For example, the requirement to have a psychiatrist was a barrier because few psychiatrists were available and had long waiting lists.

> We’re seen as a tertiary service, but if people can't access the secondary service there’s a gap isn't there, you shouldn't jump people from GP to tertiary. I think there should be the middle bit, and a lot of people don't have that middle. (Hub staff)

The referral criteria became more flexible during the evaluation period. Access to the Adult Hub required that people had an intellectual disability and a mental health problem, but no mental illness diagnosis and no psychiatrist were necessary. The criteria for the Child Hub were participants with intellectual disability and/or autism (**Table 3.1**).

Participants in both Hubs still needed to have local specialist support for ongoing treatment, but the Hubs helped people to find local support, such as LHD mental health, paediatric or psychiatric support. People might then still use the Hub services. The Hubs worked closely with the local Specialist Intellectual Disability Health Teams to coordinate ongoing local support.

> We will see someone who doesn't necessarily have a psychiatrist or has a small network around them, to try and clarify a diagnosis and advocate for them to get a psychiatrist if they need one or to open up the correct services. So often someone will be in complete distress, they’ve been lost to the system, and we can provide a lot of input there around the services that they could access and linking them in and holding some of the anxiety for a little while. (Hubs staff)

> If [Hubs] received referrals directly, so not via our team, via the person’s GP or so forth that come from [our LHD] they always contact us and say “We’ve received a referral for this person from your area, do you want to see them or do you want us to see them?” and we usually have a conversation about that. (Service provider)

Some service providers spoke about navigating referral pathways and the complexities of having several professionals involved in care. According to some providers, this complexity increased with the advent of Specialised Intellectual Disability Health Teams but they said the referral pathways to these teams had improved over time.

> So we had that child for about six months I think, just for the purpose of making that referral and having that consult. You know, for some reason the private developmental paediatrician who was involved was told that they couldn’t make that referral and it needed to come through us. (Service provider)

Service providers and families reported that Hubs offered timely, appropriate response times for consumers with complex, time sensitive needs. This responsiveness was highly valued by referrers and support people (Appendix H). They were concerned that as referrals continued to increase, the Hubs might become less responsive. The Hubs were aware that they might have to adapt further as time went on. ‘It gets harder because the more the service is known, the more it gets used.’ (Hub staff)

More referrals to the Hubs due to increased knowledge and wider eligibility criteria meant the Hubs were near capacity by the end of the evaluation. In response, they developed strategies to manage the demand, while still responding to all referrals promptly. The Hub strategies were to:

- **Triage**: Hub staff decided not use waitlists but to attend to referrals within a week if they needed support urgently. People with ongoing needs and an existing support network were booked in for a comprehensive assessment. People who did not fully fit their criteria or could access services elsewhere were referred on.
- **Levels of service**: As the Hubs accepted more people without clinical mental health support, they connected people to their local specialist support network or encouraged the local service to see them sooner. Often the Hubs briefly engaged with these people rather than the comprehensive pathway, freeing up time to take in other referrals.
- **Allocating**: The Hub teams put time aside each week for urgent appointments, while the comprehensive assessments were ongoing. That way they felt they could be responsive to both levels of need.

Managing referrals

When a participant was referred to the Hubs, the time between a referral and an intake meeting averaged 12 days (n=273, SD=28.5). Referrals that resulted in clinical contact with the Hubs averaged 41 days between the referral and first clinical contact (n=206, SD=38.6).

Clinical advice was the leading action taken from a referral made to the Hubs (n=157, 41.6%; Table 3.1). Most services delivered by the Hubs were via video call (66.0%), with 8% of contacts conducted face to face at the time of evaluation (Table 3.2). Covid and statewide locations influenced the high use of video calls. Face to face contacts increased after covid following consumer consultations.

Table 3.2: Response to referrals

Response	n (%)
Clinical advice	157 (41.6)
Case discussion	77 (20.4)
Information	56 (14.9)
Joint assessment or consultation	53 (14.1)
Referral to other services	34 (9.0)

Source: Intellectual Disability Mental Health Hubs Minimum Data Set.
Note: n=377

Table 3.3: Mode of clinical contact

Mode	n (%)
Video call	215 (66.0)
Telephone	61 (18.7)
Face to face	26 (8.0)
Written	18 (5.5)
Combination	6 (1.8)

Source: Intellectual Disability Mental Health Hubs Minimum Data Set.
Note: n =326
Implications for referrals are included in Section 3.3.

3.2 Advice

Summary

The Hubs offered specialist advice to people and professionals who supported Hub participants. Initially the Hubs focused on support for professionals, including GPs, paediatricians and mental health and disability support services. Over time, the Hubs also gave direct advice to more families and Hub participants through their assessment and treatment plans. A strength of the Hubs was the quality of the staff.

The Hubs offered consultation to clinicians to discuss people who had not been formally referred to the Hubs. Consultation increased as the Hubs became better known and as more professionals developed a relationship with the Hubs.

Over time, the Hubs became flexible about how long they remained engaged with a person’s case, consistent with the aims of the Hubs. They followed up, conducted reviews and continued to offer advice if necessary.

3.2.1 Advice to professionals

Most referrals to the Hubs resulted in advice to professionals (3.1). The Hubs offered specialist, evidence-based advice to people supporting the person with intellectual disability and mental health challenges. These supporters included mental health clinicians, primary health clinicians like GPs and paediatricians, NDIS and other service providers and families. Hub staff said advice was tailored to each participant’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.

> Starting from the beginning is that whenever there are folk come to us as a part of the Hub we do the multidisciplinary holistic approach, full assessment and finding out what are the gaps in the services. (Hub staff)
>
> Our model of care is very much a hybrid model between direct care with a consumer and tertiary consultative service. That's either by diagnosing them correctly, giving them … appropriate medication, reducing sedating medications or by giving appropriate support, psychological strategies, behaviour support and then getting the NDIS funding right … it's really different for each person … But always we're focusing on the psychosocial

> aspects of lives and that's what often the capacity building is about. (Hub staff)

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 families. Staff said it also contributed to building the capacity of people who worked and lived with a person, like service providers and families. Referrers to the Hub reported the Hub services helped to support the person more effectively (Appendix H and interviews).

> 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 … it is more about supporting the support workers and the NDIS supports that are already in place. (Hub staff)

> Capacity building for the clinicians and the service provider, capacity building for the families and their service provider, and capacity building for the team itself and also the training registrar as well. (Hub staff)

Advice was offered to service providers when they referred a person to the Hubs or when they wanted to discuss a person who was not formally referred. Some service providers said that once they developed a relationship with the Hubs through a referral, they felt confident to approach them more informally for advice about other people. Over time, more clinicians began contacting the Hubs for advice. Seeking advice often resulted in the person being supported locally without the need for a referral to the Hubs.

> The Hubs are providing that specialist input, so it’s doctors working in mainstream health and mental health services sometimes having a specialist opinion or a second opinion about how to best help someone with an intellectual disability have their needs and health needs met. (Hub staff)

> We also are doing the phone consultation and the case discussion with the referring clinician including the paediatrician or the psychiatrist to the extent that they just send an email and say “We want to kind of pick your brain in terms of medication or for this thing.” So they know how to approach us so this is the capacity building in terms of the clinicians. (Hub staff)

Flexibility in how often and for how long people could get advice from the Hubs increased over time according to all groups that were interviewed. Instead of limiting Hub contact to 1 to 4 sessions at the beginning, the Hubs increasingly stayed involved until the participant was well supported by disability and mental health services. Examples of people staying with the Hubs longer or returning to the Hubs as needed without going through another referral process increased. Hub staff said that, after the initial intense contact:

> … we'll let things settle, try and implement – let the service implement then offering advice if we need to. Then at three months we review them again, offering an update on our diagnosis and then finding what the barriers to change are, and then we're going to see them again in a year's time. (Hubs staff)

Participant follow-up

The Hubs took a consultative model, where they continued to have a supporting role, while support coordination and case management stayed with the referring clinicians. The Hubs said they kept families and providers aware that they needed to go back to the referring clinicians.

Hub follow-up sometimes seemed to occur with one part but not with all the services or supporters involved in the participant's support. Some families asked that the Hubs follow up with them directly, as they were often responsible for carrying out the Hub recommendations. Participants and families said they wanted Hubs to follow up whether their recommendations had been implemented and for support to overcome any difficulties implementing the recommendations (Appendix H).

> I believe that they've been in contact with his mental health nurse … But it's not the mental health nurse who ensures that the recommendations are followed up … they need to also be following up with me as the carer or copying me in on those communications, so that I'm able to … add information that they might not have. (Family)

The Hubs were taking a more coordinated role following up participants over the year, by the end of the evaluation. Follow up might involve working with and providing advice to several providers.

> So [longer term follow-up] really has consequences for the ability of them to access services because the service providers change quite a lot during those periods, and we might have recommended something and we need to pass on that information from one provider to another. (Hub staff)

Implications for advice to professionals

Consider communication about follow up process with all stakeholders, including the program participants and families.

Consider the limited capacity of many families to know and access health systems when making recommendations.

3.2.2 Participant involvement in Hub advice

The Hub processes for inclusive services changed during the 3 years of the evaluation (also Section 3.3), involving the person and family. Inclusive practices increased as the Hub staff engaged in ongoing learning as they worked with people with disability, families and service providers.

Hub staff said their processes were now ‘much more tailored’ to involving the Hub participants. One Hub was also working on documenting changes to improve participant engagement and participation, which they referred to as the new model of care. Although this model was still evolving, it seemed many inclusive elements had already been incorporated into Hub practice. A participant who accessed the Hub more recently said that the Hub asked for their input at the assessment meeting.

> They asked me heaps of questions. They asked me what was important in my life and what I wanted. (Service user)

Hub participants who attended meetings and received direct advice increased during the evaluation. This increase was due to changes in procedures and environments (Section 3.3). Service providers and families proposed further improvements. Many families said that often the person with disability did not feel they were able to engage in the meetings for more than a few minutes. Some suggested splitting up the meetings or having designated times in the meetings for participant engagement. Others suggested expanding on the use of communication aids.

Implications for participant involvement

Extend the improvements in engaging participants. Consider how to best engage with each participant, finding out their preferences and using the support and expertise of family and paid carers to develop individualised engagement strategies.

3.2.3 Advice to families

The Hubs gave advice to families on how best to support the person they cared for. Advice to families happened more as the Hubs became established. The advice was often about behaviour management or medication.

> [Following Hub advice] we've done a lot of stuff with him trying to build on his social skills … and his self-regulation skills. (Family)

> The private psychiatrist who they saw told them that there was nothing that could be done with this boy. So I think that was the hopelessness the family was having. But … we were able to put a [medical] formulation together … and the family was very relieved to know that something could be done. (Hub staff)

Some families received advice on how to better look after themselves while caring for the person. They mostly found the advice useful. The quantitative results also showed that the support people were happy with the recommendations made (**Appendix H**). They also reported that they were treated with kindness and respect and were happy with how the Hubs communicated with them and the person they support. Hub staff said that support for the whole family was important and part of their service.

> It’s more a holistic approach, there’s no such thing as just the [person], it is the whole family system working together. (Hub staff)

Some families said they would like advice on how to support siblings and members of the wider family.

> Because it affects them what they are seeing [name] with his self-harming behaviours and when he’s trying to harm other people. Because with [sister] he … sticks his nails into her arm and tries to bite her, and she gets very upset about it. (Family)

Implications for advice to families

Consider support and resources appropriate to family members who might not attend Hub meetings, including for extended, blended and non-kin family structures. Sources could include social work and family support resources.

3.3 Access to the Hubs

Summary

Equitable access for participants to the Hubs continued to develop. The Hub processes became more inclusive of people from rural areas, culturally and linguistically diverse communities and Indigenous people.

Equitable access for participants to the Hubs was a process that continued to develop. Access issues included inclusiveness and access for Indigenous or culturally diverse people and people living in rural areas.

3.3.1 Inclusiveness

The Hubs considered how to make Hub meetings accessible and inclusive for people and their families, especially as they implemented their new model of care (Section **3.2.2**). The Hubs introduced new strategies to enable better inclusion and engagement of participants and families in the meetings by the end of the evaluation. Hub staff offered flexibility and choice for participants and families, with the intent to increase their feelings of safety, trust and comfort.

> 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)

Some strategies were video conferences, home visits, meeting in non-medical parts of hospitals and working with local services.

<u>Video conferences</u> – or teleconferences – were good for people who preferred them to face-to-face meetings. They were also important to manage the impact of Covid and for people in rural and remote areas, or who felt uncomfortable leaving home or having people in their home who they did not know well. Some families also did not have the time or were not able to travel or commute. Video or teleconferences were necessary options since both Hubs were located in Sydney.

> This enables the reviews to be done from where the person is so they don’t have to travel a long way, they don’t have to go to a strange building or facility, there’s not a lot of changes in visions and smells and things. (Statewide Stakeholder)

Home visits increased during the evaluation, according to Hub staff. They were offered within an hour of the Hub locations, but limited Hub resources meant they were not possible across the state. Families described why home visits were helpful.

> So [Hub staff] wanted to see him on the iPad … He didn’t know what was going on … he just kept walking away. So if they came to the home, they would get to see him more and get to know him a bit better. (Family)

> He gets very upset when we take him to the hospital. He doesn’t like hospitals. When we are driving there ... he starts crying and he hits himself and bites his hand and it’s horrible … Maybe if they could come to the home to do home visits, that would be really helpful. (Family)

Meeting in community venues or non-medical areas of hospital that were quiet and homely were more suitable. The Hubs accepted that hospitals 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.

> We only went into the Hub once, but it was a really calm environment and for people … I'm talking from [participant’s] experience, who are really heightened with sound and light, it was just quiet and it was away from the busyness of the hospital. (Family)

Working with local service providers to facilitate meetings helped meet people’s preferences. In one example, the participant and family came to their local IDMH specialist’s office, where they all engaged via video conference with the Hub team.

> We had a meeting with [IDMH team clinician] but she's down at the hospital. … we had like a video thing and I think there was three people in the room … It's better if we go [to local hospital]. [Name] gets very, very stressed if she has people visit our home. (Family)

Other strategies the Hubs could consider were:

- Moving the Hub from the hospital to a community venue
- Training more Hub staff in family/carer engagement strategies such as Circle of Security

- Accessible materials like easy read and plain English, which were in development
- Considerations for supported decision making.

Some service providers and families noticed the Hubs shifted towards engaging families and participants better. They pointed out that many people with disability could take time to build trust and might not be able to engage fully in the process.

> She hasn't got much patience, any interviews and stuff … after two minutes she's had enough. (Family)
>
> He doesn’t like to talk to people that he doesn’t know. (Family)

Sometimes video-conference connections were poor. One family said the Hub staff could not hear most of what the family said, and there was no follow-up with an alternative mode of communication. Some interviewees pointed out inequities in access to telehealth, for example when people lacked the equipment or knowledge to use video conferences.

The Hubs recognised these complexities and were continuing to improve strategies to increase family and participant engagement (Sections 3.2.2, 3.2.3).

3.3.2 Access by Indigenous, culturally diverse and rural people

As the Hubs became established, they started putting strategies in place to engage people from groups who found it more difficult to access health and mental health services. These groups were Indigenous and culturally diverse people and people from rural or remote locations. 11.9% of Hub participants were Indigenous and 7.8% were born outside Australia (Appendix E). Some strategies for access were easier referral, interpreters, easy read and in-person meetings.

Easier referral for these groups was implemented. The Hubs were assembling data about the size of these groups and their needs by the end of the evaluation. The data would be the basis for improving the referral criteria. Data were not available to the evaluation about whether people from the disadvantaged groups were given some priority access.

Interpreters were used as needed for people with disability and their families:

> We use interpreters where a client and/or family member would benefit from this. Either using the service available through [LHD] or one service local to where the person lives. For online reviews we have at times been able to engage an interpreter who can be in the same space, face to face with the client / family member to try to maximise communication. (Hub staff)

Easy read and translated resources. The Hubs were working on making their reports and resources more accessible to people with disability and their families. They also provided access to easy read and existing health resources translated into several languages, One person for whom English was a second language could read simple English found the health jargon and medical terms in reports especially challenging.

> The long spelling - lots of the long spelling words and I can't so quick understand. (Family)

Face-to-face meetings for people who preferred them were sometimes able to be arranged. Face to face (not telehealth) was still largely unavailable to people who lived a distance from the Hub locations, but a few examples were evident of the effective use of local mental health or disability support to help facilitate telehealth meetings with the Hubs (see Inclusiveness above).

The use of telehealth in cases where the person with disability or their family would prefer a face to face meeting was mainly due to resources and geographical distance. This constraint raises some concerns about the equity of access for people in rural areas and the appropriateness of access for some groups where telehealth may not appropriate, such as people from Indigenous and culturally diverse communities.

> A lot of our Indigenous families really don't feel comfortable meeting across telehealth. (Service provider)

A service provider suggested speaking with culturally diverse communities to better understand their needs and how to improve service access.

Implications for access to the Hubs

Build on the Hubs' good practice and partnerships to develop strategies

- to engage with participants and their families regardless of where they live
- to increase culturally appropriate access together with Indigenous and culturally diverse participants and families, including working with community leaders

Review telehealth access to Hubs telehealth to enhance the practice and address remaining barriers from reliance on telehealth

3.4 Assessment

Summary

When a referral to the Hubs resulted in an assessment, the Hubs took a holistic approach. The multidisciplinary team reviewed the person’s medical and social histories and met with clinicians, the participant and family, and direct service providers of the Hub participant.

Recommendations from an assessment included linking with services for long term support, medication changes and strategies for communication and to manage behaviour.

The path for some referrals was assessment by Hub staff (Section 3.1). Hub clinicians said they used a comprehensive assessment process, with a multi-disciplinary team involving specialists from psychiatry, psychology, social work and occupational therapy. The first step in the assessment process was reviewing the participant’s medical and social histories. The second step was usually a consultation meeting, or conference with the Hub participant, their family and service providers.

> 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 location and mode of the meeting were important to participants and families (Section **3.3**). Support people reported being happy with the Hubs assessment process (**Appendix H**). Joint assessments or consultations varied between the Hubs (**Appendix E**). Expanding joint practice could be a way to build capacity in the sector.

The Hubs used the information from the completed assessment to develop their recommendations. In doing so, they aimed to have a holistic approach towards improving the quality of life of participants and their families. This involved looking at the person’s whole situation, including trauma, when doing assessments and developing recommendations. For example, recommendations involved linking the person and family with other services and support for the longer term (Section **4.1.2**). In many cases, the Hubs recommended reducing the dose or number of medications. The Hubs also gave people strategies to manage behaviours and improve communication so they could participate meaningfully in their community (Section 4.1.3).

> Usually the recommendations [are for medication] which is … targeting a specific behaviour rather than just everything at once. (Hub staff)

> De-diagnosing [is] saying okay well this isn't something which you're going to treat with anti-psychotic medication, it’s actually about education. How do you interact with your housemate … rather than going down the medication route and just calling it something like schizophrenia or psychosis. (Hub staff)

Hubs prepared a report about the assessment and recommendations for providers and families. In line with their holistic approach, they were working on accessible information for Hub participants and families, for example in easy read and plain English. Despite the multidisciplinary teams in the Hubs, some service providers raised concerns that the Hubs’ medically-led teams and limited resources sometimes meant a holistic approach was difficult for the Hubs to implement in the assessment.

> Without being critical we believe that the Hubs’ consultations are mostly medically focused and not holistic ... I think they touch on those things, but they probably don’t have the time to go into those things in enough detail. (Service provider)

Implications for assessment

Provide accessible information to potential referrers as to how the Hubs work with program participants holistically.

Reflect on resourcing for multi-disciplinary expertise in the teams.

3.5 Training and supervision

Summary

Training and supervision included educational programs, resources and clinical supervision. These capacity building activities were popular and reached a wide range of professionals, mainly in mental health, and also other health and education sectors. The training emphasised holistic care.

The impact of the training was strong, with training participants saying it improved their practice. They said they appreciated the general information, and case discussions and clinical supervision which were particularly useful for problem solving. They suggested training for specific disciplines and more information about the training to reach a wider range of professionals.

Resources and training for participants and families were also starting to become available.

The Hubs training and supervision had two parts:

- educational programs and resources
- clinical supervision and training.

Many people participated in capacity building activities run by the Hubs (58,540 participants, some people participated and were counted more than once; Appendix F). Online learning (58.9%) and group supervision (20.2%) were the top two capacity building activities. Due to the intensity of the capacity building type, one to one activities (0.4%) and clinical supervision (0.4%) had the lowest participation.

Most people who participated in the capacity building activities were from mixed professional backgrounds (49.7%) and from allied health (28.0%). Fewer participants were from nursing or administration backgrounds (0.3%). Most participants were from mixed sectors, including NDIS funded services (56.6%), followed by NSW Health services (19.5%) and education (10.9%).

3.5.1 Educational programs and resources

Training programs

The Hubs offered various training programs for service providers to inform them about intellectual disability mental health, and treatment approaches that were inclusive and effective for consumers. A goal of the capacity building was to assist providers to work with people with disability holistically (**3.4**).

> So our main message is telling doctors that they need to think more … about what things outside of the person are causing the behaviour … That's a big shift in medical thinking. (Hub staff)

> We're trying to reduce levels of sedation and levels of restriction and we've … promoted a much more choice enabling strategy for … the team that's looking after someone. And promoting the independence of the person and actually listening to what people are saying. (Hub staff)

Both Hubs produced training programs that were based on international evidence, best practice and developed in consultation with potential participants.

A webinar series called Project ECHO (Enhancing Community Health Outcomes) program was attended by a range of professionals working with people with intellectual disability. They included occupational therapists, speech pathologists, behaviour support practitioners, psychologists, GPs and others. The sessions typically began with a presentation and ended with a case discussion. The training sessions were very popular.

> Now we handle at least kind of 50 to 60 registrants quite easily each series, and beyond that people would probably still be waitlisted for the next series partly just so the group dynamic – so there is an opportunity for everyone to participate really, groups beyond 50 probably get a little difficult to manage. (Hubs staff)

The Hubs also ran free Zoom conferences and workshops open to anyone with an interest in the topic. One-off sessions were delivered as requested and to specific teams, for example to LHD mental health professionals, including psychiatrists; and professional groups like nurses and psychologists. Hub staff felt an unmet need remained for tailored training for specific groups, such as paediatric teams and Child and Adolescent Mental Health Services (CAMHS). They said Hub capacity for tailored training was limited.

Psychiatry registrars were offered in-service training at the Hubs to help develop IDMH expertise in the medical community. Registrars in the interviews confirmed they found the in-service training helpful for exposing them to different assessment and treatment approaches.

Section 4.2.4 discusses the impact of the training.

Resources

An increasing range of resources about intellectual disability and mental health were created and collected by the Hubs. The resources were accessible on their websites. Several service providers in both rounds of interviews considered the Hub websites difficult to find and navigate. They said the sites were buried on the NSW Health website, and resources were not directly available but needed a separate search. This suggests the Hub websites might need to be reviewed to ensure they are easily accessible for service providers and the public.

> [On] the New South Wales Health website … it's not obvious, the link to the Hub. There's no like an obvious place that you go. "If you are looking for resources, go here or there." You sort of have to go back to Google and go down the list, rather than it being in the main [webpage]. (Service provider)

> I find the website is a bit circular and clunky. Now that it's been running for a while, it would be good to review the info and links that are listed and highlight those that will be more likely to catch the attention of clinicians looking for information and education. (Statewide stakeholder)

Hubs were increasing the training and resources available to **families**. This included delivery and access to parenting training such as Circle of Security and Triple P, which families as well as Hub staff found helpful.

> So the types of support we were offered was to run a circle of security group. … [I did] a fair few modules of it, which was incredibly useful. (Family)

3.5.2 Clinical supervision

The other type of capacity building was the more intensive clinical supervision for mental health staff. Supervision largely happened on an ad-hoc basis about an individual case, not as a general arrangement. Providers said they found it useful. Hub staff acknowledged the value of clinical supervision and regretted that their capacity to offer more was limited.

> The collaboration is usually via myself and their coordinator at the Hub, and we seem to work that out really well, like we just call or email each other quite easily and throw around ideas like … where somebody should be seen and for what reasons … they've been extremely supportive in that way. (Service provider)

Implications for training

Consider how to increase tailored training for specific stakeholders in health and disability services within resource constraints

Work with the Ministry to develop strategies to incentivise participation in training

Extend and promote the training currently available to non-clinical professionals such as in disability and education services

Increase peer to peer training among training participants, e.g. through more case studies

Review websites to improve profile and navigation

3.6 Partnerships and promotion

Summary

The Hubs built partnerships to promote their activities and to collaborate with relevant services, such as in health, mental health, disability and education, when supporting Hub participants. Promotion of the capacity building activities reached a wide range of professionals across the relevant sectors (health, mental health, education and disability). Many professionals, families and participants continued to be unaware of opportunities or how and when to seek support from the Hubs, according to the evaluation data.

The Hubs have increased the number and quality of the partnerships they built with other services. Initial partnerships developed from cooperating about individual cases. These partnerships with the Hubs now extend to engagement about improving service systems, including with the LHDs (Local Health Districts), Specialty networks (Sydney Children's Hospitals Network and Justice Health and Forensic Mental Health) and NDIS (National Disability Insurance Scheme) providers.

The Hub activities for partnerships were to:

- promote Hub services to relevant partners
- develop relationships and partnerships with LHD inpatient and community mental health services, NSW Health and private care providers and NDIS providers.

3.6.1 Promoting Hub activities

Hub training was widely promoted in mental health, other health, education and disability sectors, although fewer disability professionals participated (Appendix F). Most service providers and statewide stakeholders in the interviews were aware of the training and many completed training and encouraged colleagues to do it.

> I've completed ECHO and promote that within the service for others to complete if we have staff across the district that have an interest in working with people with an intellectual disability and mental health. (Service provider)

Some providers said they would like clearer information in the promotional material about what the training included, to encourage more clinicians to attend. Some suggested that distribution could be more targeted to organisations and team leaders so that they could promote it among their staff.

> Maybe if information went through [a trusted source] … So it's not just like an email spam, because people don't have time [to check]. (Service provider)

General promotion of Hub services occurred, including through the Hub launch, presenting the service in LHDs and sending information to mailing lists of practitioners. The Hubs had an internet presence (1.1), although many service providers found navigating these web sites difficult (**3.5**).

Some service providers and families who were interviewed said they found out about the Hubs by chance, for example when talking to a colleague or friend (**4.1.2**). Some referrers recommended better promotion of the Hubs in rural and regional areas. Some statewide stakeholders suggested a liaison point in each location so that professionals, families and participants knew who to ask about how to access IDMH services.

The least engaged stakeholders included education, parents, nursing, administration (Appendix E). The least engaged sectors were specialist disability services, parents and NDIS funded services. Some statewide stakeholders suggested that the Hubs target more promotion to NDIS providers directly for capacity building and service relationships.

Implications for promoting services

Review promotional material to include details on training

Consider adding targeted distribution of training opportunities – e.g. to team leaders and in professional newsletters

Develop strategies to ensure that Hub individual assessment and support services are known to LHDs, private practitioners and potential program participants and their families.

3.6.2 Partnerships to support Hub participants

The Hub teams said they were building partnerships with primary health services, LHDs and disability and mental health service providers.

Collaborative support for Hub participants

Partnerships were evident when the Hubs worked on individual cases together with participants, families and service providers.

> We collaborate and build partnerships with services at all phases, so initial information gathering phase, referral phase, assessment phase and the recommendation phase, and we encourage the person that we're working with to include services that they think are important to them. (Hub staff)

Many partnerships were established by the end of the evaluation. These were with educational institutions, paediatric health and some specialist intellectual disability health and IDMH Teams in the LHDs. Hub staff with forensic expertise met with Justice Health and Community Justice Program to increase collaboration and referrals between their teams.

> From a mental health perspective it's all been kind of piecemeal from other places. So there's lots of people who are at risk of going into the criminal justice system … and we are holding those cases. (Hub staff)

Towards the end of evaluation Hubs also took a more active role establishing long-term support for people through partnerships, consistent with the aims of the Hubs. Often the Hubs stayed with people and families through a change in service provider, or even were the constant contact through several changes. Hub staff gave the example of a participant who often presented to the emergency department. Their behaviour was challenging, and hospital staff, including the mental health team, did not know how to support the person well. The Hubs became involved through their clinical liaison team in the hospital, taking a wider view of the person's life and putting appropriate support in place. Once the person left hospital, the local Community Mental Health Team took responsibility. When the person moved shortly afterwards to a different area, the Hubs liaised with their new Community Mental Health Team to ensure continuing support was established. Presumably as the capacity of emergency and mental health services increases, the Hubs can step back from these types of active roles.

Mental health partnerships

Limited collaboration with and between different specialities in public health systems, especially between paediatrics and CAMHS was a concern for Hub teams, providers and stakeholders. They observed that some CAMHS were reluctant to accept children and young people with autism or intellectual disability, effectively reducing their access to appropriate mental health care. The Child Hub said they advocated for these children and young people.

> I know certain CAMHS services are a bit reluctant to see these clients, and I suppose when we've advocated with them … we're trying to paint the picture that the same kind of principles you might use in general mental health are the same for this particular population. (Hub staff)

The Hub advocacy and capacity building with CAMHS appeared to have some success. By the end of the evaluation, referrals from CAMHS increased (**4.1.2**), although Hub staff were aware that many children and young people were still turned away from some CAMHS services.

NDIS partnerships

System-level partnerships were starting to emerge by the end of the evaluation.

> We have met with the NDIS at quite senior levels … we've met with positive behaviour support practitioners to try and address this from a much higher level. So the fact that we're a statewide service really enables us to have those conversations. (Hub staff)

NDIS providers also reported that the Hubs 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

Initially, 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 few resources for networking activities, according to the interviews. 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 though they have made some connections at senior levels (Section 3.6.2). They suggested that statewide agreements were needed to improve collaboration between the NDIA, NDIS providers and NSW Health.

Implications for partnerships to support Hub participants

Continue to build relationships with mental health and other services

Continue to work with the Ministry so mental health services are aware of guidelines for inclusion of people with disability

Develop strategies to inform CAMHS of the benefits of access to appropriate mental health care for children and young people with cognitive challenges.

3.7 Data development

Summary

Data development activities were underway to inform improvements to service access for people with intellectual disability and mental health needs.

The IDMH Hub Minimum Data Set (MDS) aimed to collect consistent information about the Hub participants and activities, to track participants through the Hub services and to quantify the capacity building activities of the Hubs.

The LHD data dashboard (Mental Health in the Community) had recent data about consumers (people with intellectual disability and mental health needs) accessing mental health care in NSW Health services. The dashboard can be accessed by NSW Health staff to inform local and system responses. At September 2023, the LHD data Dashboard was not available and was undergoing changes arising from updates in Ministry of Health data warehousing.

The Hubs aim to improve data on the service usage, prevalence and access to care for people with intellectual disability. Nearly half (46.2%) of LHD and Network representatives agreed this goal had progressed (Appendix G).

Three activities were underway to collect data related to the Hubs: Minimum Data Set – MDS, LHD IDMH data dashboard and statewide IDMH key performance indicators (KPIs).

3.7.1 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 aimed to collect consistent information about the Hub participants and to track the participants through the Hub services, for example:

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

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

These data about the Hub participants and capacity building activities were important because they were not routinely captured by NSW Health through the existing reporting mechanisms.

The data captured through the MDS was 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 evaluation and research
- quantify the capacity building activities of the Hubs.

The MDS was introduced in May 2021, and the Hubs completed data for all Hub participants, including those who were referred prior to May 2021. The Hubs reported the MDS provided a range of useful information about the Hub participants in one place.

Some providers and statewide stakeholders said that they would also like the Hubs to collect and distribute data about people with intellectual disability and mental health needs, such as the number of people in this cohort and their service outcomes.

3.7.2 LHD data dashboard

The Ministry was developing a data dashboard that could be accessed by NSW Health staff to view data by service, LHD and statewide. This included regularly refreshing data about consumers with intellectual disability accessing mental health care in NSW Health services.

The dashboard development was to address the problem noted by interviewees about insufficient real-time data about people with intellectual disability and mental health issues. They said this made system responses difficult. Stakeholders and service providers suggested that data on the number of people with intellectual disability and mental health needs who presented at emergency departments would be helpful. Many interviewees in different roles noted the importance of better data for psychiatrists.

> We don’t have a clear, consistent way of recording people with intellectual disability coming into health systems. (Hub staff)

3.7.3 Key performance indicators

The Ministry was exploring key performance indicators (KPIs) 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 just Hub outputs. They said the KPIs should link directly to the Hubs’ role.

Hub staff hoped that KPI data would help to show the impact of the Hubs on LHD and disability providers and consumers. Since the Hubs deliver many indirect services, building capacity and offering consultation, the service providers were usually the ones having a direct impact on people and families. But the Hubs felt measuring their impact was important to inform the further development of the Hub model.

The NSW Health national satisfaction surveys (Your Experience of Service (YES) survey and Mental Health Carer Experience Survey (CES))[3] were not completed by most Hub participants and families. YES was inaccessible to participants. The evaluation conducted a satisfaction survey with families and carers (Appendix H).

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[3] www.health.nsw.gov.au/mentalhealth/Pages/eYES.aspx; www.health.nsw.gov.au/mentalhealth/resources/Pages/carer-experience-survey-2021-22.aspx

Implications for data development

Continue to work with the Ministry to build data sets that capture:

- complete outcomes data
- real-time data about people with intellectual disability and mental health needs
- data that measure effectiveness of the Hubs.

3.8 Research and evaluation

Summary

The Hubs distributed relevant research evidence as part of their capacity building activities.

Hub staff initiated and participated in research about clinical and capacity building activities. Future opportunities to expand research activities and evaluate the Hubs would inform statewide and national practice improvement.

Hub activities include leadership and participation in research activities about the mental health needs of children and adults with intellectual disability. While clinical support and capacity building were the primary aims of the Hubs, research was a secondary activity to build evidence for statewide practice.

The Hubs conducted internal research, such as audits of referrals, satisfaction surveys of Hub users, clinical research and research about the effectiveness of capacity building activities. Formal research included evaluation of training programs. Hub staff also conducted qualitative research to assess programs with families and participants. Hub staff contributed to academic research. The Hubs distributed relevant research to professional networks and families of Hub participants through the website and training activities.

Hub staff said they would like more time and resources to be involved in a range of potential research projects, including evaluating their own services, research into IDMH interventions and literature reviews of evidenced-based practice. The newly announced Australian Government's National Centre of Excellence in Intellectual Disability Health was a future opportunity for research collaboration.

> The Hubs are trying to be part of the bigger picture, thinking about all the work that the Ministry is doing and in 3DN [Department of Developmental Disability Neuropsychiatry UNSW] to influence the National Strategy. So we talk very regularly to the Ministry ... we have a direct line of communication from services on the ground, consumers and families straight into the Ministry. So we are changing things at that systemic level as well as doing it individually with the services on the ground. (Hub staff)

Implications for research and evaluation

Develop research strategies from the Hubs' specialised and growing expertise

Develop research expertise of staff and collaborate for research resources, e.g. grant opportunities and partnerships with research institutes

Engage in knowledge translation so the Hubs can share their learnings and expertise as leaders in this area

Ministry implement process for ongoing monitoring and evaluation of the Hubs.

4 Hub outcomes

Hub outcomes are about the impacts of the Hub activities described in Section 3 and the reasons for the achievements. The outcomes include the changes for the Hub participants, providers and the wider mental health, other health and disability systems. The outcomes reported in this section align with the program logic and 3DN analysis frameworks, Appendix B. The findings are from the interviews, linked data and surveys. Few direct quotes from participants were available, but they are prioritised in the analysis presented.

Many Hub participants felt they had a better life, many families felt involved and consulted, and many stakeholders appreciated the holistic approach taken by the Hubs.

Case study: Kylie, Linh and Cindy

Kylie was 35 years old. She has an intellectual disability and challenges with depression and anxiety. Kylie lived with her mum Linh and her grandmother Cindy. Linh came to Australia from Vietnam as an unaccompanied teenage refugee. Sometimes, when Kylie was frustrated, she yelled at her mum. Linh has PTSD and Kylie's yelling can trigger flashbacks of past traumatic experiences. Linh also has a social anxiety disorder which made it difficult to leave the house or interact with people outside her family. Kylie's grandmother, Cindy, cared for both Linh and Kylie helping them manage their mental health.

When looking for help, Cindy found that Kylie's mental health needs were not deemed to be severe or pressing enough to access public mental health services and they could not find appropriate private psychiatrist services. Cindy found out about the Hubs online and asked her GP to refer them. Kylie, Cindy and Linh joined the Hub meeting on a teleconference so Linh could join without the anxiety of leaving home. The Hub also provided an interpreter so Linh could fully participate.

The Hub organised a psychiatric assessment and medication for Kylie and set up ongoing support for both Kylie and Linh with their local mental health service. The Hub also recommended that Kylie and Linh apply for NDIS support.

Since going to the Hub, Kylie feels happier and less frustrated. She has joined a NDIS supported social group with other people with disability. Linh has psychiatric support and has been supported by NDIS to connect with a local Vietnamese refugee support group online. Cindy has joined a seniors' coffee morning and is starting to look forward to rather than dread her older years. **Appendix C**

4.1 Outcomes for Hub participants and families

Summary

The Hubs improved the wellbeing of most Hub participants and families who were interviewed. The linked data were insufficient to demonstrate significant change as measured with the Health of the Nation Outcome Scales (HoNOS) and the Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA). The samples were too small and the three month follow up period used in this study may be too short. The Hubs could use outcome measures to track the wellbeing of participants during and after contact with the Hubs.

Access to mental health services improved overall for Hub participants. Families and service providers reported satisfaction with the way Hubs linked the person with psychiatrists, local mental health services, physical health services and support for the family.

Positive treatment outcomes were achieved through a combination of medication reviews and behaviour support implemented by the local support and families.

Access to NDIS services was an outcome area that improved through recommendations in the assessment report, supporting the NDIS application process, finding suitable NDIS providers and Hub training with NDIS providers.

4.1.1 Wellbeing

Wellbeing of Hub participants

The intended Hub outcomes include improved wellbeing of people with intellectual disability and their families. Most participants and families in the interviews said the Hubs had improved their wellbeing. They described many positive changes in their daily lives. They said the main reasons for the positive changes were the holistic approach of the Hubs' multi-disciplinary team and the specialised care they received.

> [My] life has changed … It was first the worst, and now it's the better. (Hub participant)
>
> There have been some really good outcomes for [participants and] families. And the [Hubs] do cover the wellbeing, the physical mental health, the

> activities, the daily functioning, because that's the model [of the Hubs], is to understand all of those bits and pieces. (Statewide stakeholder)

According to the families, improvements to health and wellbeing were due to changes in treatment and support and advice on how to better support the participant. In contrast to the positive interview data, health and wellbeing did not significantly change as measured with the Health of the Nation Outcome Scales (HoNOS) and the Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA) (**Appendix E**). Explanations might be the small sample size (HoNOS n=42, and HoNOSCA n=23) and short follow up of 3 months. The sample size of other mental health measures with a measurement both before and after starting in the Hubs were too small to analyse or had high levels of not applicable ratings.[4] These standard outcome measures could be more extensively used to track outcomes of the Hub participants if they were regularly collected.

Some families had not seen much change in the person, and some had low expectations of change. This might be due to high complexity of the person's needs or due to changes in life stage, such as a child maturing or an adult ageing. For example, one family described how the Hub team supported them and their GP, but the person was still deteriorating due to advancing age and Alzheimer's disease. Another family said they had received helpful Hub support 2 years before, but since then the child had entered adolescence and worsened again.

> I'm aware that [name] is super-complex and it's just about chipping away slowly. We've done a little bit with [Hub] and we have to just keep doing that slowly until we find some things that resonate and work. I mean, it's very hard to help [person] who wants to do things that really aren't within his realm of potential. It's just a very frustrating place for him to be. (Family)

Some families also noted that changes to medication lost their power over time.

> We managed well for probably the first 3 to 6 months [after seeing the Hub] … We had a period of success and then it all just sort of fell apart. (Family)

The Hubs re-engaged with service users when their circumstances changed, but many families seemed unaware of this or thought that it would be unfair for them to return when other people might need the service also.

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[4] Inadequate sample with pre and post scores for the HoNOS 65+ Scale, Kessler-10 Last Three Days Scale (n=9), Kessler-10 Last Month Scale (n=36 however, 70% of the responses were reported as not applicable) Children's Global Assessment Scale (n=14) and Strengths and Difficulties Questionnaire (n ranged from 6-13 for the four scales).

> But obviously I appreciate we've had our turn and there's so many other kids who would be in the same position that we were in 3 years ago when we saw him and he changed our life. I feel like we wouldn't want to be selfish by having another go. Because I feel like we were very lucky. (Family)

Wellbeing of families

According to the family and Hub interviews, Hub support for family wellbeing included asking families how they were, encouraging them to take time for themselves and addressing the feelings of guilt or failure many families experienced. The Hubs achieved these changes by offering a validating, non-judgemental service, even when circumstances changed.

> I think being under [the Hub] has made me stronger as a mother to advocate more for my child and not feel weak, because before I used to feel, is this my fault he’s doing this. (Family)

> It did [help] at the time because I felt as though they were useful and were doing something. … But I just - I fluctuate mentally; good and bad. (Family)

One family said the Hub support on how to better manage challenging behaviour improved the mental health of the whole family. Another said the support from the Hub ‘was a real lifesaver for me’.

Implications for wellbeing

Communicate to program participants and families how to re-engage with the Hubs as their needs change

Consider how to prepare parents and young people for challenges of future developmental transitions.

4.1.2 Access to mental health services

The second outcome area for participants was access to adequate mental health services. Access to these services improved overall for Hub participants according to the interviews and some quantitative data. Families and service providers reported satisfaction with the Hubs’ ability to link the person with psychiatrists, local mental health services, physical health services and support for the family.

Mental health support through the Hubs

Hubs provided participants with specialist intellectual disability mental health services that many of them were not able to access previously, due to the shortage and the high cost of some services. For many Hub participants, this was their first access to psychiatric and other mental health services. Service providers were similarly grateful for mental health support through the Hubs, especially when they were not able to find other support options.

> 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 2 years … [The Hub staff] were fantastic, they were very quick in how they responded to the referral. (Service provider)
>
> To go to a private psychiatrist, a children's psychiatrist, for somebody who is in a low socio-economic position, would be impossible … So financially [the Hub] helps families a huge amount. (Service provider)

Public mental health services

Improved access to mental health services relied on the Hubs supporting participants and their families to access mental health services. The quantitative data indicated that the Hubs improved access for consumers to services in the community, also called ambulatory services. These included community service provided by the Hubs and other community mental health services. The main types of services used in community mental health also changed. (**Appendix E**).

Table E.12 shows that the rate of treatment days in community mental health services per month increased by 80% in the three months after commencing with the Hubs program. **Table E.15** shows the greatest increase in service use was clinical rehabilitation (12.2 times more likely than before) and consultation in a unit not funded from the mental health program (5.2 times more likely) (comparison over 90 days). This change in service types is probably because the Hubs aim to address coordination problems in all parts of the health care system, not just mental health care.

Access to mental health professionals in the community, including psychiatrists, psychologists (clinical and non-clinical) and social workers also increased (Table **E.13**).

The type of activity provided by community mental health services also changed (Table E.**14**). The greatest increase was a clinical review (8.0 times more likely than before), care planning (4.8 times more likely), case management (4.5 times more likely), and assessment (3.9 times more likely; comparison over 90 days).

A reduction in emergency department presentations by Hub participants was also evident in the quantitative analysis. The Hub participants were 28% less likely to present to an emergency department after using the Hubs (Table E.5). However, there was no significant change in the rates of admission to NSW hospitals, nor in the length of hospital stays.

> It was three [ED] presentations within the last three to four months and since the Hub got involved I think we were able to contain the whole family through family anxiety and system anxiety, that there were no further ED presentations …. After one year there was no hospital admission. (Hub staff)

Despite Hub support, the most difficult task for participants, families and providers was finding a psychiatrist, especially one trained in IDMH. Hub staff viewed the lack of psychiatrists as the largest barrier for people to access appropriate mental health support. They said more specialised training for psychiatrists, as well as psychologists, was needed. The Hubs offered in-service training to psychiatry registrars (Section **3.5**).

The fieldwork showed good outcomes when Hubs succeeded in accessing a new or different psychiatrist.

> The one outcome that was very helpful from the review was connecting with the psychiatrist that we're working with because he seems to have a good understanding. (Family)

Participants faced other barriers to accessing mental health support before and after Hub involvement according to stakeholders, providers, Hub staff and families. Some barriers to adult mental health services were evident, but the barriers appeared to be much more prevalent in CAMHS. Many children and young people were managed and treated through paediatric rather than psychiatric care.

> 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 … Hub ... the [families] … are desperate and … really need to see psychiatrists. (Service provider)

Improvements in partnerships and access to public mental health were evident during the evaluation, but further intervention was needed to achieve equal access for people with intellectual disability (Section **3.6.2**).

Access to other health services and support

Support for access to physical health and other services was another outcome area for the Hubs. Access to these services improved overall for Hub participants according to the interviews and some quantitative data. Referral to other services was the outcome of 9% of referrals to the Hubs, and provision of information was the outcome on 14.9% of referrals (Table 4.1**,** Section **3.1**).

Table 4.1: Outcome of referral

Outcome	n=377 (%)
Clinical review, consultation or advice	157 (41.6)
Case discussion	77 (20.4)
Information	56 (14.9)
Joint assessment or consultation*	53 (14.1)
Referral to other services	34 (9.0)

Note: *Higher proportion for Adult Hub

Physical health care. As part of their holistic approach, Hubs supported participants to undertake regular checkups or tests related to a physical condition, such as eyesight or hearing tests and GP visits. Hub staff said they worked this way with every participant and encouraged their local provider to continue to do the same.

> Thinking about their physical healthcare, basic stuff, asking the GP to do it. Any of our correspondence involves … what bloods to take just to keep people well generally, thinking about their annual health check and making sure that people are getting the basics done. (Hub staff)

> 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)

Carer support. The Hubs also helped families access services for themselves, such as carer peer groups and carer support and information services like Carer Gateway.

> Well, they put me onto Carer Gateway and I'm very happy that they did, because they saved me quite a bit of money … Carer Gateway's been funding the lawn mowing. (Family)

Some families said they needed more support to access other services. They said the onus was often on them to follow through on referral recommendations, and this took time and knowledge of the systems that many of them did not have.

> If I had a magic wand I would make there be like support workers, heaps of them, heaps of them that have had lived experience that can put you in contact with the right people or in fact do it for you. (Family)

Implications for access

Develop strategies, support and resources to

- assist participants and families access appropriate psychiatrists and other mental health and disability services
- increase psychiatrists' experience and training in the intellectual disability speciality

4.1.3 Treatment outcomes

Part of the direct support from the Hubs was to improve treatment outcomes, including psychotropic medication and behaviour support plans.

Medication

Medication review was part of the Hub service, and often the Hub recommendations included changes to medication. The referral criteria to the Hubs contained the ongoing involvement of a clinician or health team who could implement recommendations to ensure medication reviews were effective. Hub clinicians stressed that recommendations about medication were only a small part of their treatment advice (Sections **3.2.3, 3.4**).

> On the whole, when we explain where we're coming from and formulate in a much more holistic way, people are willing to engage with us. We are trying to reduce medications, and when you provide the evidence base for that they are - people are willing to listen to it. There is … a lot of evidence out there, and the whole Royal Commission into this, that we over-prescribe or perhaps don't give people the best chance with medication that they could have. (Hub staff)

Many Hub participants, families and service providers gave examples of where changes in medication had helped (**Appendix C**).

> At the time where we were absolutely at our wits' end … Then when we had this meeting and we tried all these different medications and we found one that was working it was like this, a fairy god mother had come down and helped us out of the situation that we were in. He was able to stop screaming, stop hurting us, which was really amazing. (Family)

> The Hub provided me with advice on how to support that family through a time of crisis, particularly around some medication changes that were helpful in that time … I know that through receiving that support and putting some of those recommendations in place that family were able to move beyond that time of crisis and that was really helpful for them. (Service provider).

> They've recognised his behaviours and were able to pinpoint his medication requirements, and that certainly had an impact on his behaviours being more manageable, and from his perspective I'm certain that the less behaviours, the more interaction with society. (Service provider)

Some service providers and stakeholders raised concerns about whether Hubs should be making recommendations to prescribers about changes to medication if the Hub was seeing a person only for a short time. Some service providers said that one or two assessments, however comprehensive, were not sufficient time to properly or safely review medication. The responsibility for medications decisions and review remained with the prescribing practitioner. Presumably the Hub preference that participants were connected to local mental health services was to avoid these risks and the Hubs see many participants more than once (Section **3.1**).

> Where the Hub is helpful is when we are stuck with use of psychotropic medications. For example, they can suggest some changes to that and advise us how to monitor it and when to make further changes. (Service provider)

Some families said the positive changes due to medication were sometimes short lived and that medication changed again as the person's circumstances changed, or they entered adolescence or became 'tolerant' of the medication. Some families revisited the Hubs for a further medication review (Section **4.1.1**).

> We came out of it with a medication that we felt was really working at the time … [now] the medication probably isn't working as well as it was. (Family)

Behaviour support

Behaviour support was another part of recommendations from the Hub multidisciplinary teams and often worked well. Behaviour support often helped with reducing medication.

> Some behavioural strategy things that we were pursuing … were really good. (Family)

> 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)

> So it was really helpful to have learnt about an alternative strategy [to a medication]. I guess that was much more palatable for the family, and that child actually has remained off [medication], and I think we really bolstered a lot of non-pharmacological supports that have really helped. (Service provider)

The quantitative data about behaviour support plans were incomplete for the Child Hub. In the Adult Hub, 55.4% of participants had a behaviour support plan. The MDS does not comment on suitability or implementation of the plan (**Appendix E**).

Family involvement in treatment

Case study: Rani

Rani had four children, two with developmental disabilities, and was the carer for her husband Tej, who had 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. 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 felt supported in her role as a mother and a carer. She was hopeful for the future as Sanjay transitioned into high school. She was able to spend more time on her hobbies and on strengthening her relationships with her other children.
Appendix C

The Hubs' holistic approach increased families' capacity to be involved in their family member's treatment and support. Families spoke about helpful advice they received for managing support at home (Section **3.2.3**).

> [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 … a sort of tailored strategic approach to managing it. (Family)
>
> 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)

A few families said the Hub did not always listen or understand the difficulties they faced. These experiences have implications for the holistic approach to support within the Hubs and for other services the families are referred to (Section 3.4).

> I feel like when it gets to a certain point, if clearly things are not working then there needs to be an escalation of care and clearly something isn't right, just reassuring me that no, no, no, you're fine, you're fine, no, no, you're fine, you're just tired, that's really unhelpful. (Family)

4.1.4 Access to NDIS support

The final outcome area for participants was improved access to NDIS funded providers through referrals and support from the Hubs. Most Hub participants received NDIS funded support (78.2%; **Appendix E, Table E.1**). Many NDIS providers participated in Hub training to improve their skills working with people with intellectual or developmental disability and mental health needs (Section **3.5.1**).

The Hubs supported access to the NDIS in many varied ways. Specific recommendations for accessing or increasing NDIS support were often included in assessment reports. Hub staff also filled out application forms together with the participant or family, supporting them to request the support they needed. Hub staff said this helped participants and families to develop their own skills in navigating the support system. Finally, Hub staff helped participants to find suitable NDIS providers for their needs.

> They [Hub] linked me up with an [NDIS support] coordinator … who is more qualified in certain fields than what the last coordinator was. They also linked me up with carers that were also more qualified to handle my conditions. (Hub participant)
>
> Even just navigating the NDIS … I was doing it all by myself, I had absolutely no idea what any of these acronyms meant, I didn't know what I was doing … since [going to the Hubs] there's been more funding, which has meant that for the first time we've got a plan coordinator. (Family)

By the end of the evaluation, the Child Hub allocated staff responsibility for NDIS coordination. This role meant that the staff assisted 80% of their participants to improve access to NDIS funding (Joint Hubs minutes).

The Hubs also supported the NDIS providers connected with Hub participants to improve their services. This improved outcomes for participants and their 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. However, communication with some NIDS providers was a problem at times, such as where the Hub recommendations did not reach the frontline staff who worked directly with the participant, according to an interview. Ways to improve liaison between the Hubs and NDIS providers continued to develop.

> We've still really not worked out how best to engage with NDIS services to provide holistic care and, you know, we're still in early stages of that really. I suppose we try to, we model it by we want the NDIS providers as well as the person and their family and their health support in the room because we have to work together. But the systems aren't very good about making sure that that happens really. (Hub staff)

Implications for NDIS support

Work with Ministry to develop a strategy for statewide NDIS liaison and agreements.

4.2 Outcomes for mental health and disability service providers

Summary

The combined approach of individual participant support, training and resources improved the capacity of mental health and disability providers to deliver quality support to people with intellectual disability and mental health needs. The impact varied by location and local resources.

When mental health clinicians worked with people with disability, this exposure changed their attitudes and confidence and gave them a framework to address the added complexity.

Coordination between professionals for integrated care was developing, based on the holistic service approach. Hubs facilitated engagement and coordination by translating between different professions.

The Hubs offered education and training to mental health clinicians through online formats. The mental health clinicians said the training changed their practice. They suggested more training options were needed to encourage colleagues to participate, such as recognition of training and more afterhours options.

Professionals used specialist support from the Hubs for individual referrals, particularly when they had fewer local resources. A local IDMH position was also important so they could coordinate specialise support from the Hubs and promote Hub capacity building to local mainstream staff, according to local and Hubs staff.

This outcome area aims to improve service providers' capacity, exposure, coordination, training and specialist support.

4.2.1 Capacity

The Hubs are intended to improve the capacity of health and mental health service providers to meet the mental health needs of people with intellectual disability. Part of this goal is to improve confidence and skills of mainstream mental health staff in working with people with intellectual disability. Capacity building was through a multi-level approach, including training and individual support.

Capacity building through a multi-level approach

The Hubs built capacity through varied approaches, including working with individual practitioners and offering group or online work such as case consultation, team training and online education programs (Sections **3.2**, **3.5**). The capacity of providers and staff improved, demonstrated in the quantitative and interview data. In the surveys, just over half of LHD and Network representatives (n=13) agreed that the Hubs had increased capacity in their District or Network about intellectual disability mental health (53.8%). Similarly, 61.5% agreed that the Hubs had improved the confidence and skills of mainstream mental health professionals working with people with intellectual disability in their District or Network (**Appendix G**). At an individual level, 88.9% of referrers said that the Hubs had helped them to support their patient more effectively (**Appendix H**).

> So that's one thing, has it changed the way we practise with carers and the children with intellectual disability? Simple answer is 'yes' … (Service provider)

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 in the interviews said that after the training, they were able to use the Hub tools with other consumers, so the capacity building became entrenched and generally changed the way the provider worked with people.

> Before I was in touch with the Hub, we just focused on the basic clinical details and trying to work out the medication only … [but] it's not just about the medical treatment. When I was working with [the Hub staff], for example he used to always emphasise the need of sensory room for a patient with autism, … trying to minimise their anxiety. Getting some simple things sorted for the patient will help them in a bigger way and they will require lesser need of medications. (Service provider)

Professionals outside mental health services, including paediatricians and disability support workers, reported similar increases in capacity. This included increased confidence to work with or treat people with intellectual disability and mental health needs, and having learnt about potential benefits of non-medication approaches.

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

Capacity building through training

Hub capacity building aimed to assist professionals to work with people with disability more holistically (Sections **3.2.1** and **3.5.1**). Many professionals found the Hub training useful and relevant to building their capacity to work with people with intellectual disability.

> I think we're changing services by shifting from a medical model into a more psychological model thinking about behaviour and people being – the things that people do in their day rather than just their illness. That's the big shift that we want to see. We're changing services from prescribing medication as their main intervention to doing other things. (Hubs staff)

> I think that the teaching sessions that they present really hammer this home about the need for collaboration and partnership and the need for sort of holistic wraparound care for families of children with ID and ASD. (Service provider)

Capacity building through individual support

Service providers who made referrals to the Hubs said the Hubs had increased their capacity through working with them to support a particular person. This was especially important in LHDs and populations that had little or no access to clinical intellectual disability mental health 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)

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 speciality, 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)
>
> There’s definitely culture change that we've seen in services who are much more open to what we're doing, they have much more knowledge now the services that we work with. So from a medical doctor perspective, people have really upskilled based on the work that we've been doing. I think that the huge area is the culture change that we are enabling … Certainly we've seen that with providers that we've worked with once or twice, they consistently have been doing what we've asked before they come to us again. So we now have a wider network of providers who have been upskilled in that area. Similarly with the community mental health teams. (Hubs staff)

Implications for future capacity building

Consider strategies to increase capacity of practitioners to work in IDMH services across the State. Suggestions include:

- short-term work placements in Hubs by mainstream mental health workers to nominate as ‘intellectual disability champions’ in community mental health teams
- Ministry set training expectations for mental health practitioners to learn to work with people with intellectual disability.

4.2.2 Exposure

The Hubs intend to increase mental health clinician exposure to working with people with intellectual disability. Nearly half (46.2%) of survey respondents agreed this was achieved in their LHD or Network (**Appendix G**). This finding probably reflects that increasing exposure was an ongoing task.

The Hubs increased exposure in the mental health sector 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 with people with intellectual disability. They said their confidence to work with people with intellectual disability was growing.

> Having that high level consultation [with the Hubs] is also embedding that sense of confidence. (Service provider)

Some providers saw that addressing misconceptions about people with intellectual disability through exposure to good practice was changing 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)

> I think we do some micro stuff in relation to culture change as well ... we attempt to model best practice in working with people with intellectual disabilities to the other professionals involved. So in a multidisciplinary case review in the way that we might interview a person with intellectual disability, in the language that we might choose when we talk about a person with intellectual disability, in the way that we might formulate or frame a case or the way we might talk about functions of behaviour, the evidence that we might cite or that we might talk about. What we try to do there is show other professionals how to work best with people with intellectual disability by doing it in front of them. (Hub staff)

Some service providers said that the Hubs demonstrated to them how to work with complexity without becoming overwhelmed by the challenge.

> When you work with a purpose and you clearly identify, … you don't get drowned in complexity of these patients …. So I think working with the Hub has provided that kind of framework and structure how to approach these patients. (Service provider)

4.2.3 Coordination

The Hubs aim to increase coordination and engagement across health and disability providers to facilitate integrated care. The level of agreement about achieving this goal remained low (38.5%) in the LHD and Network survey, and the respondents did not explain why (**Appendix G**).

In the interviews, service providers said that the Hubs were a positive step towards holistic service delivery for participants. The Hubs brought together the different people involved in a participant's wellbeing, including families, 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. They said the translating helped to engage and coordinate separate systems that often operated alone.

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

Some structural limitations to the effectiveness of Hub coordination activities were evident from the interviews. According to most statewide stakeholders, the expectations on the Hubs for coordination were unrealistic given they were ‘just two small services in one big state’. Hub staff and statewide stakeholders said it was difficult to collaborate at a statewide level with NDIS providers, as there were so many organisations. Hub staff, providers and statewide stakeholders spoke about poor collaboration with and between different specialities in public health systems – for example they said Paediatrics and CAMHS were not well engaged in integrated care. They said the Hubs had made some progress with access to children and young people’s mental health services and adult mental health services (Section **3.6.2**). The Hubs suggested they would need Ministry assistance at the statewide level to support significant change. At the time of this report, the Ministry was addressing some of the structural barriers.

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

Implications for coordination

Continue to work with the Ministry, LHD IDMH teams and mental health services to develop pathways and address service gaps for Hub participants

Consider how to expand multi-disciplinary teams in the Hubs or collaborate with physical health practitioners and with domestic violence, multi-cultural and Aboriginal services.

4.2.4 Training

The Hubs intend to improve access to targeted education and training in intellectual disability for mental health clinicians (Section **3.5.1**).

The impact from the training was strong. Most LHD and Network representatives agreed (69.2%) that the Hubs improved access to targeted education in intellectual disability mental health for mental health clinicians. Over half also agreed (61.5%) that the Hubs improved the confidence and skills of mainstream mental health professionals in working with people with intellectual disability in their district/network (Appendix G).

In the interviews, most service providers who 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 service providers interviewed said they appreciated the training content and the delivery. Most people liked the online format, as it allowed them more flexibility to participate.

> The practical and informative seminars are really helpful. They provide a theoretical approach plus a way to improve service. (Service provider)

> I really like that the recordings are there, because quite often I do watch those webinars at a much later date. (Service provider)

Some providers said the training had already changed their thinking and their practice.

> I have done a webinar about working with people with disability and … it really shaped how I understand disability and mental health ... I've done multiple webinars relating to head banging and self-injurious behaviour and I've done one on behaviour strategies as well. So how I look at behaviour and how I approach those … challenging behaviours is really from the Hub. (Service provider)

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. The case discussions in the training gave the service providers opportunities to exchange information and learn from their peers.

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

> I found the education and the case studies through the Hub and the online learning have been really, really helpful. Because we get a lot of complex clients who are very difficult to manage in the community. And just kind of looking at what are the other options, what are the other pathways, what are other clinicians doing. (Service provider)

These exchanges during training were beneficial for Hub staff too, as they learnt new information about problems and resources. This information was then fed back into the Hub services and distributed to other service providers across the state.

> It's amazing how still each week I learn so much from the training participants because they're always recommending particular programs or resources that I think "Wow, I've never heard of that, that's a fantastic one to add to the toolkit" … there are excellent suggestions by very clever people like social workers

> who are able to make suggestions to support appropriate living arrangements. (Hub staff)

Most feedback about training was positive, with some service providers and other stakeholders offering suggestions for improvement. These included: reaching out to more practitioners beyond mental health including primary health providers; providing case study model training for practitioners working with children and young people; advertising and promoting the training more widely and looking at ways to incentivise busy practitioners to do the training, such as training counting towards qualifications or mandatory training expectations.

> The ECHO training for adults, if anyone has ever been to that, is absolutely brilliant. It would be so good if we could do case studies on children like that (Service provider)

> It'd be really good if they could do training for maybe psychiatrists and GPs, you know, from a medical perspective and medication perspective. A lot of referrals that we receive are from people who kind of feel like they're at their limit of knowledge and they need somebody else as a specialist to provide some more advice about that. So I think building capacity with their colleagues would be great in terms of medications … diagnoses and how they work together. (Service provider)

> The training is great but unless there's an incentive to do it often it sits there undone and it is the incentive that it's on the service contract with the LHDs that people are trained or is there money attached to qualifications. (Service provider)

> 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)

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.

> I work with children and carers so sometimes it's beneficial as the webinars are at different times that suit family and carers and they are also recorded and posted on the Hub, which allows them access any time. (Service provider)

> I think a lot of the team here deal with a lot of difficult patients … I don't think sometimes they have the time to actually attend separate webinars and stuff. (Service provider)

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

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 intellectual disability 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. The Hubs were redesigning resources to increase access by service users and families.

Implications for training

Consider more after-hours and/or self-directed training opportunities

Consider including more lived and professional experiences in training – e.g. people with disability and people who care for or work with people with disability

Review content and promotion of capacity building resources to clarify their relevance.

4.2.5 Specialist support

The Hubs intend to improve access to specialist support for MH clinicians (Section **3.5.2**). The specialist support from the Hubs to mental health and other referring clinicians occurred in response to individual referrals. In the survey, nearly half (46.2%) the LHD and Network representatives agreed the Hubs had increased access to specialist support for mental health clinicians (**Appendix G**). Support was generally short-term about individual cases. Service providers said they benefited from the opportunity (Section **3.5.2**). Rural providers and providers without specialist IDMH staff were more likely to access the Hubs for specialist support (Section **4.2.1**).

Hub staff offered support in various ways, including direct advice, specialist regular team meetings and secondments to the Hubs (Section **3**).

> As a psychiatry registrar, as a trainee in psychiatry, having the opportunity to do a rotation on this team gives me the opportunity to improve my knowledge

> or my skills and incorporate this into my future practice and share with my peers. (Hub staff)

Specialist support to local resources

The Hub model relies on supporting specialist resources and expertise at the local level to ensure continuation of appropriate services. By the end of the evaluation, existing local IDMH resources in most LHDs – IDMH Teams or specialist positions – and the emerging collaboration with the Hubs seemed to improve specialist support to local providers. 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 said the new IDMH Teams and positions were helping embed this local expertise in their services. They saw local expertise as an important channel to coordinate individual support with the Hubs and to support Hub capacity building through specialist support to local mainstream staff.

> The Hub always takes multidisciplinary and whole of the systems approach, but it is sort of secondary. When it comes to implementation, we become the primary on the floor team holding the care of that client/family. (Service provider)

Most participants who had knowledge or experience of interaction between the Hubs and the local Intellectual Disability Health Teams felt this model was working well. Examples included participants and families accessing the Hubs via video conferencing from a local IDMH Team site where they already felt comfortable and safe; building on trust and existing relationships locally to facilitate referral and trust with Hub teams for families; and IDMH Teams going to Hubs for advice and only referring in the most complex cases.

> I think one of the changes is that we do a lot more work with the Intellectual Disability Health Teams across New South Wales, so often they're referring to us and we're referring to them and we're often jointly working together. (Hub staff)

The limitation of this model was that some LHDs did not have access to an IDMH Team or it was not always possible for the family to access a team from their LHD. Many service providers, families and statewide stakeholders also raised concerns about the capacity of the Hubs to meet expectations with their limited resources.

> I think the Hubs are doing the best that they possibly can with the very limited resources that they have. (Stakeholder)

Implications for specialist support

Ministry, Hubs and local Intellectual Disability Health Teams promote the practice of the local teams and clarify the geographical area they are responsible for, which may not coincide with the LHD they are in

4.3 Outcomes for the mental health and disability service systems

Summary

Intellectual disability and mental health as a specialty practice area was developing. Stakeholders said specialists in this area would continue to be needed in the Hubs and in local mainstream services.

New pathways for people with intellectual disability and mental health needs were emerging as the capacity of mainstream providers increased. They relied on the Hubs to support individual participants, and deliver training and resources to develop this capacity. Consumer flow in mainstream services was improving but this was an ongoing process owing to a history of access barriers and exclusion criteria, a shortage of mainstream services and discontinuity in transition from children to adult services.

Effective systems change requires participation and influence from policy and practitioners across the systems, not just the Hubs themselves. Partnerships across the systems was more challenging for the Hubs, compared to direct support and capacity building with professionals.

The final outcome area is improvements to the service systems. The evaluation indicates the Hubs had changed practices and culture in mental health and disability services. The capacity building and the model of the statewide Hubs and local IDMH resources influenced the service systems. Despite scarce resources, the Hubs seemed to work with other leaders in mental health and disability to influence improvements. Two areas of system change discussed here are intellectual disability and mental health as a speciality practice area and consumer flow within and between mental health and other parts of the social service systems.

Effective systems change requires participation and influence from policy makers and practitioners across the systems, not just the Hubs themselves. Building effective partnerships for system change was more challenging for the Hubs compared to direct support and capacity building with professionals.

4.3.1 IDMH as a specialty practice area

The Hubs intend to develop intellectual disability mental health as an area of specialty practice. Service providers and statewide stakeholders saw benefits and disadvantages of this goal. In the survey, just over half of the LHD and Network representatives agreed that the Hubs had contributed to the development of IDMH as a speciality area (53.8%; **Appendix G**). Most people in the survey and the interviews thought that some level of continued specialist support would be needed for people with intellectual disability and mental health needs. Others saw specialty practice as a 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 mental health and the hospitals. (Service provider)

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 **3.5**).

Many interviewees 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. (Statewide stakeholder)

Implications for speciality practice

Clearly communicate the dual role of Hubs as offering specialist services and building capacity in the mainstream services

Continue secondment of registrars and other professionals in Hubs to build IDMH service capacity in mainstream health services.

4.3.2 Consumer flow

The Hubs aim to improve patient flow of people with intellectual disability through acute, subacute, rehabilitation and community mental health services, and thus remove bed blocks. Only 30.8% of LHD and Network representatives in the survey agreed this goal was progressing (**Appendix G**). However, the linked data findings show that progress was made towards greater access for Hub participants to public mental health services (Section **4.1.2**).

Some providers said that one of the benefits of the Hubs was that LHDs could forge new service pathways for the flow of consumers through mental health services. They said this potential was limited by current gaps in services and uncertain referral pathways. These gaps 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 (Section **3.6.2**).

Uncertain referral pathways were another difficulty that service providers faced both centrally and locally. They had to navigate within a LHD, between LHDs and with the Hubs about who was responsible, when to make referrals and where to. Service providers said they wanted greater overall guidance about roles and referral pathways.

NSW Health policy states equal entitlement to access public mental health services for whoever needs it. Service providers said that in practice, many people with intellectual disability and autism spectrum disorder were excluded from many child and adult mental health services (Section 3.1). Many referrals to the Hubs came from non-mental health specialist clinicians rather than from mental health services.

Some statewide stakeholders and service providers said practices of exclusion stemmed from limited capacity of mental health services. They said past practice was to exclude people with intellectual disability and mental health needs with the assumption that disability services would support them; some LHD mental health services had not fully transitioned.

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.

Some providers observed a transition 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 could 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 needs were fully included and supported. They said one of their functions was to improve the capacity of Children and Young People’s Mental Health and for adult mental health services to overcome some of the practice barriers.

Implications for consumer flow

Distribute information about mental health pathways for people with intellectual disability

Develop strategies to assist young people with disability and their families to transition from paediatric and youth to adult services

Ministry to work with mental health services to explore the appropriateness of referrals from DCJ (NSW Department of Communities and Justice) and NDIS.

5 Summary and implications

Case study: Max and Lucy

Max was 15 years old. Max had Autism Spectrum Disorder, ADHD, and anxiety. When anxious, Max would pick the skin on his fingers until they bled. He was also constantly questioning things at school, which disrupted the support class, and he found it difficult to make friends. He struggled to focus in school and was often in a very anxious mood, which made learning hard for him. Max wanted to do better at school and get along with the other students in his special support class. Max first visited the Hub with his mother Lucy when he was 13 years old. The Hub provided a multidisciplinary team for Max to address his health issues and manage his behaviours. The child psychiatrist reviewed his medication.

The first year after visiting the Hubs was life changing. Max settled down at school and could concentrate on the work without being disruptive. He needed less prompting to engage in self-care and made some good friends. However, with advancing adolescence Max's behaviour regressed somewhat. The medications prescribed by the Hub appeared to be less effective and Max was becoming aggressive at school and home. Max was working with his paediatrician to trial different medication options with little success, and Max's medication continued to be under review. While Max's mother Lucy was reluctant to reengage with the Hub as she thought they had had their turn, a recent suspension from school for aggressive behaviour prompted her to reconsider engaging with the Hub.

The purpose of this report is to evaluate Hub activities and outcomes to inform future implementation. The findings indicate that the Hubs achieved success across a range of intended outcomes. In the main, Hub participants, families and service providers were positive about their experiences with the Hub processes and services.

Access to specialist and mainstream 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. Service providers and families appreciated the comprehensive assessments and specialist advice from the Hubs. Many families found Hub advice about different medication and behaviour management helpful. They said it improved the lives of the participant and family. It also built the capacity and the confidence of service providers to support people with intellectual disability.

Hub training and specialist supervision 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 improved relationships between NSW Health and NDIS, through working with professionals in both parts of the service system.

The findings raise implications for the continuing work of the Hubs. Some of the findings also have implications for the broader mainstream system. Some of the reflections on the role and impact of the Hubs reflect the need to develop improved localised pathways and this requires resourcing by LHDs and Networks.

The implications could inform refinements to the Hub services, processes and communication. Discussions could include who takes responsibility for implementing changes, where the resources might come from and who should be involved. The implications from the findings in Sections 3 and 4 are summarised by topic.

5.1 Assessments and advice to professionals

Provide accessible information to potential referrers as to how the Hubs work with program participants holistically

Reflect on resourcing for multi-disciplinary expertise in the teams

Consider communication about follow up process with all stakeholders, including the program participants and families

Consider the limited capacity of many families to know and access health systems when making recommendations.

5.2 Participant and family engagement

Extend the improvements in engaging participants. Consider how to best engage with each participant, finding out their preferences and using the support and expertise of family and paid carers to develop individualised engagement strategies

Consider support and resources appropriate to family members who might not attend Hub meetings, including for extended, blended and non-kin family structures. Sources could include social work and family support resources.

Build on the Hubs' good practice and partnerships to develop strategies

- to engage with participants and their families regardless of where they live
- to increase culturally appropriate access together with Indigenous and culturally diverse participants and families, including working with community leaders

Review access to Hubs telehealth to enhance the practice and address remaining barriers from reliance on telehealth

Communicate to program participants and families how to re-engage with the Hubs as their needs change

Consider how to prepare parents and young people for challenges of future developmental transitions.

5.3 Promoting services and specialist support

Review promotional material to include details on training

Consider adding targeted distribution of training opportunities – e.g. to team leaders, professional newsletters

Develop strategies to ensure that Hub individual assessment and support services are known to LHDs, private practitioners and potential program participants and their families

Ministry, Hubs and local IDMH teams promote the practice of the local teams and clarify the geographical area they are responsible for, which may not coincide with the LHD they are in

Clearly communicate the dual role of Hubs as offering specialist services and building capacity in the mainstream services.

5.4 Access to services and consumer flow

Develop strategies, support and resources to

- assist participants and families to access appropriate psychiatrists and other mental health and disability services
- increase psychiatrists' experience and training in the intellectual disability speciality.

Distribute information about mental health pathways for people with intellectual disability

Develop strategies to assist young people with disability and their families to transition from paediatric and youth to adult services

Ministry to work with mental health services to explore the appropriateness of referrals from DCJ (NSW Department of Communities and Justice) and NDIS.

5.5 Partnerships to support Hub participants

Continue to build relationships with mental health and other services

Continue to work with the Ministry so mental health services are aware of guidelines for inclusion of people with disability

Develop strategies to inform CAMHS of the benefits of access to appropriate mental health care for children and young people with cognitive challenges

Continue to work with the Ministry, LHD IDMH teams and mental health services to develop pathways and address service gaps for Hub participants

Consider how to expand multi-disciplinary teams or collaborate with physical health practitioners and with domestic violence, multi-cultural and Aboriginal services

Work with the Ministry to develop a strategy for statewide NDIS liaison and agreements.

Consider how mainstream capacity building in intellectual disability mental health could be supported and accelerated by each local health district.

5.6 Capacity building, training and supervision

Consider how to increase tailored training for specific stakeholders in health and disability services within resource constraints

Work with the Ministry to develop strategies to incentivise participation in training

Extend training and promotion to non-clinical professionals such as in disability and education services

Increase peer to peer training among training participants, e.g. through more case studies

Review websites to improve profile and navigation

Consider more after-hours and/or self-directed training opportunities

Consider including more lived and professional experiences in training – e.g. people with disability and people who care for or work with people with disability

Review content and promotion of capacity building resources to clarify their relevance

Consider strategies to increase capacity of practitioners to work in IDMH services across the State. Suggestions include:

- short-term work placements in Hubs by mainstream mental health workers to nominate as ‘intellectual disability champions’ in community mental health teams
- Ministry set training expectations for mental health practitioners to learn to work with people with intellectual disability

Continue secondment of registrars and other professionals in Hubs to build IDMH service capacity in mainstream health services.

5.7 Data, research and evaluation

Continue to work with the Ministry to build data sets that capture:

- complete outcomes data
- real-time data about people with intellectual disability and mental health needs
- data that measure effectiveness of the Hubs.

Develop research strategies from the Hubs’ specialised and growing expertise

Develop research expertise of staff and collaborate for research resources, e.g. grant opportunities and partnerships with research institutes

Engage in knowledge translation so the Hubs can share their learnings and expertise as leaders in this area

Ministry to implement a process for ongoing monitoring and evaluation of the Hubs.

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Appendix A Program logic for IDMH Hubs

Program aim: To give multidisciplinary support for people with complex co-occurring intellectual disability and mental health 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 intellectual disability in mainstream mental health settings Provide **clinical assessment and care recommendations** for the complex care of people with intellectual disability 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 intellectual disability (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 intellectual disability and their families Improved **access** to local and specialist mental health care for people with intellectual disability **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 intellectual disability 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 with intellectual disability Improved **confidence and skills** of mainstream mental health staff in working with people with intellectual disability	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 intellectual disability

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 intellectual disability 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 intellectual disability and mental health needs	Rights / Inclusion / Person-centred approach / Promoting independence / Recovery oriented practice / Evidence based
	3. Training	Produce educational programs and resources- Kids Webinar Series and Project ECHO Clinical supervision and training	Training and education for professionals
	4. 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

Report section	Sub-headings	Program logic	3DN Guide and Core Competency Framework
	5. Data	Develop IDMH Data dashboard Develop statewide IDMH KPI Improved data on the service usage, prevalence and access to care for people with intellectual disability	Evidence based Data collection and evaluation Inclusion in policy development
	6. Research	Leadership and participation in research activities regarding the mental health needs of people with intellectual disability	Quality improvement and professional development Research, quality improvement and professional development
Hub outcomes a) for participants	1. Wellbeing	Improved wellbeing of people with intellectual disability and their families	Promoting independence Recovery oriented practice
	2. Access	Improved access to local and specialist mental health care for people with intellectual disability **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	

Report section	Sub-headings	Program logic	3DN Guide and Core Competency Framework
b) for providers	1. Capacity	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 intellectual disability	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 intellectual disability	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 intellectual disability 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

Report section	Sub-headings	Program logic	3DN Guide and Core Competency Framework
c) for the system	1. 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
	2. Consumer 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 were written from multiple stories in the fieldwork data to protect privacy and confidentiality.

Scott and Barbara

Scott was 16 years old with diagnoses of ADHD, intellectual disability and Autism Spectrum Disorder. Barbara was his mother. Scott's behaviour was sometimes dangerous and abusive to Barbara. She was home-schooling Scott, after he was expelled for aggressive behaviour towards other students.

Barbara often felt that nobody understood how challenging caring for Scott was and that people were judging her. She often judged herself as a bad parent.

When Barbara sought support to help manage Scott's behaviour, she had difficulty finding appropriate, affordable mental health services who would see Scott. Luckily one of the mental health staff at the hospital knew about the Hubs. They made some calls and organised support to refer Scott and Barbara to the Hub.

When Barbara and Scott met with the Hub, Barbara felt she was listened to and that her role as a parent and a carer was understood. This contrasted with many past encounters with services, when she had felt invisible or judged.

The Hub reviewed and changed Scott's medication, helped Barbara to get Scott more NDIS support, including respite, occupational therapy and one-on-one support. The Hub also connected Barbara to a group of parents of children and young people with disabilities, which helped Barbara to feel less isolated.

Since going to the Hub, Scott was no longer as aggressive at home, and he was trialling a two day a week return to school. Barbara had a bit more time to do things she enjoyed and had a deep appreciation of the challenges she had faced and overcome providing support to Scott. She felt confident to stand up for herself and educate people who 'do not get it'. She no longer felt like a bad parent.

Kylie, Linh and Cindy

Kylie was 35 years old. She has an intellectual disability and challenges with depression and anxiety. Kylie lived with her mum Linh and her grandmother Cindy. Linh came to Australia from Vietnam as an unaccompanied teenage refugee. Sometimes, when Kylie was frustrated, she yelled at her mum. Linh has PTSD and Kylie's yelling can trigger flashbacks of past traumatic experiences. Linh also has a social anxiety disorder which made it difficult to leave the house or interact with people outside her family. Kylie's grandmother, Cindy, cared for both Linh and Kylie helping them manage their mental health.

When looking for help, Cindy found that Kylie's mental health needs were not deemed to be severe or pressing enough to access public mental health services and they could not find appropriate private psychiatrist services. Cindy found out about the Hubs online and asked her GP to refer them. Kylie, Cindy and Linh joined the Hub meeting on a teleconference so Linh could join without the anxiety of leaving home. The Hub also provided an interpreter so Linh could fully participate.

The Hub organised a psychiatric assessment and medication for Kylie and set up ongoing support for both Kylie and Linh with their local mental health service. The Hub also recommended that Kylie and Linh apply for NDIS support.

Since going to the Hub, Kylie feels happier and less frustrated. She has joined a NDIS supported social group with other people with disability. Linh has psychiatric support and has been supported by NDIS to connect with a local Vietnamese refugee support group online. Cindy has joined a seniors' coffee morning and is starting to look forward to rather than dread her older years.

Max and Lucy

Max was 15 years old. Max has Autism Spectrum Disorder, ADHD, and anxiety. When anxious, Max would pick the skin on his fingers until they bled. He was also constantly questioning things at school, which disrupted the support class and he found it difficult to make friends. He struggled to focus in school and was often in a very anxious mood, which made learning hard for him. Max wanted to do better at school and get along with the other students in his special support class. Max first visited the Hub with his mother Lucy when he was 13 years old. The Hub provided a multidisciplinary team for Max to address his health issues and manage his behaviours. The child psychiatrist has reviewed his medication.

The first year after visiting the Hubs was life changing. Max settled down at school and could concentrate on the work without being disruptive. He needed less prompting to engage in self-care and made some good friends. However, with advancing adolescence, Max's behaviour regressed somewhat. The medications prescribed by the Hub appeared to be less effective and Max was becoming aggressive at school and home. Max was working with his paediatrician to trial different medication options with little success and his Max's medication continued to be under review. While Max's mother Lucy was reluctant to reengage with the Hub as she thought they had their turn, a recent suspension from school for aggressive behaviour prompted her to reconsider engaging with the Hub.

Case studies in the Interim report

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 was 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 had four children, two with developmental disabilities, and was the carer for her husband Tej, who had 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. 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 felt supported in her role as a mother and a carer. She was hopeful for the future as Sanjay transitioned into high school. She was able to spend more time on her hobbies and on strengthening her relationships with her other children.

Appendix D Evaluation methods

Co-design

Co-design involved the evaluators and other stakeholders of the evaluation working together to improve the evaluation process and reports. In the Hubs evaluation, the following people took part in the co-design:

- 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, participants from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander people.

These stakeholders collaborated via meetings and e-mails. Contact was in larger or smaller groups, depending on the task. At the beginning of the evaluation, co-design was used to:

- 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 the data linkage
- finalise the sampling framework
- finalise data collection protocols and instruments for fieldwork and surveys, to reflect research practices that are culturally and ethically appropriate and generally inclusive
- engage stakeholders in the Hubs to build fieldwork relationships.

Co-design continued throughout the evaluation. It was used to adjust methodologies for second-round data collection, and to obtain feedback on all report drafts.

Program documents

The evaluation reviewed available program documents from the 2 Hubs and the Ministry. The Ministry sent the documents to the SPRC to analyse against the program logic. The documents were:

- Minutes of meetings between the Hubs and the Ministry from 2020 to 2023 (2 to 3 meetings a year)

- A table of staffing developments in the Hubs, by half-yearly intervals

These documents helped the evaluation to assess how the Hubs evolved over time, and the possible role of staffing changes in the Hubs' development.

Interviews and focus groups

The interviews and focus groups (qualitative data collection) assessed Hub activities, satisfaction, outcomes and innovation arising from the Hubs as well as opportunities to improve service quality and effectiveness. Some people wanted to take part in interviews or focus groups, but they were not able to or preferred not to. Instead, they sent written responses to the interview/focus group questions.

In the first round, many Hub participants had limited contact with the Hubs, with the Hub contact more likely to be with the family or carer or support worker. Therefore, many Hub participants were not able to talk about their experience of the Hub service. Instead they talked about changes to their mental health, function and quality of life, which may have occurred because of the Hubs. By the 2nd round of data collection, the Hubs were more focused on participant engagement and the Hub participants interviewed were able to speak about their experiences with the Hub firsthand.

The evaluators conducted 2 rounds of qualitative interviews and focus groups with stakeholders of both Hubs. The stakeholders were:

- Hub participants – people with intellectual disability and mental health needs who used 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
- state-wide stakeholders – involved in governance, advocacy or policy.

The first round of interviews was in March to May 2021 and the second round in April to May 2023. Research experience and relevant literature[5] suggest that the sample sizes in Table 2.1 were enough to allow the evaluators to capture the views and experiences of a wide range of participants. The sample size was also adequate to

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[5] 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

reach theoretical saturation. This is the point when no new findings appear, and all themes and concepts are well developed.

We spoke to Hub **participants** face-to-face unless they had other preferences. With participant permission, **families and carers** were interviewed face-to-face during the Hub visits, alternatively by phone or video. The interviews were 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 could access support before, during and after the interviews.

Hub staff and **service providers** were interviewed individually or in small groups, mostly by phone or video. Similarly, **state-wide stakeholders** such as Ministry staff, mental health and intellectual disability peak bodies and community organisations and referring partners were invited to individual interviews or small focus groups. This depended on their preferences and what was practical. Most interview were done remotely. In the first round this was main due to Covid and geographical distance. By the second round most people chose to interact over teleconference. Interviews and focus groups were semi-structured. Semi-structured means that the interviewer flexibly used a list of suggested questions. The person being interviewed could respond to the questions or just tell their story. All interview data was confidential.

We used a flexible and inclusive approach to conduct research with people with intellectual disability and mental illness. A range of accessible methods were used, including: standard interviews, observation, informal discussion, storytelling and photo stories and written or documented responses.

Interviews were conducted with easier to read questions and the use of 'Concrete Reference Tools' such as picture cards. We adapted the interviews to the person's communication needs and preferences.

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

In response to the COVID-19 pandemic, we developed strategies to help protect interview participants and researchers during fieldwork. These strategies included social distancing and hygiene measures consistent with the health advice at the time. Where participants and service providers preferred, we conducted interviews remotely.

Recruitment

Recruitment of all interview and focus group participants was at arm’s length to avoid any coercion or privacy concerns.

Hub participants: Hub participants were invited by service providers to share their experience.

Approaches included:

- Hub staff placed recruitment flyer in waiting area at the Hub
- Hub staff verbally introduce the study to current Hub participants during a consultation, and to former Hub participants by appropriate contact method, e.g. phone, letter, e-mail.
  If a Hub participant was interested, Hub staff asked whether they agreed to being contacted by the researcher and, if so, Hub staff ascertained the appropriate method of contacting the Hub participant, e.g. telephone, letter, email.
- Hub staff forwarded recruitment flyers to service providers across NSW (e.g. clinicians) who referred people to the Hubs or consulted the Hubs about particular people. The service provider could then forward the recruitment flyer to the person or verbally introduce the evaluation to them.
  If a person was interested, the service provider asked whether they agreed to being contacted by the researcher and, if so, the service provider ascertained the appropriate method of contacting the person, e.g. telephone, letter, email.

Families: Family members and carers (this included, where appropriate, Public Guardian, appointed guardian or person responsible) were approached for interview only with the consent of the Hub participant. Where appropriate, consent was sought from a person responsible or guardian to make such approaches. (Note: family carers who had the authority of the person responsible or appointed guardian provided their own consent to participate in the research). The invitation was verbal or through the recruitment flyer.

Service providers and statewide stakeholders: Hub managers identified suitable staff and service providers for the interviews/focus groups and asked them if they would like to participate. Statewide stakeholders were invited by NSW Health to participate. The invitation could be sent verbally, by e-mail or through forwarding the information and consent form.

Consent

Participation in the interviews and focus groups was voluntary. Evaluation participants had as much time as they needed to decide whether to take part. The project timeline was generous enough to avoid rushing people.

SPRC produced information sheets and consent forms about the evaluation, written in appropriate, accessible ways for the various groups of people interviewed. Service providers talked with Hub participants through the information sheets and what the evaluation involved.

Researchers collected informed consent from Hub participants (and/or guardian or person responsible), service providers and statewide stakeholders before the interviews. This could be written consent on the consent form, or verbal consent. The latter was recorded by the researcher on the verbal consent form or audio-recorded.

After each interview and focus group in round 1, we asked the evaluation participants whether we might contact them again to ask about taking part in round 2. If they agreed, this did not constitute a commitment. They were free to decline taking part when round 2 happened. We replaced round 1 participants who chose not to do a round 2 interview or focus group with other people, using the same recruitment methods as in round 1.

Linked program and outcome data

Data sources

Part 1: Heath service use patterns and outcomes before and after enrolment in the Hubs

Part1 of this study used the NSW Admitted Patient Data Collection, NSW Ambulatory Mental Health, NSW Emergency Department Data Collection, NSW Mental Health Outcomes Collection, NSW Registry of Births Deaths and Marriages and the Hubs minimum data collection.

Part 2: Capacity building activities

Part 2 of this study used the Hubs minimum data collection.

Ethics

Ethics approval was received from the NSW Population and Health Services Research Ethics Committee (2021/ETH11163) and from the AH&MRC ethics committee (1759/20).

Analysis

Part 1

We used the self-controlled case series method to compare health service use patterns, participant wellbeing and mental health outcomes before and after enrolment in the Hubs. We considered data up to one year prior to an individual's enrolment date to be the pre-exposure (control) period, and data up to three months after the enrolment date to be the post-exposure (risk) period.

Poisson regression with fixed-effect models was used to determine whether rates of health service utilisation in the post-exposure period differed from the rates in the pre-exposure period. Variables that did not vary within an individual (e.g., sex, remoteness, and socioeconomic status) was not included in the model. We chose this method because we were unable to identify a control group of people that matched the characteristics of the Hubs participants.

The analysis explored how the program impacted on health service utilisation across emergency, admitted, and community based public mental health services, including:

i) rates of emergency department presentations

ii) re-admission rates to inpatient facilities

iii) length of stay in an inpatient facility

iv) treatment days in ambulatory mental health services

Descriptive analyses were undertaken to explore the demographics of the cohort, types of emergency department presentations, community mental health services that they participated in, and health outcomes as measured on the Health of the Nations Outcome Scales (HoNOS and HoNOSCA).

The Hubs were establishing during the evaluation data period (1 year prior and 3 months post). The 3 months post may not reflect change now that the Hubs are more established.

Note: There were inadequate number of participants with pre and post scores for the Health of the Nations Outcome 65+ Scale, Kessler-10 Last Three Days Scale (n=9), Kessler-10 Last Month Scale (n=36 however, 70% of the responses were reported as not applicable) Children’s Global Assessment Scale (n=14) and Strengths and Difficulties Questionnaire (n ranged from 6-13 for the four scales).

Part 2

Descriptive analyses were completed on the available quantitative data. These analyses explored:

i) the numbers of people who participated in the activities

ii) the types of capacity building activities

iii) the professional background of people who participated in the activities

iv) which sector the people who participated in the activities came from.

Workforce capacity building survey

The aim of this survey was to measure the impact of the Hubs on the capacity of health professionals who have referred to the Hubs in the area of intellectual disability mental health.

Study design

A pre-post study design

Ethics

Ethics approval was received from Sydney Local Health District Ethics Review Committee: X20-0530 & 2020/ETH03089.

Survey tool development

The workforce capacity survey tool developed was based on the published by Weise and Trollor (https://www.tandfonline.com/doi/full/10.3109/13668250.2017.1310825). The team also added some addition question that ask specifically about the Hubs.

There were three key elements to the survey: i) demographic questions, ii) reasons for referral, and iii) attitudes, knowledge, skills, confidence and training needs in the area of intellectual disability mental health.

The survey was be made available online through Qualtrics software.

A paper-based version of the survey was also be made available at the request of participants.

Recruitment

An email invitation to take part in the survey was sent to a person when they referred to the Hubs. If the person agreed to being directly contacted by the research team, they were contacted via telephone about participating in survey. If the research team was unable to contact the person after two telephone calls, a reminder email was sent.

Consent

Referrers were provided with a copy of the information sheet via email and at the start of the survey.

The research team collected informed consent through the survey before the person participated.

Data analysis

The research team planned to conduct paired t-tests and McNemar’s tests and also use linear mixed model analysis. However, there was an inadequate number of responses to conduct these analyses.

Local Health District capability building survey

The aim of this survey was to measure the impact of the Hubs on the capacity on local health districts/networks in the area of intellectual disability mental health.

Ethics

Ethics approval was received from Sydney Local Health District Ethics Review Committee: X20-0530 & 2020/ETH03089.

Survey tool development

There survey tool mapped onto two key elements: i) demographic questions, and ii) impact of the Hubs on the districts/network’s capacity in the area of intellectual disability mental health. The questions asked in the survey tool mapped onto the project logic.

The survey was made available online through Qualtrics software.

A paper-based version of the survey was also made available at the request of participants.

Recruitment

The research team confirmed which local health districts/networks had accessed the Hubs services. The Manager of the Hubs services then used this list to invite the Mental Health Directors from each of the identified districts/networks to participate in the on-line survey. The invitation asked the Directors to nominate two representatives to participate. The two representatives included one person from child and youth, and one person from adult and older persons mental health programs. The executive assistant to the Director forwarded the invitation to participate to the nominated representatives. If the nominated representative declined to participate the executive assistant asked the Director to nominate an alternative person who is able and consents to participate.

Consent

Directors and nominated representatives were provided with a copy of the information sheet via email and at the start of the survey.

The research team collected informed consent through the survey before the person participated.

Data analysis

Descriptive and thematic analyses were completed.

Satisfaction surveys

The aim of these surveys was to measure the level of satisfaction of Hub participants, families and referrers with the Hub services that they have received.

Ethics

Ethics approval was received from Sydney Local Health District Ethics Review Committee: X20-0530 & 2020/ETH03089.

Survey tool development

Three survey tools were developed, these included on for Hub participants, families of Hub participants, and referrers to the Hub.

The survey tools were co-designed with lived experience researchers and members of the Hubs teams. The tools mapped onto two key elements: i) demographic questions, and ii) satisfaction with the Hubs service.

The surveys were made available online through Qualtrics software.

A paper-based version of the surveys was also made available at the request of participants.

Recruitment

Hub participants and their families were invited by email from a staff member at the Hubs to participate in the online survey. Invitations were sent in a joint email to Hub participants and their families.

Referrers who had had a referral accepted at a Hub service were invited by email from a staff member at the Hubs to participate in the online survey.

Consent

Participants were provided with a copy of the information sheet via email and at the start of the survey.

The research team collected informed consent through the survey before the person participated. Where required this was collected from a person’s parent or a guardian or person responsible.

Data analysis

Descriptive and thematic analyses were completed.

Appendix E Linked data results

Summary of demographics, referrals, health service use patterns before and after participation in the Hubs.

The Hubs were establishing during the evaluation data period (1 year prior and 3 months post). The 3 months post may not reflect change now that the Hubs are more established.

Table E.1: Demographics of participants in the Hubs

Variable	Category	Child Hub n=220 (%)	Adult Hub n=166 (%)	Total n=386 (%)
Sex	Female	40 (18.2)	71 (42.8)	111 (28.8)
	Male	172 (78.2)	90 (54.2)	262 (67.9)
	Missing	8 (3.6)	5 (3.0)	13 (3.4)
Indigenous status	Non-indigenous	183 (83.2)	134 (80.7)	317 (82.1)
	Indigenous	25 (11.4)	21 (12.7)	46 (11.9)
	Missing	12 (5.5)	11 (6.6)	23 (6.0)
Born in Australia	No	14 (6.4)	16 (9.6)	30 (7.8)
	Yes	198 (90.0)	145 (87.3)	343 (88.9)
	Missing	8 (3.6)	5 (3.0)	13 (3.4)
Living situation	With family	165 (75.0)	67 (40.4)	232 (60.1)
	Out of home care	22 (10.0)	N/A	
	Supported independent living	0 (0.0)	74 (44.6)	74 (19.2)
	Other *	8 (3.6)	25 (15.1)	33 (8.5)
	Unknown	25 (11.4)	0 (0.0)	25 (6.5)
Have an intellectual disability	No	95 (43.2)	20 (12.0)	115 (29.8)
	Yes	125 (56.8)	146 (88.0)	271 (70.2)
Severity of intellectual disability (n=271)	Mild	25 (20.0)	53 (36.3)	78 (28.8)
	Moderate	45 (36.0)	59 (40.4)	104 (38.4)
	Severe	33 (26.4)	29 (19.9)	62 (22.9)
	Profound	8 (6.4)	5 (3.4)	13 (4.8)

Variable	Category	Child Hub n=220 (%)	Adult Hub n=166 (%)	Total n=386 (%)
	Other	14 (11.2)	0 (0.0)	14 (5.2)
Have Autism	No	33 (15.0)	98 (59.0)	131 (33.9)
	Yes	187 (85.0)	68 (41.0)	255 (66.1)
NDIS Recipient	Yes	160 (72.7)	142 (85.5)	302 (78.2)
	No	60 (27.3)	24 (14.5)	84 (21.8)

*e.g. homeless, hospital, residential aged care, independent

NDIS: National Disability Insurance scheme

Table E.2: Outcome of referral (N=377)

Outcome	n (%)
Clinical advice	157 (41.6)
Case discussion	77 (20.4)
Information	56 (14.9)
Join assessment or consultation	53 (14.1)
Referral to other services	34 (9.0)

Table E.3: Mode of clinical contact (N=326)

Mode	n (%)
Video call	215 (66.0)
Telephone	61 (18.7)
Face to face	26 (8.0)
Written	18 (5.5)
Combination	6 (1.8)

Emergency Department Presentations to a NSW Health Facilities

Table E.4: Descriptive characteristics of emergency department presentations one year before and three months after commencing with the Hubs program (N=233).

Variable	Category	Before n (%)	After n (%)
Visit type	Emergency presentation	1296 (93.2)	224 (90.7)
	Other	94 (6.8)	23 (9.3)
Mode of arrival	State ambulance vehicle	824 (59.3)	159 (64.4)
	Private vehicle	442 (31.8)	55 (22.3)
	Police/Correctional services	95 (6.8)	28 (11.3)
	Other	29 (2.1)	5 (2.0)
Mode of separation	Admitted	259 (18.7)	33 (13.5)
	Departed	1128 (81.3)	212 (86.5)
Triage category	Resuscitation and Emergency	251 (18.1)	57 (23.1)
	Urgent	628 (45.2)	108 (43.7)
	Semi-urgent	401 (28.9)	62 (25.1)
	Non-urgent	109 (7.8)	20 (8.1)

Table E.5: Self-control case series regression analysis of the rates of emergency department presentations per person per month one year before and three months after commencing with the Hubs program (N=233).

		IRR	95% CI	p
IDMH Hubs	Before (Reference)	1	-	-
	After	0.72	0.53 – 0.96	0.03

All admitted patients to a NSW hospital

Table E.6: Rates of admitted patient episodes and length of stay per person per month one year before and three months after commencing with the Hubs program (N=168).

	Before Mean (Standard Deviation)	After Mean (Standard Deviation)
Admitted patient episode	0.10 (0.01)	0.09 (0.01)
Length of Stay for admitted patient episode	0.60 (0.01)	0.54 (0.02)

Table E.7: Regression analysis of rates of admitted patient episode per person per month one year before and three months after commencing with the Hubs program (N=168)

		IRR	95% CI	p
IDMH Hubs	Before (Reference)	1	-	-
	After	0.88	0.64 – 1.21	0.43

Table E.8: Regression analysis of length of stay per admitted patient episode per person per month one year before and three months after commencing with the Hubs program (N=168)

		IRR	95% CI	p
IDMH Hubs	Before (Reference)	1	-	-
	After	0.92	0.59-1.45	0.72

Psychiatric admissions to a NSW hospital

Table E.9: Rates of psychiatric admitted patient episodes and length of stay per person per month one year before and three months after commencing with the Hubs program (N= 63)

	Before Mean (Standard Deviation)	**After Mean (Standard Deviation)**
Psychiatric admitted patient episode	0.03 (0.01)	0.03 (0.01)
Length of Stay for psychiatric admission	0.44 (0.01)	0.39 (0.2)

Table E.10: Regression analysis of rates of psychiatric admitted patient episode per person per month one year before and three months after commencing with the Hubs program (N=63).

		IRR	**95% CI**	**p**
IDMH Hubs	Before (Reference)	1	-	-
	After	1.1	0.81 – 1.57	0.46

Table E.11: Regression analysis of length of stay for psychiatric admissions per person per month one year before and three months after commencing with the Hubs program (N=63).

		IRR	**95% CI**	**p**
IDMH Hubs	Before (Reference)	1	-	-
	After	0.88	0.43-1.81	0.73

Ambulatory Mental Health Services

Table E.12: Regression analysis of rates of ambulatory treatment days per month one year before and three months after commencing with the Hubs program (N=267)

		IRR	95% CI	p
IDMH Hubs	Before (Reference)	1	-	-
	After	1.80	1.36 – 2.39	0.00

Table E.13: Rate of provider type per 100 persons per 90 days of ambulatory mental health services one year before and three months after commencing with the Hubs program^*

Provider type	Before	After	Rate Ratio
Clinical Nurse Consultant	19	38	2.0
Clinical Nurse Specialist	28	10	0.4
Clinical Psychologist	85	323	3.8
Occupational Therapist	83	74	0.9
Psychiatric Registrar	47	408	8.6
Psychologists (non-clinical)	48	56	1.2
Registered Nurse	123	17	0.1
Social Work	60	140	2.3
Staff Specialist NOS	78	1289	16.4

^provide types of small sell sizes have been excluded from table

*Provider type is counted for all ambulatory mental health services, including the Hubs
NOS= Not otherwise specified

Table E.14: Rate of activity per 100 persons per 90 days provided by the ambulatory mental health services one year before and three months after commencing with the Hubs program^#

Activity Code*	Before	After	Rate Ratio
Administration	15	22	1.4
Assessment	86	332	3.9
Carer support	24	74	3.1
Care conference	23	71	3.1
Counselling and education	17	49	3.0
Care management, NOS	121	542	4.5
Care Planning	113	536	4.8
Psychotherapies	26	79	3.0
Documentation & report writing	142	501	3.5
Clinical review	51	405	8.0
Medication activity	51	56	1.1
Service Coordination	18	15	0.8
Triage	9	8	0.8

NOS: not otherwise specified

^activity types of small sell sizes have been excluded from table

* The code associated with the Mental Health classification value that best describes the service/activity that is being undertaken by the service provider. The activity may or may not be client related

[#] activity code is counted for all ambulatory mental health services, including the Hubs

Table E.15: Rate of principal service category of ambulatory mental health services per 100 persons per 90 days one year before and three months after commencing with the Hub Programs^#

Principal service category*	Before	After	Rate Ratio
Acute - Clinical	231	317	1.4
Consultation (to a service unit not funded from the MH program)	57	298	5.2
Emergency - Clinical	35	60	1.7
Consultation (to a MH Service Unit)	24	43	1.8
MH Service NOS	40	61	1.5
Emergency/acute - Clinical/social	12	13	1.1
Rehabilitation - Clinical	142	1736	12.2
Mental Illness Prevention	8	6	0.7
Non acute - Clinical/social	53	38	0.7
Extended - Clinical	155	144	0.9
Early intervention - Psychosis	30	18	0.6

NOS: not otherwise specified, MH: mental health
^provide types of small sell sizes have been excluded from table
* The primary purpose or treatment goal of the activity or service contact

primary service category is counted for all ambulatory mental health services, including the Hubs

Appendix F Capacity building activities

Table F.1 Capacity building participants by activity, discipline and sector

	Category	**Number of occasions (%)***
Activity type	Online learning	34,488 (58.9)
	Group supervision	11,800 (20.2)
	Formal face to face learning	7,532 (12.9)
	Other	2,832 (4.8)
	Inservice	1,416 (2.4)
	1:1 activities	236 (0.4)
	Clinical supervision	236 (0.4)
Discipline of participants	Mixed	28,864 (49.7)
	Allied Health	16,264 (28.0)
	Medical	10,300 (17.7)
	Education	1,888 (3.2)
	Parents	472 (0.8)
	Nursing	172 (0.3)
	Administration	172 (0.3)
Sector of participants	Mixed**	33,024 (56.6)
	NSW Health	11,396 (19.5)
	Education	6,372 (10.9)
	NSW Health Mental Health	3,564 (6.1)
	Higher Education Students	2,832 (4.9)
	Specialist Disability Service	472 (0.8)
	Parents	472 (0.8)
	NDIS funded services	172 (0.3)

Source: Intellectual Disability Mental Health Minimum Dataset
Note:*excludes missing and unknown data. **includes participants from the sectors below

Appendix G LHD and Network capacity building survey

Table G.1 LHD and Network capacity building survey

Question	Agree n (%)
Overall, the Hub service(s) have increased the capacity of your district/network in the area of intellectual disability mental health.	7 (53.8)
Overall, the clinical support provided by the Hub service(s) have increased the capacity of your district/network in the area of intellectual disability mental health.	7 (53.8)
Overall, the workforce development opportunities provided by the Hub service(s) have increased the capacity of your district/network in the area of intellectual disability mental health.	8 (61.5)
The Hub service(s) have increased the capacity of mental health services in your district/network to meet the mental health needs of people with intellectual disability.	6 (46.2)
The Hub service(s) have increased access to specialist intellectual disability mental health support for mental health clinicians in your district/network.	6 (46.2)
The Hub service(s) have helped to improve patient flow through acute, subacute, rehabilitation and community mental health services for people with intellectual disability in your district/network.	4 (30.8)
The Hub service(s) have increased coordination and engagement across health and disability providers to facilitate integrated care for people with intellectual disability in your district/network.	5 (38.5)
The Hub service(s) have improved access to targeted education in intellectual disability mental health for mental health clinicians in your district/network.	9 (69.2)
The Hub service(s) have increased mental health clinicians' exposure to working with people with intellectual disability in your district/network.	6 (46.2)

The Hub service(s) have improved the confidence and skills of mainstream mental health professionals in working with people with intellectual disability in your district/network.	8 (61.5)
The Hub service(s) have contributed to the development of intellectual disability mental health as an area of specialty practice.	7 (53.8)
The Hub service(s) have improved data on the service usage, prevalence, and access to care for people with intellectual disability.	6 (46.2)

Source: LHD and Network capacity building survey conducted by UNSW
Note: n=13 from 8 LHDs and Networks (8/18)

Appendix H Satisfaction surveys

Satisfaction survey distributed to referrers to the Hubs

Table H.1 Referrer demographics

Question	Response	n(%)
Hub referred to	Child Hub	6 (33.3)
	Adult Hub	12 (66.7)
Gender	Female	11 (61.1)
	Male	7 (38.9)
Practice location	Urban	9 (50.0)
	Regional / rural / remote	9 (50.0)

Source: Satisfaction survey completed by referrers to the Hubs
Note: n=18

Table H.2 Referrer satisfaction with Hub service

Question	Response	n(%)
Overall, how satisfied were you with the Hub service?	Very satisfied/satisfied	15 (83.3)
	Neutral	1 (5.6)
	Very dissatisfied/dissatisfied	2 (11.1)
How satisfied were you with the referral process?	Very satisfied/satisfied	17 (94.4)
	Neutral	0 (0.0)
	Very dissatisfied/dissatisfied	1 (5.6)
How satisfied were you with the Hub ability to link the person with other support services?	Very satisfied/Satisfied	9 (50.0)
	Neutral	3 (16.7)
	Very dissatisfied/dissatisfied	3 (16.7)
	n/a	3 (16.7)
How satisfied were you with the way the Hub team members communicated with you?	Very satisfied/satisfied	15 (83.3)
	Neutral	0 (0.0)
	Very dissatisfied/dissatisfied	3 (16.7)
Did you receive the type of support you wanted from the Hub?	Yes, definitely	9 (50.0)
	Yes, to some extent	7 (38.9)

	No, not really	2 (11.1)
	No, definitely not	0 (0.0)
Has the service helped you to support your patient more effectively?	Yes, it has helped a great deal	9 (50.0)
	Yes, it has helped somewhat	7 (38.9)
	No, it hasn’t helped much	2 (11.1)
	No, it made things worse	0 (0.0)
How satisfied were you with the way the Hub ended their service with the person?	Very satisfied/satisfied	12 (66.7)
	Neutral	2 (11.1)
	Very dissatisfied/dissatisfied	1 (5.6)
	n/a	3 (16.7)
How likely are you to recommend the hub service to your colleagues?	Very likely/likely	17 (94.4)
	Neutral	0 (0.0)
	Very unlikely/unlikely	1 (5.6)

Source: Satisfaction survey completed by referrers to the Hubs
Note: n=18

Satisfaction survey distributed to families of Hub participants

Table H.3 Family respondent demographics

	Response	n (%)
Gender	Female	15 (100)
Age	25-54 years old	9 (60.0)
	55+ years old	6 (40.0)
Hub service used	Child Hub	7 (46.7)
	Adult Hub	8 (53.3)

Note: n=15

Table H.4 Family satisfaction with Hub service

Question	Response	n (%)
How happy were you with this way of delivering the service?	Happy	13 (86.7)
	Not sure	1 (6.7)
	Unhappy	1 (6.7)
How happy were you with the assessment process (first appointment or session)?	Happy	13 (86.7)
	Not sure	0 (0.0)
	Unhappy	1 (6.7)
	The person I support didn't have an assessment	1 (6.7)
How happy were you with the treatment provided or recommendations made for the person you support?	Happy	13 (86.7)
	Not sure	1 (6.7)
	Unhappy	1 (6.7)
	The person I support didn't get treatment or receive recommendations	0 (0.0)
How happy were you with the services ability to link the person you support with other support services?	Happy	10 (66.7)
	Not sure	1 (6.7)
	Unhappy	1 (6.7)
	The person I support didn't get help to find other support services	3 (20.0)
How happy were you with the way the Hub team members communicated with you?	Happy	13 (86.7)
	Not sure	1 (6.7)
	Unhappy	0 (0.0)
	The team didn't communicate with me	1 (6.7)
How happy were you with the way the Hub team members communicated with the person you support?	Happy	11 (73.3)
	Not sure	0 (0.0)
	Unhappy	0 (0.0)
	The team didn't communicate with the person I support	4 (26.7)

Question	Response	n (%)
Did team members treat you with kindness and respect?	All of the time	15 (100.0)
	Sometimes	0 (0.0)
	Never	0 (0.0)
	I didn’t meet with the team	0 (0.0)
Did team members treat the person you support with kindness and respect? (14 responses)	All of the time	12 (85.7)
	Sometimes	0 (0.0)
	Never	0 (0.0)
	The person I support didn’t meet with the team	2 (14.3)
How happy were you with the way the Hub team member(s) transferred the care of the person you support back to the referring health professional?	Happy	9 (60.0)
	Not sure	2 (13.3)
	Unhappy	1 (6.7)
	They haven’t stopped working with the person I support	3 (20.0)
How likely are you to recommend the Hub service to others if they need similar care or treatment to the person you support?	Likely	13 (86.7)
	Neutral	0 (0.0)
	Unlikely	2 (13.3)
Overall, how happy were you with the service that the person you support received?	Happy	13 (86.7)
	Not sure	1 (6.7)
	Unhappy	1 (6.7)

Source: Satisfaction survey completed by family of Hub participants
Note: n=15