Evaluation of the Intellectual Disability Health Service

Health and Social Policy Branch,
NSW Ministry of Health

Final Report

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Acknowledgements

We also acknowledge the talent and artistry of Emma Walke, who designed the artwork for our acknowledgement of Aboriginal and Torres Strait Islander peoples. The design shows a story of connection to country and people, representing the breadth of work we do with Aboriginal and Torres Strait Islander communities across Australia. The colours represent the land, and the lines in between represent the water that connects us all.

Recognising the contribution of lived experience

We acknowledge the valuable contributions of people with disabilities, their families, carers and supporters, whose lived experiences provide critical insight into improving health services. By listening and learning from their perspectives, we gain a deeper understanding of what is important and how we can make our services more inclusive, to enhance health experiences and outcomes for all.

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ARTD consultancy team

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Contents

1. The project ---- 1
1.1 The system context ---- 1
1.2 The Intellectual Disability Health Service ---- 1
2. The evaluation ---- 5
2.1 Scope and purpose ---- 5
2.2 Key evaluation questions ---- 5
2.3 The structure of the report ---- 7
2.4 Methods ---- 8
3. Implementation of the IDHS ---- 12
3.1 How IDHS staff are delivering health assessments relative to the core service elements ---- 12
3.2 How IDHS staff are delivering capacity building ---- 18
3.3 How IDHS staff are collecting data and reporting ---- 19
3.4 Resources used for core service delivery ---- 20
3.5 Impact of IDHS governance and delivery structures on service delivery ---- 24
3.6 Factors that impacted implementation ---- 27
4. Reach of the IDHS ---- 28
4.1 Reach of comprehensive health assessments ---- 28
4.2 Reach of capacity-building supports ---- 31
4.3 The impact of governance and service delivery structures on the equity of service ---- 32
4.4 Factors that impacted reach ---- 34
5. Effectiveness of the IDHS ---- 35
5.1 Satisfaction with the overall service ---- 35
5.2 Effectiveness of comprehensive health assessments ---- 36
5.3 Effectiveness of capacity-building supports ---- 42
5.4 Effectiveness of monitoring and evaluation ---- 45
5.5 Longer-term outcomes ---- 46
6. Factors influencing the implementation, reach and outcomes of the IDHS ---- 47
7. Recommendations ---- 51
7.1 Recommendations for Ministry of Health ---- 51
7.2 Recommendations for both IDHS staff and Ministry of Health ---- 53
7.3 Recommendations for LHDs and IDHS staff ---- 55

Appendix 1. Data collection instruments ---- 57
A1.1. Interview guide for IDHS staff ---- 57
A1.2. Interview guide for other government and sector stakeholders ---- 59
A1.3. Healthcare provider survey ---- 61
A1.4. IDHS Executive Sponsor survey ---- 66
Appendix 2. Organisations represented by other government and sector interviewees ---- 67
Appendix 3. Healthcare provider survey data ---- 68
A3.1. Respondents by LHD and Hub and Spoke ---- 68
A3.2. Respondents' role and area they work in ---- 69
A3.3. Respondents by support received ---- 70
Appendix 4. Program logic ---- 71
Appendix 5. NAP data definitions ---- 72
Connect with us ---- 73

Executive summary

The Intellectual Disability Health Service

The NSW Ministry of Health (the Ministry) established the Intellectual Disability Health Service (IDHS) in 2019 to address significant barriers people with intellectual disabilities faced in accessing appropriate healthcare. Implementing a hub-and-spoke model, the service currently operates through 7 Local Health Districts (LHDs) hosting IDHS Teams (hubs) and 8 LHDs hosting IDHS Positions (spokes). The service aims to increase access to coordinated and inclusive healthcare, build confidence among people with intellectual disabilities to navigate the health system and enhance the skills and confidence of NSW Health staff and primary care providers supporting this population. Core service elements include comprehensive health assessments, capacity building for NSW Health and primary health clinicians, and partnership development with relevant health services.

What ARTD did (and didn't do)

The Health and Social Policy Branch (HSPB) in the Ministry engaged ARTD to evaluate the IDHS and how its hub-and-spoke model is working across NSW. The ARTD team designed the evaluation with the assistance of the HSPB and an evaluation working group[1] and conducted the evaluation in 2024 and 2025. The team used the Consolidated Framework for Implementation Research to guide analysis of what's helping or hindering implementation and help the recommendations. The team employed the methods outlined in Figure 1.

Figure 1: Snapshot of research methods

The evaluation focused on the operational effectiveness of the IDHS. The scope did not extend to primary data collection from people with disability as the ARTD team understood that this is the subject of a separate project. Limited data was available about the outcomes for clients. While there were discussions about the scale of the IDHS, the evaluation also did not explore how specific resources (such as staff, funding, or time) should be allocated. This warrants further consideration, particularly in relation to the IDHS's role in enhancing the accessibility of mainstream health services and its capacity-building work.

[1] The evaluation working group comprises key stakeholder representatives from the Mental Health Branch, Centre for Aboriginal Health, Agency for Clinical Innovation Intellectual Disability Health Network, Carers NSW and Council for Intellectual Disability, as well as people with lived experience.

What ARTD found

Table 1: Summary of the evaluation findings

Key evaluation question	Program logic components	Summary
Implementation		
To what extent are the resources being used to deliver the core elements of the service? a. How are different IDHS Teams and Positions leveraging successes and mitigating risks?	**Output:** Core components of care are implemented. **Output:** Clear referral pathways with GPs are in place.	**IDHS Teams and Positions are primarily delivering core elements of the service in line with the operational guidelines.** They ensure they receive referrals from GPs and other primary health clinicians; implement a multidisciplinary approach; and provide comprehensive health assessments to clients with intellectual disability and complex needs and capacity building supports to NSW Health and primary health clinicians. However, IDHS staff indicated that while they largely direct their time to these core service elements, **some of the work they undertake extends beyond the service model** – such as longer-term case management and local navigation support. IDHS staff viewed this work as necessary. However, without **further assessment, outside the scope of** this evaluation, ARTD cannot confirm whether those perceptions align with broader system requirements. Additionally, some IDHS staff noted this work reduced their capacity to take on new referrals into the service and planned capacity-building work with NSW Health and primary health clinicians. IDHS Teams and Positions identified that they **leveraged success and mitigated risks** by making use of their existing relationships, adapting their practice to meet local needs and building strong governance structures between their partner LHDs.
How do governance and delivery structures (including the structure of the hub-and-spoke model and virtual versus face-to-face delivery) impact service delivery and equity of access?	**Output:** Governance structures are established and functioning at state-wide and local levels.	The IDHS Operational Guidelines do not provide explicit guidance about the amount of clinical and capacity building activity to be provided in the Spoke LHDs. This was intended to be negotiated between LHDs through their MOU's. The Guideline provides information about the role and key responsibilities of the Teams and Positions in relation to the referral, intake and assessment process. **As such, when hub-and-spoke partnered LHDs negotiated these governance and delivery structures, some aspects enabled more effective service delivery to people with intellectual disability and complex needs**. IDHS Teams and Positions emphasised that it was not the structure of the overall service itself, but the processes they implemented within their hub-and-spoke partnerships – including holding regular meetings between the Teams (hubs) and Positions (spokes), sharing systems and processes (e.g., referrals and triaging

Key evaluation question	Program logic components	Summary
		processes) and engaging with multimodal delivery (e.g., virtual and face-to-face assessments) – that contributed to improved collaboration between the hubs and spokes. **However, while the hub-and-spoke model is designed to extend specialised services across regions, its effectiveness appeared limited when key aspects of these processes were not implemented.** For instance, when hubs and spokes did not engage in both virtual and face-to-face assessments, Spoke LHDs perceived that it led to reduced geographic equity. NSW Health non-admitted patient data between 2022 and 2024 showed that Teams saw less clients from their partner (Spoke) LHD than in their own LHD.
Reach		
What are the enablers and barriers for IDHS in reaching and delivering support to its target audience? a. For health assessments: people with intellectual disability, complex health conditions and unmet healthcare needs requiring specialised care? b. For capacity building: NSW Health and primary health clinicians receiving training,	**Output:** Clients and their families/carers access the service. **Output:** NSW Health and primary health clinicians receive training, expert advice and support on the needs of people with intellectual disability and how to appropriately support them and their families/carers.	Between 2019 and 2024, the IDHS – delivered by just over 30 full-time equivalent (FTE) staff – **supported 3,410 eligible clients through comprehensive health assessments and delivered 59,994 occasions of service.** Because there is no up-to-date data on the number of people with intellectual disability and complex needs and no reference point for benchmarking clients supported per FTE, the ARTD team was not able to assess whether the IDHS is reaching enough people. However, the consistent year-on-year increase in new clients – there was 23% growth in client numbers between 2023 to 2024 – suggests growing reach and improved access for people with intellectual disability and complex needs, many of whom may not have otherwise received support. IDHS staff also reported operating at or near capacity. **Reach to NSW Health and primary health clinicians for capacity building is less clear due to limited data**. IDHS staff reported that they spent more time on clients with intellectual disability and complex needs than on building the capacity of NSW Health staff and general practitioners. This is unsurprising given the operational guidelines advise prioritising health assessments over capacity building. **Several factors influenced the IDHS's ability to reach both clients and NSW Health and primary health clinicians:** • Staff relationships with local healthcare providers – often built through previous roles – were key enablers in building awareness of the service, and as a result reach for both comprehensive health assessments and ad hoc, incidental capacity building. • Service delivery mode also shaped access, with IDHS staff perceiving that virtual comprehensive health assessments improved equity for rural and remote clients.

Key evaluation question	Program logic components	Summary
expert advice and support on the needs of people with intellectual disability? c. How does this vary by region or hub?		• Time constraints across both Hub and Spoke LHDs limited the service's ability to meet demand for comprehensive health assessments, and the time LHDs had for planned capacity-building activities, although staff also noted less desire for these kinds of capacity building activities relative to ad hoc, incidental capacity building. Staff noted that clinicians preferred flexible, real-time support that addressed immediate needs – an approach that was better aligned with their workflows. Time constraints and limited buy-in from mainstream NSW Health and primary health staff were key barriers to planned training uptake. • System gaps, such as the lack of local navigation and longer-term case management services, placed pressure on IDHS staff to take on work beyond the IDHS Teams and Positions scope, reducing capacity for new referrals for comprehensive health assessments, capacity building activity including clinician support. **While these factors were consistent across regions, Spoke LHDs faced additional challenges due to having fewer resources.**
Experience		
What evidence exists regarding the satisfaction of clients, NSW Health and other primary health clinicians with the service provided?	**Output:** Clients and families/carers receive healthcare plans that they have been consulted on and involved in creating. **Output:** The IDHS strengthens relationships	**The IDHS delivers a highly valued and specialised service for people with intellectual disability, their families/carers and healthcare providers.** This is reflected in the healthcare provider survey respondents endorsing the service with a Net Promoter Score of 36,[2] which is a favourable result and indicates that many survey respondents would recommend the service to others. IDHS staff and government stakeholders consistently observed that when people with intellectual disability and their families/carers were aware of and able to access the service, they appreciated its contribution. Healthcare provider that responded to the survey echoed this sentiment, with most indicating they would recommend the service. Although client feedback collected by LHDs was inconsistent and limited (3 out of 15 LHDs collected clients' or their families'/carers' feedback), responses from clients with intellectual disability and their families/carers indicated that they valued the healthcare assessments provided. Among other positive aspects, respondents

[2] A score of 20 or above is view as favourable. See www.qualtrics.com/experience-management/customer/good-net-promoter-score.

Key evaluation question	Program logic components	Summary
	between NSW Health and primary health clinicians.	cited the personable nature of IDHS staff, which helped build trust and comfort, and the quality and relevance of recommendations provided during assessments. **Healthcare providers that responded to the survey and received some form of education, support or advice (capacity building) from the IDHS, value the service.** They agreed or strongly agreed that IDHS staff were knowledgeable (93%, n=72), listened to them (92%, n=72) and provided advice that was useful (86%, n=67). IDHS staff felt this was especially the case when they provided ad hoc, incidental support that allowed them to address NSW Health and primary health clinicians' immediate needs, particularly given the time pressures clinicians face.
Outcomes		
What evidence is there that intended short-term and intermediate outcomes have been observed (e.g., NSW Health and primary health clinicians are more skilled and confident in supporting people with intellectual disability and their families/carers)?	**Short-term and intermediate outcomes**	**IDHS staff reported that most clients achieved short-term and intermediate outcomes through their engagement with the IDHS**, although limited client data prevents a definitive assessment. IDHS staff observed that clients, particularly those with complex needs, benefited from the service's comprehensive health assessments and support navigating the health system. Survey responses from healthcare providers that reported their clients received comprehensive health assessments reinforce this view. Of respondents, 87% agreed or strongly agreed that IDHS assessments were comprehensive (n=20) and 76% reported that clients received clear referral pathways (n=19).[3] Similarly, healthcare provider survey respondents that had clients engage with the IDHS also noted that the service effectively supported clients and families/carers (83%, n=30), helped them navigate the health system (81%, n=37) and increased their confidence in accessing care (67%, n=24). In terms of capacity building, **healthcare providers themselves reported positive outcomes from their engagement with IDHS staff**. Most respondents (83%, n=66) knew where to access support and information, 79% (n=62) felt more knowledgeable about caring for people with intellectual disability, and 74% (n=58) felt

[3] The number of survey responses varies by question, as healthcare providers were only shown questions relevant to their experience. For example, some had not referred a client to the IDHS. A Net Promoter Score is calculated as the percentage of 'Promoters' (very satisfied customers) minus the percentage of 'Detractors' (very unsatisfied customers).

Key evaluation question	Program logic components	Summary
		more confident in providing care. Additionally, 75% (n=57) had begun applying IDHS-provided information in their practice. The **drivers of these outcomes varied**. From the perspective of IDHS staff, client success was linked to having time to establish staff relationships, access to specialist clinicians, such as psychiatrist or psychologists, and the ability to provide local navigation or longer-term case management support. Similarly, IDHS staff reported that ad hoc, incidental capacity building was seen to best support outcomes.
What evidence is there that other clinicians and GPs are contributing to these outcomes?	**Long-term outcomes**	**IDHS staff often found it difficult to comment on long-term outcomes, as these are influenced by multiple factors beyond their role and are not always directly observable.** However, in some instances, IDHS staff were able to identify examples where clinicians and GPs are contributing to the longer-term outcomes outlined in the program logic. Notable progress includes the opening of a supporting sedation pathway trial and collaboration with the Central and Eastern Sydney Primary Health Network's GROW program, where primary health clinicians are integrating capacity-building practices.
Learnings and future direction		
Which elements are most important for scaling the service effectively?		Feedback from IDHS staff highlights **several elements and processes that could be scaled to support consistent and efficient service delivery.** These elements and processes include operational practices within the IDHS but also broader, system-level enablers, some of which fall outside NSW Health's direct control or the service itself. For example: • regular communication between hubs and spokes, with weekly or fortnightly meetings, to strengthen coordination. • annual review of Memorandums of Understanding between Team and Position LHDs, to ensure alignment on roles, responsibilities and purpose. • expanding the use of virtual health assessments to improve access, especially in rural and remote areas. • ensuring all comprehensive health assessments include pre- and post-contact with clients and families/carers, to build rapport. • standardising referral processes across partnered hubs and spokes, to reduce administrative burden.

Key evaluation question	Program logic components	Summary
		• actively sharing resources, tools and expertise across IDHS Teams and Positions, to support consistency efficiency and quality.
What are future learnings for the IDHS?		Future Learnings for the IDHS are set out in Future Learning and recommendations below.

Future learnings and recommendations

The IDHS is a highly valued, specialised service, but its reach and impact for clients, families/carers and healthcare providers – across both NSW Health and primary health clinicians – is limited by growing demand, and provision of support that extends beyond the service's scope. While this evaluation identifies increasing demand as a key constraint, it also highlights a significant limitation: the absence of comprehensive data. This means the ARTD team is unable to confirm the scale and nature of demand for the IDHS, and it represents a critical gap in understanding the reach of and need for the service.

This evaluation offers the following recommendations for the NSW Ministry of Health, local health districts (LHDs) and the IDHS Teams and Positions directly involved in service delivery, including recommendations to address the data gap described above.

It is recommended that NSW Ministry of Health:

- conducts need analysis to inform IDHS planning and resourcing
- consider ongoing approaches to address current health and disability service gaps and limitations
- continues to share information to advocate for system-wide change
- map the role of the IDHS within the broader health and disability systems such as Child and Adolescent Mental Health Services, the Statewide Intellectual Disability Mental Health Outreach Service and disability navigation services.

It is recommended that both IDHS staff and NSW Ministry of Health:

- support implementation of effective practices e.g through annual review of Memorandums of Understanding, standardising referral processes across hubs and spokes and update guidelines
- strengthen collaboration between the IDHS and Statewide Intellectual Disability Mental Health Outreach Service to improve client access to psychological and psychiatric support
- increase promotion of the IDHS to improve awareness and reach
- establish formal connections with local Aboriginal communities and services including formal connections with Aboriginal Health Workers to improve LHD engagement with Aboriginal clients.

It is recommended that LHDs and IDHS staff:

- link with Local Area Coordinators and Disability Navigators to manage workload
- review IDHS workforce activity and align it with service priorities.

Chapter 7 provides further detail on each recommendation and how it links to the evaluation findings.

1. The project

1.1 The system context

The NSW health system is a complex network designed to provide a wide range of health services to all residents across the state. NSW Health operates more than 220 public hospitals. It also provides community health and other public health services for the NSW community through a network of Local Health Districts (LHDs), specialty networks and non-government affiliated health organisations.

Individuals with intellectual disability often face significant barriers to accessing health services. Sometimes healthcare professionals do not understand or effectively manage their needs. Communication difficulties and societal stigma can further complicate their ability to receive appropriate care.[4] The physical accessibility of healthcare facilities and the adaptability of health services to accommodate specific disabilities also remain challenges. Healthcare barriers contribute to disparities in health outcomes of people with intellectual disability, necessitating targeted efforts to enhance accessibility and inclusivity within the health system.

1.2 The Intellectual Disability Health Service

After piloting a specialised service for people with intellectual disability, the NSW Ministry of Health (the Ministry) established the Intellectual Disability Health Service (IDHS) in 2019. The aim of the new service was to ensure equitable access to quality healthcare for people with intellectual disability, emphasising preventive care and the efficient management of public health resources across LHDs.[5] The Ministry also established 2 Statewide Intellectual Disability Mental Health Hubs at the same time, to help children and young people and adults with intellectual disability access appropriate mental healthcare.[6]

In 2023, the *Disability Royal Commission Final Report* highlighted the importance of supporting people with disability to have equitable access to all health services.[7] Recommendation 6.33 of the report highlighted the importance for all states and territories to 'develop specialised health and mental health services for people with cognitive disability'

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[4] Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2023). *Final Report – Volume 6, Enabling Autonomy and Access*.

[5] That is, the South Eastern Sydney, Northern Sydney, South Western Sydney, Hunter New England, Western NSW, Sydney and Western Sydney LHDs.

[6] NSW Health (2024). *Statewide Intellectual Disability Mental Health Hubs*. Accessed 6 November 2024.

[7] Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2023). *Final Report – Volume 6, Enabling Autonomy and Access*.

by providing specialist assessment and clinical services as well as training and support for healthcare providers.

1.2.1 IDHS objectives and aims

The central objectives of the IDHS are to increase:

- access to coordinated and inclusive healthcare in the community for people with intellectual disability and complex needs
- the level of confidence that people with intellectual disability have in the health system
- the level of confidence, skills and relationships of healthcare staff supporting people with intellectual disability.

The IDHS does this by:

- delivering comprehensive health assessments for eligible people[8]
- building the capacity and capability of healthcare staff supporting people with intellectual disability
- working in partnership with other relevant healthcare providers.

The IDHS's comprehensive health assessments and capacity building activities are delivered with flexibility to meet the needs of both clients and healthcare staff. The below box provides a broad overview of what these may include.

Comprehensive health assessments may include:

- an assessment of client's physical, mental, and psychological health
- a review of the supports currently in place for clients; a review of medical history
- medication reviews
- a review of healthy living and preventative health factors
- a review of disability supports

[8] Individuals are eligible for the IDHS if they have an intellectual disability, or suspected (unconfirmed) intellectual disability, where there is substantial evidence to support this (including anecdotal evidence); and a GP (or other medical specialist, such as a paediatrician) who can implement the healthcare plan recommendations and follow through with care, and a complex or chronic health condition; or their current health care team need specific advice on tailored support so they can provide reasonable adjustment for the client with intellectual disability; or their current health care team need specific advice on clinical considerations related to the client's complexity; or complex circumstances; for example, relating to stability of care and supports, socio-economic status, social isolation and/or experience of trauma. See the operational guidelines for more information: https://www.health.nsw.gov.au/disability/Documents/core-service-elements.pdf

- a review of current barriers to accessing services.

Capacity building can include:

- providing joint consultation, case conferences and expert advice to NSW health and primary health clinicians on assessment and care of people.

More detail on these core elements is provided in the IDHS operational guidelines, IDHS core service elements,.

1.2.2 IDHS delivery model

The IDHS is a specialised statewide service within NSW Health designed to support people with intellectual disability to access coordinated, respectful and inclusive healthcare. The service provides comprehensive health assessments and time-limited interventions, rather than longer-term case management or routine reviews. It is designed to complement mainstream health services, stepping in when local teams face challenges in addressing complex or chronic health conditions.

The IDHS model includes a strong commitment to building the capacity of healthcare professionals across the system. It focuses on enhancing their skills, knowledge and confidence to deliver inclusive and responsive care for people with intellectual disability. This can be achieved through training, consultation and fostering collaborative relationships that support health clinicians in adapting their practice to meet diverse needs.

Eligibility for the service is based on the presence of intellectual disability with a complex or chronic health condition, and the involvement of a GP or specialist who can implement care recommendations. The model is flexible and responsive to local resources and population needs, aiming to enhance both individual outcomes and systemic capacity and capability.

The IDHS uses a hub-and-spoke model. In this model, 7 LHDs (the hubs) host the IDHS Teams, and 8 LHDs (the spokes) host partner IDHS Positions. The structure of IDHS Teams and Positions is shown in Table 2.

Table 2: IDHS Teams and Positions structure

LHD where IDHS Team is based (hub)	Partner LHD where IDHS Position is based (spoke)
Hunter New England	Central Coast
Sydney	No partner
Western Sydney	No partner
South Eastern Sydney	Illawarra Shoalhaven Nepean Blue Mountains
South Western Sydney	Southern NSW
Northern Sydney	Mid North Coast

LHD where IDHS Team is based (hub)	Partner LHD where IDHS Position is based (spoke)
	Northern NSW
Western NSW	Murrumbidgee Far West

Source: IDHS operational guidelines.

Hub LHDs are resourced to employ the IDHS Teams, while partner LHDs are resourced to employ an IDHS Position. Each IDHS Team includes approximately 4 full time equivalent (FTE) positions, a clinical nurse consultant (CNC), social worker, rehabilitation physician, psychiatrist or psychologist, paediatrician and an administration role. The IDHS Position (approximately one FTE) is typically a CNC or senior allied health professional.

The IDHS Teams and Positions work in collaboration to deliver a service for patients in the partner district. The Teams role involves:

- accepting eligible referrals from partner districts,
- hosting intake meetings where triage and prioritisation is determined,
- including partner districts in client consults, and
- sharing the healthcare plan and report with the IDHS position.

The IDHS Position's role supports this and involves:

- determining whether referrals are for eligible people,
- providing documentation and evidence to support triage,
- participating in client consultations, discussions and other activities to support the development of the report and healthcare plan, and
- progressing any actions identified for the IDHS position in the healthcare plan.

IDHS Teams may also deliver capacity building activities in their partner LHDs.

The Ministry's Health and Social Policy Branch support the IDHS. This includes convening quarterly online Network meetings with the IDHS and IDHS Workshops. The purpose of the Network is to provide a supportive space for members to connect, share resources and feedback, build professional skills and collaborate on evidence-based strategies and statewide capacity-building efforts.

2. The evaluation

2.1 Scope and purpose

Given the NSW and broader policy context, the purpose of this evaluation is to provide an understanding of the implementation and reach of the Intellectual Disability Health Service (IDHS) delivered through the hub-and-spoke model within the NSW health system. It identifies key elements for scaling the service and offers insights for continuous improvement. Additionally, the evaluation aims to assess short-term and intermediate outcomes related to governance, clinician collaboration and data-informed service delivery. The evaluation supports the intent of Recommendation 6.33 of the *Disability Royal Commission Final Report* by contributing evidence on the IDHS and informing the ongoing refinement of the service.

2.2 Key evaluation questions

The evaluation answers questions about IDHS implementation, reach, experience and outcomes, as well as provides feedback on potential learnings. The data collection methods the ARTD team used to answer the key evaluation questions (KEQs) are detailed in Table 3.

Table 3: KEQs by program logic outputs and outcomes

KEQ	
Implementation	
1. To what extent are the resources being used to deliver the core elements of the service? a. How are different IDHS Teams and Positions leveraging successes and mitigating risks?	**Output:** Core components of care are implemented. **Output:** Clear referral pathways with GPs are in place.
2. How do governance structures (including the structure of the hub-and-spoke model and virtual versus face-to-face delivery) impact service delivery and equity of access?	**Output:** Governance structures are established and functioning at state and local levels.
Reach	
3. What are the enablers and barriers for IDHS in reaching and delivering support to its target audience? a. For health assessments: people with intellectual disability, complex health conditions and unmet healthcare needs requiring specialised care? b. For capacity building: NSW Health and primary health clinicians receiving training, expert advice and support on the needs of people with intellectual disability?	**Output:** Clients and their families/carers access the service. **Output:** NSW Health and primary health clinicians receive training, expert advice and support on the needs of people with intellectual disability and how to appropriately support them and their families/carers.

KEQ	
c. How does this vary by region or hub?	
Experience	
4. What evidence exists regarding the satisfaction of clients, NSW Health and other primary health clinicians with the service provided?	**Output:** Clients and families/carers receive care plans that they have been consulted and involved in creating. **Output:** The IDHS strengthens relationships between NSW Health and primary health staff.
Outcomes	
5. What evidence is there that intended short-term and intermediate outcomes have been observed (e.g., NSW Health and primary health clinicians are more skilled and confident in supporting people with intellectual disability and their families/carers)?	All short-term and intermediate outcomes
6. What evidence is there that other clinicians and GPs are contributing to these outcomes?	Long-term outcomes
Learnings and future directions	
7. Which elements are most important for scaling the service effectively?	
8. What are future learnings for the IDHS?	

2.3 The structure of the report

The report answers all KEQs as shown in Table 4, with areas of overlap between KEQS dealt with together.

Table 4: Where the KEQs are answered

KEQ	Chapter number(s)	Chapter heading(s)
1	3	Implementation of the IDHS
1a	3, 6	Implementation of the IDHS; Factors influencing the implementation, reach and outcomes of the IDHS
2	3, 4	Implementation of IDHS; Reach of the IDHS
3	4	Reach of the IDHS
4	5	Effectiveness of the IDHS; Effectiveness of comprehensive health assessments and capacity building
5	5	Effectiveness of the IDHS; Effectiveness of comprehensive health assessments and capacity building
6	5	Effectiveness of the IDHS, Longer Term outcomes
7	6, 7	Factors influencing the implementation, reach and outcomes of the IDHS; Recommendations
8	7	Recommendations

2.4 Methods

The evaluation used a mixed methods design to answer the key evaluation questions. The methods are described in Table 5. Data collection instruments, including the IDHS staff interview guides, other government and sector stakeholder interview guides, healthcare provider survey and IDHS Executive Sponsor survey, are provided in **Appendix 1.**

Table 5: Evaluation methodology

Source	Method	Sample	Timing	Detail
Health and Social Policy Branch	Scoping interviews	n=2	Sep 24	The ARTD team conducted scoping interviews with the Executive Director and Director (Disability Youth and Paediatric Health) of the Ministry's Health and Social Policy Branch to confirm the purpose and scope of this evaluation.
Documents	Review	N/A	Oct 24 – Jan 25	The team completed a brief scan of additional documents the Health and Social Policy Branch and IDHS provided, to better understand how each of the IDHS Teams and Positions are delivering the service.
Admin data	Review	N/A	Oct 24 – May 25	**Purpose:** The team analysed de-identified administrative datasets the Health and Social Policy Branch and IDHS provided, to understand the reach of the service across the Local Health Districts (LHDs) and how satisfied clients were with the service. **Sample:** The team received NSW Health non-admitted patient (NAP) data for all LHDs from the Health and Social Policy Branch. 3/15 LHDs also provided client satisfaction survey data they collected on an ad hoc basis. **Limitations:** The team understands that the NAP data may be under-reported or inaccurately captured for some components. It also does not describe the kind of service event that has occurred, and that some data elements such as initial and subsequent data are too unreliable to be used as they are reported inconsistently across LHDs. Only some IDHS Teams gather data on client satisfaction, so this data was not provided for all LHDs. Time periods, questions asked, and response numbers varied substantially between LHD resulting in the data not being directly comparable.

Source	Method	Sample	Timing	Detail
IDHS staff	Interviews	n=15	Nov 24 – Jan 25	**Purpose:** These interviews helped the team gain perspective on how the service is being implemented across the state, the reach of the service and the outcomes being achieved. **Sample:** The team interviewed staff implementing the service from all LHDs. For Hub LHD locations, each interview was with 3 to 6 people, and for Spoke LHD locations, the team conducted individual interviews.
Government and sector stakeholders	Interviews	n=6	Feb – Mar 25	**Purpose:** These interviews built the team's understanding of the IDHS and how it fits within the NSW health system and broader disability and health ecosystem. **Sample:** The team conducted individual and group interviews with stakeholders employed in NSW Health as well as external stakeholders who have experience and extensive knowledge of healthcare and intellectual disability. Appendix 2 provides a list of the organisations represented by interviewees.
IDHS Executive Sponsors	Survey	n=10	Feb – Mar 25	**Purpose:** The aim of this survey was to gain insight into how LHD executive stakeholders view and value the IDHS. **Response rate:** 67% (n=10/15) **Sample:** IDHS Executive Sponsors (n=15) from all LHDs received the short survey. **Limitations:** Respondents completed the survey using an anonymous link without demographic data. This means the team could not attribute an LHD to the response.
Healthcare providers	Survey	n=121	Mar – Apr 25	**Purpose:** The survey aimed to explore the service's reach and how providers experienced and were impacted by the service, while also identifying contextual factors affecting these outcomes and areas for improvement. **Response rate:** 23% (n=121/529). Responses came from nurses, doctors, allied health professionals and psychologists. They worked in outpatient services, community mental health services, emergency departments and community health. Appendix 3 provides response breakdowns by the type of healthcare provider and the area they work in. **Sample:** Healthcare providers that had either referred a client with intellectual disability or received support or education (capacity building) from the IDHS. **Limitations:** The IDHS provided healthcare provider contact lists to ARTD; however, not all healthcare providers who engaged with the service were included due to incomplete records. The number of healthcare providers supplied per LHD varied widely, from as few as 4 to more than 50. A small

Source	Method	Sample	Timing	Detail
				number of healthcare provider survey respondents initially skipped the question regarding their clients' experiences with comprehensive health assessments. To address this, the survey was redistributed to those respondents with the missing questions, and more than half the respondents completed them.

2.4.1 Analysis

To answer the key evaluation questions, we analysed interview data thematically and produced descriptive statistics from survey and administrative sources. These were triangulated to generate key findings.

In addition to answering the key evaluation questions, and to provide a theory-driven lens to analysis the evaluation drew on the *Consolidated Framework for Implementation Research* to help identify key factors that have enabled or limited the implementation, reach and effectiveness of the Intellectual Disability Health Service (IDHS). The Framework identifies 5 domains that require attention for successful implementation.

1. **outer setting** – the external influences; for example, policies, funding, community needs
2. **intervention characteristics** – what is being implemented; for example, the complexity of the service
3. **inner setting** – the internal context; for example, culture, leadership, communication
4. **characteristics of the individuals** – the knowledge, beliefs and attitudes of those involved in implementation
5. **process** – how implementation is carried out; for example, planning, engaging, evaluating.

The Framework has assisted with analysis to answer KEQs 2 to 6 and identify elements of the IDHS that could be scaled or adapted, as outlined in Chapter 7. A full analysis of the IDHS against the framework is provided separately in Section 6.

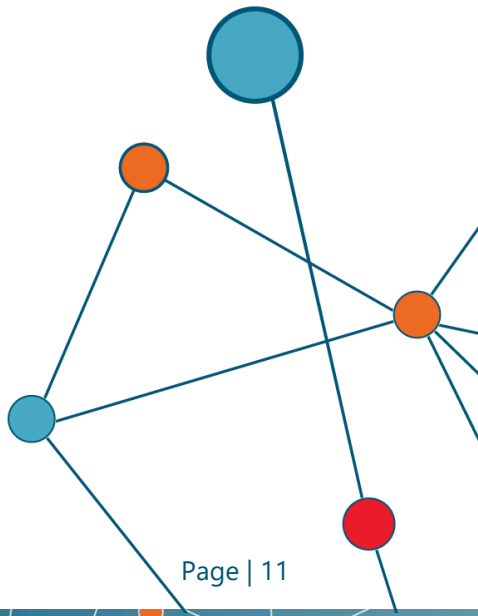
2.4.2 Confidence in evaluation findings

For this evaluation, the ARTD team used existing data and collected primary data from multiple sources to ensure it had a comprehensive understanding of the IDHS. This included qualitative insights from IDHS staff and other government and sector stakeholders, and quantitative data from administrative datasets, healthcare provider surveys and IDHS Executive Sponsor surveys.

The evaluation scope did not extend to primary data collection from people with intellectual disability and complex needs and limited administrative data was available about the outcomes for service users. The evaluation therefore focussed on the service's operational effectiveness and NSW Health accepted that the evaluation would not yield this data. ARTD understands that generating more evidence of the lived experience is the subject of a separate project.

While each data source offers valuable perspectives, there are limitations when qualitative data is considered in isolation. For example, when IDHS staff self-report service outcomes and achievements, this may introduce bias. Similarly, feedback from other government stakeholders was gathered from a small sample, which may not fully represent broader views.

To address these limitations, the team compared data across multiple data sources and held regular meetings with the evaluation working group to validate and contextualise emerging insights. This multipronged approach strengthens the team's confidence in the robustness of the findings.



3. Implementation of the IDHS

This chapter presents findings on the implementation of the Intellectual Disability Health Service (IDHS) in relation to:

- adherence to the IDHS operational guidelines (see the IDHS core service elements, a public-facing summary of the guidelines)
- the impact of governance structures on service delivery.

It aims to answer KEQ 1 and the first half of KEQ 2.

Level of program logic	Output
Output	Core components of the model of care are implemented.

3.1 How IDHS staff are delivering health assessments relative to the core service elements

All IDHS staff mentioned that when delivering core elements of the service, they adhered to the operational guidelines. Due to the flexibility of the guidelines, IDHS approaches to delivery varied by Local Health District (LHD).

3.1.1 Referrals are received from GPs or medical specialists and triaged based on clinical need

Table 6: Referral and intake

Service stage	Standard approach	IDHS delivery
Referral and intake	• Referrals are made by a GP or other medical specialist (e.g., paediatrician) using the referral form or a comprehensive referral letter. • If the client does not have a GP or equivalent to oversee their healthcare, the IDHS supports identifying an appropriate GP or equivalent as part of the intake process. • Referrals are triaged and prioritised according to clinical need and risk assessment. • Consent to service obtained from client/guardian/person responsible.	

Referrals are typically received from GPs or primary health clinicians directly by the IDHS Team or through IDHS Positions. This is reflected in the 2024 NSW Health non-admitted patient (NAP) data, which identifies GPs as the leading source of referrals, accounting for 27%. Private practitioners followed at 22%, with health services and hospitals contributing 11% and 9%, respectively. Notably, 15% of referral sources were not reported (see Table 7).

Table 7: Referral sources in 2024

Referral source	n	%
Private practice – GP	5,008	27%
Private practice – Other	4,045	22%
Health service	1,924	11%
Hospital	1,675	9%
Non-health service	668	4%
Not reported	2,810	15%
Other	2,104	12%
Total	**18,234**	**100%**

Note: Data accuracy may be impacted by inaccurate data entry.

Source: NSW Health NAP data, 2024, Q15.

Some staff observed that while GPs provided referrals to the service, disability support workers often played a crucial role in bridging the gap in awareness of the service among GPs – raising visibility, initiating contact and facilitating the GP referral process. The IDHS staff, in turn, supported GPs by providing the necessary referral forms.

These referrals are reviewed by an IDHS staff member who gathers supporting evidence to assess the potential client's eligibility for the service. Referrals are **triaged and prioritised based on clinical need and risk**, with some Teams noting the use of structured intake processes that include reviewing documentation, liaising with stakeholders and preparing clients for a clinic. In cases where a client is deemed ineligible or the referral is not accepted, some IDHS staff work collaboratively with the client and their carer or family to identify alternative local supports or services that may be more appropriate. One Team also described a process where follow-up is allocated specifically to **obtain consent** and collect relevant information from key workers. While most IDHS Teams and Positions follow the referral process of their partner LHD, inconsistencies remain. Some IDHS staff reported that the referral process is unclear or not well streamlined, particularly due to overlapping services such as the Statewide Intellectual Disability Mental Health Outreach Service (SIDMHOS) and the Child and Adolescent Mental Health Services (CAMHS). This has led to confusion among

referrers and to additional administrative burden for IDHS staff, who often spend significant time redirecting clients to the appropriate service and mitigating delays in care.

3.1.2 All Teams are implementing a multidisciplinary and collaborative approach to conducting health assessments

Table 8: Consultation

Service stage	Standard approach	IDHS delivery
Consultation	• Person-centred and trauma informed– clients and their care providers are asked about communication needs, social history, expectations. • Collaborative consultations – where appropriate, and with consent, other health care providers (e.g., GP, paediatrician, allied health care providers), school staff, support workers, NDIS service providers. • Assessment of a client's physical, mental, and psychosocial health and medical examination if required. • Consultations may be virtual (if appropriate) or in -person. • Consultations identify client's health care needs and gaps in services/supports.	

Staff appear to be actively delivering a **person-centred and trauma-informed approach** as part of the core service. Teams and positions consistently reported participating in pre-consultation engagement, where clients and their care providers are contacted to gather insights into their **healthcare needs and support gaps**. This includes discussions with referrers about the client, stakeholder meetings involving GPs, paediatricians and support services, and file reviews to understand the client's social history and care context. The use of reasonable adjustments in service delivery during the pre-consultation phase ensures that clients can engage meaningfully, and the keyworker model supports continuity and personalised care. Additionally, the emphasis on multisector case conferences before clinics reflects a commitment to understanding and planning around each individual's communication needs and broader social circumstances. These practices align strongly with trauma-informed principles and person-centred care.

All Teams adopt a **multidisciplinary and collaborative approach** to healthcare assessments, often working with a mix of health professionals within their Teams as well as external sector stakeholders such as NDIS service providers and schools. Throughout the assessment process, IDHS staff collaborate with a range of primary health clinicians, both within and outside their immediate team, to support a multidisciplinary model of care, often including registered nurses, allied health professionals, doctors and psychologists or psychiatrists. In some LHDs, this collaboration extends beyond the health sector to include stakeholders from other sectors such as education and community and justice services during case conferences, ensuring clients receive the most holistic and effective care possible. Some IDHS staff also

reported that the psychologist and psychiatrist role within the IDHS Team provided a more comprehensive, timelier and coordinated health assessment. When this role was vacant due to resignations, leave and challenges recruiting psychologist and psychiatrists, the IDHS Teams referred to the Intellectual Disability Mental Health Hub, a longer process for clients and their carers.

Service delivery across IDHS Teams demonstrates significant variation in both mode and structure, with a strong emphasis on flexibility and responsiveness to client needs. While some Teams continue to deliver assessments exclusively in person, others have adopted a hybrid model that includes both in-person and virtual consultations. The mode is dependent on a range of factors including their willingness to provide multi-modal support, client circumstances and regional accessibility, with hubs in remote LHDs more reliant on virtual assessments. The variability in virtual versus in-person delivery is evident in the NSW Health NAP data. Over the 2022–2024 calendar period, one hub LHD delivered 94% of its occasions of service virtually and just 6% in person, while another hub LHD delivered 81% in person and 19% virtually.[9] Teams also adapt by conducting clinics in outreach locations or meeting families/carers halfway to reduce travel burdens. In regional and rural areas, where access is limited, services are often delivered virtually, and some Teams do not adhere to fixed appointment times or locations, instead prioritising client readiness and availability.

3.1.3 Healthcare plans are a core practice, but the processes for conducting them vary across Teams

Table 9: Report and healthcare plan

Service stage	Standard approach	IDHS delivery
Report and healthcare plan (with recommendations)	• Together with the client and their family/carer, a detailed healthcare plan is developed based on a report which summarises the assessment. • The IDHS provides the client (and as appropriate, and with consent) their carer and family, treating team and GP with a copy of the healthcare plan and report. • The IDHS may contact the referrer and/or other health/disability professionals to discuss the recommendations/care plan. • The IDHS contacts other health/disability professionals to discuss the healthcare plan and report.	

IDHS Teams deliver both a comprehensive report and a tailored healthcare plan with recommendations for referrals and ongoing care. IDHS staff report this is a core part of service delivery, though the specific processes and level of formality vary.

[9] NSW Health NAP data, 2022-2024, Q28.

All Teams develop a clinic report following the client's assessment, which forms the basis for a healthcare plan. This report is typically **shared with the client's GP and guardian**, and Teams describe **engaging with the client and their family or carer to inform the development of the plan**. The extent to which this process is collaborative and consistently includes all relevant parties differs across locations, depending on team structure and available resources.

IDHS staff noted that they **engage with referrers and other healthcare or disability professionals** to discuss recommendations and coordinate care. This includes stakeholder meetings with GPs, paediatricians and support services, as well as multisector case conferences held before clinics to map out complex cases. IDHS staff also reported that healthcare plans often include **referrals to other specialist health services** (for example, allied healthcare, mental healthcare), additional assessments (for example, behavioural or sensory) and practical recommendations for primary care providers, such as medication changes or support strategies. In some cases, IDHS staff also provide advice on linking clients to community or disability services. While these practices align with the intended service elements, the consistency of implementation across all Teams is not always clear, and some processes may be more developed or formalised in certain locations than in others.

3.1.4 Some Teams provide time-limited clinical care, while others engage in longer-term case management

Table 10: Time-limited clinical care

Service stage	Standard approach	IDHS delivery
Time-limited clinical care	• If required, time-limited clinical care (virtual or in person) may be provided by the IDHS e, g. medical, nursing, psychiatric treatment, and/or counselling services.	**Partially**

Some IDHS Teams reported that they provide **time-limited clinical care**, both virtually and in-person, depending on client needs and service capacity, while others do not. This includes medical input in health assessments and follow-up appointments. This indicates that time-limited care is not consistently applied across all Teams. Some staff described providing more intensive, longer-term clinical involvement and case management – especially for clients with complex needs. This variation highlights that while time-limited care is a feature of the model, the duration and intensity of clinical involvement often depend on the team's structure and capacity, the specific needs of the client and the availability of other local services and/or supports. Please see Section 3.4.2 on case management.

3.1.5 Most Teams actively follow-up with their clients, recognising this as a vital component of delivering effective support and care

Table 11: Discharge and follow-up

Service stage	Standard approach	IDHS delivery
Discharge	• The client is discharged from the service when the assessment has been completed, the report and the healthcare plan communicated, and any appropriate referrals made by the IDHS. • Before discharge, the IDHS will advise the client and their carer/family to continue care and follow-up with the primary treating clinician/team. • A discharge letter may also be provided to referrer, client/family and other relevant parties.	
Follow-up	• Within 3–6 months of discharge, and at the discretion of the IDHS, they may follow-up with the referrer or client. • Primary care physicians can seek further advice from the IDHS on discharged clients.	

Once the appropriate actions from the healthcare plan have been implemented, IDHS Teams generally discharge the client. In line with core service expectations, some Teams reported that they ensure that the **report and recommendations are shared** with the GP and relevant parties, and that appropriate referrals are made prior to discharge. Most IDHS Teams and Positions also conduct a **follow-up** with the client and/or their carer or family to confirm that the recommendations are relevant and that the client is receiving the necessary care and support. Staff consistently emphasised that follow-up is a critical component of ensuring continuity of care and successful implementation of recommendations.

However, IDHS staff suggest that this process is not always timely or consistent. Several staff noted that system-level challenges, such as inability to access specialised health services, often delay discharge, and Teams remain involved. In some cases, this has led to longer-term case management beyond the scope of the model. While the use of formal discharge letters was not consistently mentioned, the overall approach reflects an effort to transition clients appropriately once care planning and coordination are complete.

Although the core service elements reference a 3 to 6-month follow-up window, this timeframe was not explicitly reflected in interviews with staff. Instead, follow-up appears to be discretionary and based on clinical need.

3.2 How IDHS staff are delivering capacity building

3.2.1 Most teams embed practical capacity building through ad hoc engagement with health professionals rather than planned training

Table 12: Capacity building

Capacity-building options	IDHS delivery

Capacity building can include:
• Providing joint consultation, case conferences, and expert advice to NSW Health and primary health clinicians (e.g., GPs and general practice teams) on the assessment and care of people with intellectual disability, to:
  • Better understand the needs of people with intellectual disability
  • Develop strategies to provide appropriate care, including reasonable adjustments
  • Identify pathways and services for people with intellectual disability.
• Establishing formal links with mainstream hospital and community-based services, including private practice, emergency departments, allied health, clinical staff, and general practice teams.
• Delivering webinars, skills training and other education sessions.
• Development and/or promotion of communication resources to support people with intellectual disability (e.g., Easy Read resources).
	

IDHS staff are consistently delivering several components of capacity building, with a strong emphasis on practical, collaborative approaches. **Joint consultations and case conferences** are widely used to support primary health clinicians – particularly GPs – in understanding the needs of people with intellectual disability and developing appropriate care strategies to support these clients. These interactions often occur in response to specific, individual client situations, allowing primary health clinicians to learn in context and apply reasonable adjustments directly to their practice.

Planned education and training sessions are also being implemented to some extent, with some staff delivering webinars, short education series and presentations on topics related to supporting clients, such as NDIS support, the Disability Royal Commission findings and what the IDHS does. These sessions are promoted through newsletters and internal channels and often tailored to current clinical challenges. Mentoring and student placements are another area of shared practice. Some Teams noted they develop and share communication resources such as Easy Read materials and social stories to enhance accessibility and support clinicians in their interactions with clients.

While staff report delivering planned capacity-building activities to some extent, they consistently find that **one-on-one ad hoc support** is more effective and better received by primary health and NSW Health clinicians. Clinicians tend to be more engaged when seeking advice related to specific clients, as learning that is directly connected to their current cases feels immediately relevant and applicable. This responsive, relationship-based approach allows staff to adapt their support to clinician feedback and emerging needs, resulting in meaningful and lasting impacts.

3.3 How IDHS staff are collecting data and reporting

Table 13: Capacity building

Operational guidelines[10]	IDHS delivery
• IDHS staff will record activities to ensure consistent, standardised data is available. This will assist with performance monitoring of delivery of the IDHS.	

All hubs and spokes submitted NAP data, in line with the operational guidelines, as well as implemented their own data collection and monitoring processes to inform their service delivery. This includes:

- gathering client feedback data to ensure they are meeting the needs of their clients
- looking at NAP data to identify service gaps and areas for improvement
- meeting with their partner LHD at regular intervals to review their monitoring data
- creating their own grading system or Excel spreadsheet to track their clients' journeys and progress.

Although staff are collecting standardised NAP data, no 2 IDHS Teams and Positions followed the same monitoring and evaluation processes. At the time of data collection, staff indicated that this is due to many factors that have made data collection, monitoring and reporting challenging for staff, including:

- inadequate systems for data collection specifically on client experience

[10] While the public-facing IDHS core service elements do not include data and reporting elements, these are referenced in the operational guidelines. This section is based on the guidelines.

- perception of a lack of guidance from the Ministry regarding detailed data capturing and monitoring requirements[11], especially regarding capturing ad hoc, incidental capacity building
- the time burden of capturing data.

3.4 Resources used for core service delivery

3.4.1 More information would be valuable to be captured to better understand how staff are spending their time

IDHS staff are primarily focused on delivering the core elements of the service, which includes health assessments, capacity building, and data and reporting. However, as noted in 3.3., challenges capturing data has made it difficult to estimate time allocated to these tasks.

While there was no consensus on the exact percentage of time spent on tasks, all Teams indicated that the majority of their time was dedicated to **health assessments**. This included not only conducting the assessments themselves, but also the substantial preparation and follow-up work required, as well as the ad hoc, incidental capacity building that often occurred alongside, where staff provided advice to the referring primary health clinicians. Reflections from Positions were similar: most described health assessments as a significant component of their role, due to their responsibility in supporting both clients and Teams throughout the process, both before and after the assessment. However, a few reported minimal involvement, explaining that health assessments were not a core focus of their work, as they were more engaged in supporting the community or referrers through ad hoc, incidental capacity building.

Teams and Positions reported that a smaller portion of their time was dedicated to **planned capacity building**. This was largely attributed to the significant time demands of health assessments and providing support to referrers and primary health clinicians. When discussing **other tasks**, Teams and Positions primarily referred to administrative duties, professional development, research, attending meetings and service navigation for people with intellectual disability who did not receive comprehensive health assessments.

[11] As ARTD understands it, the Ministry has since distributed a data collection tool for IDHS Teams and Positions and this is currently being implemented. The data collected via the tool has been agreed through meetings with the IDHS Teams and Positions.

3.4.2 Sometimes the IDHS provides longer-term case management and service navigation for clients beyond the scope of the service

Most IDHS staff felt that their work aligned with the IDHS operational guidelines and noted that the updated guidelines had helped clarify their roles and responsibilities. However, some also acknowledged that some of their work extended beyond the scope of the service. Such work varied by role, with some Teams adopting a longer-term case management approach and certain Positions assisting with service navigation.

Longer-term case management

The main component of work that extended beyond the service's scope was **longer-term case management**, which remains a significant part of the role for some Teams and Positions. Longer-term case management was provided when there are gaps in support, such as people with intellectual disability finding it difficult to access health services. Staff use this approach to tailor care for clients, bridging broader service gaps and responding to limitations in existing healthcare pathways. An example of this included actioning recommendations in the care plan, such as prescribing medication. They reflect that this enables them to support clients holistically by addressing both psychosocial and health needs, often through collaboration with multidisciplinary teams and other sectors.

For some Teams, longer-term case management involves regular check-ins with clients to monitor progress and maintain continuity of care. For others, it includes incorporating social work interventions – often led by social workers – to help connect clients with services outside the health system.

However, this work often extends beyond the scope of the IDHS as outlined in the core service elements[12] and operational guidelines (see Table 14). Staff often assist clients and families/carers in navigating complex disability and health service systems over extended periods, which adds to their workload. Work outside the service scope, limits the IDHS capacity to accept new referrals and deliver capacity building activating including with partner districts (as explored in Chapter 4).

Table 14: Operational guidelines

Operational guidelines
• The IDHS supports this engagement through short-term coordination of care supports and navigation (Section 1.1 of the guidelines) • The IDHS does not provide ongoing responsibility/case management services for clients (Section 2.6 of the guidelines)

[12] See Section 3.1.4 on time-limited clinical care.

We have to tailor case management in our district if we [have] produced a very lovely report with a list of recommendations … I think the likelihood of getting those [recommendations] actually put into place would be very low, and that's because of the tyranny of distance and service availability here in our districts. So, it's very challenging for families and providers to actually get people with an intellectual disability into the services that they require – they need the extra hand holding and case management. – IDHS Team

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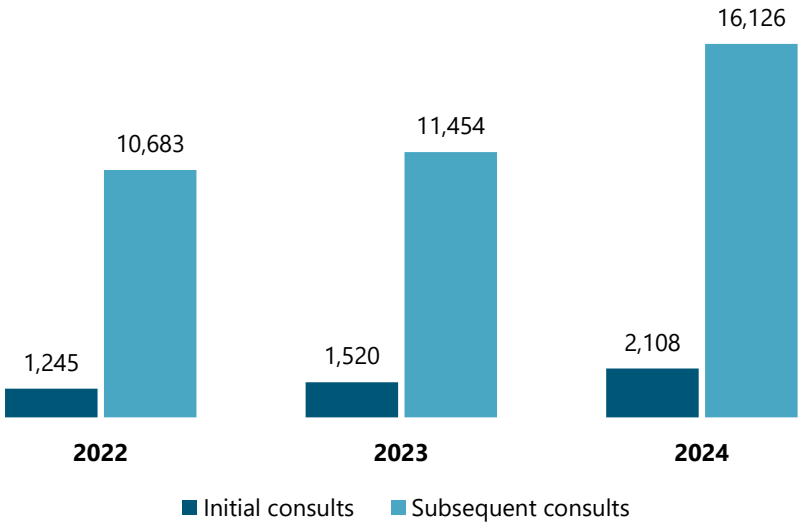
Time and time again [longer-term case management is] what is needed to get things across the line and actually get people where we're recommending. And they need those services and intervention. – IDHS Team

The prevalence of longer-term case management is supported by the NAP data, where the number of subsequent consults significantly exceeds the number of initial consults (see Figure 2). While this data does not accurately represent the number of subsequent individual consults and a small number of subsequent consults are likely to be needed, this data still suggests that IDHS Teams are spending more time supporting existing clients than taking on new referrals or undertaking additional capacity building with NSW Health clinicians.

Figure 2: Numbers of occasion of service(initial and subsequent consults)



Note: An OOS refers to each individual service or support activity reported.

Source: NSW Health NAP data, 2022–2024 calendar period Q2.

The number of clients that recorded more than 20 occasions of service (OOS)[13] may also suggest that IDHS staff provide ongoing care. In 2022, 19% of all IDHS clients recorded more than 20 OOS. These figures declined to 16% in 2023 and to 10% in 2024, respectively (see Table 15). According to NAP data, the average number of OOS per client (the total number of OOS divided by the total number of clients) over the last 3 years is 12 (see Table 16). While this data may just reflect that that a client is seeing more health professionals from the multi-disciplinary team, it suggests some level of ongoing care. Although there is no definition of how many OOS per client is considered to be in or out of scope, this data explains that, on average, each client is receiving more than 10 OOS.

Table 15: Number of clients with more than 20 OOS

Year	Clients with >20 OOS n	Clients with >20 OOS %	Total clients n	Total clients %
2022	172	19%	901	100%
2023	186	16%	1,180	100%
2024	153	10%	1,541	100%
Total	**511**	**14%**	**3,622**	**100%**

Note: If a client often sees multiple providers on the same day, their average OOS per service event looks inflated compared to someone who usually only sees one provider per day.

Source: NSW Health NAP data, 2022–2024, Q21

Table 16: Average number of OOS per client

Year	Total clients	Total OOS	Average OOS per client
2022	901	11,928	13
2023	1,180	12,974	11
2024	1,541	18,234	12
Total	**3,622**	**43,136**	**12**

Source: NSW Health NAP data 2022–2024, Total clients (Q1), OOS (Q4).

[13] A non-admitted patient (NAP) OOS is a NAP service or NAP support activity reported for each provider type and service type combination on each occasion a service is provided to the patient within one appointment on one calendar day. It includes direct and indirect services and support activities. For example, an OOS could be a clinic consultation, even if the client fails to attend, case coordination, or a phone call with a client with significant therapeutic content to warrant noting in the client's record.

Supporting clients through local navigation and building external sector capability

Some IDHS staff noted that where an individual may not be able to be seen by an IDHS Team for a health assessment, some Positions have undertaken investigations to identify local alternative services and support mechanisms.

Some IDHS staff described how they offered planned capacity-building support to other sectors, such as disability and education. This support, outside the scope of the IDHS, aimed to empower disability support and school staff to advocate more effectively in healthcare settings.

3.5 Impact of IDHS governance and delivery structures on service delivery

All IDHS staff report that they deliver a quality service within their own LHD, adhering to the core service elements and operational guidelines (as noted in Chapter 3). However, they reported mixed experiences with the governance and delivery structures between the Hub and Spoke LHDs collaborating to deliver the IDHS, as well as the delivery structures between IDHS staff and the Ministry. When IDHS Hubs and Spokes spoke of their local governance structures, they used an operational lens.

3.5.1 The Ministry has established delivery structures to support Teams and Positions in providing the service; however, staff indicated that greater clarity and guidance is needed in certain areas

Despite the Ministry having established structures to support service delivery, such as quarterly meetings with all IDHS staff and annual workshops, some staff identified areas where additional support from the Health and Social Policy Branch (HSPB) would be valuable.

Clarifying the role of the IDHS in the broader system, particularly in relation to overlapping services

IDHS staff and other government and sector stakeholders highlighted ongoing confusion regarding the role of the IDHS and its alignment with parallel services, such as Disability Navigators, CAMHS and SIDMHOS. This lack of clarity has led to uncertainty among clients, primary health clinicians and healthcare providers about appropriate referral pathways and processes. As a result, IDHS staff take on additional administrative tasks to guide people to the correct services.

Providing clearer guidance on data collection processes to ensure consistency across Teams and Positions

IDHS staff frequently expressed a desire for clearer guidance from the Ministry regarding the types of data they should collect for monitoring and reporting purposes. While NAP data is already being collected consistently across the service, staff are seeking direction on additional data points to ensure their efforts align with the Ministry's requirements. ARTD understands that the HSPB has since provided updated guidance; however, this need for clarity was a common theme raised during staff interviews.

3.5.2 Varying governance and delivery structures within hub-and-spoke partnerships impacted the effectiveness of service delivery

The IDHS experienced varying impacts of the hub-and-spoke model on service delivery, reflecting the distinct structures agreed upon by each hub and spoke LHD. IDHS staff perceived some structures to be more effective than others, as outlined below.

IDHS Teams and Positions that regularly communicated fostered greater trust and collaboration

When the IDHS Teams and Positions had strong relationships, they often felt like a unified team. This cohesion was fostered through regular communication at in-person and virtual meetings, where they discussed case conferences, examined monitoring data and shared updates on service delivery changes. The frequency and format of these meetings varied across LHDs, with some holding quarterly planning days and others conducting weekly online check-ins. For IDHS Positions, the ability to contact their partner Team outside of scheduled meetings further strengthened their relationships and enhanced service quality. Staff also noted that higher-level governance meetings with senior executives facilitated shared practices and understanding. The IDHS Teams that frequently engaged in capacity-building activities with the Position in their partner district/s, led to greater satisfaction for the Positions.

Shared and consistent systems within hub-and spoke partnerships supported service delivery

Another mechanism reported to enhance service delivery within the hub-and-spoke model is the implementation of shared and consistent systems and processes across the IDHS Team and Position. Shared systems facilitate seamless and coordinated operations. Staff highlighted various methods of collaboration with their partner LHDs, such as using a shared Microsoft Planner tool, standardising the referral process across the 2 or 3 LHDs and using the same electronic medical record (eMR) system. In one instance, the Team administrative officer played an integral role in collaboration by maintaining a checklist to ensure all service

components were met and by uploading relevant documents to both LHD eMRs.[14] This approach significantly reduced the administrative burden for the Position, which they greatly appreciated. Conversely, variations in systems and processes, such as differing referral forms, eMRs and reporting outcomes, resulted in increased administrative workload due to task repetition and a lack of staff collaboration.

The [Specialised Intellectual Disability Health Team] administrator is very, very good and so she'll upload documents to both eMRs like referrals and reports that other people have sent us … So that's a sort of tailoring approach and kind of improving that workflow and that admin burden. – IDHS Position

However, sharing resources with non-partner LHDs has not yet been established. Some IDHS staff noted that greater information sharing could help reduce administrative burden, avoid 'reinventing the wheel' and promote greater consistency in processes across the LHDs.

Up-to-date Memorandums of Understanding helped clarify roles and responsibilities within hub-and-spoke partnerships

Some IDHS Teams and Positions highlighted the importance of their Memorandum of Understanding (MOU), as it offers a clear overview of their processes, as well as of the roles and the responsibilities of each LHD. One Team that recently updated their MOU noted that it has enhanced their understanding of how to work effectively with their Position by clearly defining responsibilities and collaboration channels. Conversely, others mentioned that while their MOU outlines governance structures, it remains quite vague and requires updating.

Virtual or hybrid delivery enabled greater equity among regions

The inclusion of virtual or hybrid client consultation and engagement with the partner Position has been a positive development in service delivery. One partnership, which operates entirely virtually, reported particularly strong client outcomes, high client satisfaction with flexible virtual care options, and enhanced cross-sector collaboration through interdisciplinary case conferencing and planning. Positions in this partnership expressed high levels of satisfaction, noting that they felt like a single, unified team – often feeling a stronger connection with the partnering Team than with colleagues in their own LHD. They said that because they met virtually for all meetings and were involved in case conferences, they felt as though they were working side-by-side in the same office – unlike some Positions in outreach LHDs, who often experience a sense of isolation due to the face-to-face delivery model.

[14] ARTD anticipates that this action will no longer be necessary following the implementation of the Single Digital Patient Record, which will provide access to patient records across all LHDs without requiring manual data entry.

So, the SIDHT [Specialised Intellectual Disability Health Team] that I work with works almost entirely virtually as well. So that's made it really easy because I work virtually. So, I work very closely with them in that fashion. – IDHS Position

3.6 Factors that impacted implementation

The IDHS service model, as outlined in the operational guidelines, is being implemented as intended. Structures and processes are in place to support delivery, and staff are actively delivering the service in line with the core service elements. However, IDHS staff identified a range of external and systemic factors that influenced how effectively and efficiently the service was delivered to support outcomes for clients. In some cases, IDHS staff have tailored their approach to respond to these factors – sometimes resulting in work that extended beyond the scope of the service (see Chapter 6).

These factors included:

- **gaps in ongoing health care, support and services** for people with intellectual disability, particularly where there is no consistent GP or other referring clinician who is able to act on healthcare plan and recommendations, leading to healthcare needs not being met.
- **variable awareness and engagement** from Primary Health Networks, LHDs and other healthcare providers, which in some cases limited the ability of IDHS staff to support clients effectively or participate in capacity-building activities led by their colleagues.

4. Reach of the IDHS

This chapter presents findings on the effectiveness of the Intellectual Disability Health Service (IDHS) in reaching and engaging eligible individuals with intellectual disability, as well as NSW Health and primary care clinicians who work with them. It considers whether the service is being delivered in a way that ensures equitable access – both culturally and geographically. It also explores the factors that have either facilitated or hindered this reach, aiming to address the second half of KEQ 2 and KEQ 3. For this report, the ARTD team defines 'reach' as the extent to which eligible clients and healthcare providers engage with the service.

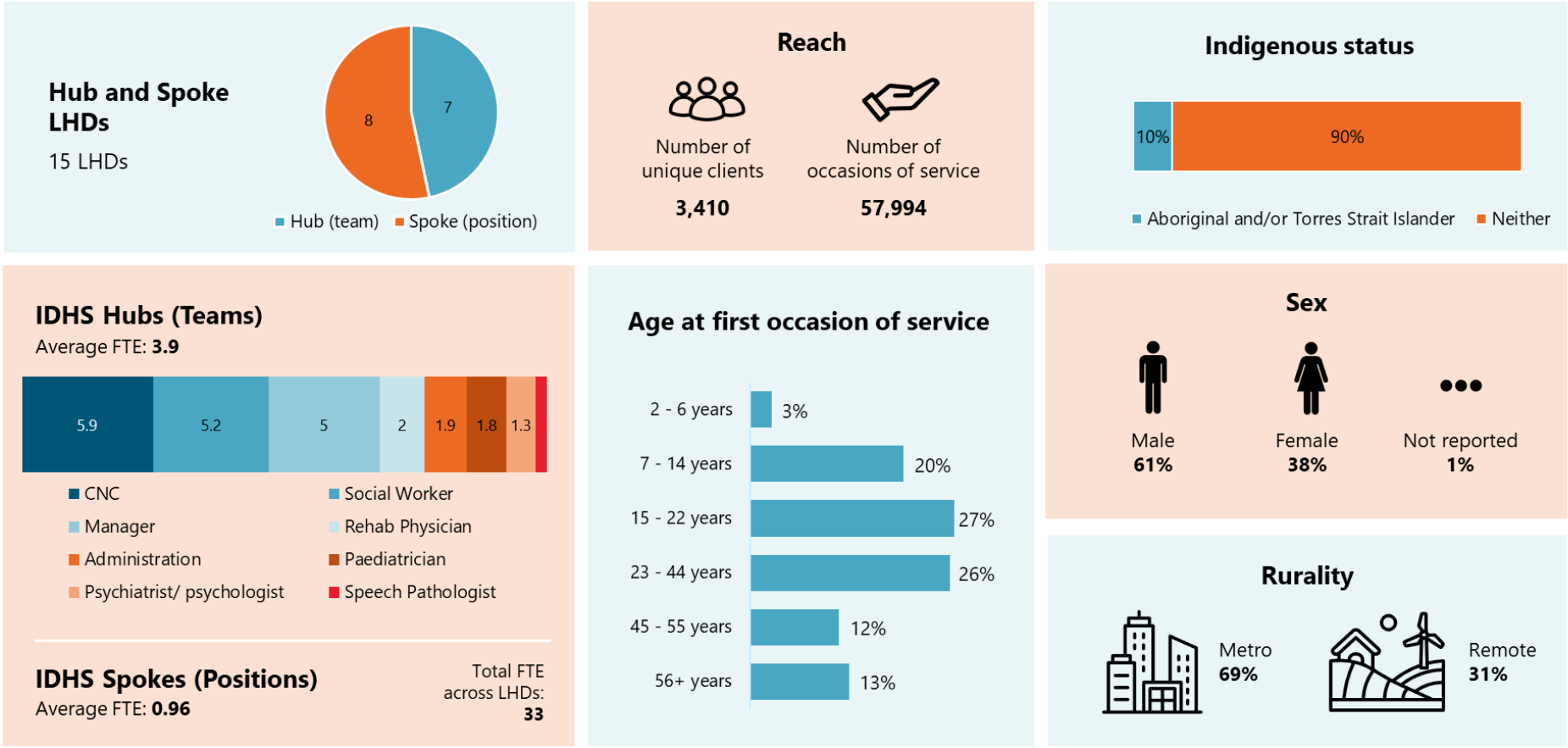
4.1 Reach of comprehensive health assessments

4.1.1 The IDHS reaches eligible clients with intellectual disability, though the extent of reach cannot be fully assessed

During the 2019 to 2024 reporting periods, the IDHS effectively reached 3,410 unique eligible clients and provided more than 57 thousand occasions of service across in person, virtual, non-client contact and other modes such as email. The service has been delivered by approximately 33 full-time equivalent (FTE) staff, averaging 4 FTE in each hub (Team) LHD (Local Health District) and one FTE in each spoke (Position) LHD.

More than half of the IDHS clients with intellectual disability were male (61%) and from metropolitan areas (69%). While support was provided across all age groups, the most common age ranges were 15 to 22 and 23 to 44 years. Additionally, around 10% of clients identified as Aboriginal and/or Torres Strait Islander (see Figure 3).

Figure 3: Extent of reach and demographics of IDHS clients figures – 2019-2024

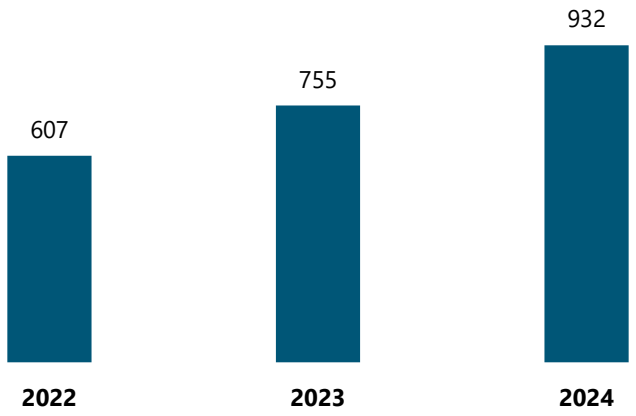


Note: FTE data reflects information provided over points in time, and staffing levels changed between 2019 and 2024. Additionally, while NAP data is drawn from the same time period, demographic breakdowns – such as age, Indigenous status and rurality – have varying totals due to the exclusion of unknown values. Unknown values range from 5 to 50 individuals.

Sources: NSW Health NAP data, 2019–2024 and FTE data from the 2024 Performance Review discussions. The number of unique clients (Q1), the number of occasions of service (Q4), Indigenous Status (Q10), Age (Q6), Sex (Q7), Rurality (Q25).

It is challenging to determine whether current reach figures are fully appropriate. This is due to the lack of accurate data regarding the size of the service's target population, as well as limitations in the IDHS's current data collection on key characteristics of that population. However, the consistent increase in client numbers over the past 3 years suggests ongoing improvement in service access. Notably, there was a 23% increase in new clients between 2023 and 2024 (see Figure 4).

Figure 4: Number of new unique clients seen per year



Source: NSW Health NAP data, 2022–2024, Q1.

4.1.2 It is possible the service is experiencing unmet demand

While the IDHS has successfully supported several thousand clients, IDHS staff and government stakeholders consistently report that unmet demand persists across all LHDs. Although comprehensive data on unmet demand is not available, many IDHS staff noted that capacity constraints sometimes led to eligible clients not receiving a comprehensive assessment. In some instances, IDHS Positions chose to support individuals locally rather than refer them to the Team, anticipating that there would be an extended wait time for a comprehensive assessment or they may not be accepted. One Position staff member estimated that only one in every 20 referred clients was seen by their partner Team.

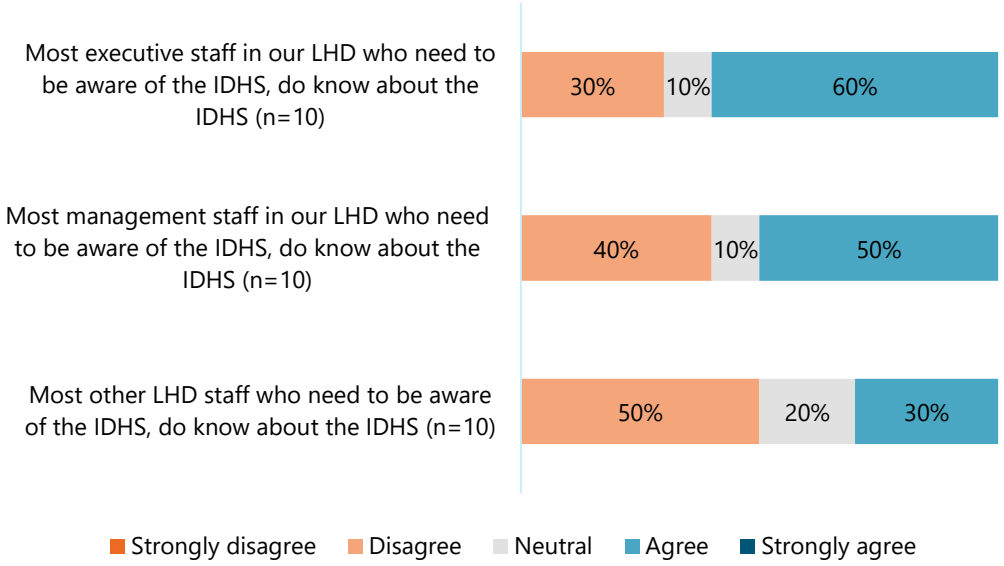
This perception was echoed in survey responses. Some healthcare providers indicated they would not refer others in similar situations to the IDHS (e.g., referring clients with intellectual disability and complex needs) and several IDHS Executive Sponsors expressed hesitation in recommending the model within their LHD. The common concern across these responses was: a belief that the service lacks sufficient capacity to take on additional referrals for clinic consultation. Many respondents felt that, with increased resources, the IDHS could expand its ability to offer assessments and better meet existing demand.

No quantitative data regarding the extent of unmet demand the service may be experiencing was available to the evaluation. IDHS should consider capturing this in the future.

4.1.3 While increasing awareness of the IDHS remains important, some staff expressed concern that they may not be able to meet the resulting rise in demand

IDHS staff and government stakeholders noted that limited awareness of the service may be affecting access. As shown in Figure 6, while 60% (n=6) of IDHS Executive Sponsors agreed that relevant executives were informed about the service, awareness appeared to decline as information moved through successive management levels and reached broader LHD staff.

Figure 5: IDHS Executive Sponsors' agreement with statements about their LHD's knowledge of the IDHS



Source: IDHS Executive Sponsor survey (n=10).

Despite recognising the need to improve awareness, many IDHS staff expressed concern about promoting the service further, given current capacity constraints.

4.2 Reach of capacity-building supports

4.2.1 IDHS staff are able to engage with NSW Health and primary health clinicians through flexible, opportunistic capacity building

As outlined in the operational guidelines, IDHS Teams and Positions are advised to prioritise comprehensive health assessments over capacity-building activities. Consequently, it is not surprising that IDHS staff did not feel particularly effective in engaging NSW Health and primary health clinicians for capacity-building work. Staff noted that planned, targeted capacity-building efforts – such as presentations – were often met with limited engagement.

In contrast, they reported greater success with ad hoc, incidental capacity-building interactions.

Despite ad hoc capacity-building work being viewed as effective, other government and sector stakeholders observed that managing both clinical and capacity-building responsibilities effectively may be unrealistic. With some questioning the value of attempting to do both, which limited reach of people with intellectual disability and complex need.

ARTD cannot quantitatively assess the reach of capacity-building supports to NSW Health and primary health clinicians, as this data was not consistently captured at this time.

4.3 The impact of governance and service delivery structures on the equity of service

4.3.1 Although the hub-and-spoke model aims to extend the specialised service across regions, its effectiveness was diminished when Teams and Positions did not fully collaborate

While Teams' (hubs) funding includes an amount for 'outreach', most IDHS Positions and government and sector stakeholders perceived that the hub-and-spoke model **did not achieve geographic equity**. This was the case for both conducting comprehensive health assessments and providing capacity-building to NSW Health and primary health clinicians. For **clients with intellectual disability and complex needs**, this inequity was reflected through IDHS staff noting that Teams delivering fewer clinics in spoke districts compared to their own. Similarly, those in spoke districts felt less able to provide capacity-building activities than their hub-based counterparts, partly due to differences in role expertise, such as not having medical qualifications.

This challenge was particularly evident when IDHS Teams and Positions did not feel unified – especially where Teams did not offer virtual assessments, had limited in-person clinic availability, and did not support capacity building in their partner LHD(s). In these cases, the IDHS Positions noted that individuals' referrals from their districts were not always accepted by the Team, often due to high caseloads and limited capacity to take on new clients, particularly when longer-term case management was being provided to existing clients.

You know, these are people who are struggling to navigate the system – a GP or a specialist has referred them. They meet the criteria … I don't understand how [people with intellectual disability] can be pushed back [by the IDHS Team] … then in the end [they] come back and say all right, we could see them … then that's another 6 months wait. – IDHS Position

I think that [it's] not working well. I think us only having bimonthly clinic appointments … I don't think that's working well because what happens is that we have to really pick carefully which clients we're going to take to those clinics. – IDHS Position

These sentiments were supported by some of the IDHS Executive Sponsors, who stated the current hub-and-spoke model was not working within Position LHDs and seems to be more beneficial for clients within Team LHDs.

We are finding the model does not work well, and with funding only being sufficient for 0.9 FTE of a clinician. The over-stretched Hub Team to which we are connected does not have capacity to deliver what is expected as per the operational guidelines. Our clinician struggles to get engagement from our staff locally and with GPs, as well as with the Hub Team. The LHDs with which we are partnered in the hub-and-spoke model are not a natural fit for us, and it requires extensive travel for the Hub Team to come onsite in our LHD to run clinics. –

IDHS Executive Sponsor

In addition, IDHS staff and other government stakeholders reported a perceived increase in prevalence of intellectual disability in certain LHDs, raising questions about whether the current hub-and-spoke allocation remains optimal (see Chapter 6). However, without population data, it is not possible to assess whether this perceived increase is accurate. Some hubs and spokes have attempted to address these challenges by offering virtual care and more in-person clinics and by supporting Positions with capacity building.

4.3.2 Some LHDs reported challenges engaging with Aboriginal and remote communities

Data reported in Section 4.1.1 suggests that 10% of clients identified as Aboriginal and/or Torres Strait Islander and 31% lived in rural or and remote locations, however some IDHS staff reported challenges with these groups in their LHD. One Position felt it was more difficult for metropolitan Teams (hubs) to understand contextual factors associated with providing services in rural and remote areas. Government and sector stakeholders also noted that reaching these groups requires consideration of contextual factors that enable more effective engagement and reach.

I suppose the difficulties [may be] because a rural population and rural services are very different to metrocentric ones. So, it is around a metropolitan service getting to know what is available in the rural sector and then building that little trust and communication between myself and the team. – IDHS Position

4.3.3 Better integration of Hubs and Spokes would support access in geographically distant areas

These observations align with findings from the article 'Hub and spokes in intellectual disability mental health support', which highlights both the strengths and limitations of the hub-and-spoke model. The model is recognised for its ability to centralise specialised expertise and build workforce capacity, enabling hubs to act as centres of excellence that support spokes through training, consultation and clinical leadership. However, the article also emphasises that, without adequate support and integration of the spokes, the model can inadvertently lead to disparities in service access – particularly in geographically distant or under-resourced areas.[15]

4.4 Factors that impacted reach

IDHS staff identified several factors as impacting the ability of the IDHS to extend its reach, especially in Spoke LHDS, for both comprehensive health assessments and capacity-building work. The factors included:

- **the differing priority PHNs, LHDs and healthcare providers placed on intellectual disability**, which impacted engagement with the service.
- **IDHS staff members' pre-existing relationships** with healthcare providers, which enabled greater awareness of the service and, as a result, greater reach. The opposite was true when relationships were not established.
- **Teams and Positions' physical location**, which allowed staff to meet with local NSW Health and primary health clinicians face-to-face, establish relationships and build awareness. This was not the case in the broader region.
- **Teams prioritising their own LHD's clients and NSW Health and primary health clinicians over partner LHDs** when supporting health assessments and capacity building, hindering reach. The opposite was observed when Teams did not prioritise the clients from their own LHD over their Spoke LHD, allowing for a more equitable reach.
- **the IDHS mode of delivery** – virtual or face-to-face – which enabled or hindered individuals' ability to access the service. For example, those in remote communities who were able to receive virtual supports were supported in a timelier manner.

Chapter 6 explores these factors in more detail.

IDHS staff noted that these factors had a more negative impact on IDHS Positions with fewer resources to establish relationships and raise awareness of the service.

[15] Trollor, J., Reppermund, S. & Salomon, C. (2022). Hub and spokes in intellectual disability mental health support. *Australian Journal of Social Issues*, 57(3), 445–460. https://doi.org/10.1002/ajs4.70019

5. Effectiveness of the IDHS

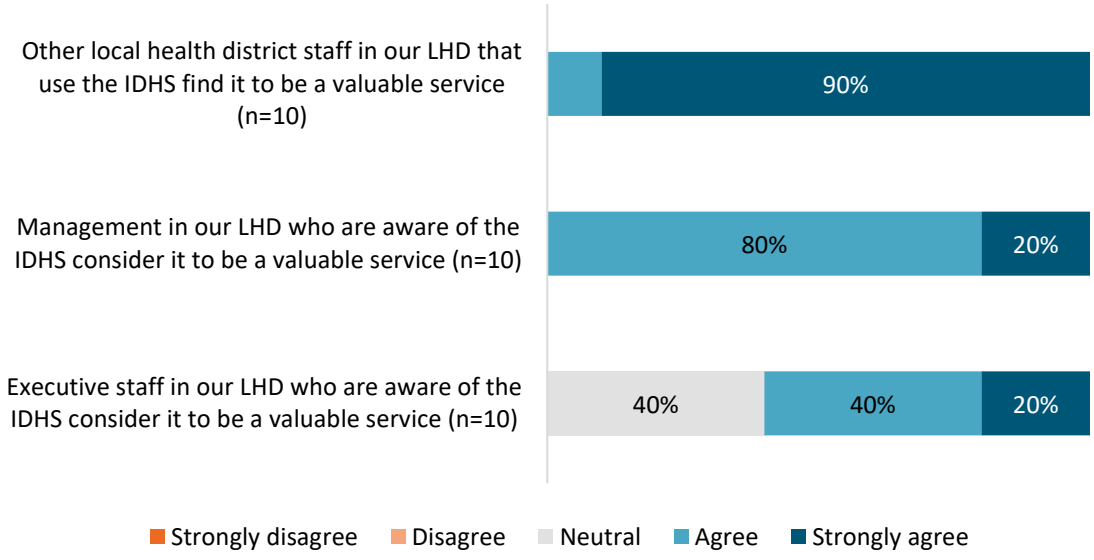
This chapter considers the effectiveness of the Intellectual Disability Health Service (IDHS) in achieving client satisfaction and client outcomes. In doing so, it seeks to answer KEQs 4 to 6. This chapter will first consider overall satisfaction with the service, before examining in more detail satisfaction with and outcomes achieved through comprehensive health assessments, followed by capacity building.

Findings in this section are drawn from IDHS staff interviews, other government and sector stakeholder interviews, Executive Sponsor surveys and healthcare provider surveys. Client Satisfaction Survey data from 3 Local Health Districts (LHDs)is also reported.

5.1 Satisfaction with the overall service

Across all LHDs, **the evaluation findings suggest the IDHS has delivered a valuable service to the clients who receive it**. IDHS staff and other government and sector stakeholders noted that when people were aware of the service and were able to access it, in the short term it provided a valuable service. This sentiment was also highlighted in the Executive Sponsor survey, where IDHS Executive Sponsors mostly agreed or strongly agreed that most of those employed in their LHD that are aware of the service, find it to be a valuable service (see Figure 7).

Figure 6: IDHS Executive Sponsors' agreement with statements about the value of the IDHS



Source: IDHS Executive Sponsor survey (n=10).

Similarly, healthcare providers valued the service, as evidenced by how highly respondents rated their likelihood of recommending the IDHS to a healthcare provider in a similar

situation (i.e., the reason for them attending the service such as referring a client with intellectual disability and complex needs). On average, they rated this likelihood at 83 out of 100. The healthcare providers who completed the Net Promoter Score (NPS) question (n=83) together gave the service an NPS of 36, calculated as the percentage of 'Promoters' (very satisfied customers) minus the percentage of 'Detractors' (very unsatisfied customers). This is a favourable NPS, indicating high levels of satisfaction with the service.

Many IDHS staff and other government and sector stakeholders felt that the service's greatest value was intrinsically linked to comprehensive health assessments and ad hoc capacity building. These aspects are explored in greater detail below.

5.2 Effectiveness of comprehensive health assessments

5.2.1 The findings suggest that most clients who received health assessments were satisfied with them

While only a small number of client satisfaction surveys were provided to the evaluation (3 LHDs), the data and interviews with IDHS staff suggests that clients who **received care from the IDHS appreciated the comprehensive health assessments**.

When one LHD asked clients or their carers whether they were satisfied with the service and whether they would recommend it, they all agreed (100%, n=4).[16] Another LHD asked whether the IDHS met the needs of carers of people with intellectual disability and all but one agreed (80%, n=4).

[It was the] best consult I've ever had – thank you. [I] feel like you listened and for the first time we may have gotten somewhere … best consult in 19 years. – Health assessment client

Similarly, most healthcare providers who completed the survey who referred clients for a health assessment and received it (n=45) expressed a willingness to refer future clients with intellectual disabilities, with an average likelihood rating of 83%. This suggests a high level of satisfaction with the service among their clients.

5.2.2 Clients' satisfaction with IDHS was linked to the personable nature of the IDHS staff and how the comprehensive assessment was provided

The IDHS **appeared to be most successful**, at least from the perspective of clients and their families/carers, when staff:

[16] To maintain anonymity, the LHD that provided this data is not named.

- were friendly, caring, and understanding
- listened to clients and their families/carers
- were open to questions
- provided good, clear information and recommendations.

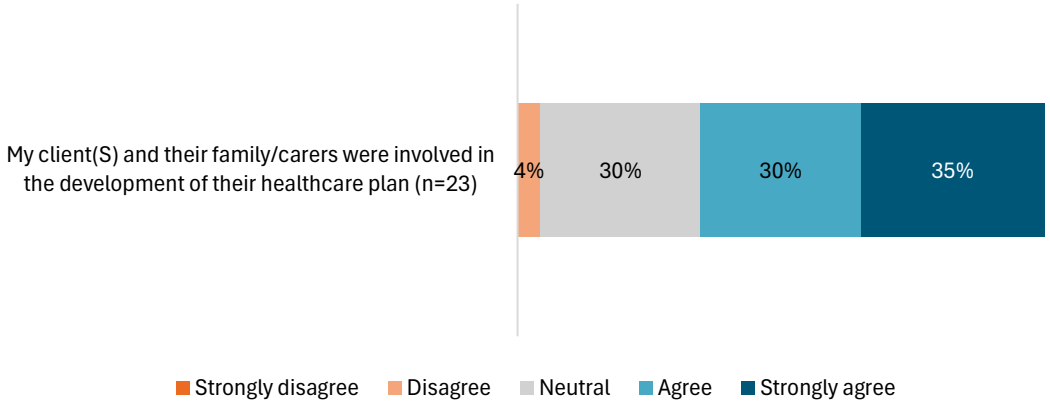
When one LHD asked clients about these factors, all but one of the respondents agreed that the IDHS staff listened to them all or most of the time (98%, n=55) and when they asked the team questions, the team gave them answers they could understand (98%, n=64).

Best part of the experience with Specialist Intellectual Disability Health Team: friendly, supportive and helpful. – Health assessment client

In addition to this, client survey responses indicated that how the support was provided was linked to greater value. The majority of clients and families/carers responding to one LHD survey agreed that they were involved in decision-making (97%, n=60) and that the service was delivered in an organised manner (95%, n=58). Correspondingly, in a separate LHD's survey, most respondents also agreed that the IDHS was delivered in an organised way.

The findings about involving clients and their families/carers in decision-making are supported by healthcare provider survey respondents who had referred clients. These respondents agreed or strongly agreed their client(s) and their families/carers were involved in developing healthcare plans (65%, n=15) (see Figure 7).

Figure 7: Healthcare providers' agreement with a statement about clients' and families'/carers' involvement in developing healthcare plans



Note: Some respondents were only show specific items or skipped items.

Source: Healthcare provider survey.

5.2.3 Some clients provided one-off comments of how the service could improve

Although most clients valued the service, some noted some dissatisfaction with the service through their respective LHD surveys. One-off suggestions for improvement included that the IDHS could work harder to take a trauma-informed approach; there could be greater clarity for clients about next steps, including follow-up; and the IDHS Team could have been more involved in supporting and implementing actions.

[We were asked] some repeated questions, [and we found] telling the same story again traumatic. – Health assessment client

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[Client] felt sad/upset after the consult following questions [regarding the past] … [client] suggested asking questions in different way. [Client] was not sure who to contact after the consult for support. – Health assessment client

5.2.4 IDHS and Health staff suggest that most clients achieved short-term and intermediate outcomes; however, due to limited client data, this cannot be conclusively assessed

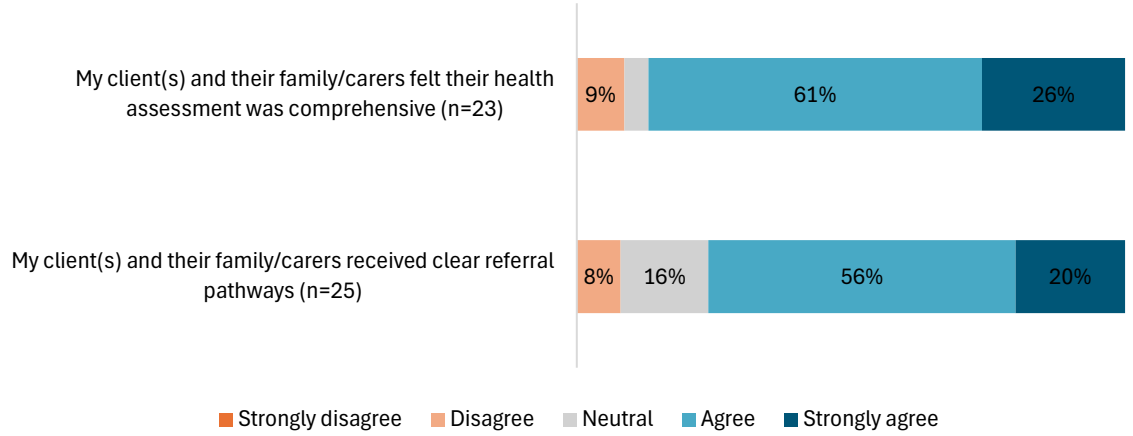
Table 17: Comprehensive health assessment short-term and intermediate outcomes

Level of program logic	Outcomes
Short-term	• Clients of the IDHS and their families/carers **receive comprehensive health assessment** and **referrals to services** to address their needs. • Clients and their families/carers **are supported by the GP** to access specialist services and know where to receive further support where required. • Clients and their families/carers are **guided in their interactions with the health system** by healthcare plans.
Intermediate	• Clients and their families/carers **feel supported to navigate the health system**. • Clients and their families/carers **feel more confident** accessing care. • Clients of the IDHS have their **immediate health needs met** by a range of specialists coordinated by their GP.

Healthcare staff and IDHS staff believe their clients are achieving short-term and intermediate outcomes; however, due to limited client data, this cannot be conclusively assessed. Most healthcare survey respondents agreed that most of their clients achieved short-term outcomes as set out in the program logic (Figure 9 and Appendix 4). As shown in Figure 8, survey respondents agreed or strongly agreed that their clients felt their healthcare

assessment was comprehensive (87%, n=20) and that their clients received clear referrals (76%, n=19).

Figure 8: Healthcare providers' agreement with statements about short-term outcomes achieved for their clients in regard to their healthcare assessments



Note: Total respondent numbers vary across questions in the matrix, as open-ended responses LHDs gathered from clients and/or their families/carers indicated that clients appreciated that the IDHS provided quality information and recommendations that met their needs and that the multidisciplinary team enabled this.

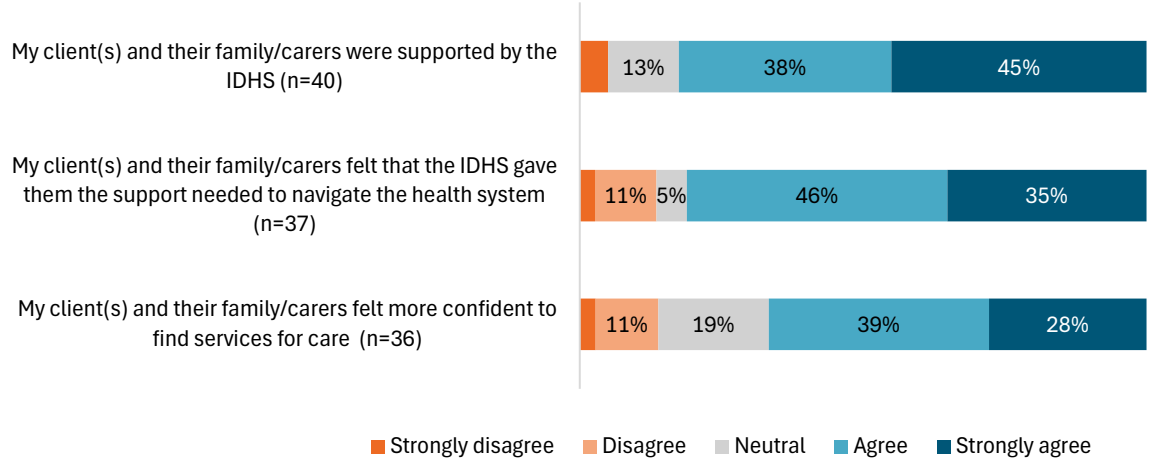
Source: Healthcare provider survey.

Some open-ended responses provided for Client Satisfaction Surveys also indicated that clients appreciated that the IDHS provided quality information and recommendations that met their needs and that the multidisciplinary team enabled this. For example:

> *Good to have all the professionals in the room together. [The] service is amazing, helped with NDIS and health, very refreshing. – Health assessment client*

The nature of the comprehensive health assessments and associated supports provided by the IDHS (see Chapter 3) likely contributed to clients and their families/carers feeling more informed and confident to take action. As shown in Figure 10, healthcare provider survey respondents agreed or strongly agreed that their clients and their families/carers were supported by the IDHS (83%, n=33), received help navigating the health system (81%, n=30) and felt more confident in identifying appropriate care services (67%, n=24).

Figure 9: Healthcare providers' agreement with statements about outcomes achieved for their clients as a result of healthcare assessments



Note: Total respondent numbers vary across questions in the matrix because some participants skipped certain items.

Source: Healthcare provider survey.

Many IDHS staff believed their support may have helped some clients achieve positive outcomes; however, they were not able to definitively assess whether all clients experienced meaningful or consistent improvements. Some examples provided by IDHS staff centred around clients receiving support *to navigate the health system* and as a result *having their immediate health needs met*, such as:

- clients progressing through sedation pathways
- clients accessing services that they couldn't engage with earlier, for example, receiving healthcare procedures under sedation at the Westmead Hospital One Stop shop clinic [17]
- clients making a change in their medication that is effective.

Other examples of outcomes achieved included clients having reduced emergency department readmissions and reduced referrals of the same client to the IDHS, implying clients had *greater access to services for care*.

In some cases, IDHS clients also provided feedback on positive short-term outcomes through LHD client surveys, including that they had started acting on the recommendations, referred someone in a similar situation to them or been able to access other broader supports, such as placement in school.

[17] NSW Health (2023), Westmead Hospital 'one-stop shop' clinic makes access to healthcare easier for adults with a disability.

Was great to have fresh eyes and ideas. Sometimes people are stuck in their way … it was so good to think differently. GP has received the report and has implemented all interim recommendations. – Health assessment client

5.2.5 Factors impacting client satisfaction and outcomes of comprehensive health assessments

Most IDHS staff and surveyed healthcare providers viewed comprehensive health assessments as effective in achieving client satisfaction and outcomes from comprehensive health assessments. As outlined in Chapter 6, several factors have acted as both enablers and barriers to success. These factors include:

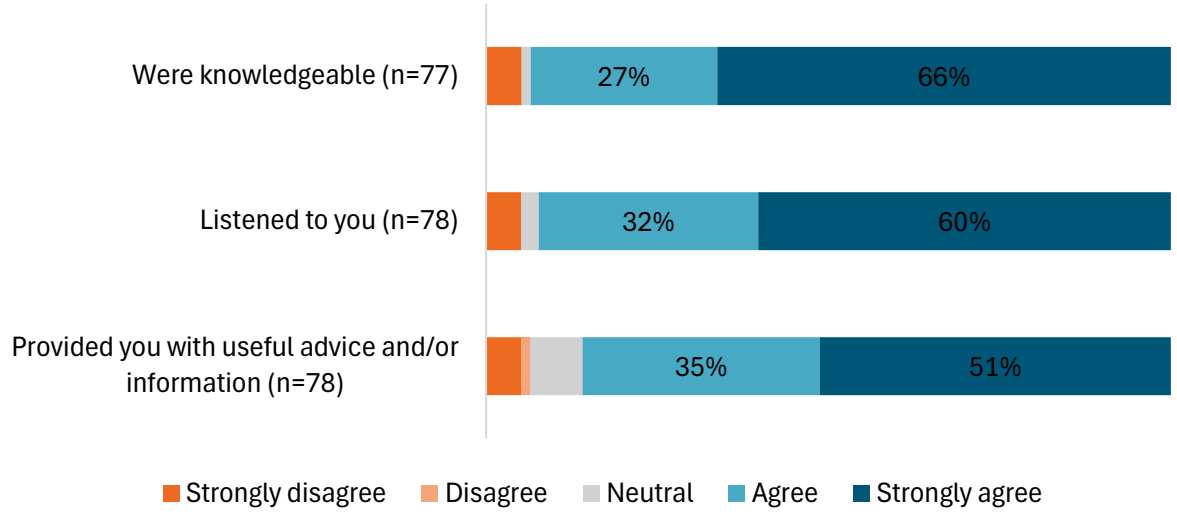
- IDHS staff building familiarity with clients through preliminary and follow-up meetings, and in some instances providing **longer-term case management supports**, which anecdotally led to better client experiences.
- **use of the Team psychologist or psychiatrist when needed** allowed specialist mental health input in the multidisciplinary assessment, thereby improving client satisfaction. When Hubs LHDs were unable to have these health professionals available, it was sometimes necessary to refer a client on for further specialist intellectual disability mental health assessment and clients were less satisfied.
- the decision of IDHS staff to **provide local navigation or longer-term case management**, which helped impact outcomes – for example, whether clients had access to local services.

5.3 Effectiveness of capacity-building supports

5.3.1 Healthcare providers were satisfied that the IDHS staff were knowledgeable, listened to them and provided useful advice

Survey respondents from healthcare providers indicated they appreciated how the training and supports were delivered. Healthcare providers who responded to the survey agreed or strongly agreed that IDHS staff were knowledgeable (93%, n=72), listened to them (92%, n=72) and provided useful advice and guidance (86%, n=67) (see Figure 11).

Figure 10: Healthcare providers' agreement with statements about the IDHS staff they interacted with



Note: Total respondent numbers vary across questions in the matrix because some participants skipped certain items.

Source: Healthcare provider survey.

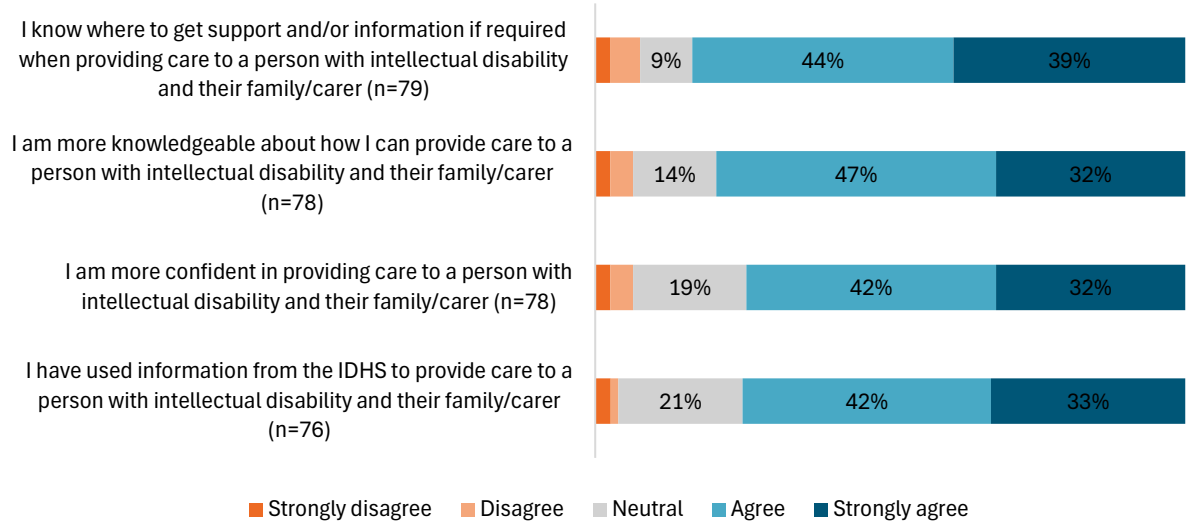
5.3.2 There is some evidence that capacity building outcomes have been achieved for healthcare providers that received training and support from the IDHS

Table 18: Capacity building short-term and intermediate outcomes

Level of program logic	Outcomes
Short-term	• NSW Health and primary health clinicians are more skilled and confident in supporting people with intellectual disability and their families/carers. • NSW Health and primary health staff work in collaboration.
Intermediate	• When required, NSW Health and primary health staff know where to access support regarding working with people with intellectual disability. • People with intellectual disability have increased access to high-quality care from health professionals who can appropriately support them.

Most healthcare providers who responded to the survey agreed they had achieved some of the short-term outcomes outlined in the program logic (see Figure 12 and Appendix 4). This was particularly true for the outcome related to *providers feeling more skilled and confident in supporting people with intellectual disability and their families/carers*. Figure 11 illustrates this, showing that respondents agreed or strongly agreed with statements such as those about knowing where to obtain support and/or information if needed (83%, n=66), being more knowledgeable (79%, n=62), feeling more confident (74%, n=58) and having used information from the IDHS to provide care to individuals with intellectual disabilities (75%, n=57).

Figure 11: Healthcare providers' agreement with statements about their experiences after receiving support from IDHS staff



Note: Total respondent numbers vary across questions in the matrix because some participants skipped certain items.

Source: Healthcare provider survey.

While IDHS staff were not always able to comment directly on the outcomes achieved for healthcare providers, some did share examples of observed change. For instance, staff noted that some healthcare providers told them they felt less isolated when supporting people with intellectual disability or had increased confidence in engaging with them.

Most IDHS staff also noted evidence of increased *collaboration between NSW Health and primary health clinicians* that led to *primary health clinicians knowing where to access support,* particularly between the IDHS and primary care providers. This was often attributed to greater awareness and understanding of the IDHS, which in turn led to increased engagement from both NSW Health and primary health staff, either to access capacity-building opportunities or to refer clients with complex needs.

IDHS staff implied that where positive outcomes were achieved for healthcare providers, this had flow-on impacts to people with intellectual disability, as shown in the below case study.

Case study: Maternity services building confidence in working with clients with intellectual disability

A notable success story involves effective capacity building with local maternity services within an LHD, which has led to improved care for pregnant women with intellectual disabilities as well as fewer referrals of pregnant women from these locations to the IDHS. Instead of directly managing these cases, the IDHS Team worked with maternity services across multiple locations[18] to implement best practices for supporting women with intellectual disabilities during labour and birth. They also provided easy-to-read information from reliable national and international sources on relevant topics, enhancing the quality of care.

5.3.3 Factors that impact satisfaction and capacity building outcomes of healthcare providers

IDHS staff identified factors that impacted healthcare providers' satisfaction with the support they received for capacity building – for example:

- IDHS staff believed that capacity-building support was **most valuable for healthcare providers when delivered ad hoc and informally**. They noted that this approach allowed healthcare providers to learn and promptly apply the knowledge to their work
- **competing priorities** among healthcare providers often limited their ability to fully engage with and apply the information they obtained from planned education.

These factors are also discussed in Chapter 6.

5.4 Effectiveness of monitoring and evaluation

5.4.1 IDHS staff captured consistent NAP data; however, most LHDs had not used it to inform and improve IDHS service delivery

Table 19: Monitoring and evaluation short-term outcomes

Short-term outcomes
• Consistent data is available for service monitoring and evaluation

All IDHS staff consistently recorded non-admitted patient (NAP) data in accordance with the Operational Guideline and NSW Health requirements, successfully achieving the short-term outcome of having *consistent data available for service monitoring and evaluation*. However, many staff members found it challenging to allocate sufficient time for NAP data collection

[18] To maintain anonymity, the locations of these services have not been named.

and analysis. At the time ARTD was collecting data for this evaluation, many IDHS staff expressed that they did not want to invest time and resources into additional data collection regarding capacity building or client feedback until the NSW Ministry of Health (the Ministry) provided further guidance and clarity. ARTD understands that, as planned, since evaluation data collection, the Ministry and IDHS have implemented an additional data collection form and reporting process with items to record capacity building activity.

5.5 Longer-term outcomes

Table 20: IDHS longer-term outcomes

Longer-term outcomes
• Clients of the IDHS have any ongoing needs met in the community. • The IDHS contributes to people with intellectual disability having fewer preventable hospitalisations. • Clients and their families/carers are well equipped to navigate the health system and have good health literacy. • The IDHS supports people with intellectual disability to have fewer adverse experiences in the NSW health system and they and their families/carers feel well and supported. • The IDHS contributes to people with intellectual disability having fewer adverse experiences in the NSW health system and they and their families/carers feeling well supported.

IDHS staff often found it difficult to comment on long-term outcomes, as these are influenced by multiple factors beyond their role and are not always directly observable. As such, there is limited evidence that NSW Health clinicians and GPs are contributing to the longer-term outcomes outlined in the program logic (see Table 20 and Appendix 4). Most IDHS Teams and Positions found it challenging to provide detailed commentary on these outcomes. However, some provided examples, including:

- the recent opening of a paediatric clinic for procedures under sedation
- a Team's collaboration with the Central and Eastern Sydney Primary Health Network's GROW program, where primary health clinicians have started integrating capacity-building practices into their work.

Some IDHS staff mentioned that greater buy-in from Primary Health Networks and LHDs would drive greater change. Despite this, some staff expressed confidence that over time, they can continue to further develop clinicians' skills and capabilities to improve long-term client outcomes.

6. Factors influencing the implementation, reach and outcomes of the IDHS

This chapter summarises key factors that have enabled or limited the implementation, reach, and effectiveness of the Intellectual Disability Health Service (IDHS).Given the complexity of the IDHS, which sits at the intersection of health – a state-mandated area – and disability – a federally mandated area – it is not unexpected that many factors can influence the service's ability to reach people with intellectual disability and complex needs and healthcare professionals; implement supports; and achieve positive outcomes.

IDHS staff and other government and sector stakeholders identified a range of barriers and enablers to implementation. To better understand how the reported enablers and barriers can be leveraged or managed in the IDHS, the ARTD team has analysed them using the Consolidated Framework for Implementation Research.[19]

The enablers and barriers listed throughout this chapter are discussed under the 5 domains. In many cases, the presence of a factor acted as an enabler, while its absence created a barrier – meaning the same factor played different roles across locations depending on local implementation and context.

6.1.1 Outer setting

External influences have impacted Local Health Districts' (LHDs') approaches to delivering the IDHS service, which in turn have impacted reach and effectiveness for clients.

Table 21: Outer setting

Factor	Enabler	Barrier
Local conditions: *Economic, environmental, political and/or technological conditions enable the outer setting to support implementation.* All IDHS staff and many other government stakeholders mentioned that gaps in healthcare and disability services for people with intellectual disability have led the IDHS to fill roles beyond its scope (e.g., longer-term case management and extended support). These gaps include limited availability of services and healthcare providers with the capacity to support people with intellectual disability.	–	X

[19] https://cfirguide.org

Factor	Enabler	Barrier
Local conditions: Some IDHS staff reported a perception that there has been an increase in the number of people with intellectual disability across various LHDs since the service began. ARTD cannot verify this due to a lack of up-to-date population data, this perception has led some staff to suggest that their LHD is not adequately resourced, limiting their ability to provide geographically equitable care and impacting the service's reach.	–	X
External pressures: *External pressures drive implementation and/or delivery of the innovation.* Some IDHS staff noted that LHDs' and Primary Health Networks' differing prioritisation of intellectual disability within their strategies, policies and frameworks (e.g., disability inclusion action plans) impacted their engagement with the IDHS.	X	X

6.1.2 Intervention characteristics

Table 22: Intervention characteristics

Factor	Enabler	Barrier
Innovation adaptability: *The innovation can be modified, tailored or refined to fit local contexts or needs.* IDHS staff found that the adaptability of the IDHS has meant they are able to tailor the model to meet the needs of the clients in their LHD. They at times work beyond the service's scope (e.g., longer-term case management work or supporting clients to navigate the local health system).	X	X
Innovation complexity: *The innovation is complicated, which may be reflected by its scope and/or the nature and number of connections and steps.* IDHS staff and other government and sector stakeholders noted NSW Health and primary health clinicians were confused about the role of the IDHS and other services for people with intellectual disability, including the Intellectual Disability Mental Health Hubs, Disability Navigators and Child and Adolescent Mental Health Services. They highlighted the importance of clearer communication – both to IDHS staff and the broader community – about the distinct roles of each service and the reasons a person might be referred to one over another.	–	X
Innovation design: *The innovation is well designed and packaged, including in how it is assembled, bundled and presented.* Many IDHS staff felt the IDHS Operational Guideline provided clarity about the innovation's design, helping some IDHS Teams and Positions better understand their roles and responsibilities..	X	X

6.1.3 Inner setting

Table 23: Inner setting

Factor	Enabler	Barrier
Structural characteristics: *Infrastructure components support functional performance of the inner setting.* IDHS staff noted that service delivery was smoother with partnered hubs and spokes that shared the same processes (e.g., referral pathways) and systems (e.g., electronic medical records), as this alignment supported collaboration. In contrast, staff saw differing systems between partners as a barrier to effective service delivery.	X	X
Relational connections/communications: *There are high-quality formal and informal relationships, networks and teams within and across inner setting boundaries.* IDHS staff who had strong relationships with their partnered hubs or spokes, – enhanced through regular structured meetings with operational and executive staff, open lines of communication and consistent involvement in intake meetings – reported that these connections enhanced their ability to build awareness of the IDHS and as a result reach people more effectively. Conversely, those without such relationships experienced greater challenges. IDHS Positions also highlighted the value of the spoke network in supporting service delivery as they could share knowledge about different processes (e.g., sedation pathways) and share resources that reduced duplication.	X	X
Innovation domain: *The innovation is well designed and packaged, including in how it is assembled, bundled and presented.* IDHS staff noted that when IDHS Teams provided hybrid or virtual health assessments, they were able to be more equitable, in the sense that they were able to provide assessments to more clients in rural/regional partner districts than Teams that only provided limited in-person clinics.	X	X
Available resources: *Resources are available to implement and deliver the innovation (i.e., funding, space, materials and equipment).* Most IDHS staff mentioned that having a psychologist or psychiatrist in the IDHS Team significantly influenced the effectiveness of a Team's multidisciplinary approach. Teams reported challenges maintaining role continuity and where the role was vacant in the Team, more time was spent by clients to see multiple services such as the Statewide Intellectual Disability Mental Health Outreach Service.	X	X
Available resources: Some IDHS Positions noted that having limited in-person Team clinics (e.g., only 2 per year) negatively influenced reach and in turn how satisfied clients felt with the service. Where more in-person clinics were provided – or where virtual assessments were used to supplement them – the opposite effect was observed.	X	X

6.1.4 Individual setting

Table 24: Individual setting

Factor	Enabler	Barrier
Implementation leads/team members: *Individuals who lead efforts to implement the innovation.* Many IDHS staff mentioned that when staff had pre-existing relationships with healthcare providers, this supported greater engagement. This was especially the case for those who had previously worked in the health system, for example as nurses and GPs.	X	X

6.1.5 Process

Table 25: Process

Factor	Enabler	Barrier
Teaming: *Join together, intentionally coordinating and collaborating on interdependent tasks, to implement the innovation.* IDHS staff noted that when Teams (hubs) involved Positions (spokes) in their intake and multidisciplinary team meetings, this resulted in greater collaboration and Positions feeling valued in service delivery. In comparison, when these practices were absent, staff viewed this as a barrier to delivery.	X	X
Assessing needs: *Collect information about priorities, preferences and needs of people.* Some IDHS staff mentioned that preliminary check-ins (before assessments) were key in understanding the communication needs of people with intellectual disabilities. Some staff did this by meeting clients in familiar settings, such as their home or a car park, to ensure they felt comfortable and satisfied during assessments.	X	–
Assessing needs: Most IDHS staff mentioned that when they focused their capacity-building time delivering ad hoc, incidental capacity building that met busy healthcare providers' needs (e.g., 15-minute sessions), they were able to reach more providers and as a result achieve better outcomes with them.	X	–
Assessing needs: While providing ongoing support to clients is outside the scope of the IDHS, many IDHS staff mentioned that it led to the client accessing services.	X	X
Planning: *Identify roles and responsibilities, outline specific steps and milestones and define goals and measures of implementation success in advance.* Some IDHS staff mentioned that a clear Memorandum of Understanding supported most Teams and Positions to understand their roles and responsibilities.	X	–

7. Recommendations

This chapter outlines strategic recommendations for NSW Health and Local Health Districts (LHDs) to consider in order to maximise the effectiveness of the Intellectual Disability Health Service (IDHS). It draws on findings from the evaluation and provides recommendations that can be implemented by NSW Health and LHDs. While some potential enablers lie outside the service's direct influence, the focus remains on actionable strategies that are realistic within the IDHS context.

7.1 Recommendations for Ministry of Health

7.1.1 Conduct needs analysis to inform IDHS planning and resourcing

Finding: There is currently no comprehensive statewide data on the number of people with intellectual disability who have complex care needs. In addition to this, Teams and Positions do not always consistently capture data on the intensity and length of services provided. This lack of visibility makes it difficult to assess the reach of the IDHS and accurately identify where additional support is required. **Recommendation 1:** NSW Ministry of Health, in partnership with relevant organisations, should undertake further research or a comprehensive needs analysis to identify the distribution and scale of need for providing healthcare support for people with intellectual disability and complex healthcare needs across NSW. This should also include prioritising data on the intensity and length of services required for eligible clients and whether they come from a Hub or Spoke LHD. This evidence base will support more informed decisions on resource allocation and service planning to better meet community needs.

This needs analysis could also support and align with the Special Commission of Inquiry into Healthcare Funding, which has acknowledged the challenges in managing complex care needs for people with intellectual disability. Linking the needs analysis to the Inquiry's broader goals could help ensure that future funding decisions are responsive, equitable and evidence based.

7.1.2 Consider ongoing approaches to address current health and disability service gaps and limitations

Finding: IDHS staff noted that while case management is outside the scope of the IDHS, it is often seen as a core component of their work. This reflects, current service system gaps, the complexity of the health and disability systems and the importance of continuity and coordination across services.

Staff reported that ad hoc, incidental capacity building was often more effective than structured capacity-building activities. This raises questions about whether the approach outlined in the operational guidelines remains fit for purpose.

Recommendation 2: To better support people with intellectual disability and complex healthcare needs, NSW Ministry of Health should continue to assess the value of IDHS staff providing direct support to eligible clients alongside delivering structured capacity-building activities. Addressing service system gaps may require expanding the scope for longer-term case management; however, it is important to balance this with the need to maintain broad capacity-building efforts and reaching more new eligible clients.

7.1.3 Continue to share information to advocate for system-wide change

Finding: There are current gaps within the health and disability systems that affect both the ability of healthcare staff to deliver appropriate care and the capacity of people with intellectual disability and complex needs to access services that meet their needs.

Recommendation 3: Ministry of Health should continue to:

- **engage both state and federal agencies** to highlight and address gaps in service delivery, particularly where responsibilities intersect between health (state) and disability (federal) systems.
- **disseminate relevant information to the IDHS** such as updates on programs, policies and funding mechanisms (for example, Medicare items, the Comprehensive Health Assessment Program) that can be leveraged to strengthen support for NSW Health and primary care clinicians and improve outcomes for people with intellectual disability.

7.1.4 Map the role of the IDHS within the broader health and disability systems

Finding: Some IDHS staff have reported some confusion for clients and primary health clinicians about referral pathways and service navigation, as they are unsure where to go or how to access appropriate support. The role of the service in relation to NDIS Information Linkage and Capacity Building is sometimes unclear.

Recommendation 4: NSW Health could consider a mapping exercise to clarify how the IDHS aligns with other services that support people with intellectual disability, such as Child and Adolescent Mental Health Services, the Statewide Intellectual Disability Mental Health Outreach Service and disability navigation services. This would more clearly define the IDHS boundaries and roles in parallel with other services, which could help improve coordination

across services, reduce confusion for clients and providers, and support more streamlined and effective care pathways.

NSW Health should also consider how the capacity-building aspect of the service may be considered a general foundational support. This is important in the context of current discussions between the Commonwealth and state and territory governments about roles and responsibilities for providing general foundational supports for people with disability.

7.2 Recommendations for both IDHS staff and Ministry of Health

7.2.1 Support implementation of effective practices and update guidelines

Finding: IDHS staff have identified a range of mechanisms and processes that they perceive as supporting effective service delivery and collaboration to meet clients' needs.

These practices include:

- IDHS Teams and Positions engaging in **regular communication** – such as weekly or fortnightly strategic and operational meetings, including intake meetings – which fostered stronger trust and collaboration across the service
- **maintaining shared and consistent systems** within hub-and-spoke partnerships, which enabled streamlined, coordinated operations, thereby helping to alleviate workload burden and improve service delivery
- **having up-to-date Memorandums of Understanding**, reviewed annually, which clarified roles and responsibilities within hub-and-spoke partnerships and supported effective collaboration through clearly defined processes and communication channels
- **using virtual or hybrid service delivery models**, which promoted greater equity across regions by expanding client reach and enhancing team cohesion and unity.

Recommendation 5: IDHS staff should adopt the identified effective practices, outlined in the finding above, across all Hubs and Spokes to support improved service delivery and collaboration. To support this, NSW Ministry of Health should update the IDHS operational guideline to incorporate these practices, establishing clear expectations while maintaining flexibility for local adaptation. Together, IDHS staff and the Ministry should review these guidelines to strengthen service delivery and better support clients, NSW Health and primary health clinicians.

7.2.1 Strengthen collaboration between the IDHS and SIDMHOS to improve client access to psychological and psychiatric support

Finding: IDHS staff and other government stakeholders highlighted the importance of including psychological assessment as part of a holistic health assessment for clients. However, when the psychologist and psychiatrist positions are not filled within an IDHS Team referral to the Intellectual Disability Mental Health Hubs has led to delays for clients due to competing priorities and limited availability.

Recommendation 6: IDHS staff should strengthen their collaboration with Intellectual Disability Mental Health Hub staff to streamline referral pathways and enhance service coordination. This could include establishing agreed protocols for prioritising IDHS referrals, implementing regular communication channels between services, and exploring opportunities for joint planning to address capacity constraints. NSW Ministry of Health should actively support and facilitate these partnerships through resourcing, guidance and monitoring. Strengthening this collaboration will enable more timely psychological assessment and improve client experiences and outcomes.

7.2.2 Better promote the IDHS to improve awareness and reach

Finding: IDHS staff and other government stakeholders noted that there is limited awareness of the service, which has affected its reach among potential clients, NSW Health and primary health clinicians.

Recommendation 7: To improve community and clinician awareness of the IDHS, NSW Health could consider coordinated strategies to promote the service at a state level. At the same time, LHDs and IDHS Teams and Positions could more actively promote the service within their local networks and partnerships. This could involve incorporating IDHS information into local referral pathways, orientation materials and stakeholder engagement activities. However, it is important to acknowledge that staff may face capacity constraints from doing so, particularly when also managing increasing demand.

7.2.3 Establish formal connections with Aboriginal Health Workers to continue to improve the LHDs engagement with Aboriginal clients

Finding: Some IDHS Teams and Positions have reported challenges in reaching Aboriginal people with intellectual disability. Staff noted that this is a cohort where more targeted engagement is needed to improve access to appropriate care and support. Aboriginal Health Workers are trusted members of the health system for Aboriginal people and could play a

vital role in bridging gaps between services and communities. One government stakeholder highlighted that building relationships with individuals who are respected and trusted by Aboriginal communities may provide the additional support needed to improve engagement and service reach.

Recommendation 8: To improve accessibility and reach within Aboriginal communities, IDHS staff should consider establishing formal connections with Aboriginal Health Workers. While these connections are typically formed at the local level, NSW Ministry of Health could consider providing centralised support to enable and strengthen these relationships. This could include highlighting success stories of engagement or raising awareness of the IDHS among Aboriginal communities, services or healthcare providers. This would involve facilitating knowledge sharing, for example through a platform such as Healthdirect.

7.3 Recommendations for LHDs and IDHS staff

7.3.1 Link with Local Area Coordinators and Disability Navigators to manage workload

Finding: IDHS Positions reported that they often find local solutions for individuals with intellectual disability and complex care needs. This increases their workload and diverts time from core capacity building responsibilities.

Recommendation 9: IDHS Positions could consider establishing formal connections with NDIS Local Area Coordinators and Disability Navigators to assist in identifying and coordinating local supports. These roles are designed to help individuals navigate the disability service system and can play a key role in reducing the burden on IDHS staff, though their capacity may also be limited.

7.3.2 Review IDHS workforce activity and align it with service priorities

Finding: There is currently no structured or consistent way to understand how IDHS staff are using their time. This makes it difficult to assess whether workforce capacity is aligned with service priorities, or to identify opportunities for improving efficiency and impact. Without this visibility, it is challenging to make informed decisions about resourcing, role design or service planning.

Recommendation 10: IDHS staff could consider undertaking a review of how time is prioritised across key functions to build a clearer picture of current workforce activity. This would support internal reflection on whether time use aligns with service goals and help

identify opportunities for optimisation. A time and motion study could explore prioritisation and workload, inform future planning, clarify role expectations and support more sustainable service delivery for people with intellectual disability and complex needs.

Appendix 1. Data collection instruments

A1.1. Interview guide for IDHS staff

Hello [insert interviewee's name],

My name is [insert interviewer's name] and I am a [insert interviewer's position] at ARTD Consultants.

Thank you for agreeing to talk with us about your involvement with the Intellectual Disability Health Service. Your feedback is crucial in helping us provide information back to the Health and Social Policy Branch at the NSW Ministry of Health to understand how the service is working in your context and any areas for improvement.

[if before 4/12] We are coming to the network meeting on the 4th of December to give you an overview of the purpose of the evaluation, how we will engage with you along the way and the different methods we will use to capture data. Essentially, these interviews are the first step of the process and these will be followed by interviews with government stakeholders and surveys with healthcare providers.

Participation is voluntary and we can stop the interview at any point or skip a question if you feel uncomfortable answering it. You are also welcome to contact ARTD later to have your information withheld from reporting if you would like.

Do you mind if I record the interview today? Doing so will allow me to focus on our discussion and will let me update my interview notes at a later stage. Any information provided will only be used for research and evaluation purposes, and you will not be identified in any of our reporting.

Do you have any questions for me before we begin?

Today we will follow the guide, but it will be a conversation.

Table A1: Interview questions

#	Question
Intro	To start, can you tell me your name, role title and how long you have been involved in the IDHS?

#	Question
1	How do you and your **team approach delivering the IDHS** in your LHD and partner LHD(s)? • What is working well? • What is not working well? • Have you tailored this approach? And if so, what do you think has been effective about this or not so effective? • *[interviewer note: includes adapting the service model, eligibility criteria, referral processes, level of engagement and capacity building]*
2	**Focusing on administration/governance of IDHS:** Could you please describe how your team have established local governance structures (hub-and-spoke model)? Including with your partner LHD(s)? • When has this been effective and when has this not been effective? • *[interviewer note: i.e., mentoring support]*
3	From your perspective, how effective have you/your team been in using **monitoring tools and data** for the delivery of your service? What do think has enabled or limited this?
4	We understand that each service is different, and we would like you to please provide an estimate of the percentage of your time at work that you spend on 1) health assessments, 2) capacity building with health staff and 3) other tasks? • What do you think is the ideal percentage for each activity? *[interviewer note; record the six numerical estimates for each interview]* • Do you think many of these tasks are within scope of your role description?
5	**Focusing on health assessments for a moment:** From your perspective, do you think the service is effective in **reaching** people with intellectual disability and complex healthcare needs? What has enabled or limited this? *[Prompt: your involvement of clients and families/carers in healthcare plans/assessments]* In what situations or circumstances are people most likely to reach the service?
6	Do you think the support provided to **clients meets their needs**? Why/why not? What if any suggestions do you think could improve the health assessment component of the service – recognising that this is not the sole or even main purpose of the service?

#	Question
7	When the service has helped a person with intellectual disability, what aspects of the service or the context have **contributed to this success**? When the service has not helped a person with intellectual disability, what aspects of the service or the context have contributed to this challenge? • *Prompt: Do you think the health assessment and referrals to services is beneficial?* • *Prompt: Do you think clients and families/carers feel more supported to navigate the health system and confident in accessing care?*
8	**Now thinking about capacity building:** When the service **has been effective in engaging NSW Health and primary health clinicians for building skills, confidence and knowledge,** what aspects of the service or context have contributed to this success? When the service **has not been effective** in engaging NSW Health and primary health clinicians for building capacity, what aspects of the service or context have contributed to this challenge? *[prompt: communication/collaboration with healthcare providers]*
9	Do you think the capacity-building support provided to NSW Health and primary health clinicians has been sufficient? Why/why not?
10	What do you think the impact has been for NSW Health and primary health clinicians? • Do you have any examples of this? • *Prompt: Do you think NSW Health and primary health clinicians feel more confident to support people with intellectual disability?* • *Prompt: Do you think IDHS strengthened relationships and collaboration between NSW Health and primary health clinicians?*
11	Is there anything you think could be improved with the service?

A1.2. Interview guide for other government and sector stakeholders

Hello [insert interviewee's name],

My name is [insert interviewer's name] and I am a [insert interviewer's position] at ARTD Consultants.

The Health and Social Policy Branch at the NSW Ministry of Health has engaged ARTD Consultants to evaluate the NSW Health Intellectual Disability Health Service (IDHS).

Thank you for agreeing to talk with us about your involvement with the IDHS. Your feedback is crucial in helping us provide information to Health and Social Policy Branch to understand how the service is working in your context and any areas for improvement.

The purpose of this evaluation is to provide an in-depth understanding of the implementation and reach of the IDHS, as well as identify key elements for scaling the service and offer insights for continuous improvement.

Participation is voluntary and we can stop the interview at any point or skip a question if you feel uncomfortable answering it. You are also welcome to contact ARTD later to have your information withheld from reporting if you would like.

Do you mind if I record the interview today? Doing so will allow me to focus on our discussion and will let me update my interview notes at a later stage. Any information provided will only be used for research and evaluation purposes, and you will not be identified in any of our reporting.

Do you have any questions for me before we begin?

Today we will follow the guide, but it will be a conversation.

Table A2: Interview questions

#	Question
Intro	To start, can you tell me your role title and your connection with the IDHS?
1	From your perspective, how does the IDHS fit into the overall health system as it relates to people with intellectual disability that require health services? • How does IDHS interact with the system? • Do you think it complements or duplicates work in the health/disability landscape?
2	What, if anything, do you think is most valuable about IDHS?
3	*As you are probably aware, a component of the work the IDHS delivers are **health assessments.*** From your perspective, do you think the service is effective in reaching people with intellectual disability and complex healthcare needs? What may enable or limit this?
4	Do you think the service meets clients' assessment needs? Why/why not? • What, if anything, do you think may make it more effective? • What, if anything, limits the IDHS Team's and Position's ability to provide this?
5	*Another component of IDHS is to **build the capacity of health professionals**.* From your perspective, do you think the service is effective in reaching NSW Health and primary health staff to build their skills, confidence and knowledge to support people with intellectual disability? What may enable or limit this?

#	Question
6	Do you think the service is effective in building the skills, confidence and knowledge of NSW Health and primary health staff? What may enable or limit this?
7	Do you think capacity-building work is valued by health professionals? • What, if anything, do you think may make it more effective? • What, if anything, limits the IDHS Team's and Position's ability to provide value?
8	From your perspective, what impact, if any, has the IDHS had for: • people with intellectual disability (regarding healthcare outcomes)? • healthcare providers? • the system?
9	From your perspective, as someone within the health system not delivering the IDHS, is there anything you think could be improved with the service?

A1.3. Healthcare provider survey

Thank you for taking the time to complete this short survey about your experience with the Intellectual Disability Health Service (IDHS). ARTD have been engaged to complete an evaluation of the IDHS by the NSW Ministry of Health.

Your feedback will be important for us to understand your experience with the service, your satisfaction, and the impact of the service on you and your clients with intellectual disability. It will also support continuous improvement of the IDHS.

Please note:

- to engage with this survey, you do not need to have extensive experience with the service – anything you can say will be very helpful
- the survey is voluntary, and your responses will remain de-identified
- the survey should only take **5 to 10 minutes to complete**.

Please complete the survey by the 6th of April.

If you have any technical questions about the survey, please contact ARTD at keely.mitchell@artd.com.au.

Table A3: Survey questions about the person and their connection to the IDHS

First, we would like to ask you some questions about yourself and your connection with the Intellectual Disability Health Service.

#	Question	Piping	KEQ
1	Which of the following best describes your role (when you had contact with the Intellectual Disability Health Service)? [tick all that apply] a. Nurse b. Dentist c. Doctor d. General Practitioner e. Occupational therapist f. Psychiatrist g. Psychologist h. Paediatrician i. Speech therapist j. Other (please specify)		
2	What area do you work in (when you had contact with the Intellectual Disability Health Service)? [tick all that apply] a. Emergency department b. Outpatient service c. Surgical ward – public hospital d. Medical ward – public hospital e. Other ward – public hospital f. Community mental health service g. General practice h. Other (please specify)		
3	Have you referred a client to the IDHS for a comprehensive assessment? a. Yes b. No		
4	How many have you referred? [open text]	Show if said 3a	
5	Have you received any kind of training, expert advice, information or support from the IDHS? a. Yes b. No	For those that said 3b and 5b, pipe them to 15	
6	When did you first have contact with the IDHS? • In the last 6 months • In the last year or 2 • More than 2 years ago	Show if said either 3a or 5a	KEQ 3: enablers and barriers for IDHS reaching and delivering support

Now we will ask you questions about how the Intellectual Disability Health Service worked for yourself [for capacity building, ticked 5a]

Table A4: Survey questions about how the IDHS worked

#	Question	Piping	KEQ
7	On the last occasion that you made an enquiry with the IDHS, how long did it take for the service to get back to you? a. Straight away (i.e., that day) b. Within a week c. A couple of weeks d. Between 2 weeks and a month e. Longer than a month f. They didn't get back to me g. I am not sure	Show if said 5a If said 7f, pipe to 17	KEQ 4: experience
8	Please indicate your agreement with the following statements. The people you communicated with at the service: *[strongly disagree, disagree, neutral, agree, strongly agree]* a. Listened to you b. Were knowledgeable c. Provided you with useful advice and/or information		KEQ 4: experience
9	Please indicate your agreement with the following statements about your interaction with IDHS: *[strongly disagree, disagree, neutral, agree, strongly agree]* a. I know where to get support and/or information if required when providing care to a person with intellectual disability and their family/carer b. I am more knowledgeable about how I can provide care to a person with intellectual disability and their family/carer c. I am more confident in providing care to a person with intellectual disability and their family/carer d. I have used information from the IDHS to provide care to a person with intellectual disability and their family/carer		KEQ 5: outcomes [options derived from the program logic]

Now we will ask you some questions about how you and your client found the referral system [those that ticked 3a]

Table A5: Survey questions about the referral system

#	Question	Piping	KEQ
10	How long did your client have to wait between being referred to the IDHS and having their first consultation? a. Within a week b. A couple of weeks c. Between 2 weeks and a month d. Between a month to 3 months e. Over 3 months f. They didn't have their first meeting g. I am not sure	Show if said 3a If said 10f pipe to 17	KEQ 4: experience
11	Did your client(s) receive a health assessment? a. Yes b. No c. Some clients did, some did not		KEQ 1: core elements being delivered
12	What did your client receive? *[open text]*	Show if said 11b	KEQ 1: core elements being delivered
13	Please indicate your agreement with the following statements for clients that <u>did receive</u> a health assessment. As a result of your client(s) being referred to the IDHS: *[strongly disagree, disagree, neutral, agree, strongly agree, don't know]* • My client(s) and their family/carers felt their health assessment was comprehensive • My client(s) and their family/carers were involved in the development of their healthcare plan • My client(s) and their family/carers received clear referral pathways • My client(s) and their family/carers were supported by the IDHS	Show if said 11a and 11c	

#	Question	Piping	KEQ
14	Please indicate your agreement with the following statements for clients that <u>did not receive</u> a health assessment. As a result of your client/s engaging with the IDHS: *[strongly disagree, disagree, neutral, agree, strongly agree, don't know]* • My client(s) and their family/carers were supported by the IDHS • My client(s) and their family/carers felt that the IDHS gave them the support needed to navigate the health system • My client(s) and their family/carers felt more confident to find services for care	Show if said 11b and 11c	KEQ 5: outcomes [options derived from the program logic] To analyse against whether they had or had not received a healthcare plan.
15	How likely are you to refer future clients with intellectual disability and complex healthcare needs to the IDHS for a health assessment *[Slider question]* 0 Not all likely 10 Extremely likely		KEQ 4: experience
16	Can you help us understand the reasons for your rating? *[insert text box]*		KEQ 4: experience

For everyone

Table A6: Survey questions for everyone

#	Question	Piping	KEQ
17	How likely are you to recommend the IDHS to another health care professional working with a client with intellectual disability? [*Slider question]* 0 Not all likely 10 Extremely likely		KEQ 4: experience
18	Can you tell us why you gave that answer? *[insert text box]*		KEQ 4: experience

Thank you for completing this survey; your responses will be very helpful.

A1.4. IDHS Executive Sponsor survey

Please indicate your agreement with the following statements about the IDHS Team or Position in your district: [**strongly disagree, disagree, neutral, agree, strongly agree]**

Awareness

1. Most **executive staff** in our LHD who need to be aware of the IDHS, do know about the IDHS.
2. Most **management staff** in our LHD who need to be aware of the IDHS, do know about the IDHS.
3. Most **other LHD staff** who need to be aware of the IDHS, do know about the IDHS.

Value

4. **Executive staff** in our LHD who are aware of the IDHS consider it to be a valuable service.
5. **Management staff** in our LHD who are aware of the IDHS consider it to be a valuable service.
6. **Other LHD staff** who are aware of the IDHS consider it to be a valuable service.

NPS

7. How likely are you to recommend that another LHD like yours implement the IDHS similarly in their area? (With 0 meaning 'not at all likely' to 10 meaning 'highly likely')
8. Can you help us understand the reason for your rating? [Open text]

Appendix 2. Organisations represented by other government and sector interviewees

Table A7: Organisations represented

#	Organisation
1	Agency of Clinical Innovation, NSW Ministry of Health
2	Centre for Aboriginal Health, NSW Ministry of Health
3	Centre for Disability Studies and Central and Eastern Sydney Primary Health Network
4	Council for Intellectual Disability
5	Mental Health Branch, NSW Ministry of Health
6	National Centre of Excellence in Intellectual Disability Health
7	University of New South Wales

Appendix 3. Healthcare provider survey data

A3.1. Respondents by LHD and Hub and Spoke

The ARTD team collected a total of 121 responses across all LHDs. The breakdown of responses is in Table A8 and Table A9.

Table A8: Response breakdown by LHD

LHD	n	%
Central Cost	11	9%
Far West	10	8%
Hunter New England	6	5%
Illawarra Shoalhaven	1	1%
Murrumbidgee	11	9%
Mid North Coast	2	2%
Nepean Blue Mountains	15	12%
Northern New South Wales	13	11%
Northern Sydney	2	2%
South Eastern Sydney	10	8%
Sydney	9	7%
Southern New South Wales	9	7%
South Western Sydney	7	6%
Western New South Wales	15	12%
Total	**121**	**100%**

Source: Healthcare provider survey.

Table A 9: Response breakdown by Hub or Spoke LHD

Hub or spoke	n	%
Hub	49	40%
Spoke	72	60%
Total	**121**	**100%**

Source: Healthcare provider survey.

A3.2. Respondents' role and area they work in

Survey responses by role and area worked in are broken down in Table A10 and Table A11. Please note, for both questions respondents were able to tick all that applied, meaning totals will not equal 121.

Table A10: Response breakdown by role

Role	n	%
Nurse	41	33%
Social worker	15	12%
Doctor	14	11%
Paediatrician	13	10%
Occupational therapist	7	6%
Physiotherapist	3	2%
Psychologist	2	2%
Dentist	1	1%
Psychiatrist	1	1%
Other (please specify)	28	22%
Total number of responses	**125**	**100%**

Source: Healthcare provider survey. Note that some respondents had multiple roles.

Other healthcare-related roles included neurologist, paediatric neurologist, epileptologist, midwife, exercise physiologist, mental health clinician and manager of allied health services. Other non-healthcare roles included case manager, Disability Navigator, educator, Aboriginal Liaison Officer, care coordinator and education support officer. These responses are included in the survey.

Table A11: Response breakdown by area worked in

Area they work in	n	%
Outpatient service	36	30%
Community mental health service	16	13%
Emergency department	10	8%
Community health	10	8%
General practice	10	8%
Private practice	5	4%
Palliative care	3	2%

Area they work in	n	%
Community dental	1	1%
Outreach public hospitals	1	1%
Primary healthcare	1	1%
Other (please specify)	29	24%
Total number of responses	**122**	**100%**

Source: Healthcare provider survey. Note that some respondents worked in more than one area.

Other areas included day surgery units, education centres, disability strategies and hospital wards more broadly.

A3.3. Respondents by support received

Some survey respondents had engaged with capacity-building supports and had referred a client, while some had engaged with neither (n=37). The latter respondents completed the survey at this point.

Table A12: Respondents who engaged with capacity-building supports

Response	n	%
No	69	58%
Yes	52	52%
Total	**120**	**100%**

Source: Healthcare provider survey.

Table A13: Respondents who referred a client

Response	n	%
No	41	34%
Yes	79	66%
Total	**120**	**100%**

Source: Healthcare provider survey.

Appendix 4. Program logic

Improved health of people with intellectual disability in NSW

Inputs	State activities (eventually be inputs)	Local Health District activities	Outputs	Short term outcomes	Intermediate term outcomes	Long term outcomes
NSW Health funding NSW Health Disability and Inclusion plan Existing governance structures NSW Health policies (e.g. person centred care, hospitalisation of PWD) Staff to implement the service The Service Framework to Improve Health Care for People with Intellectual Disability 2012 ACI Intellectual Disability Health Network and resources including the Essentials Framework	Develop state-wide Intellectual Disability Health Service (IDHS) model of care including outlining the core components of the clinical service, eligibility criteria and referral processes Statewide coordination function to facilitate implementation of the model	Tailor locally responsive elements and deliver core components of model of care Consistently implement core components, eligibility criteria and referrals processes Communications and engagement to include promotion and explanation of the service	Core components of the model of care are implemented. Clients and their families/carers access the service Clear referral pathways with GPs are in place	Clients of the IDHS and their families/carers, receive a comprehensive health assessment and referrals to services to address their needs	Clients of the IDHS have their immediate health needs met by a range of specialists coordinated by their GP	Clients of the IDHS have any ongoing needs met in the community Contributes to people with ID have fewer preventable hospitalisations
				Clients and their families/carers are supported by the GP to access specialist services and know where to receive further support where required	Clients and their families and carers feel supported to navigate the health system	Clients and their families and carers are well equipped to navigate the health system and have good health literacy Supports people with intellectual disability receiving coordinated care across NSW Health and primary health system
	Embed person and family centred care principles into model of care	Involve clients and their families/carers in their assessment and care plan development	Clients and their families/carers receive care plans that they have been consulted and involved in creating	Clients and their families/ carers feel supported and consulted by the IDHS in the care plans Clients and their families/carers are guided in their interactions with the health system by care plans	Clients and families/carers feel more confident in accessing care	
	Strengthen state-wide governance structures and coordination mechanisms with local structures	Strengthen local governance within state structures	Governance structures are established and functioning at state-wide and local levels	Implementation of IDHS is guided and supported by effective governance structures to increase accountability, transparency, efficiency and responsiveness		Contributes to people with intellectual disability having fewer adverse experiences within the NSW Health system and they and their families/carers feeling well supported
	Develop annual capacity building plan and support use by districts	Locally tailor and implement capacity building plans to provide training, expert advice and support to NSW Health clinicians on supporting people with intellectual disability and their families/carers during interactions with the NSW Health system	NSW Health and primary health clinicians receive training, expert advice and support on the needs of people with intellectual disability and how to appropriately support them and their families/carers	NSW Health and primary health clinicians are more skilled and confident in supporting people with intellectual disability and their families/carers	NSW Health and primary health staff know where to access support when required regarding working with people with intellectual disability People with intellectual disability have increased access to high quality care from health professionals who can appropriately support them	
		Establish professional collaboration mechanisms between IDHS and primary health to build capacity of primary health to support people with intellectual disability	The IDHS strengthens relationships between NSW Health and primary health staff	NSW Health and primary health staff work in collaboration		
	Develop data monitoring tools with consistent data definitions and support district use of tools	IDHS staff use monitoring tools to record activity	Program data including client activity data, are collected and reported to the Ministry regularly	Consistent data are available for service monitoring and evaluation	Evidence is used to inform and improve IDHS service delivery	

N.B: 'clients' refer to people accessing a comprehensive health assessment through the IDHS. PWID refers to the broader community of PWID (including clients) who will benefit from the capacity building and cultural change within mainstream services

Appendix 5. NAP data definitions

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