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A scoping study of the need for a tertiary intellectual disability mental health service in New South Wales

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1. Background

People with an intellectual disability represent approximately 1-2% of the population [1-3]. Compared to the general population, people with an intellectual disability experience a very poor health status characterised by multiple morbidities [4], premature mortality [5, 6], and elevated rates of physical and mental health problems [7, 8]. Yet, people with an intellectual disability and co-occurring mental ill health experience challenges in accessing mental health care [9-13], including high risk groups such as those transitioning between child and adult services. Significant contributors to this population's inequitable access to mental health care are an ill-equipped public mental health sector, and the lack of specialist intellectual disability mental health services.

Our preliminary analysis of a statewide linked dataset indicates that compared to the NSW population, people with intellectual disability experience mental health admissions which are twice as long and cost twice as much, and that they present twice as often to emergency departments. The higher needs and costs, and the continuing poor mental health status of this population group means that urgent action is required by the NSW Government to address this issue.

Two successive National Roundtables on the Mental Health of People with Intellectual Disability [14, 15] and the NSW Mental Health Commission's Strategic Plan [16] both recommend the need for a specialist intellectual disability mental health service that can i) provide both timely and appropriate access to mental health care for people with an intellectual disability with complex needs, and ii) enhance the capacity of the mainstream mental health sector in this area. However, such a service is yet to be designed or implemented in NSW.

2. Overarching project summary

This project is a scoping study for a Statewide adult tertiary intellectual disability mental health service (Statewide adult tertiary IDMH service) in New South Wales (NSW). The overarching aim of this project was to determine and reach consensus on the key priorities and resource requirements of a Statewide adult tertiary IDMH service in NSW. Our specific objectives were to:

1. Consult with NSW Health Mental Health services to determine and quantify the need for a Statewide adult tertiary IDMH service.
2. Identify and reach consensus on the key clinical priorities of a Statewide adult tertiary IDMH service.
3. Determine how this service can best enhance the capacity of the mainstream mental health workforce to meet the needs of people with an intellectual disability and co-occurring mental ill health.
4. Determine how this service can meet the needs and provide a timely and quality service to people with an intellectual disability with complex needs.
5. Identify the resources required to run a Statewide adult tertiary IDMH service.

3. Overarching methodology

To achieve the aims and objectives of this project a multi-method approach was used. This approach involved the following components:

1. *Survey of NSW Mental Health Directors and key Local Health District (LHD)/Specialty Network representatives.*
   This online survey aimed to identify what support the mainstream mental health workforce requires from a Statewide adult tertiary IDMH service. It also sought to determine the potential rate of referral of people with an intellectual disability, mental illness and high degree of complexity, at an LHD/Specialty Network level.

2. *Consultation with key stakeholders around the key clinical priorities of a Statewide adult tertiary IDMH service*.
   The aim of these consultations was to identify and reach consensus on the key priorities (clinical and non-clinical) and how a Statewide adult tertiary IDMH service should operate. We used a mixed-methods approach to consult with three key stakeholders including:
   a) People with intellectual disability
   b) Family members and support persons of people with intellectual disability, and
   c) Intellectual disability mental health experts.

4. Project component summaries: Methods and results

4.1 Survey of NSW Local Health District/Specialty Network Mental Health Service Representatives

4.1.1 Materials and methods

Consenting mental health directors were asked to nominate a representative from emergency psychiatry teams, community-based teams, inpatient services, old age services, and rehabilitation services within their LHD/Specialty Network. The nominated mental health service representatives were then invited by the research team via email to complete an online survey (Appendix A). The survey comprised three components:

1. Profile of service representatives: Information about the LHD/Specialty Network being represented, current primary work service type (e.g. emergency psychiatry team or equivalent, community-based team, inpatient), the service representative's gender, number of years' experience working in intellectual disability and in mental health, professional background and primary work role
2. Specialist support needs of services: Information about the perceived need for additional specialist support including the number of service users who might benefit, potential areas where support would be helpful, access to existing specialist support
3. Is there a need for a Statewide adult tertiary IDMH service and how could it best meet your service needs?: Information about the perceived need for a Statewide adult tertiary IDMH service including the number of potential referrals per year, areas in which support is needed, preferred methods of working with the service (including making referrals, ongoing communication, alternatives to face-to-face consultation), professionals that should be involved, opportunities for capacity building.

The online survey was open for 2.5 months. Invites were sent out to potential service representatives in waves, dependent on when mental health directors forwarded their nominees to the researchers. Service representatives were encouraged to complete the online survey within two weeks. Two reminder emails were sent to potential service representatives.

Ethics approval was granted by the South Eastern Sydney Local Health District Human Research Ethics Committee; approval number 16/352 (LNR/16/POWH/693). Site specific approval was obtained from the Research Governance Office for each LHD/specialty network that participated. Completion of the survey implied consent.

4.1.2 Participants

Sixteen LHDs/Specialty Networks that granted site specific approval were approached to participate. Mental health directors from 14 of those LHDs/Specialty Networks responded, sending a list of nominees. A total of 241 representatives were nominated by Mental Health Directors and invited to participate, of whom 162 service representatives completed the survey. One service representative's data was excluded as they had not been nominated by a Mental Health Director. A total of 161 service representatives from 14 LHDs/Specialty Networks were included in the final analysis (response rate of 67%).

Profile of service representatives

Table 4.1.1 presents a profile of the service representatives who completed the online survey. The majority of service representatives were female (64%), with a primary professional background in nursing (55%). The most common primary service type service representatives were working in was community-based teams (36%), followed by general inpatient services (21%). Managerial roles were the most common primary work role (39%), followed by medical (16%) and allied health roles (12%). There were numerous other roles (31%), including nurse unit managers, case managers, and Aboriginal mental health workers. Service representatives had a median of 17 years (IQR = 10-25) of experience working in the area of mental health, and a median of 8 years (IQR = 1-15) working with people with intellectual disability.

Table 4.1.1 Profile of service representatives

Demographic	Response	n[a] (%)
Gender (n=159)	Female	101 (64)
	Male	58 (36)
LHD/Specialty Network (n=160)	South Eastern Sydney	26 (16)
	Western NSW	25 (16)
	Western Sydney	24 (15)
	Nepean Blue Mountains	16 (10)
	Illawarra Shoalhaven	12 (8)
	Murrumbidgee	11 (7)
	Northern Sydney	11 (7)
	Northern NSW	7 (4)
	South Western Sydney	7 (4)
	Central Coast	6 (4)
	Southern NSW	6 (4)
	Sydney	5 (3)
	Children's and Paediatric Services Network	3 (2)
	Far West	1 (1)
Current primary work service type (n=160)	Community based teams	57 (36)
	Inpatient (e.g. acute, subacute/general, intensive care)	34 (21)
	Rehabilitation (e.g. inpatient/community)	19 (12)
	Emergency psychiatry team or equivalent	14 (9)
	Old age (e.g. inpatient, community)	13 (8)
	Children's and paediatric services	4 (3)
	Other	19 (12)
Primary professional background (n=159)	Nursing	88 (55)
	Psychiatry	22 (14)
	Social work	19 (12)
	Occupational Therapy	13 (8)
	Psychology	12 (8)
	Medical	3 (2)
	Other	2 (1)
Current primary work role (n=159)	Managerial	62 (39)
	Medical	25 (16)
	Allied health	19 (12)
	Intellectual disability mental health specialist	3 (2)
	Education	1 (1)
	Other	49 (31)

[a]Does not include missing data

4.1.3 Results

Specialist support needs of services

Almost all (n = 157; 99%) service representatives said that they would find it helpful to have additional specialist support or advice to meet the needs of people with intellectual disability and co-occurring mental ill health. Service representatives reported that their services would find additional specialist support helpful for a median of 15 people with intellectual disability (IQR = 7-30) per year (see Table 4.1.2 for a summary by LHD/speciality network). There was a slightly higher median per service in rural and remote versus metropolitan LHDs, and a markedly higher median for the Children's and Paediatric Services Network. For those individuals requiring additional support, services in each LHD/Specialty network would find a variety of additional types of specialist support or advice helpful (see Table 4.1.3). When asked to rank the areas in which they thought additional support/advice would be most helpful, service representatives endorsed the following top five areas: 1) assessment, 2) diagnostics, 3) mental health care planning, 4) partnering and collaborating with key stakeholders, and 5) non-pharmaceutical mental health interventions.

Table 4.1.2 Number of people with an intellectual disability each service would find additional mental health support helpful by LHD/specialty network

LHD/Specialty Network	**n**	**Median per service**	**Minimum per service**	**Maximum per service**
Metropolitan LHDs				
Central Coast	6	35	15	100
Illawarra Shoalhaven	12	13	5	80
Nepean Blue Mountains	15	35	3	100
Northern Sydney	9	12	5	40
South Eastern Sydney	26	10	2	100
South Western Sydney	7	9	2	40
Sydney	5	10	0	100
Western Sydney	24	16	0	100
All metropolitan LHDs	*104*	*15*	*0*	*100*
Rural and regional LHDs				
Far West	1	15	15	15
Murrumbidgee	11	20	5	80
Northern NSW	7	25	8	50
Southern NSW	6	11	5	30
Western NSW	24	15	1	100
All rural and regional LHDs	*49*	*20*	*1*	*100*
Specialty network				
Children's and Paediatric Services Network	3	50	50	70
All LHDs/Specialty Network	**156**	**15**	**0**	**100**

Table 4.1.3 Key areas in which a service would find additional specialist support or advice helpful

Key areas	**n (%)**
Assessment	114 (71)
Partnering and collaborating with key stakeholders	111 (69)
Mental health care planning	102 (63)
Transfer of care	98 (61)
Adapting service to meet diverse needs	95 (59)
Diagnostics	95 (59)
Mental health interventions – non-pharmaceutical	95 (59)
Referrals	83 (52)
Providing recovery orientated support	78 (48)
Communication	72 (45)
Mental health interventions –pharmaceutical	69 (43)
Providing a responsible, safe and ethical practice	58 (36)
Intake	48 (30)

Approximately a third (n = 55; 35%) of service representatives said that they were currently able to access additional specialist support or advice for people who required additional support. Table 4.1.4 shows where they accessed the services from, whether needs were met (by metropolitan LHDs, rural and remote LHDs, and specialty network, and examples of such services). Almost half said that they accessed additional support from professionals within their own service/hospital who specialised in intellectual disability mental health, and reported that these professionals 'sometimes to very often' met their service's support/advice needs. Examples of such professionals were intellectual disability mental health staff specialists, mental health or allied health professionals with intellectual disability experience, and clinical nurse co-ordinators.

Table 4.1.4 Services accessed to provide additional support/advice for people with intellectual disability and co-occurring mental ill health (n=55)

Service	LHD/Specialty Network[a]	n[b]	Service/professional's ability to meet service's support/advice needs[c]			Examples
			Always/ Very often n (%)	Sometimes n (%)	Rarely/Never n (%)	
Internal IDMH specialist services	Metropolitan LHDs	12	5 (42)	7 (58)	0 (0)	IDMH service; consultant service; network ID co-ordinator; psychological medicine, occupational therapy and social work departments
	Rural and Remote LHDs	1	1 (100)	0 (0)	0 (0)	
	Specialty Network	2	1 (50)	1 (50)	0 (0)	
	All LHDs/Specialty Network	**15**	**7 (47)**	**8 (53)**	**0 (0)**	
Internal professionals who specialise in IDMH	Metropolitan LHDs	21	9 (43)	10 (48)	2 (10)	Staff specialist in IDMH; psychiatrists, psychologists, nurses or allied health professionals who specialise in ID; clinical nurse co-ordinators; intellectual disability co-ordinator
	Rural and Remote LHDs	2	0 (0)	2 (100)	0 (0)	
	Specialty Network	3	2 (67)	1 (33)	0 (0)	
	All LHDs/Specialty Network	**26**	**11 (42)**	**13 (50)**	**2 (8)**	
External IDMH services that are publicly funded	Metropolitan LHDs	15	3 (21)	9 (64)	2 (14)	Westmead Hospital ID support specialist; Concord Hospital ID clinic; Kogarah Developmental Assessment Service; NSW Health services; NDIS; Partners in Recovery; ASPECT
	Rural and Remote LHDs	4	0 (0)	4 (100)	0 (0)	
	Specialty Network	1	0 (0)	1 (100)	0 (0)	
	All LHDs/Specialty Network	**20**	**3 (16)**	**14 (74)**	**2 (11)**	
External IDMH services that are privately funded	Metropolitan LHDs	6	1 (17)	5 (83)	0 (0)	Autism Advisory and Support Services; Benevolent Society; Northcott; Windgap Foundation; employment organisations; private psychiatrists
	Rural and Remote LHDs	2	1 (50)	1 (50)	0 (0)	
	Specialty Network	0	-	-	-	
	All LHDs/Specialty Network	**8**	**2 (25)**	**6 (75)**	**0 (0)**	
External professionals who specialise in IDMH and work within a publicly funded service	Metropolitan LHDs	9	3 (38)	4 (50)	1 (13)	Benevolent society; Disability Trust; House with No Steps; GP, physiotherapists, occupational therapists, psychologists; Family and Community Services; professionals within group homes
	Rural and Remote LHDs	6	0 (0)	4 (67)	2 (33)	
	Specialty Network	1	0 (0)	1 (100)	0 (0)	
	All LHDs/Specialty Network	**16**	**3 (20)**	**9 (60)**	**3 (20)**	

External professionals who specialise in IDMH and work within a privately funded service	Metropolitan LHDs	4	1 (25)	1 (25)	2 (50)	Private psychiatrists; supported living accommodation providers
	Rural and Remote LHDs	0	-	-	-	
	Specialty Network	0	-	-	-	
	All LHDs/Specialty Network	**4**	**1 (25)**	**1 (25)**	**2 (50)**	

[a]Metropolitan LHDs- Central Coast, Illawarra Shoalhaven, Nepean Blue Mountains, Northern Sydney, South Eastern Sydney, South Western Sydney, Sydney, Western Sydney; Rural and remote LHDs- Far West, Murrumbidgee, Northern NSW, Southern NSW, Western NSW; Specialty Network- Children's and Paediatric Services Network

[b]Number of mental health service representatives that reported they could access advice/support from each type of service (service representatives could choose more than one type of service)

[c]Excludes missing data

Key: ASPECT- Autism Spectrum Australia; ID- intellectual disability; IDMH- intellectual disability mental health; NDIS- National Disability Insurance Scheme; Internal service-within a service representative's service or LHD/Specialty Network; External service-outside of a service representative's service or LHD/Specialty Network.

Is there a need for a Statewide adult tertiary IDMH service?

Overall, service representatives agreed that there was a need for a Statewide adult tertiary IDMH service in NSW (*M* = 4; *SD* = 1.48; 1-Strongly disagree-5 Strongly agree). The number of referrals that each service representative said that their service would expect to make to a Statewide adult tertiary IDMH service is displayed in Figure 4.1.1. The majority of service representatives said that their service would refer between 3-20 individuals per year (54%). Thirteen percent said that their service would refer over 50 individuals per year. Table 4.1.5 shows the estimated number of referrals that service representatives estimated their service would make, presented by LHD/specialty network. The median referrals per service was similar across metropolitan, and rural and remote LHDs, but considerably higher for the Children's and Paediatric Services Network.

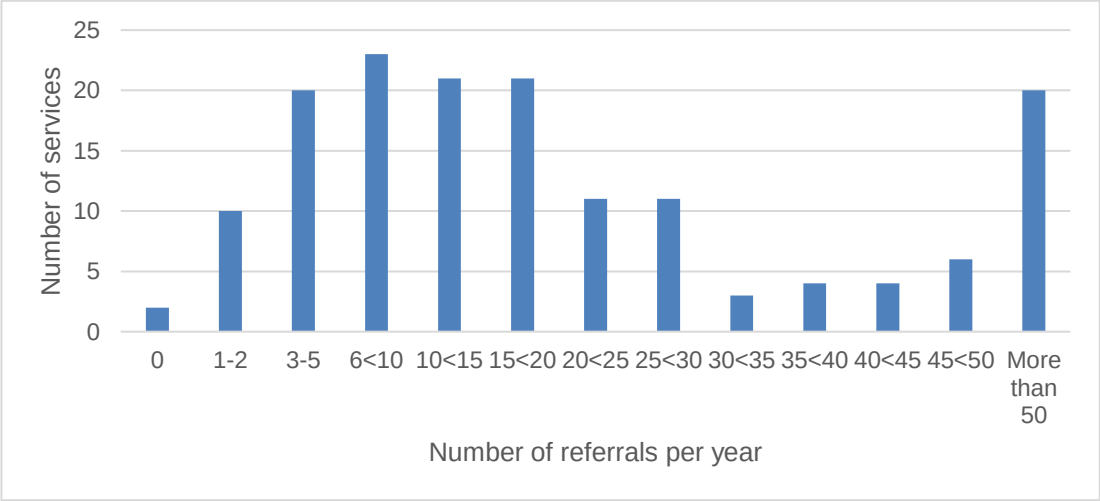

Figure 4.1.1 Number of referrals to a Statewide adult tertiary IDMH service that service representatives reported their service would make per year (n=156)

Table 4.1.5 Service representatives' estimated number of referrals to a Statewide adult tertiary IDMH service per service per year by LHD/speciality network

LHD/Specialty Network	n	Median per service per year	Minimum per service per year	Maximum per service per year
Metropolitan LHDs				
Central Coast	6	20<25	0	More than 50
Illawarra Shoalhaven	11	6<10	3-5	More than 50
Nepean Blue Mountains	16	15<20	1-2	More than 50
Northern Sydney	10	10<15	1-2	More than 50
South Eastern Sydney	25	10<15	0	More than 50
South Western Sydney	7	20<25	1-2	30<35
Sydney	5	6<10	1-2	More than 50
Western Sydney	24	20<25	1-2	More than 50
All metropolitan LHDs	*104*	*15<20*	*0*	*More than 50*
Rural and regional LHDs				
Far West	1	6<10	6<10	6<10
Murrumbidgee	11	15<20	3-5	More than 50
Northern NSW	7	15<20	3-5	25<30
Southern NSW	6	6<10	3-5	45<50
Western NSW	24	15<20	1-2	More than 50
All rural and regional LHDs	*49*	*15<20*	*1-2*	*More than 50*
Specialty network				
Children's and Paediatric Services Network	3	45<50	25<30	More than 50
All LHDs/Specialty Network	**156**	**15<20**	**0**	**More than 50**

If such a Statewide adult tertiary IDMH service existed, people with an intellectual disability may be referred for a range of reasons (Table 4.1.6). The top five reasons service representatives gave for making a referral to a Statewide adult tertiary IDMH service were for 1) assistance with case review for a person who requires complex solutions, 2) assistance with diagnostic complexity, 3) assistance with assessment of behaviours of concern, 4) assistance when existing services are unable to accept a referral for person, and 5) assistance with case review of people with intellectual disability who are frequent users of mental health services.

Table 4.1.6 Reasons a service would make a referral to a Statewide adult tertiary IDMH service

Key reasons	n (%)
Assistance with a case review for a person who requires complex solutions	116 (72)
Assistance with the assessment of behaviours of concern (also known as challenging behaviour)	115 (71)
Advice and assistance with linking the person with appropriate support service	111 (69)
Assistance with diagnostic complexity	103 (64)
Advice on challenging behaviour (also known as behaviours of concern)	102 (63)
Assistance when existing specialist services are unable to meet the persons needs	100 (62)
Assistance when existing services are unable to accept a referral for the person	99 (61)
Advice on the management of a person who also has complex medical comorbidity	94 (58)
Assistance with a case review of people with an ID who are frequent users of mental health services	94 (58)
Advice and assistance with determining an appropriate discharge plan/transfer of care plan	93 (58)
Advice on the best ways to support people with an ID who are at risk of self-harm or harm to others	92 (57)
Assistance with a case review of people with an ID with failed mental health interventions	92 (57)
Advice when the prescribed mental health intervention(s) are not effective in managing the persons mental ill health	91 (57)
Advice on the best ways to support people with an ID who are at risk of losing their support services	89 (55)
Assistance with a case review of people with an ID who have long stays within mental health services	89 (55)
Advice on the best ways to support people with an ID who are at risk of homelessness	87 (54)
Advice determining the most appropriate non-pharmaceutical mental health intervention(s)	83 (52)
Advice regarding communicating with the person with an ID	71 (44)
Advice on the management of a person who also has complex genetic disorder(s)	69 (43)
Advice regarding psychopharmacological management	66 (41)
Assistance with developing and implementing a mental health care plan	64 (40)
Advice on policy and procedure to ensure that it meets the needs of people with an ID	61 (38)
Advice on suicide prevention strategies	57 (35)
Advice on preventative mental health programs	51 (32)
Advice regarding communicating with the person’s support network	44 (27)
Other	16 (10)

[a] Examples of other reasons to make a referral included advice on rare genetic syndromes, assistance with accessing ID services in other LHDs/Specialty Networks for state-wide units, sexual health, and advice on working with family members and non-government organisations.

Key: ID (intellectual disability)

Characteristics of a Statewide adult tertiary IDMH service and how it could run to meet the needs of people with intellectual disability and referring mental health professionals

Service representatives said that their first preference would be to make referrals online, with their second preference via the telephone, then paper-based forms, and finally other methods such as face-to-face or via video-conferencing. Service representatives' most preferred method for ongoing communication between their service and a Statewide adult tertiary IDMH service was face-to-face, followed by the telephone, then email, video-conferencing, and finally other methods such as Skype.

Ranked in order of service representatives' preference, potential methods for working with a Statewide adult tertiary IDMH service include 1) clinicians consulting directly with the specialist and working together to recommend strategies, 2) the specialist seeing the patient directly and working collaboratively to recommend strategies, 3) the service handing over clinical care to the specialist, 4) the specialist reviewing case notes and recommending strategies, and 5) other methods (such as consulting directly with the Statewide adult tertiary IDMH service, then working with the person with intellectual disability and their family and support persons to recommend strategies). If a professional from the Statewide adult tertiary IDMH service was not able to work with a mental health service in person, service representatives' most preferred methods for working with them would be via video-conferencing, then telephone, email, and finally other methods such as Skype.

Numerous professionals could be involved in the Statewide adult tertiary IDMH service (Table 4.1.7). The professionals that service representatives would most prefer to be involved in the operation of the service were ranked as follows: 1) psychiatrists, 2) psychologists, 3) nurses, 4) occupational therapists 5) social workers 6) speech pathologists, and 7) other professionals.

Table 4.1.7 Professionals that should be involved in the operation of a Statewide adult tertiary IDMH service

Professional	**n (%)**
Psychiatrist	138 (86)
Psychologist	138 (86)
Social Worker	137 (85)
Occupational therapist	131 (81)
Nurse	128 (80)
Speech Therapist	94 (58)
Other[a]	20 (12)

[a]Examples of other professionals included dieticians, exercise physiologists, behavioural specialists, neurologists, developmental paediatricians, and education specialists.

Service representatives were asked how a Statewide adult tertiary IDMH service could best support their service when a person with intellectual disability was experiencing an acute crisis (open-response question; Table 4.1.8). The most common responses were to provide advice (e.g. on assessment, management, and services that they could refer their patients to; n =18; 14%), to offer consultation-liaison services and assist with service co-ordination (n =14; 11%) and to provide a telephone or video conferencing helpline (n = 14; 11%). A small number of service

representatives did not believe that a Statewide adult tertiary IDMH services should have a role in providing crisis support (n = 4; 3%).

Table 4.1.8 Ways a Statewide adult tertiary IDMH service could support services when a person with intellectual disability is in an acute crisis

Suggested roles of a Statewide adult tertiary IDMH service	**n (%) n=129**
General advice on assessment/management/service referral	18 (14)
Consultation-liaison/co-ordination of service provision	14 (11)
Telephone/video conferencing helpline	14 (11)
Assessment strategies/management and care plans/discharge planning	13 (10)
Work in collaboration with referring clinician/shared care	9 (7)
Specialists to assist with behaviour management plan	8 (6)
Tertiary service to see the person with intellectual disability face-to-face	7 (5)
Short notice assessments/available and flexible service	5 (4)
24-hour crisis support/specialist response team	4 (3)
Tertiary service would not have a role in providing support in the case of acute crisis	4 (3)
Assist with accommodation/respite services/offer specialised temporary accommodation for crises	3 (2)
De-escalation techniques/containment	3 (2)
Facilitate admission to hospital	3 (2)
Temporarily take over care of the person with intellectual disability	3 (2)
Other[a]	21 (16)

[a] Examples of other suggested roles included: refer to crisis teams; assistance with management in the community to avoid admission; communication strategies; acute psychological support; providing formulations; having an advanced directive noting how individual would like care tailored; in-services to assist with providing acute care.

Another role of a Statewide adult tertiary IDMH service may be to support mental health services to build capacity in the area of intellectual disability mental health through various methods (Table 4.1.9). The top ranked ways in which such a service could help to build capacity were to 1) assist in the development of a localised service pathway for people with an intellectual disability, 2) deliver education and training, 3) participate in case reviews, 4) assist in developing a localised working group between mental health and local disability services to reach an agreement on how to best work together to meet the needs of people with an intellectual disability, and 5) participate in the review and development of policy and procedure to meet the needs of people with an intellectual disability.

Table 4.1.9 Ways in which a Statewide adult tertiary IDMH service could best support a service to build capacity in the area of intellectual disability mental health

Methods to build capacity	**n (%)**
Deliver education and training	118 (73)
Assist in the development of a localised service pathway for people with an ID	117 (73)
Participate in case reviews	108 (67)
Assist in developing a localised working group between mental health and local disability services to reach an agreement on how to best work together to meet the needs of people with an ID	94 (58)
Participate in the review and development of policy and procedure to meet the needs of people with an ID	85 (53)
Assist in the development and implementation of an intellectual disability mental health workforce development strategy	84 (52)
Support the service to develop and implement quality improvement projects in the area of intellectual disability mental health	77 (48)
Assist in the development of strategies to support the service to implement the Guide, Core Competency Framework and Toolkit, and Positive Cardiometabolic Early Intervention Framework	67 (42)
Facilitate peer group meetings that discusses challenges and strategies for meeting the needs of people with an ID	67 (42)
Role model clinical decision making in the development and implementation of interventions	67 (42)
Formal professional mentoring	66 (41)
Role model the assessment process	59 (37)
Role model clinical decision making in reaching diagnosis	58 (36)
Provide case scenarios of successful interactions of with people with an ID	56 (35)
Other[a]	7 (4)

[a] Examples of other ways to build capacity included advocating and investing in local accommodation and support services, education on drug and alcohol issues (including interventions and strategies), employing dual qualified staff (ID and mental health) to provide service, support and education.

Key: ID (intellectual disability)

4.2 Consultation with people with intellectual disability around the need for a Statewide adult tertiary intellectual disability mental health service and how it could best operate to meet their needs

4.2.1 Materials and methods

Participants who were interested in taking part contacted 3DN, UNSW directly. Participants were invited to take part in interviews which were facilitated in collaboration with the Council for Intellectual Disability (CID). They were informed they could bring a support person to the interview if they would like to.

Interviews were based on a question guide (Appendix B) that included three parts:

1. Demographic details
2. Experiences accessing mental health services: History of accessing mental health services including the types of professionals/services accessed, and views on the need for a Statewide adult tertiary IDMH service.
3. Development of a Statewide adult tertiary IDMH service: Views on ways such a service could operate to meet the needs of people with an intellectual disability, their family members/support persons and other health professionals (e.g. general practitioner, treating psychiatrist).

The interview question guide was developed in consultation with a consumer reference group comprising people with an intellectual disability. Part three of the question guide was framed around a case study (see Appendix B) developed as per the suggestions of the consumer reference group. Each interview was tailored to the communication needs of participants, for example by using non-verbal communication aids such as pictures and flash cards.

Ethics approval was granted by the UNSW Sydney Human Research Ethics Committee (approval number HC17986). Informed written consent was obtained.

4.2.2 Participants

The CID distributed recruitment materials (in Easy English format) advertising this consultation study to their members and networks. Potential participants were considered to be eligible to take part in the interviews if they had an intellectual disability and resided in NSW.

Seven participants have taken part in the study to date. Five took part without a support person present, while two asked for a CID staff member to be present during the interviews to provide support/help with the interpretation of questions. No participants required communication aids. A profile of these participants is presented in Table 4.2.1.

Table 4.2.1 Profile of people with intellectual disability who participated in consultation

Alias	Profile[a]
'Alice'	Alice is a woman in her 40s who lives in a major city. She lives with her family. She does not currently work, but has participated in intellectual disability advocacy work and enjoys hobbies and sports. She regularly sees her GP and other specialists for a physical disability. She has experienced mental health issues, and has seen a counsellor.
'Patrick'	Patrick is a man aged in his 50s. He lives alone in a major city and is supported by various care organisations. He works in supported employment and has worked on intellectual disability advocacy projects. Patrick regularly sees his GP and other specialists. He has a history of mental health concerns and has seen a psychiatrist and psychologists.
'Benjamin'	Benjamin is a man in his 30s. He lives in a city with his family. He works in supported employment and has been involved with intellectual disability advocacy work. Benjamin sees his GP regularly, along with a counsellor for mental health concerns. He has also experienced a physical injury.
'Madeleine'	Madeleine is a woman in her 50s. She lives in a city and is quite independent. She works part-time in supported employment. In the past she has worked with intellectual disability advocacy groups. She sees her GP and a psychologist regularly. In the past she also sought services from community mental health services for mental health concerns.
'Wendy'	Wendy is a woman in her 30s. She lives in a city with family. She is supported by family and friends, and also attends regular meetings at an intellectual disability advocacy group. Wendy currently works. She does not see her GP regularly, nor any other health professionals. She has no history of mental health concerns, and has not accessed any mental health services.
'Sarah'	Sarah is a woman in her 30s. She lives in a regional city on her own. While she does not work due to mental health issues, she participates in advocacy work. She sees her GP and a psychologist regularly and has a current Mental Health Care Plan. She receives support from her family and disability organisations.
'Catherine'	Catherine is a woman in her mid-40s who lives on her own in a city. She described having a limited support network. She does not see a GP regularly but sees a psychiatrist once every three months. Catherine participates in occasional advocacy work.

[a]Some demographic details have been changed to ensure anonymity

4.2.3 Results

Experiences accessing mental health services

In general, five participants who had seen a mental health professional were reasonably satisfied with the service they had received. Patrick found it positive when his psychologist "*listens to him*". Alice said that she liked the fact her counsellor was "*down to earth*". Madeleine had positive experiences with a psychologist in the past who used simple language and let her "*set the pace*" (i.e. discuss things when she was ready). Alice said that there was "*nothing in particular*" that her counsellor could have done differently to help her. Benjamin was generally satisfied with the service he had received, but said his counsellor could have known more about services/resources available for people with intellectual disability. Sarah said that she had had mixed experiences

seeing mental health professionals. While she was pleased with her current psychologist as she has *"lots of experience seeing people with disability"* and can *"calm her down"* when she is anxious, she also had less positive experiences with professionals in other settings. For example, in community mental health centres, where she felt that professionals have had little experience with intellectual disability. Catherine was less satisfied with the mental health services she has received. She sees a psychiatrist regularly, and has seen a psychologist in the past, but does not feel that she has seen much improvement in her mental health condition. She said she feels frustrated that she always has to *"prove to doctors that I have mental health issues".*

Five participants spoke of the difficulties and barriers either they, or other people with intellectual disability, have faced when they accessed services from various mental health/health professionals. Benjamin, Madeleine, Sarah, and Catherine said some professionals have little experience in the area of intellectual disability, and have difficulties communicating with people with intellectual disability (e.g. using jargon and technical terms rather than plain English). Further, written information is often not available in plain English or Easy English. Sarah believed strongly that mental health professionals need to learn how to talk to people with intellectual disability, for example *"not coming on too hard"* with too much 'blunt' information that scares them. They should slow down, gain trust, explain things, and talk to the person's family or support person to take the stress off the individual. Benjamin commented that when he was in hospital, he found that his doctors and nurses had difficulty understanding him and did not explain things to him (e.g. why medication was being given). He also commented that professionals were not aware of support services for this population. While Wendy had not accessed mental health services, she commented that counselling is too expensive, and consumers can only access a limited number of sessions through Medicare. Catherine said she felt that people with mental health issues do not get the support they need.

Counsellors, psychiatrists and psychologists were generally seen either in their clinics or made home visits. Madeleine and Sarah accessed some services from a community mental health service.

<u>Views on the development of a Statewide adult tertiary IDMH service (referred to as an 'expert team')</u>

The need for an expert mental health team

All participants agreed that there should be an expert mental health team (i.e. a Statewide adult tertiary IDMH service) to help people with intellectual disability, their family and support persons, and referrers. There was consensus that one of the functions of such a team would be to speak directly with people with intellectual disability about their mental health concerns, provide advice, and formulate a plan to support them. Only one participant, Madeleine, commented that the expert team may not always need to deal directly with the person with intellectual disability or their family. Instead they could provide support and advice to the person's GP and psychiatrist. Sarah said that it may be good for the expert team to only speak to the person's family and support persons at some points so they do not stress/scare the person with intellectual disability. Benjamin said that the expert team should "*ask them [the person with intellectual disability] questions as some people with intellectual disability find it difficult to speak up*". Catherine thought that people with intellectual disability should see the expert team, rather than regular psychiatrists, as the team would have

specialist experience. All participants thought an expert team should speak with the person's regular health professionals to provide advice and develop a management plan. Benjamin believed such an expert team would be helpful as they would be knowledgeable about intellectual disability and could help to identify the types of services an individual may need. Wendy commented that an expert team could provide advice to doctors, particularly with regards to interventions (such as group counselling and goal setting). Catherine said that such an expert service could help psychiatrists and other doctors to know what to do and understand warning signs, and as they will have specialist experience in one area, they will be able to *"fix problems".* Her only concern was how different groups (i.e. the expert team, psychiatrists, GPs etc) will decide *"who will do what".*

Supporting family and support persons of people with intellectual disability

Five participants thought that an expert team should provide support to the family and support persons of people with intellectual disability. This could be achieved by talking with them directly, providing them with information, and discussing ways in which they could support the individual. Benjamin thought that the expert group should talk to the whole family, not just one or two people. If the expert team spoke directly with families, Alice and Sarah believed this would help to reduce the person with intellectual disability's stress (as they were not dealing with issues on their own).

What would the expert mental health team need to know?

Regarding what the expert team would need to know about the individual with intellectual disability, participants reported that they should have information on the person's physical and mental health history, their 'normal' behaviour, their current mental health concerns, and what services they have accessed. Sarah said that it was also important to know how and when the person developed intellectual disability as it was different for those born with intellectual disability, compared to developing it later in life. Information could be gathered by talking with the person's GP, asking the individual questions, and speaking with family or friends. Madeleine commented that the expert team should retain patient information so that the individual does not have to recount their history if they access the service again in future. Benjamin thought that they would need to know the person "*inside out*" (e.g. their history and living situation). Wendy said the expert team would need to know about the person's mental health history, substance use, and relevant risk factors.

With regards to what the expert team should know in general, participants thought those working in the service should be experts in intellectual disability and mental health (i.e. have had training around how to support people with intellectual disability). Benjamin and Sarah also said that the specialists should know which types of medications are suitable for people with intellectual disability.

What would help the expert mental health team to work with people with intellectual disability?

Alice, Benjamin, Madeleine, and Sarah mentioned the importance of specialists knowing how to communicate effectively with people with intellectual disability (i.e. avoiding jargon, using flexible communication methods, especially for people who may be non-verbal etc). They also said that more Easy Read materials should also be available. Benjamin said that the expert team should explain information to people with intellectual disability by sitting down with them, breaking down the information and explaining things clearly. He also thought there should be special teams

available to see CALD individuals. Madeleine said that the service should follow-up with people, and that individuals should be able to seek help from the expert term again in future if needed (with a new referral). Alice suggested distributing cards/flyers containing the expert team's contact details to hospitals so that mental health professionals could easily contact the team. Catherine mentioned that the expert team should be reliable, with people able to see the same professional each appointment so that they did not have to deal with frequent changes.

Where should the expert mental health team work?

The most common location mentioned for the expert team to work in was a hospital (six participants mentioned this location). Sarah commented that there should also be a doctor and nurse who knows about intellectual disability in every emergency department. Four participants thought there should be a number of expert mental health teams across NSW (e.g. in each hospital), while two thought there should just be one or two expert teams that service all of NSW. Wendy commented that the teams should be in hospitals where there is the greatest need. Sarah thought that there should be an expert team in each hospital across Sydney, but only one team per regional area. In rural areas, she thought teams should be in community centres as people may have to travel long distances to the nearest hospital. Participants thought the team(s) should also work out in the community. Alice said they should travel to group homes as people who live in such accommodation often lack support. Wendy commented that they could also have their own offices. One participant, Patrick, thought that the team should work in a clinic (rather than a hospital) as "*a person with intellectual disability may be frightened to go to a hospital*". Benjamin thought they should be based somewhere accessible, or do home visits. Another option, mentioned by Sarah, was for expert teams to see people with intellectual disability and co-occurring mental health issues in the community, rather than mainstream mental health professionals working with them in community mental health centres.

All participants thought that the expert team should be accessible face-to-face, with three also mentioning the telephone. Seeing participants face-to-face and communicating via the telephone was seen as equally important to Patrick. Benjamin stressed that the service should not be exclusively online as many people with intellectual disability do not have access to a computer. Further, Sarah said that it was best to see people face-to-face as misunderstandings can occur over the phone with no opportunity to correct.

Helping other doctors and health professionals work with people with intellectual disability

Six participants said that an expert team could help train and educate other mental health and health professionals (e.g. by running courses) on how best to work with people with intellectual disability and mental ill health. Benjamin said that not all GPs know about intellectual disability and "*some doctors confuse intellectual disability with brain injury*". Areas in which they thought mainstream health professionals needed training included communicating with people with intellectual disability (especially those who are non-verbal), how to build rapport (e.g. talking directly to the person with intellectual disability during consultations, not merely to their support person), and around prescribing psychotropic medication for this population.

4.3 Consultation with family members and support persons around the need for a Statewide adult tertiary intellectual disability mental health service, and how it could best support people with an intellectual disability

4.3.1 Materials and methods

Family members and support persons of people with an intellectual disability and co-occurring mental ill health completed an online or paper-based survey. The survey sought to determine the participants' views regarding the need for a Statewide adult tertiary IDMH service in NSW, and how it could best operate to meet their needs and the needs of the people that they support. The survey consisted of three parts:

1. Demographics: Information about the person completing the survey including age, gender, postcode, relationship to the person/s with an intellectual disability (e.g. family member, unpaid or paid support person), and information about the person/s with an intellectual disability that they support (e.g. age range, level of intellectual disability, cultural background)
2. Mental health services accessed and the perceived need for additional support or advice: Information about the types of mental health services accessed (e.g. general practitioner, emergency service, inpatient or outpatient service). Participants were asked whether each service accessed was able to meet the mental health needs of the person/s they support, if a highly specialised support service would have assisted each mental health professional or service to meet the needs of the person/s they support, and whether they believe that a Statewide adult tertiary IDMH service would assist in meeting the needs of people with an intellectual disability.
3. How a Statewide adult tertiary IDMH service should best operate: Views on eligibility, conditions of priority access, location, clinical and other roles, primary areas of focus (which were subsequently ranked from most to least important), professionals involved, and referral sources.

Questions were either closed or open-ended and participants were offered the opportunity to add any other comments in free text fields. Information about the survey was disseminated by email to individuals and organisations in NSW who are in contact with family members and support persons of people with an intellectual disability.

When planning the consultation our Project Advisory Group highlighted the need to expand our recruitment approach so as to better reach family members and support persons from culturally and linguistically diverse (CALD) backgrounds. In response to the recommendations of our Project Advisory Group we consulted with representatives from the Transcultural Mental Health Centre and developed an expanded recruitment approach to reach CALD groups. This component was funded by the NSW Mental Health Commission. The project materials were translated into three languages targeted based on our consultations with the Transcultural Mental Health Centre. The selected languages were Arabic, Simplified Chinese, and Vietnamese. Translations were completed by the NSW Multicultural Health Communication Service (flyers and surveys) and Multicultural NSW (EmailLink). Unique surveys were created for each language using the survey monkey platform.

Ethics approval was granted by the UNSW Sydney Human Research Ethics Committee (approval number HC17985). Consent to participate was obtained before participants completed the survey.

4.3.2 Participants

A total of 42 people completed the online survey. The majority of participants were female (76.2%) and had a median age of 53.5 years (IQR=38.0-60.0). As described in Table 4.3.1, the participants predominately identified as being either a family member (45.2%) or paid support person (35.7%) of a person with an intellectual disability and co-occurring mental ill health. On average the participants had been involved in supporting people with an intellectual disability for 15 years (SD=10.4, Range=1.0-41.0). Nineteen percent of respondents completed a translated version of the survey.

Table 4.3.1 Participant Demographics

Variable	Category	n (%)
Gender	Male	10 (23.9)
	Female	32 (76.2)
Support role	Family member	19 (45.2)
	Family member and support person (non-paid)	4 (9.5)
	Family member and support person (paid)	1 (2.4)
	Support person (non-paid)	3 (7.1)
	Support person (paid)	15 (35.7)

The majority of participants were involved in supporting an adult (25+ years) (71.4%) and person/s with a moderate level of intellectual disability (52.4%) (Table 4.3.2).

Table 4.3.2 Demographics of person receiving support

Variable	Category	n* (%)
Age group	Adolescent (12-17 years)	4 (9.5)
	Younger person (18-25 years)	8 (19.0)
	Adult (25+ years)	30 (71.4)
Level of intellectual disability	Mild	11 (26.2)
	Moderate	22 (52.4)
	Severe or Profound	9 (21.4)
Identify as Aboriginal and/or	Yes	5 (12.2)
Torres Strait Islander	No	36 (87.8)
Identify as culturally and/or	Yes	15 (36.6)
linguistically diverse	No	26 (63.4)

4.3.3 Results

Experience of contact with mental health services and the need for a Statewide adult tertiary IDMH service ('highly specialised tertiary support service').

The participants reported that the people that they support had come in contact with a range of mental health services. People with an intellectual disability were most likely to have come in contact with a general practitioner (85.7%), a community-based service (66.7%), private practice (61.9%), or an emergency service (52.4%) (Table 4.3.3). Participants reported that the ability of mental health services to meet the mental health needs of people with an intellectual disability and co-occurring mental ill health was overall limited. However, specialist intellectual disability mental health services and private practices were considered likely to be able to meet some or a lot of the person's mental health needs (80.0% and 76.9% respectively). The majority of the participants reported that outpatient services (62.6%), emergency services (50.0%), and non-government services (50.0%) were able to meet a little or none of the mental health needs of the person that they support.

Table 4.3.3 Types of mental health services that the person with an intellectual disability has been in contact with and the ability of that service to meet their mental health needs.

Mental health service type	**Service contact n (%)**	**Ability of that service to meet the person's mental health needs**			
		Not at all	A little	Some	A lot
General practitioner	36 (85.7)	4 (11.4)	11 (31.4)	14 (40.0)	6 (17.1)
Emergency	22 (52.4)	3 (13.6)	8 (36.4)	10 (45.5)	1 (4.5)
Inpatient	18 (42.9)	2 (11.8)	6 (35.3)	7 (41.2)	2 (11.8)
Outpatient	17 (40.5)	1 (6.3)	9 (56.3)	4 (25.0)	2 (12.5)
Community-based	28 (66.7)	1 (3.8)	11 (42.3)	9 (21.4)	5 (19.2)
Private practitioner	26 (61.9)	1 (3.8)	5 (19.2)	14 (53.8)	6 (23.1)
Non-government	19 (45.2)	2 (11.1)	7 (38.9)	6 (33.3)	3 (16.7)
Specialist intellectual disability mental health service	15 (35.7)	1 (6.7)	2 (13.3)	8 (53.3)	4 (26.7)

The majority of participants agreed (72.5%) that a highly specialised tertiary service would assist in meeting the mental health needs of people with an intellectual disability. Of the mental health services accessed, there was a high level of agreement that a highly specialised support service would have assisted each these services to meet the mental health need of people with an intellectual disability and co-occurring mental ill health. In particular, the greatest proportion of agreement that a highly specialised support service would have assisted were for inpatient (94.2%), community based (88.9%), and outpatient (87.5%) services (Table 4.3.4).

Table 4.3.4 Agreement that a highly specialised support service would have assisted the service to meet the mental health needs of the person/people you support.

Service type	Level of agreement		
	Strongly Disagree/ Disagree	Undecided	Strongly Agree/ Agree
General practitioner (n=36)	2 (5.7)	3 (8.6)	30 (85.7)
Emergency (n=22)	2 (9.1)	4 (18.2)	16 (72.7)
Inpatient (n=18)	1 (5.9)	0 (0.0)	16 (94.2)
Outpatient (n=17)	1 (6.3)	1 (6.3)	14 (87.5)
Community-based (n=28)	1 (3.7)	2 (7.4)	24 (88.9)
Private practitioner (n=26)	1 (3.8)	4 (15.4)	21 (80.8)
Non-government (n=19)	1 (5.6)	2 (11.1)	15 (83.3)
Specialist intellectual disability mental health service (n=15)	1 (6.7)	2 (13.3)	12 (80.0)

*excludes missing data

Characteristics of a highly specialised (tertiary) service to meet the needs of people with an intellectual disability and co-occurring mental ill health

The participants agreed that a range of individuals should be able to make a referral to a highly specialised (tertiary) service (Table 4.3.5). In particular, the highest level of agreement was for general practitioners (83.3%), mental health professionals (73.8%), and disability professionals (73.8%) to be able to make a referral.

Table 4.3.5 Referral pathways to a highly specialised (tertiary) intellectual disability mental health service

Type of professional	n (%)
General practitioner	35 (83.3)
Mental health professional	31 (73.8)
Disability professional	31 (73.8)
A member of the persons support network	25 (59.5)
Person with an intellectual disability	17 (40.5)
Other	4 (9.5)

In relation to eligibility of access to a highly specialised tertiary service, the majority of participants reported that everyone with an intellectual disability and suspected mental illness should be eligible (71.4%) (Table 4.3.6). The participants also reported that priority access should be given to people who have complex needs, especially those at risk of self-harm or harm to others, have or are at risk of coming in contact with the criminal justice system, are unable to access or have their needs met by services, or are experiencing housing issues (qualitative data not tabulated).

Table 4.3.6 Eligibility of a highly specialised (tertiary) service

Eligibility	Yes
Everyone with an intellectual disability and suspected mental illness (e.g. depression, anxiety, post-traumatic stress disorder)	30 (71.4)
People with an intellectual disability and complex mental health needs (e.g. people with multiple issues in their life which can impact on their mental health such as addiction, housing problems, physical health issues, contact with the criminal justice system etc.)	24 (57.1)
People with an intellectual disability whose needs were unable to be met within other mental health services	22 (52.4)

The majority of participants reported that a highly specialised tertiary service should be run within the public mental health system (72.5%) (Table 4.3.7). There was also a strong level of agreement that this service should provide face to face clinical contact (87.5%), advice to mental health service providers (92.5%) and disability service providers (92.5%), and advice related to mental health service and policy development (90.0%) (see Table 4.3.8).

Table 4.3.7 Location to run a highly specialised (tertiary) service

Location	n (%)
Within the public mental health system	29 (72.5)
Within the private mental health system	2 (5.0)
Within the non-government mental health system	4 (10.0)
Other	5 (12.5)

Table 4.3.8 Agreement of the type of service to be provided by a highly specialised (tertiary) service

Service provided	Level of agreement		
	Strongly Disagree/ Disagree	Undecided	Strongly Agree/ Agree
Provide face to face clinical contact with the person with an intellectual disability	3 (7.5)	2 (5.0)	35 (87.5)
Provide advice to mental health service providers	3 (7.5)	0 (0.0)	37 (92.5)
Provide advice to disability service providers	3 (7.5)	0 (0.0)	37 (92.5)
Provide advice related to mental health service and policy development	4 (10.0)	0 (0.0)	36 (90.0)

The participants reported a range of key areas in which mental health services need highly specialised (tertiary) support or advice (Table 4.3.9). The most highly rated areas included recommending psychological interventions (85.7%), mental health assessment (81.0%), assessment of behaviours of concern (78.6%), mental health care planning (76.2%), and advice on the best ways to support people with an intellectual disability who are at risk of losing their support services (73.8%) and are at risk of self-harm or harm to others (71.4%).

Table 4.3.9 Key areas in which mental health services need highly specialised (tertiary) support or advice

Key areas	n (%)
Recommending psychological interventions (e.g. cognitive behavioural therapy)	36 (85.7)
Mental health assessment	34 (81.0)
Assessment of behaviours of concern (also known as challenging behaviour)	33 (78.6)
Assistance with mental health care planning	32 (76.2)
Advice on the best ways to support people with an ID who are at risk of losing their support services	31 (73.8)
Advice on the best ways to support people with an ID who are at risk of self-harm or harm to others	30 (71.4)
Advice on preventative mental health programs	29 (69.0)
Advice regarding communicating with the person with an intellectual disability	29 (69.0)
Advice regarding communicating with the person with an intellectual disability's support network	29 (69.0)
Advice on the best ways to support people with an ID who are at risk of homelessness	28 (66.7)
Recommending psychotropic medications (e.g. anti-depressant medications)	27 (64.3)
Assistance with case reviews	26 (61.9)
Other	6 (14.3)

Key: ID- intellectual disability

Of the key areas identified by the participants, the most likely to be ranked within the top five most important areas included; assessment of behaviours of concern (74.1%), advice on the best ways to support people with an intellectual disability who are at risk of self-harm or harm to others (68.0%), mental health assessment (66.7%), recommending psychological interventions (60.0%), mental health care planning (59.3%), and recommending psychotropic medications (57.1%) (Table 4.3.10).

Table 4.3.10 Proportion of participant that ranked the key area within their top 5 important areas

Key areas	n (%)*
Assessment of behaviours of concern (also known as challenging behaviour) (n=33, 6 missing)	20 (74.1)
Advice on the best ways to support people with an ID who are at risk of self-harm or harm to others (n=30, 5 missing)	17 (68.0)
Mental health assessment (n=34, 4missing)	20 (66.7)
Recommending psychological interventions (e.g. cognitive behavioural therapy) (n=36, 6 missing)	18 (60.0)
Assistance with mental health care planning (n=32, 5 missing)	16 (59.3)
Recommending psychotropic medications (e.g. anti-depressant medications) (n=27, 6 missing)	12 (57.1)
Advice regarding communicating with the person with an intellectual disability (n=29, 7 missing)	11 (50.0)
Advice on the best ways to support people with an ID who are at risk of losing their support services (n=31, 5 missing)	12 (46.2)
Advice regarding communicating with the person with an intellectual disability's support network (n=29, 7 missing)	9 (40.9)
Advice on the best ways to support people with an ID who are at risk of homelessness (n=28, 6 missing)	8 (36.4)
Assistance with case reviews (n=26, 5 missing)	7 (33.3)
Advice on preventative mental health programs (n=29, 5 missing)	7 (29.2)

*excludes missing data

Key: ID- intellectual disability

The participants reported that a range of professionals should deliver a highly specialised (tertiary) intellectual disability mental health service (Table 4.3.11). However, of the professionals selected, Psychiatrists (46.2%) and Psychologists (34.5%) were the most likely to be ranked as the most important professional groups to deliver the intellectual disability mental health service.

Table 4.3.11 Type of professionals should deliver a highly specialised (tertiary) intellectual disability mental health service

Type of professional	n (%)
Psychologists	33 (78.6)
Psychiatrists	29 (69.0)
Social Workers	23 (54.8)
Nurses	22 (52.4)
Occupational Therapists	22 (52.4)
Speech Therapists	16 (38.1)
Other	11 (26.7)

4.4 Consultation with intellectual disability mental health experts around the key priorities (clinical and non-clinical) of a Statewide adult tertiary intellectual disability mental health service

4.4.1 Materials and methods

An online Delphi method was used (Figure 4.4.1). Survey questions (Appendix D) were designed in consultation with a Project Advisory Group and administered via Survey Monkey.

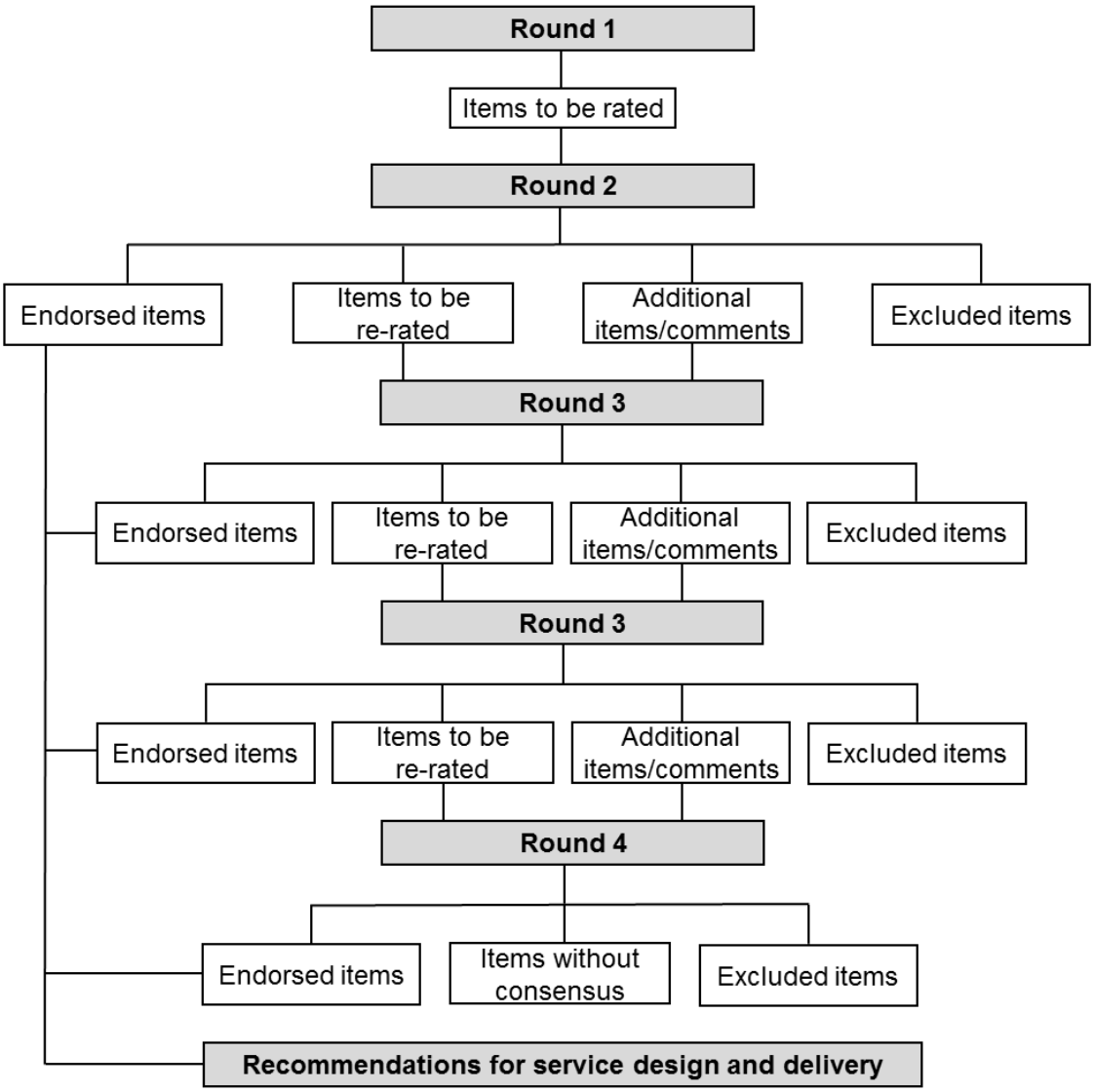

Figure 4.4.1 Online Delphi method. In round one, participants were asked to generate ideas based on the survey questions about how a Statewide adult tertiary IDMH service should operate. Subsequent rounds asked participants to rate their agreement with the ideas generated in round one using a 5-point Likert scale (1=Strongly Disagree, 2=Disagree, 3=Neutral, 4=Agree, 5=Strongly Agree). Participants were also given the opportunity to identify additional content or change wording. After each round, participants were provided with a summary of the feedback (e.g. summarising similar comments into an underlying theme). New items were generated and

presented in round two (two questions) and round three (one modified question) (see Appendix D). Items that did not reach consensus (see definition below) were re-presented in the subsequent round. Participants were provided two weeks to respond to each round, with the exception of round four (four weeks) as this fell over a major holiday period.

Descriptive statistics were analysed for each item in rounds two to four. Qualitative responses were thematically analysed and independently coded by two researchers. A priori criteria were set for item consensus and removal. Consensus was defined as ≥70% of participants responding "agree" or "strongly agree" to an item, a median response >3.5, with no contradictions from the qualitative data. Items were to be removed if ≥70% of participants responded "disagree" or "strongly disagree" to an item, or qualitative responses suggested the item should be removed. Criteria was amended during round two such that if only one participant's qualitative response suggested an item should be removed, majority agreement was also needed to support removal.

Ethics approval was granted by the UNSW Sydney Human Research Advisory panel (approval number HC17192). Informed consent was obtained from all participants.

4.4.2 Participants

Intellectual disability mental health experts were identified through the research team's knowledge of active intellectual disability mental health clinicians in NSW, peak bodies in intellectual disability health and advocacy, and the snowballing technique. Eligible participants were required to be currently practising in NSW, self-identify as specialising in intellectual disability mental health, and have experience working with people with intellectual disability and co-occurring mental ill-health. See Figure 4.4.2 for further details about sample recruitment and retention.

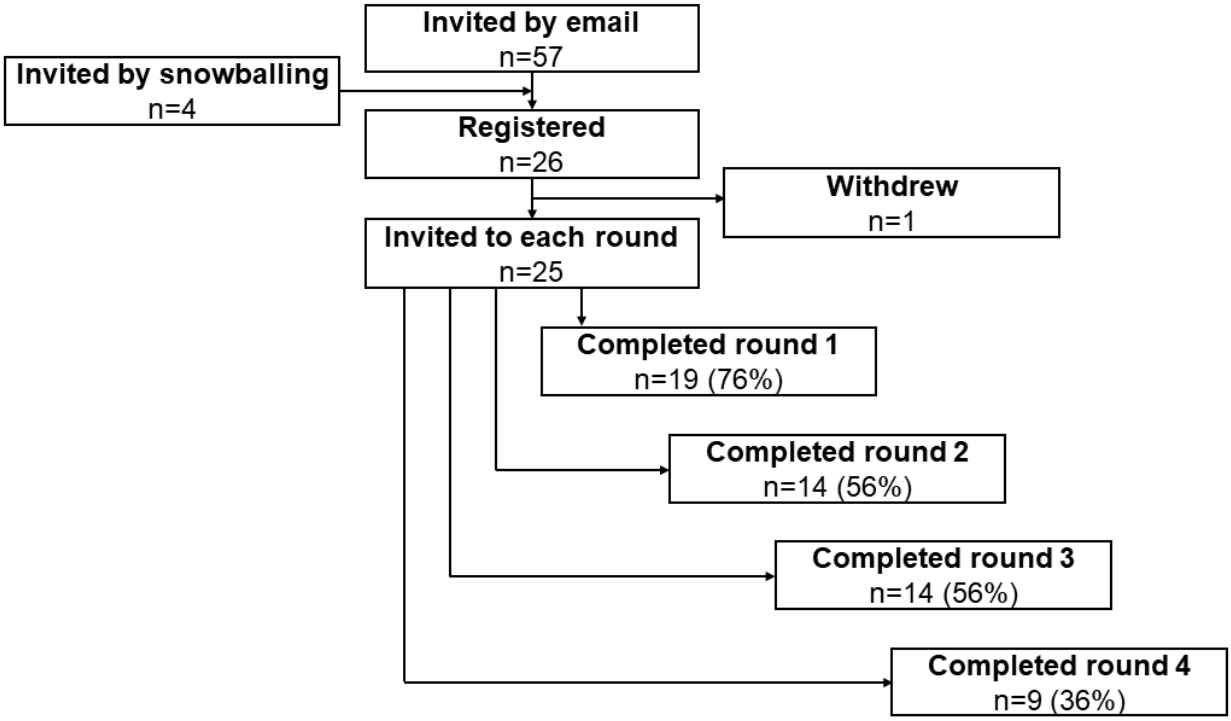

Figure 4.4.2 Delphi sample recruitment and retention. Fifty-seven experts were invited directly by email. Twenty- six people registered to participate (four of these were recruited via snowball sampling). Three registrants did not meet the eligibility criteria (e.g. people involved in ID service development that did not self-identify as “specialising” in IDMH) but were considered appropriate to participate given their relevant experience. One participant withdrew, leaving a total of 25. Once the Delphi began, all participants were invited to each round and no further participants were accepted. The Delphi was ended after four rounds as responses to remaining items had stabilised. ID= intellectual disability; IDMH= intellectual disability mental health

4.4.3 Results

Patients

People with complex needs, people identified as at risk and people aged 18-25 years experiencing difficulty transitioning to adult services were identified as specific targets of the service. The majority of participants (57%) indicated that 15 years should be the lower age limit. It was agreed that patients should have their own general psychiatrist, or if not, be willing to engage with one in an ongoing manner. No exclusion criteria were identified.

Professionals

Most participants (93%) agreed that a multidisciplinary team was essential to a Statewide adult tertiary IDMH service. The top five minimally required professionals were, in rank order, a psychiatrist, behaviour support specialist, disability physician or general practitioner who specialises in working with people with an intellectual disability, clinical psychologist, and clinical nurse consultant. Qualitative responses supported the use of a network of professionals to act as a second tier of the service, accessed according to individual needs. Participants agreed that the

service should accept referrals from clinicians providing specialist mental health support and that open referrals were not appropriate.

Service roles

Agreed clinical roles included providing: short-term assessment, diagnosis and treatment of mental illness and severe challenging behaviours; strategies to the person's regular health professional for ongoing clinical management; consultation-liaison and second opinions; high-level clinical advice including state-wide review at a quaternary level; assistance in coordination of intellectual disability mental health services; and service evaluation (monitoring and review of referrals, actions and clinical outcomes). Agreed non-clinical roles focused on building the skills of the mainstream workforce through leadership in training and supervision, including evaluation of service impact.

Location and reach

Participants agreed that the service should be in the Sydney metropolitan area. Strategies to increase service reach and access included: provision of regional face-to-face interviews followed by telephone consultations; a program of outreach services to rural LHDs; and a range of technology-based strategies.

Working with people with intellectual disability, the person's support network, and referrers

Participants endorsed a wide range of principles and practical ways of working with people with an intellectual disability, which aligned with other publicly available documents [17-21]. These focused on rights, accessibility, quality standards, approaches and adaptations to clinical practice, and sector collaboration. Practical ways of working with people with intellectual disability included direct engagement (with necessary adaptations e.g. accessible clinics/additional time allocation etc).

Principles and practical ways of working with the person's support network included: allocating time for family or support persons to express their concerns and provide background information, with consent from, and while maintaining focus on, the person with an intellectual disability; providing an inclusive environment; effective communication; provision of education; working with other service providers.

Participants agreed that when working with referrers, the service should demonstrate respect for opinion and skills while building capacity and providing a positive experience in working with people with an intellectual disability. Practical ways of working with referrers included ensuring clear communication, prompt responses to referrals and clear letters outlining the assessment outcomes and recommendations. Experts highlighted the need to work with referrers throughout the consultation process. This included keeping them informed of progress, offering for them to participate in consultations, and holding case conferences. They stressed that the patient's care should not be 'handed over' to the Statewide adult tertiary IDMH service; the aim is to support referrers and improve their knowledge and confidence over the longer term.

5. Summary and recommendations

5.1 The need for a Statewide adult tertiary IDMH service

- There is consensus among people with an intellectual disability, their family and support persons, and mental health professionals that there is a need for a Statewide adult tertiary IDMH service in NSW.
- A Statewide adult tertiary IDMH service is needed because:
    - The needs of people with an intellectual disability are not being meet across the mental health sector.
    - Only a third of mental health professionals were able to access additional support or advice that they needed when providing a service to people with an intellectual disability and co-occurring mental ill health.
- Key areas that mental health services need additional specialist support and/or advice included:
    - Assessment and diagnostics
    - Mental health care planning
    - Mental health interventions
    - Partnering and collaborating with key stakeholders
    - Communication with people with an intellectual disability

5.2 Eligibility for a Statewide adult tertiary IDMH service

- Intellectual disability mental health experts recommended that people with an intellectual disability aged between 18-25 years who experience difficulty transitioning to adult services were identified as specific targets of the service.
- There is consensus among the key stakeholders that priority access should with given to people with an intellectual disability who have complex needs. In particular, priority access should be given to those at risk of self-harm or harm to others, those who have or are at risk of coming into contact with the criminal justice system, those who have not been able to access or have their needs met by other services, and those experiencing issues with housing.

5.3 Key clinical priorities of a Statewide adult tertiary IDMH service

- A range of clinical priorities were identified by the key stakeholders. The priorities most frequently identified included:
    - The assessment and diagnosis of mental ill health
    - The management and treatment of mental ill health
    - Assistance with behaviours of concern
- For mental health service representatives and intellectual disability mental health experts a key clinical priority was assistance with case reviews within a consultation-liaison capacity.

5.4 How a Statewide adult tertiary IDMH service could meet the needs and provide a timely and quality service to people with an intellectual disability with complex needs

Referral

- Family and support persons thought general practitioners, mental health professionals, and disability professionals should be able to make referrals. Of note, a majority believed a member of the person's support network should be able to make a referral, and just under half thought that the person with an intellectual disability should be able to refer themselves.
- In contrast, intellectual disability mental health experts believe that referrals should only be accepted from clinicians providing specialist mental health support, and that open referrals were not appropriate. This fits with how a Statewide adult tertiary IDMH service model generally operates. However, it is important to acknowledge that family and support persons highlighted the need for open referrals, indicating that there may be barriers to accessing primary and secondary services that need to be addressed.
- Experts recommended ensuring clear communication with referrers, prompt responses to referrals and clear letters outlining the assessment outcomes and recommendations.

Working with the Statewide adult tertiary IDMH service

- The key stakeholders all identified that it was important for a Statewide adult tertiary IDMH service to be able to i) work directly with the person with an intellectual disability and co-occurring mental ill health and their support network, and ii) provide advice to clinicians working with the person.
- It was also important that the Statewide adult tertiary IDMH service work in collaboration with the person's existing support network and service providers.
- Notably, people with an intellectual distality commented that the tertiary specialists should engage in information gathering prior to an assessment so they are aware of the person's history, their mental health concerns and the services they have accessed.
- Regarding how the Statewide adult tertiary IDMH service could assist a service in an acute crisis, mental health service representatives responded that it could offer advice (e.g. on assessment), offer consultation-liaison services and assist with service co-ordination, and provide a telephone or video conferencing helpline. However, some did not believe a Statewide adult tertiary IDMH service should have a role in crisis management.
- Intellectual disability mental health experts stressed that the patient's care should not be 'handed over' to the Statewide adult tertiary IDMH service; the aim is to support referrers and improve their knowledge and confidence over the longer term.
- The key stakeholders all reported a preference for working with the Statewide adult tertiary IDMH service face-to-face (this included an outreach service to regional areas). However, when this is not possible alternative telephone or video conferencing could be used. People with intellectual disability were also strongly in favour of seeing specialists face-to-face. As some people with intellectual disability have no computer access, they did not believe access to the team should be exclusively online.

5.5 The resources required to run a Statewide adult tertiary IDMH service

- A diverse range of resources would be required including:
    - Staffing: Mental health staff, family and support persons, and intellectual disability mental health experts were all strongly in favour of the Statewide adult tertiary IDMH service being staffed by psychiatrists, psychologists, and nurses. Social workers and occupational therapists were also seen as important professionals to include. Intellectual disability mental health experts were almost all in agreement that a multidisciplinary team was essential and mentioned, in addition to the above professionals, the importance of behaviour support specialists, and disability physicians/GPs who specialise in intellectual disability.
    - Service housing: A location to house the service would be needed. There seems to be agreement that this should be within the Sydney metropolitan area, within the public mental health system and perhaps within a hospital.
    - Funding face-to-face consultation: Funding would be required to facilitate face-to-face consultation including transport and accommodation costs to see people within the community and to deliver outreach services to regional and rural areas.
    - Access to technology: The service would require access to appropriate technologies to facilitate video and tele-conferencing when face-face consultation was not possible.
    - Resources for service evaluation: Evaluation of service impact should be built into the Statewide adult tertiary IDMH service model. This would include monitoring and review of referrals, actions and clinical outcomes.

5.6 How a Statewide adult tertiary IDMH service could best enhance the capacity of the mainstream mental health workforce to meet the needs of people with intellectual disability and co-occurring mental ill health

- All groups thought that a key role of the Statewide adult tertiary IDMH service would be to provide education, training and supervision to the mainstream mental health workforce to build skills and capacity.
- Areas in which people with intellectual disability thought mainstream health professionals particularly needed training included how to communicate and build rapport with people with intellectual disability.
- Other suggested ways that a Statewide adult tertiary IDMH service could enhance the capacity of the mainstream workforce included:
    - assisting with the development of localised service pathways.
    - participating in case reviews,
    - developing localised working groups between mental health and local disability services to agree on how to best work together to meet the needs of people with intellectual disability,
    - reviewing and developing policy and procedure in this area

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APPENDIX A. Survey of NSW Mental Health Directors and key Local Health District Representatives: Survey items

Part one: Demographics

	Item	Categories
1.1	What local health district do you work for?	• Central Coast • Illawarra Shoalhaven • Nepean Blue Mountains • Northern Sydney • South Eastern Sydney • South Western Sydney • Sydney • Western Sydney • Far West • Hunter New England • Mid North Coast • Murrumbidgee • Northern NSW • Southern NSW • Western NSW • Children's and Paediatric Services Network • Justice and Forensic mental health network • St Vincent's Health Network
1.2	I am completing this survey as a representative from	Emergency psychiatry team or equivalent Community based teams Inpatient (e.g. acute, subacute/general, intensive care) Old age (e.g. inpatient, community) Rehabilitation (e.g. inpatient, community) Children's and paediatric services Other (describe)
1.3	What is your gender?	• Male • Female
1.4	How many years of experience do you have working in mental health?	n/a numerical
1.5	How many years of experience do you have working with people with an intellectual disability	n/a numerical
1.6	What is your professional background?	• Nursing • Occupational Therapy • Medical • Psychiatry • Psychology • Social Work • Other (describe)
	What is your current primary work role?	Allied health Education Intellectual disability mental health specialist Medical Managerial Other (describe)

Part two: Service information and workforce

Item		Categories
2.1	Would your service find it helpful to have additional specialist support or advice to meet the needs of people with an intellectual disability and co-occurring mental ill health?	• Yes • No
2.2	For how many people with an intellectual disability per year would your service find some additional specialist support or advice helpful?	(numerical) per year
2.3	For the people you identified above (Q2.2), what are the key areas in which your service would find some additional specialist support or advice helpful?	• Intake • Assessment • Diagnostics • Mental health interventions –pharmaceutical • Mental health interventions – non-pharmaceutical • Mental health care planning • Referrals • Transfer of care • Providing a responsible, safe and ethical practice • Providing recovery orientated support • Adapting service to meet diverse needs • Communication • Partnering and collaborating with key stakeholders
2.4	Please rank the key areas that you identified from most to least important.	List automatically generated from Q2.3
2.5	For the people you identified above (Q2.2), is your service currently able to access additional specialist support or advice (either within or from outside your service)?	• Yes • No
	If yes:	
	2.5.1 Where does your service access this additional specialist support or advice from, please select as many options as appropriate?	• Internal - intellectual disability mental health specialist service(s) • Internal – professional(s) who specialise in the area of intellectual disability mental health • External - intellectual disability mental health service(s) (publicly funded) • External - intellectual disability mental health service(s) (privately funded) • External – professional(s) who specialise in the area of intellectual disability mental health and work with in a public funded service • External – professional(s) who specialise in the area of intellectual disability mental health and work with in a privately funded service
	2.5.2 Please provide us with some details about the service or professionals that you access	• Details provided for each service identified
	2.5.3 Is this service/professional (identified in 2.5.1) able to meet your services current support/advice needs?	• Always • Very often • Sometimes • Rarely • Never

Part three: Is there a need for a specialist tertiary intellectual disability mental health service and how could it best meet your service needs?

	Item	Categories
3.1	To what extent do you agree that there is a need for a state-wide specialist tertiary intellectual disability mental health service in NSW?	• Strongly Disagree • Disagree • Undecided • Agree • Strongly Agree
3.2	If such a service existed, how many referrals per year do you think your service would make to this service?	• 0 per year • 1-2 per year • 3-5 per year • 6<10 per year • 10<15 per year • 16<20 per year • 20<25 per year • 26<30 per year • 30<35 per year • 36<40 per year • 40<45 per year • 45<50 per year • More than 50 per year
3.3	If such a service existed, my service would likely make a referral to this service for (please select all that apply):	• Assistance with diagnostic complexity • Assistance with a case review for a person who require complex solutions • Assistance with the assessment of behaviours of concern (also known as challenging behaviour) • Assistance with a case review of people with an ID who are frequent users of mental health services • Assistance with a case reviews of people with an ID with failed mental health interventions • Assistance with a case reviews of people with an ID who have long stays within mental health services • Assistance with developing and implementing a mental health care plan • Advice regarding psychopharmacological management • Advice determining the most appropriate non-pharmaceutical mental health intervention(s) • Advice when the prescribed mental health intervention(s) are not effective in managing the persons mental ill health • Advice on the management of a person who also has complex medical comorbidity • Advice on the management of a person who also has complex genetic disorder(s) • Advice on suicide prevention strategies • Advice on the best ways to support people with an ID who are at risk of self-harm or harm to others • Advice on the best ways to support people with an ID who are at risk of homelessness • Advice on the best ways to support people with an ID who are at risk of losing their support services • Advice on preventative mental health programs • Advice and assistance with determining an appropriate discharge plan/transfer of care plan • Assistance when existing services are unable to accept a referral for the person

		• Assistance when existing specialist services are unable to meet the persons needs • Advice regarding communicating with the person with an intellectual disability • Advice regarding communicating with the person's support network • Advice and assistance with linking the person with appropriate support service • Advice on challenging behaviour (also known as behaviours of concern) • Advice on policy and procedure to ensure that it meets the needs of people with an ID • Other (please describe)
3.4	Now please rank the reasons for referral from most to least likely	• List automatically generated from Q3.3
3.5	If such a service existed:	
	3.5.1. My services preferred method to make referrals would be? (please rank from most to least preferred method)	• On-line • Paper based form • Telephone • Other (please describe)
	3.5.2 My services preferred method of ongoing communication with the specialist service would be? (please rank from most to least preferred method)	• Email • Face-to-face • Telephone • Video conferencing • Other (please describe)
	3.5.3 My services preferred method of working with this service would be? (please rank from most to least preferred method)	• We consult directly with the specialist and we work together to recommend strategies • The specialist reviews case notes and recommends strategies • We hand over clinical care to the specialist • The specialist sees the patient directly and works collaboratively with me to recommend strategies • Other (please describe)
3.6	How could this service best work with your service if they were not able to be there in person?	• Email • Telephone • Video conferencing • Other (please describe)
3.7	What types of professionals do you think should be involved in the operation of a specialist tertiary service?	• Nurses • Occupational Therapists • Psychiatrists • Psychologist • Social Workers • Speech Therapists • Other (please describe)
3.8	Please rank the types of professionals that you identified from most to least important to be involved in the operation of the service	List automatically generated from 3.7
3.9	How could this service best support your service when the person with an intellectual disability is in an acute crisis?	n/a open ended response

3.10	How could this service best support your service to build capacity in the area on intellectual disability mental health? Please select all that you think are relevant	• Participate in the review and development of policy and procedure to meet the needs of people with an ID • Assist in the development and implementation of an intellectual disability mental health workforce development strategy • Assist in the development of strategies to support the service to implement the Guide, Core Competency Framework, and Positive Cardiometabolic Early Intervention Framework • Support the service to develop and implement quality improvement projects in the area of intellectual disability mental health • Assist in developing a localised working group between mental health and local disability services to reach an agreement on how to best work together to meet the needs of people with an intellectual disability • Assist in the development of a localised service pathway for people with an intellectual disability • Facilitate peer group meetings that discusses challenges and strategies for meeting the needs of people with an ID • Participate in case reviews • Formal professional mentoring • Deliver education and training • Role model the assessment process • Role model clinical decision making in reaching diagnosis • Role model clinical decision making in the development and implementation of interventions • Provide case scenarios of successful interactions of with people with an ID • Other (please describe)
3.11	Now please rank the options that you have selected from most to least important	List automatically generated from 3.10

APPENDIX B. Consultation with people with an intellectual disability: Interview question guide

This provides a guide to the questions asked at each interview. However, the exact wording was modified to meet the needs of each participant. This included using visual aids, presentations in Easy English, and non-verbal forms of communication where appropriate.

Part one: Experiences accessing mental health services

1. Have you ever been to see a mental health worker? This could be people like a counsellor, a psychologist, or a psychiatrist

   If yes:

   2. Where do you go when you need help with your mental health?
      a. Prompts: did you go to the doctor/hospital
   3. At the <insert responses>, are the doctors/mental health workers good at helping people with an intellectual disability? Why/why not?

   If no:

   4. Where would you go if you needed help with your mental health?
      a. Prompts: would you go to the doctor/hospital

All:

5. Do you think there should be a team of doctors/mental health workers who specialise/ are experts in treating people with intellectual disability and mental ill-health?

Part two: Development of a tertiary service

Case example:

Greg was feeling pretty good for the past year.
He liked to go out with his friends. He liked meeting people and chatting.

Greg sees his psychiatrist every 3 months.
He also takes medication for his mental health.

But Greg stops going out with his friends.
He feels too sad to go outside.
He does not want to talk to anyone.
Greg's Mum is worried about him.

Greg phones his psychiatrist. He makes an appointment to go see him.
Greg takes his Mum with him for support.
Greg tells his psychiatrist how he has been feeling. He says he needs some extra help to cope.

1. If there were an expert team of doctors/mental health workers who specialise in treating people with intellectual disability and mental ill-health, do you think this would help Greg and his psychiatrist? How might they be able to help?
   a. Prompt: what would experts do that is better than what regular hospital doctors and nurses do?
2. How could the expert team help family and carers of people with an intellectual disability and mental ill-health?
3. What would the expert team need to know?

4. What would help the expert team to work with people with intellectual disability?
    b. Prompts: to help with communication, etc.
5. How could the expert team help other doctors and health professionals be better at working with people with intellectual disability?
6. Where should the expert team work?
7. Is there anything else that an expert team could do to make sure people with intellectual disability and mental ill-health get the best treatment?

APPENDIX C. Consultation with family members and support persons: Survey items

Eligibility screening items

	Item	Categories
0.1	Are you over 18 years old?	• Yes • No
0.2	Do you live in NSW	• Yes • No
0.3	Are you a family member or support person (paid or non-paid) of a person with an intellectual disability and co-occurring mental ill health?	• Yes • No
0.4	Do you have experience in supporting a person with an intellectual disability and co-occurring mental ill health to access adult mental health services in NSW or in transitioning to adult mental health services?	• Yes • No

Part one: Demographics

	Item	Categories
1.1	What is your gender?	• Male • Female • Other
1.2	What is your age?	n/a numerical
1.3	What is your postcode?	n/a numerical
1.4	How are you involved in the support of a person/people with an intellectual disability and co-occurring mental ill health?	• I am a family member • I am a support person (non-paid) • I am a support person (paid) • Other (please describe)
1.5	How many years have you been involved in supporting a person/people with an intellectual disability and co-occurring mental ill health?	• n/a numerical
1.6	What is the age group of the person/people that you support? (if you support more than one person please select the age group that applies to most people)	• Adolescent (12-17 years) • Younger person (18-25 years) • Adult (25+ years) • Older person (65+ years)
1.7	What is the level of the person's/peoples' intellectual disability that you support? (If you support more than one person please select the level applies to most people)	• Mild • Moderate • Severe • Profound
1.8	Does the person/people that you support identify as being Aboriginal and/or Torres strait islander? (If you support more than one person please select the answer that applies to most people)	• Aboriginal • Torres strait islander • Aboriginal and Torres strait islander • None of the above
1.9	Does the person/people that you support identify as being from a culturally and/or linguistically diverse background? (If you support more than one person please select the answer that applies to most people)	• Yes • No

1.10	What type of mental health services has the person/people that you support been in contact with? (please select all that apply)	• General practitioner • Emergency service • Inpatient service • Outpatient service • Community-based service • Private practitioner • Specialist intellectual disability mental health service • Non-government service • Other (please describe)

Part two: Do mental health service need additional support or advice?

Item		Categories
2.1	For each service that you identified in question 1.10, please rate how much that professional/service was able to meet the mental health needs of the person/people that you support (note responses from Q1.10 will automatically be generated in this question)	• A lot • Some • A little • Not at all
2.2	For each service that you identified in question 1.10, do you agree that a highly specialised support service would have assisted this professional/service to meet the mental health needs of the person/people that you support? (note responses from Q1.10 will automatically be generated in this question)	• Strongly Disagree • Disagree • Undecided • Agree • Strongly Agree
2.3	How much do you agree that a highly specialised (tertiary) service would assist in meeting the mental health needs of people with an intellectual disability?	• Strongly Disagree • Disagree • Undecided • Agree • Strongly Agree

Part three: If a highly specialised (tertiary) service existed, how could it best meet the needs of the person/people that you support?

	Item	Categories
3.1	If a highly specialised (tertiary) intellectual disability mental health service existed, who should be eligible to access this service? (please select all that apply)	• Everyone with an intellectual disability and suspected mental illness (e.g. depression, anxiety, post-traumatic stress disorder) • People with an intellectual disability and complex mental health needs (e.g. people with multiple issues in their life which can impact on their mental health such as addiction, housing problems, psychical health issues, contact with the criminal justice system etc.) • People with an intellectual disability who's needs were unable to meet within other mental health services • Other (please describe)
3.2	If a highly specialised (tertiary) intellectual disability mental health service existed, who should be given priority access?	n/a open ended questions
3.3	If a highly specialised (tertiary) intellectual disability mental health service existed, where should this service be run?	• Within the public mental health system • Within the private mental health system • Within the non-government mental health system • Other (please describe)
3.4	If a highly specialised (tertiary) intellectual disability mental health service existed, how much do you agree that it should: 1.4.1 Provide face-to-face clinical contact with the person with an intellectual disability? 1.4.2 Provide advice to mental health service providers? 1.4.3 Provide advice to disability service providers? 1.4.4 Provide advice related to mental health service and policy development? 1.4.5 Are there other roles that you think they should have (please describe)	• Strongly Disagree • Disagree • Undecided • Agree • Strongly Agree (This agreement scale will be used for each of the questions)
3.5	What do you think are the key areas that mental health services need highly specialised (tertiary) support or advice? (please select all that are relevant)	• Mental health assessment • Assessment of behaviours of concern (also known as challenging behaviour) • Recommending psychotropic medications (e.g. anti-depressant medications) • Recommending psychological interventions (e.g. cognitive behavioural therapy) • Assistance with mental health care planning • Advice regarding communicating with the person with an intellectual disability

		• Advice regarding communicating with the person with an intellectual disability support network • Assistance with case reviews • Advice on the best ways to support people with an ID who are at risk of self-harm or harm to others • Advice on the best ways to support people with an ID who are at risk of homelessness • Advice on the best ways to support people with an ID who are at risk of losing their support services • Advice on preventative mental health programs • Other (please describe)
3.6	Please rank the key areas that you identified from most to least important.	• List automatically generated from the response to 3.5
3.7	If a highly specialised (tertiary) intellectual disability mental health service existed, what types of professionals should deliver this service? (please select all professionals that you think are important)	• Nurses • Occupational Therapists • Psychiatrists • Psychologists • Social Workers • Speech Therapists • Other (please describe)
3.8	Please rank the types of professionals that you identified from most to least important to be involved in the delivery of the specialist service	• List automatically generated from the response to 3.7
3.9	If a highly specialised (tertiary) intellectual disability mental health service existed, who should be able to make a referral to this service? (please select all that are appropriate)	• Disability professional • General practitioner • Mental health professional • Person with an intellectual disability • A member of the person's support network • Other (please describe)
3.10	Do you have any other comments about how a specialist service could best operate in NSW?	• n/a open ended response

APPENDIX D. Consultation with intellectual disability mental health experts: Online Delphi items

Theme	Items	
Patients	1	Are there consumers/patients who should be a specific target for such a service?
	2	Are there consumers/patients who should receive priority for such a service?
	3[a]	What should the lower age limit be of patients accepted to the service?
	4	Are there any consumer/patient subgroups who should be excluded from such a service?
Professionals	5	What referral sources should be accepted?
	6	What professional(s) should be involved in the delivery of such a service?
Service roles	7	What should be the clinical role(s) for such a service?
	8	What should be the non-clinical role(s) for such a service?
Location and reach	9	What is your preferred geographical location/s for such a service?
	10	How could this service maximise its reach and service access (e.g. are there tools/technology that could assist)?
Working with people with an ID, the person's support network, and referrers	11	What are the key principles that such a service should apply when working with people with an intellectual disability?
	12	What are the key practical ways that such a service should work with people with an intellectual disability?
	13	What are the key principles that such a service should apply when working with the person's support network (family, formal and informal support persons)?
	14	What are the key practical ways that such a service should work with the person's support network (family, formal and informal support persons)?
	15	What are the key principles that such a service should apply when working with the referrer?
	16	What are the key practical ways that such a service should work with the referrer?
Questions added in round two[b]		
Professionals	6a	How much do you agree with the following statement: "A multidisciplinary team is essential"?
	6b	At a minimum, which professionals should be included in a multidisciplinary team for this type of service?

[a]In round three, item three was changed to multiple choice to ensure that responses were within the scope of the study (i.e that they reflected an appropriate age limit for an adult service); [b]Two questions were added in round two to clarify ambiguous responses.