ACT Government | **Canberra Health Services**

Dear ████

DECISION ON YOUR ACCESS APPLICATION

I refer to your application under section 30 of the *Freedom of Information Act 2016* (FOI Act) received by Canberra Health Services (CHS) on 2 January and rescoped on 14 January 2020.

This application requested access to:

> *"Copies of all documents relating to any discussions held between Canberra Health Services staff and/or external stakeholders, including* ████ *Consultant Psychiatrist,* ████ *regarding supports services explicitly for people on the autism spectrum engaging with Health services in the ACT, including Mental Health services. This request is for records, including meeting agendas, notes, notices and minutes from 1/1/2018 to date. This does not include policy documents covering disability generally."*

I am an Information Officer appointed by the Chief Executive Officer of Canberra Health Services (CHS) under section 18 of the FOI Act to deal with access applications made under Part 5 of the Act. CHS was required to provide a decision on your access application by **Wednesday 12 February 2020.**

I have identified 13 documents holding the information within scope of your access application. These are outlined in the schedule of documents included at Attachment A to this decision letter.

Decisions
I have decided to:

- grant full access to 1 document;
- grant part access to 12 documents.

My access decisions are detailed further in the following statement of reasons and the documents released to you are provided as Attachment B to this letter.

In reaching my access decision, I have taken the following into account:
- The FOI Act;
- The contents of the documents that fall within the scope of your request; and
- The *Human Rights Act 2004.*

Full Access
I have decided to grant full access to one document at reference 1.

Partial Access
I have decided to grant partial access to 12 documents at references 2-13.

Public Interest Factors Favouring Disclosure
The following factors were considered relevant in favour of the non-disclosure of the documents:

- Schedule 2.1 (a) (i) promote open discussion of public affairs and enhance the government's accountability.

Public Interest Factors Favouring Non-Disclosure
The following factors were considered relevant in favour of the non-disclosure of the documents:

- Schedule 2.2 (a) (ii) prejudice the protection of an individual's right to privacy or any other right under the *Human Rights Act 2004.*

The information that has been redacted is related to staff mobile numbers, personal information of employees of non-government agencies and third parties. On balance, I determined the information identified is contrary to the public interest and I have decided not to disclose this information. Additionally, documents at reference 13 include out of scope information.

Charges
Processing charges are not applicable to this request.

Disclosure Log
Under section 28 of the FOI Act, CHS maintains an online record of access applications called a disclosure log. The scope of your access application, my decision and documents released to you will be published in the disclosure log not less than three days but not more than 10 days after the date of this decision. Your personal contact details will not be published.

https://www.health.act.gov.au/about-our-health-system/freedom-information/disclosure-log.
Ombudsman review
My decision on your access request is a reviewable decision as identified in Schedule 3 of the FOI Act. You have the right to seek Ombudsman review of this outcome under section 73 of the Act within 20 working days from the day that my decision is published in ACT Health's disclosure log, or a longer period allowed by the Ombudsman.

If you wish to request a review of my decision you may write to the Ombudsman at:

The ACT Ombudsman
GPO Box 442
CANBERRA ACT 2601
Via email: ACTFOI@ombudsman.gov.au
Website: ombudsman.act.gov.au

ACT Civil and Administrative Tribunal (ACAT) review
Under section 84 of the Act, if a decision is made under section 82(1) on an Ombudsman review, you may apply to the ACAT for review of the Ombudsman decision. Further information may be obtained from the ACAT at:

ACT Civil and Administrative Tribunal
Level 4, 1 Moore St
GPO Box 370
Canberra City ACT 2601
Telephone: (02) 6207 1740
http://www.acat.act.gov.au/

Further assistance
Should you have any queries in relation to your request, please do not hesitate to contact the FOI Coordinator on (02) 5124 9831 or email HealthFOI@act.gov.au.

Yours sincerely

Karen Grace
Executive Director
Canberra Health Services

12 February 2020

FREEDOM OF INFORMATION SCHEDULE OF DOCUMENTS

Please be aware that under the *Freedom of Information Act 2016*, some of the information provided to you will be released to the public through the ACT Government's Open Access Scheme. The Open Access release status column of the table below indicates what documents are intended for release online through open access.

Personal information or business affairs information will not be made available under this policy. If you think the content of your request would contain such information, please inform the contact officer immediately.

Information about what is published on open access is available online at: http://www.health.act.gov.au/public-information/consumers/freedom-information

APPLICANT NAME	WHAT ARE THE PARAMETERS OF THE REQUEST	FILE NUMBER
███████████	*"Copies of all documents relating to any discussions held between Canberra Health Services staff and/or external stakeholders, including* ███████████ *Consultant Psychiatrist,* ███████████ *regarding supports services explicitly for people on the autism spectrum engaging with Health services in the ACT, including Mental Health services.* *This request is for records, including meeting agendas, notes, notices and minutes from 1/1/2018 to date. This does not include policy documents covering disability generally."*	FOI20/01

Ref Number	Page Number	Description	Date	Status Decision	Factor	Open Access release status
1.	1-5	Ministerial Brief: Health Care provided to Detainee's with Autism and data collection	25/06/2018	Full release		Yes
2.	6-11	Email: FW: Letter – Mental Health Services for Autistic People with attachment	06/08/2018	Partial release	Schedule 2.2 (a) (ii) prejudice the protection of an individual's right to privacy or any other right under the *Human Rights Act 2004;*	Yes

3.	12-72	Email: FW: Papers for Forum on Mental Health Services for people with Intellectual Disability with attachments (Attachment Statement of Intent- Mental Health Services for Autistic People is at reference 2)	12/11/2018	Partial release	Schedule 2.2 (a) (ii)	Yes
4.	73-76	Email: Agenda and Terms of Reference Mental Health Services for People with Intellectual Disability with attachments (Attachments are at reference 2)	14/11/2018	Partial release	Schedule 2.2 (a) (ii)	Yes
5.	77-79	Email: RE: Agenda and Terms of Reference Mental Health Services for People with Intellectual Disability with attachment	14/11/2018	Partial release	Schedule 2.2 (a) (ii)	Yes
6.	80-87	Email: Mental Health Services for people with Intellectual Disability Working Group Minutes and updates	23/01/2019	Partial release	Schedule 2.2 (a) (ii)	Yes
7.	88-121	Email: Re: Mental Health Services for people with Intellectual Disability Working Group Minutes and updates with attachments (Attachment WISH Autism Report in publically available and not included in this pack)	26/01/2019	Partial release	Schedule 2.2 (a) (ii)	Yes
8.	122-155	Email: Mental Health Services for People with Intellectual Disability with attachments (Attachment C- National Recommendations is at reference 3 Communique)	04/06/2019	Partial release	Schedule 2.2 (a) (ii)	Yes
9.	156-160	Email: Mental Health Services for people with Intellectual Disability with attachments (Attachment C in at reference 3 Communique)	14/06/2019	Partial release	Schedule 2.2 (a) (ii)	Yes

No.	Page	Description	Date	Decision	Exemption	Consultation
10.	161	Email: Stakeholder Meeting – Mental Health Services for People with Intellectual Disability	27/06/2019	Partial release	Schedule 2.2 (a) (ii)	Yes
11.	162-169	Ministerial Brief- Meeting with ████████ and ██████████ about people with autism spectrum disorder attending emergency departments in the ACT	08/08/2019	Partial release	Schedule 2.2 (a) (ii)	Yes
12.	170-171	Email: Care of the Autism patient in the hospital setting with attachment	04/09/2019	Partial release	Schedule 2.2 (a) (ii)	Yes
13.	172-179	Catch up notes (Action Plan is at reference 12)	17/09/2019	Partial release	Out of scope	Yes
Total Number of Documents						
13.						

ACT Government
Health

MINISTERIAL BRIEF

RECEIVED MO
25 JUN 2018

UNCLASSIFIED

To:	Minister for Mental Health	Tracking No.: MIN: 18/887
From:	Michael De'Ath, Interim Director-General	
Subject:	Health Care provided to Detainee's with Autism and data collection	
Critical Date:	Not applicable	
Critical Reason:	Not applicable	

- DG   22/6.18
- DDG   .../.../...

Purpose
To provide you with information on the services provided to detainees from ACT Health and ACT Corrective Services for detainees at the Alexander Maconochie Centre with a diagnosis of Autism Spectrum Disorder.

Recommendations
That you:

1. Note the information contained in this brief; and

Noted / Please Discuss

2. Agree to sign the attached letter to Mr Buckley.

Agreed / Not Agreed / Please Discuss

Shane Rattenbury MLA 6/7/18

Minister's Office Feedback

I would like to have a more detailed discussion about improving disability screening

UNCLASSIFIED

Background

1. Currently, as part of the induction process for detainees at the Alexander Maconochie Centre (AMC) individuals self-identify as having a disability, which may refer to physical or intellectual disabilities, or development conditions such as Autism Spectrum Disorder (ASD). This information is captured in the ACT Corrective Services (ACTCS) induction form and as it relies on self-identification, the data is likely to underrepresent actual figures.

Issues

2. The data is not captured in a format that allows for the data be easily extracted. At this time, ACTCS is unable to provide the definitive number of current detainees who identify as having ASD.

3. Once the new Corrective Services Information Management Solution (CSIMS) is deployed in 2019, detainee data will be collated into an online system, from which reports on detainee numbers and identifying factors, including disability status, may be generated. The information captured in CSIMS will continue to rely on self-identification and it is likely that the data will continue to underrepresent actual figures.

4. As part of the 2018-19 Budget, the ACT Government announced the investment of $580,000 to develop a Disability Justice Strategy as part of its continuing commitment to people with disabilities under the National Disability Strategy.

5. The strategy will respond to the disadvantage people with disability face when dealing with the justice system, including more effective responses from, and equal access to, the justice system.

6. ACTCS will continue to work with ACT Health and the Community Services Directorate to identify where barriers to access may exist, and to establish initiatives to address those barriers.

7. Justice Health Services (JHS) identifies detainees with Autism Spectrum Disorder (ASD) through a number of methods, including:
   - Self-identification on induction to the AMC;
   - Information provided by community health providers; and
   - Correctional Psychological and Support Services (CPSS).

8. JHS provides the general health care and treatment for all detainees in the AMC, this includes those detainees with autism and their co-occurring health needs. If a detainee had a diagnosis of autism that diagnostic information is contained in their clinical record.

9. Clinically, people who have a diagnosis of autism may have a higher rate of associated chronic illnesses and general health issues including epilepsy, gastrointestinal disorders, feeding and nutritional problems, and can also have associated mental illness.

Financial Implications
10. Not applicable.

Consultation
Internal
11. Not applicable.

Cross Directorate
12. ACT Corrective Services.

External
13. Not applicable.

Benefits/Sensitivities
14. Not applicable.

Media Implications
15. There has been media attention to this issue on the Canberra Times on 3 June 2018, titled *ACT government unsure how many prisoners have disability*.

Signatory Name:	Katrina Bracher	Phone: 51313
Action Officer:	Dannielle Nagle	Phone: 51062

Shane Rattenbury MLA

Member for Kurrajong

Minister for Climate Change and Sustainability
Minister for Justice and Consumer Affairs
Minister for Corrections
Minister for Mental Health

Mr Bob Buckley
Chair
Speaking Out for Autism Spectrum Disorder
chair@sofasd.org.au

Dear Mr Buckley *Bob*

Thank you for your email of on 3 June 2018 regarding detainees with a diagnosis of Autism Spectrum Disorder (ASD) in the Alexander Maconochie Centre (AMC) and what supports are available for detainees with ASD.

The management of people in the AMC with Autism Spectrum Disorder is undertaken collaboratively by ACT Corrective Services (ACTCS) and Justice Health Services (JHS).

As part of the induction process, detainees may self-identify as having a disability, which may refer to physical or intellectual disabilities, or development conditions such as Autism Spectrum Disorder (ASD). This information is captured in the ACTCS Induction form.

JHS and ACTCS recognise the disadvantages facing people in custody who have ASD in particular qualitative impairments in social communication and social interaction. ACTCS offer a supported environment and care coordination for detainees with identified complex needs. JHS provides care and treatment for all detainees with ASD and their co-occurring health needs. The provision of health care to detainees is undertaken by a team comprising of general practitioners, nurses, psychiatrists, mental health nurses, psychologists, social workers and occupational therapists.

ACTCS do capture data on the number of detainees with autism, however not in a format that allows for the data to be easily extracted. At this time ACTCS are unable to provide the definitive number of current detainees who have self-identified as having autism. I recognise that this is an area that needs addressing and have asked ACTCS and JHS to work collaboratively on improving the data collection and storage processes at the AMC.

AUSTRALIAN CAPITAL TERRITORY LEGISLATIVE ASSEMBLY

London Circuit, Canberra ACT 2601, Australia GPO Box 1020, Canberra ACT 2601, Australia
Phone +61 2 6205 0005 Email rattenbury@act.gov.au

🐦 @ShaneRattenbury 📘 shanerattenburymla

One important part of this work is the development of a new ACTCS electronic information system from which reports on detainee numbers and identifying factors, including disability status, may be generated.

In addition, the ACT Government has committed to the development of an ACT Disability Justice Strategy as part of a continuing commitment to people with disabilities under the National Disability Strategy. Issues such as screening, data collection and support services for people with a disability in a correctional setting, including those with ASD, will be considered through this process.

Thank you for raising this important matter with me.

Yours sincerely

Shane Rattenbury MLA
Minister for Mental Health

6 JUL 2018

Daly, Kelly (Health)

From:	Hemming, Michelle
Sent:	Monday, 6 August 2018 12:33 PM
To:	Furner, Catherine (Health); McIntyre, Shirley-Anne (Health); JacksonHope, David (Health)
Cc:	Waterson, Rebecca (Health)
Subject:	FW: Letter - Mental Health Services for Autistic People [SEC=UNCLASSIFIED]
Attachments:	Mental Health Services for Autistic People.pdf

Hi All

Re Amber's request for information – can you please provide that to me and I'll progress to Amber

Thanks

Regards
Michelle Hemming
Executive Officer
Mental Health, Justice Health and Alcohol & Drug Services
1 Moore St, level 3
Phone: 6205 5142
Mobile:

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ACT Government Health | CANBERRA HOSPITAL AND HEALTH SERVICES
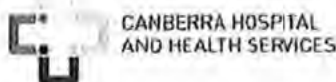
From: West, Alice (Health)
Sent: Monday, 6 August 2018 12:01 PM
To: Hemming, Michelle (Health) <Michelle.Hemming@act.gov.au>
Subject: FW: Letter - Mental Health Services for Autistic People [SEC=UNCLASSIFIED]

From: Shuhyta, Amber (Health)
Sent: Monday, 6 August 2018 12:00 PM
To: Furner, Catherine (Health) <Catherine.Furner@act.gov.au>; McIntyre, Shirley-Anne (Health) <Shirley-Anne.McIntyre@act.gov.au>; Kipling, Wendy <Wendy.Kipling@act.gov.au>
Cc: Jooste, Lydia (Health) <Lydia.Jooste@act.gov.au>; Ord, Jon (Health) <Jon.Ord@act.gov.au>; West, Alice (Health) <Alice.West@act.gov.au>
Subject: FW: Letter - Mental Health Services for Autistic People [SEC=UNCLASSIFIED]

Dear Cathy, Shirley-Anne and Wendy,

I am compiling briefing points on the attached letter and would appreciate your thoughts and input.

Amber Shuhyta
Director Mental Health Strategic Policy | Health Policy and Strategy
Level 4, 2-6 Bowes Street, WODEN

1

Ph 02 6205 3763| Ext 53763 | ███████

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From: Smith, Cathie (Health) **On Behalf Of** Mental Health DLO
Sent: Monday, 6 August 2018 10:39 AM
To: DDGHPS <DDGHPS@act.gov.au>
Cc: Shuhyta, Amber (Health) <Amber.Shuhyta@act.gov.au>; Ord, Jon (Health) <Jon.Ord@act.gov.au>
Subject: Letter - Mental Health Services for Autistic People [SEC=UNCLASSIFIED]

Hi All, please see attached which has been sent to Minister Rattenbury.

The Minister has asked for this to be on the next Executive Agenda which is now Monday 13th August 2018. For discussion, and ACT Health's thoughts/views.

Sending this through in advance for your consideration prior to next Monday's meeting.

Please let me know if you need anything further.

Thanks

Cathie Smith | Directorate Liaison Officer | ACT Mental Health
Phone: 02 620 55030 | Mobile: ███████ Email: mentalhealthdlo@act.gov.au
Office of Shane Rattenbury MLA | Minister for Mental Health
Level 2, London Circuit | GPO Box 1020, Canberra ACT 2601

To
The Hon. Shane Rattenbury
Minister for Mental Health
GPO Box 1020
Canberra ACT 2601

Date 15 July 2018

Statement of Intent

Mental Health Services for Autistic People

This document describes our intention to provide a short report to the ACT Government on gaps that autistic people[1] or people with autism spectrum disorder (ASD) currently experience while accessing or trying to access mental health services in the ACT. The report aims to inform the development of the vision and the workplan of the recently established Office for Mental Health and Wellbeing, and will be submitted by November 2018.

We observe that autistic people in the ACT currently appear to lack the right to appropriate and effective mental health services. We expect the ACT Government to recognise and address the right of autistic people in the ACT to access appropriate and effective mental health services. We ask that the new Office for Mental Health and Wellbeing advise the ACT Government on how best to ensure the rights of autistic citizens to effective mental health services and to improve mental health services for autistic people in the ACT.

Autistic citizens in the ACT are often denied, or find it challenging to gain, then maintain access to appropriate mental health services. Refusal or denial of mental health services may be more likely for autistic people, particularly when they have a known history of distressed behaviour (also called problem or challenging behaviour, or behaviour(s) of concern). The lack of necessary supports in the ACT is especially concerning for autistic people (including children and adolescents) with more extreme distressed behaviour, also because there is a flow-on effect that impacts on the physical and mental health of family members and carers. The consequences for children, young people and adults who do not receive timely, appropriate mental health services when they are most needed can be severe including misdiagnosis, entry to the justice system, self harm and removal from their families. At best they struggle to attend their place of work or study and to maintain relationships and housing.

Research and experience show autistic people often have comorbid mental health conditions (e.g., anxiety, depression), more often than the general public. Hence autistic people have greater needs for appropriate and effective mental health services, yet they often cannot access them in the current system.

Areas of particular concern include:

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[1] Many autistic people prefer identity-first language to person-first language (person with ASD), see http://autisticadvocacy.org/about-asan/identity-first-language/

- Mental health services refusing service based on ASD diagnosis, without an effective referral to another service, in the absence of a mental health safety net
- Medical/health staff who are unaware or dismissive of ASD diagnoses
- Lack of ASD training for mental health staff (and for health staff generally)
- Staff shortages and workforce planning for specialist mental health services in the ACT, public and private (e.g., not enough paediatric psychiatrists, developmental neurologists, behaviour specialist services)
- Confused and conflicted responsibility between ACT Health and NDIS (results in delays and exclusion from services)
- Inappropriate responses in emergencies involving autistic people
- Lack/shortage of accommodation suitable for autistic people with extremely distressed behaviours, including children and adolescents. Currently, parents may be forced to relinquish care of the child in order to get appropriate accommodation and care.
- Lack of support for families caring for autistic people with extremely distressed behaviour
- Lack of support for autistic people in forensic settings
- Lack of supportive environments for autistic people when accessing health services (reduced noise/light/people traffic)
- Need for holistic mental health supports for autistic students across all their environments, including school settings, living arrangements, therapy and care (the cross-directorate structure of the Office for Mental Health and Wellbeing will be helpful in addressing this)
- Need to recognise and register professional behaviour support in relation to distressed behaviour and extremely distressed behaviour
- Need for systemic case management so autistic people cannot just drop off the health and mental health service systems

A particular concern is **CAMHS (Child and Adolescent Mental Health Service)** refusing treatment for autistic children and adolescents because of their ASD diagnosis. Families are told CAMHS cannot treat or house them because CAMHS clinicians were not trained to treat autistic patients/clients, and their treatment is outside of CAMHS' responsibilities. The option for clients who can afford it or get NDIS funding is long waiting lists for private services, if available - services that may also decide to not treat autistic clients, in particular those with extremely distressed behaviour.

Increasing rates of ASD require long-term planning

Autism used to be described as rare but **ASD diagnoses have increased substantially** in recent times. This highlights the importance and timeliness of ensuring that mental health services for autistic people are adequate now and into the future. The Australian Bureau of Statistics reports[2] that in 2015, **2.8% of Australian children** aged 5 to 14 years were autistic

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[2] http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features752015 . These data indicated ASD diagnoses increased at 12.4% per year from 2012 to 2015 or 42.1% over the three years. Currently, the number of autistic Australians at least doubles each 5 years. There is also evidence that there are high rates of undiagnosed ASD associated with psycho-social disability and

(see table below). At this rate, ASD is now more common in children than intellectual disability (note: 30-50% of autistic children also have intellectual disability).

Age (years)	ASD diagnoses
0-4	0.4%
5-9	2.8%
10-14	2.8%
15-19	1.8%
20-24	1.2%
25-29	0.7%
30-34	0.2%
35-39	0.2%
40+	0.1%

ASD diagnoses are at substantially higher rates among children. The lower rates for older Australians with an ASD diagnosis does **not** result from substantial numbers of people being "cured" or losing their diagnosis, but is due to substantial under-diagnosis of ASD in the past. The growing number of children in the 5-9 and 10-14 ASD cohort means there will be a larger number of adults with ASD diagnoses in the future.

Without targeted and appropriate interventions, autistic people are at risk of poor outcomes in adulthood; they are likely to have poor employment prospects and a reduced ability to live independently. The long term outcome of not supporting ASD children and young adults is that these people are likely to require frequent and ongoing access to mental health and community services throughout their lifetime.

We are families who are unable to access the appropriate services that our children need, in particular, mental health services. We are also concerned that autistic adults cannot access the mental health services they need in the ACT.

Support for our advocacy comes from:

- *Speaking Out for ASD* (SOfASD) in the ACT
- *Autism Aspergers Advocacy Australia* (known as a4)
- Dr Alexander YC Lim (Psychiatrist, Managing Director or ZedThree Specialist Centre)

Autistic people in the ACT and their families need better mental health services. We intend to provide a report with supporting evidence that makes the case for improving mental health services for autistic people.

Thank you for your consideration.

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homelessness. ASD diagnosis rates in the ACT appear to be below the national average (http://sofasd.org.au/d7/node/142), but we do not know why this is the case.

Kind regards

Fiona Brammall - Founder of *Canberra Autism Spectrum Parents and Relatives* (CASPAR)

Bob Buckley - Chair of *Speaking Out for ASD* (SOfASD); Convenor of *Autism Aspergers Advocacy Australia* (a4)

Michelle Hatton - Parent of Autistic/Bipolar Teenager; Social Worker and Teacher

Bron Sparkes - Parent of Autistic Teenager

Dr Alexander YC Lim - Psychiatrist; Managing Director of ZedThree Specialist Centre

Dr. Ulrike Troitzsch (contact) - Parent of Autistic Child

Daly, Kelly (Health)

From:	Lee, Melissa (Health)
Sent:	Monday, 12 November 2018 12:09 PM
To:	Aloisi, Bruno (Health); Braun, Helen (Health); Burvill, Stefanie (Health); Calvin, Sam (Health); Kerr, Sheridan; Lewis, Llew (Health); Smith, Meghan (Health); Gibson, Sally
Subject:	FW: Papers for Forum on Mental Health Services for people with Intellectual Disability [SEC=UNCLASSIFIED]
Attachments:	Mental Health Services for people with Intellectual Disability Discussion Paper V1.0 29181108.docx; Attachment A - Communique National Recommendations.pdf; Attachment B - Statement of Intent letter.pdf

Hello,

Attached are discussion papers (see below for more information) for the meeting to be held on Thursday 15th November 2018 from 2:30 to 4:30pm in Training Room 1, 1 Moore St, Canberra City.

As you would be aware, you have been added to the invitation list for this forum. We hope that you will be able to attend, but understand it is extremely short notice. Even if you can't make it we wanted to bring your attention to this important discussion and invite you to contribute in any way you are able. We would welcome your thoughts/advice out of session as the ACT Health and Canberra Health Services position paper is being drafted following this discussion. There will be further opportunities to contribute prior to finalisation of the position paper over the next couple of months.

Warm Regards

Melissa

P: 02620 75994 | M: ▮▮▮▮▮   E: Melissa.Lee@act.gov.au

From: Lee, Melissa (Health)
Sent: Thursday, 8 November 2018 4:40 PM
To: McIntyre, Shirley-Anne (Health) <Shirley-Anne.McIntyre@act.gov.au>; Ratnayake, Priyani <Priyani.Ratnayake@act.gov.au>; ▮▮▮▮▮▮▮▮▮▮ ZedThree Specialist Centre ▮▮▮▮▮▮▮ Bowrah, Victoria (Health) <Victoria.Bowrah@act.gov.au>; Sweetman, Rebecca (Health) <Rebecca.Sweetman@act.gov.au>; Kipling, Wendy <Wendy.Kipling@act.gov.au>; Charles, Amanda <Amanda.Charles@act.gov.au>; Parker, Katherine <Katherine.Parker@act.gov.au>; Bingham, Jaime (Health) <Jaime.Bingham@act.gov.au>; Donley, Mandy <Mandy.Donley@act.gov.au>; Rogers, Lee-Anne (Health) <Lee-Anne.Rogers@act.gov.au>; ▮▮▮▮▮▮▮▮▮ ANU CMHR ▮▮▮▮▮▮▮ ▮▮▮▮▮ Kaur, Tej <Tej.Kaur@act.gov.au> ▮▮▮▮▮▮▮▮▮ ▮▮▮▮▮▮▮▮▮ Redmond, Margaret <Margaret.Redmond@act.gov.au>; JacksonHope, David (Health) <David.JacksonHope@act.gov.au>; Chief Psychiatrist <ChiefPsychiatrist@act.gov.au>; Shuhyta, Amber (Health) <Amber.Shuhyta@act.gov.au>; Wafer, Matthew (Health) <Matthew.Wafer@act.gov.au>; Campbell, AliceC (Health) <Alice.C.Campbell@act.gov.au>; Walker, Janelle (Health) <Janelle.Walker@act.gov.au>; Kirkham, Anna <Anna.Kirkham@act.gov.au>
Cc: Dunne, Ellen <Ellen.Dunne@act.gov.au>; Ord, Jon (Health) <Jon.Ord@act.gov.au>
Subject: Papers for Forum on Mental Health Services for people with Intellectual Disability [SEC=UNCLASSIFIED]

Hello everyone,

Thank you to those who have indicated their availability for the forum next Thursday 15th November 2018 from 2:30 to 4:30pm in Training Room 1, 1 Moore St, Canberra City.

Please find attached

A Discussion Paper on mental health services for people with intellectual disability

Attachment A - the Communique of Recommendations from the National Roundtable on Mental Health Services for People with Intellectual Disability

Attachment B -Statement of Intent regarding mental health services for Autistic People

These papers are being distributed to those attending as well as those that are unavailable as input would be welcome out of session. There will also be opportunity to contribute further following this initial meeting.

Warm Regards

Melissa

Melissa Lee | Senior Policy Officer
P: 02620 75994 | M: ███████ E: Melissa.Lee@act.gov.au
Mental Health Policy | Policy, Partnerships and Programs
Health Policy and Strategy | ACT Health | ACT Government
Level 4, 2-6 Bowes Street, WODEN | GPO Box 825, Canberra ACT 2601 | act.gov.au

"We acknowledge the traditional custodians of the ACT, the Ngunnawal people. We acknowledge and respect their continuing culture and the contribution they make to the life of this city and region."
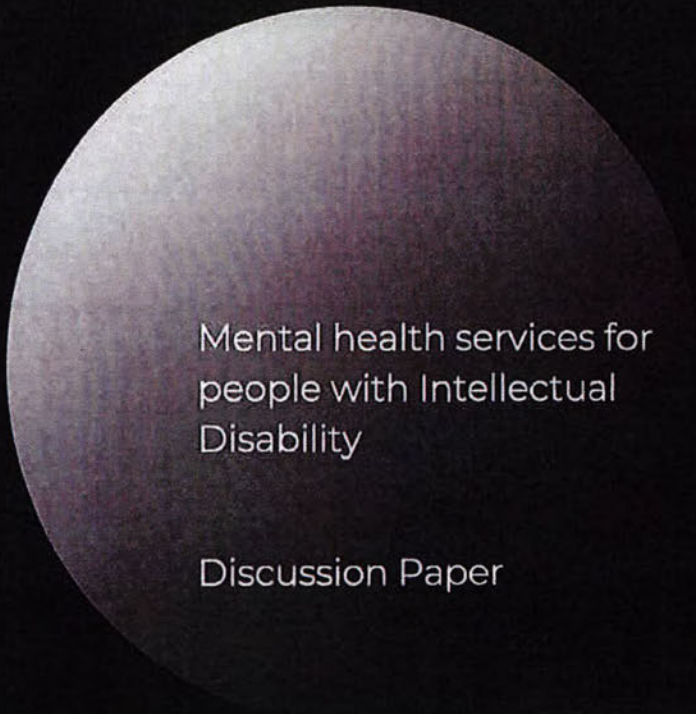
Mental health services for people with Intellectual Disability

Discussion Paper

November 2018

ACT Government | **ACT Health**

ACT Government | **ACT Health**

Contents

Introduction

Mental health services for people with intellectual disability (ID) has been identified as an area for action by the ACT Government Minister for Mental Health and there is strong community interest in seeing mental health service responses improve across the ACT health and human services sectors. This paper is designed to provide a snapshot of current services, issues, gaps and policy directions to inform discussions by stakeholders that have been invited to assist with the development of a strategic direction or position for how mental health services for people with ID can be improved in the ACT.

This work will inform actions under the Fifth National Mental Health and Suicide Prevention Plan (the Fifth Plan) and the ACT Mental Health and Suicide Prevention Plan, an integrated plan currently being developed by the Capital Health Network (CHN) the ACT region's Primary Health Network, ACT Health and Canberra Health Services.

In general this discussion paper focuses on the mental health needs of people with ID. This is a diverse group with widely varying levels of disability. The paper also considers services for people with Autism Spectrum Disorder (ASD). While this adds another level of diversity, there is crossover in these groups and many of the issues faced in accessing services align and require a similar response. It is acknowledged that specific needs within these groups may need particular attention.

For simplicity, the paper uses people first language. It is acknowledged that this may not be the preference of all individuals.

Definitions

Intellectual Disability (ID) is a lifelong disability that becomes apparent during the developmental period (under 18 years of age). It includes assessment of adaptive functioning as well as IQ (below 70).

Severity of Intellectual Disability can be classified as mild, moderate, severe and profound and reflects the level of impairment experienced by the person.

Borderline Intellectual Functioning refers to the impact of estimated IQ scores within the 70 to 75 range. It is considered "borderline' as it is on the borderline of the criteria for the diagnosis of intellectual disability. As with Intellectual disability, assessment of adaptive functioning plays an important role in identifying the level of disability the person experiences and the need for services and supports.

Autism Spectrum Disorder (ASD) is a lifelong developmental disability characterised by marked difficulties in social interaction, impaired communication, restricted and repetitive interests and behaviours, and sensory sensitivities. Autism Spectrum Disorder includes autistic disorder (or 'classic' autism); Asperger's disorder; and pervasive developmental disorder not otherwise specified (PDD-NOS), also known as atypical autism. People with Autism Spectrum Disorder have intellectual disability if they meet the criteria for intellectual development disorder in the DSM-V assessment scale.

Diagnostic Overshadowing refers to the tendency for clinicians to overlook symptoms of mental illness in people with ID and other developmental disorders and/or attributing these symptoms/behaviours to their intellectual disability.

Background

People with ID experience far higher rates of mental illness across the lifespan, not only in high prevalence disorders like anxiety and depression but also higher rates of schizophrenia in young people and higher rates of dementia in older people. Despite this, there are multiple challenges for people with ID to access appropriately skilled mental health services.

Over recent years, work has been done to understand and address the complexities and challenges in service delivery for this group. The first National Roundtable on the Mental Health of People with Intellectual Disability was held in 2013, which agreed on the eight elements of an effective mental health system for people with ID. In 2014, Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers was published by the Department of Developmental Disability Neuropsychiatry, which outlined a framework for mental health professionals to improve accessibility and quality of services they provide to people with ID. This guide offers practical strategies that can be implemented by local services, however it also acknowledged the work still to be done at the policy, resource and provider level if Australian services are to meet their obligations under the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006).

The Fifth Plan identifies people with disability, especially ID, as a target group for 'specific and appropriate application' of activity under the Fifth Plan.

> *Integrated, accessible and person-centred supports and services are key to ensuring that people with disability, particularly people with intellectual disability, can experience better mental health and realise their potential.*

(Department of Health , 2017)

A second national roundtable was held in 2018, which aimed to translate research into practical recommendations, building on the eight elements. A Communique from the National Roundtable was published in August 2018 that provides a practical guide for national and local action to develop a better response to the mental health care needs of people with ID.

Statistics

People with intellectual disability represent 1.8% of the population (AIHW, 2003). In ACT this translates to approx. 7340 individuals	Mental illness in people with intellectual disability is 2-3 times greater than in the general population	People with Autism Spectrum Disorder are at greater risk of psychosis – 10% compared with 2-3% of persons with ID and 1% of general population.
40% of children with ID have MH problems that may be serious enough to lead to a psychiatric diagnosis	14% of all children with MH problems will also have an ID (50,000 in Australia)	Fewer than 10% of people with ID accessed appropriate treatment compared with 35% of people with mental health issues in the general population.

ID not only impacts the people themselves but also those caring for them, in particular their families. Not surprisingly, the social and financial costs of care have been assessed to increase with severity of ID. The average expenses of raising a child with severe disability are at least 3 times that of raising a child without a disability. Total expenditure on services and assistance for people with ID by Australian Governments was estimated at $3.361 billion in 2005-06. A 2014 Canadian study estimated the annual costs for caring for an adolescent (aged 14-17) with Autism Spectrum Disorder (ASD) ranged from $26-132K CAD depending upon the severity. (Genereaux, D., et al, 2016)

Further impacts on productivity result from the reduced ability of families to participate in the workforce. Estimated cost to parents caring for children with moderate to severe ID was $48-58K over a 12 month period with over 70% of all families sacrificing work opportunities in order to have the time to care for their dependant. Combined family expenses and Government costs estimate that ID costs Australian society $14,720 billion each year. (Doran, C.M., et al, 2012)

Complexity

Many people with ID present with a degree of complexity and an atypical profile and presentation of mental illness. This requires a high level of expertise of clinical staff and a coordinated cross-agency approach to service provision.

Diagnostic overshadowing is a major risk in people with ID presenting with symptoms often labelled as 'behavioural' rather than explored as symptoms of mental illness. Further, the misinterpretation of 'behavioural issues', is often used as exclusion criteria for mental health treatment services. However, uncharacteristic 'behavioural issues' or increased intensity of baseline behaviours can often be a response to symptoms of mental illness.

It is also important to acknowledge that people with ID may have experience of trauma and this will have a significant impact on the incidence of mental health and behaviours of concern. For example, the presentation of ASD and responses to trauma can look very similar and require experienced staff to accurately assess what is going on for the person.

Teasing out the biological, environmental and psychiatric components for persons with ID can be challenging, however it is achievable when undertaken by health professionals who have adequate specialised training.

Access

In Australia, access to services for people with ID across the age range for mental health assessment, treatment and interventions is significantly reduced compared to the general population. Eligibility for services can be difficult to assess and illnesses are often misdiagnosed and poorly managed.

Systemic and organisational barriers to appropriate access to mental health services include: a poor understanding of mental health and ID and the resulting challenges in assessment of mental illness; lack of specialist services to facilitate access and provide expertise around diagnosis and treatment; and lack of cross-sector collaboration.

Specific Issues and System Gaps

Policy

Policy development and service provision in Australia lags behind international standards. This is reflected in the low numbers of staff with expertise in this area and the small numbers of specialist units or teams nationally. Policy also tends to be vague with no clearly defined actions or measurable outcomes.

The national roundtable recommendations present an evidence informed framework to support the development of strategic policy, actions and improved services. The ACT Mental Health and Suicide Prevention Plan, currently in development, presents an opportunity to incorporate specific actions to improve services for people with ID and ASD. The Office for Mental Health and Wellbeing is also well positioned to support the cross-sector collaboration required in this work.

Disability and the Justice System

The ACT Government is currently developing a Disability Justice Strategy to drive the reforms and culture change necessary to address the barriers identified in the Australian Human Rights Commission report 'Equal before the law: towards disability justice strategies'. This report recommends that local disability justice strategies need to encompass:

1. *Safety of people with disabilities and freedom from violence.*
2. *Effective access to justice for people with disabilities.*
3. *Non-discrimination.*
4. *Respect for inherent dignity and individual autonomy including the freedom to make one's own decisions.*
5. *Full and effective participation and inclusion in the community, and*

In implementing such strategies, five principles should be adopted:

1. *be prepared in partnership with people with disabilities;*
2. *be coordinated across the agencies that deliver outcomes in the criminal justice system;*
3. *ensure accountability through our system of parliamentary democracy and public administration;*
4. *involve actions that are embedded in operational plans; and*
5. *be monitored for effectiveness and adjusted in light of experience.*

(ACT Community Services and Justice and Community Safety Directorates, 2018)

It will be important to be aware of developments in the Disability Justice Strategy incorporate relevant considerations and ensure the strategic actions align.

Multiple Disadvantage

The social and economic disadvantage for people already experiencing disadvantage due to ID is further compounded by a co-morbid mental illness. This presents as poor health outcomes, low income and increased experience of poverty by people and their families, reduced levels of education and employment and increased likelihood of experiencing discrimination. This systemic

disadvantage further limits the extent to which people can participate in the community. (Victorian Health Promotion Fund, 2012)

People with Borderline Intellectual Functioning

Up to 13% of the population function in the borderline intellectual range. These people are generally unlikely to receive specialist ID services and rely on mainstream services to identify potential issues and ensure needs are met.

People with borderline intellectual functioning may have related neurodevelopmental problems, behavioural disorders, including antisocial behaviours and strong determinants for developing psychosocial issues through disadvantage and vulnerability. Depending on the person's level of adaptive functioning, recognition of disability (including psychosocial disability) and mental illness can be difficult.

This population tends to experience particular disadvantage and psychosocial stress due to the challenges experienced in education, employment and accessing the supports that might assist their adaptive functioning. Assumptions are often made that persons in this population have a higher level of cognitive and decision making capacity than is actually the case. As a result people with borderline intellectual functioning are over-represented in the justice system, alcohol and drug services and mental health services.

Lack of identification of mild disability or borderline intellectual functioning in people with mental illness can result in increased behavioural issues, increased use of coercive practices and poorer recovery outcomes as suitable adaptations are not made by clinical services.

Autism Spectrum Disorders (ASD)

Within the range of neurodevelopmental disorders, ASD requires some specific consideration given the diversity of presentations across the spectrum and the high prevalence of mental illness, such as depression and anxiety as well as an increased incidence of psychosis in this population. The role of primary care is critical for adults with ASD where there is a significant lack of ASD specific services. (Foley, K., Trollor, J, 2105)

Concerns expressed by stakeholders in the ACT community have highlighted issues with access to suitable mental health services and supports by people with ASD, especially early intervention in the person's environment. Where people do access services there is concern of a lack of staff understanding and expertise of the person's needs in relation to ASD including how to adapt health environments

to support engagement. Issues have also been identified with the capacity of the specialist workforce to meet demand,

Stakeholders identified a lack of clarity in the roles and responsibilities between health, NDIS, disability and social services, raising concerns about supports for people with ASD in forensic settings, access to positive behavioural support, the lack of accommodation options and support for families. (See Attachment B, Statement of Intent)

Current ACT Context

Since 2002, the Mental Health Service for People with Intellectual Disability (MHS-ID) has provided comprehensive clinical assessment and psychiatric treatment to persons primarily aged 17 years and older with a known or suspected intellectual disability and a known or suspected mental illness / disorder, including ASD.

Children and adolescents requiring a diagnosis or treatment for ID and ASD are frequently referred to the ACT Health Community Paediatric and Child Health Service (CPCHS). CPCHS sees children aged 0 – 16 years with neurodevelopmental and behavioural presentations. The proportion of clients seen with co-morbid mental health concerns, trauma or incidence of 'Adverse Childhood Experiences' is estimated to be greater than 50%.

While paediatricians can diagnose children with ASD, they have historically referred to Therapy ACT (TACT) or the Child Development Autistic Spectrum Disorder Assessment Team (CDASDAT), both run by the ACT Community Services Directorate (CSD). This is in recognition of the importance of a multi-disciplinary approach to diagnosis. TACT ceased services with the transition to the NDIS and the CDASDAT service is currently experiencing significant pressures and delays.

Paediatricians and GPs struggle to provide mental health services to people with ID – hence their direct referrals to Child and Adolescent Mental Health Services (CAMHS), Adult Community Mental health Services (ACMHS) and the MHS-ID. It is rightly expected that the Canberra Health Services mental health teams will provide assessment, treatment and care for persons with complex presentations of mental health issues alongside a diagnosis of ID or ASD.

The assessment, diagnosis and treatment of mental health concerns for people with ID and ASD does present challenges to identify the real cause of a person's symptoms or behaviours. CAMHS and ACMHS will provide services for people with ID or ASD where they have also identified a diagnosis of moderate to severe mental illness, however, they do not specialise in the diagnosis or treatment of ID

or ASD and will re-direct people with ID or ASD where they have not been able to identify a moderate to severe mental illness.

The roles and responsibilities of community paediatricians, GPs and mental health services is poorly defined and often unresolved between services. For example, CPCHS experience a lack of clear referral or treatment pathways for ongoing mental health care despite the high likelihood that children with ID and ASD will need it. CAMHS often require the question of an ASD diagnosis to be answered before they can provide an opinion related to a mental health concern. Following mental health assessment, the person may be referred back to the paediatrician, GP or specialist to continue management of an identified mild to moderate mental health issue, assuming they have the expertise and skill to provide this care. Furthermore, disability specialists are often cautious about leaving what could be symptoms of depression or anxiety unaddressed while the person waits for an ASD assessment and are seeking a mental health opinion as an adjunct to their medical opinion.

MHS-ID have noted the increasing demand for expert consultancy services for young people referred to CAMHS. It is estimated that 22% of psychiatric resources for the MHS-ID team in the 2017-18 financial year were provided to persons who entered the service at less than 17 years of age. This includes direct referrals from paediatricians.

NDIS support packages are provided to people with ID and ASD, however, well rounded and collaborative therapeutic and behavioural support services are severely lacking since the cessation of Disability ACT and Therapy ACT. The NDIS does not provide funding to cover 'health' services, however some therapeutic support that is aimed at improved functioning can be funded. If a person is not eligible for therapeutic supports through the NDIS they will be reliant on the provisions of Mental Health Care Plans (6-10 sessions) or perhaps Chronic Complex Care Plans (5 sessions only) through their GP. It is also important to note that people are still experiencing significant waiting times for access to NDIS funding and they may receive no therapy while waiting for their NDIS package.

The Multidisciplinary Network Student Engagement Teams (NSET) in the ACT Education Directorate support students and assists schools to make adjustments for students who require support to successfully engage with education. NSET therapists do not provide individual therapy but rather work in partnership with schools, aiming to improve educational outcomes for all students. Most of the work occurs in the classroom to enable therapy strategies to be integrated into class programs. Students with ID and ASD in ACT Public Schools are also able to

access school psychologists who can address mild to moderate mental health issues. As part of the ACT Education Directorate's review of psychology services, consideration of the provision of group interventions such as PEERS or Secret Agent Society, aimed at strengthening social skills of students with Autism, will be introduced.

On 1 September the Senior Practitioner Act 2018 came into effect in the ACT. This legislation provides a formal framework for the reduction and elimination of restrictive practices by service providers in the ACT. The intent of the legislation is to provide a formal framework for the reduction and elimination of restrictive practices and applies to people receiving education, disability, child care and protection and any other service prescribed by regulation. It enshrines the principle that providers should only use restrictive practices in very limited circumstances – as a last resort, in the least restrictive way and for the shortest period possible in the circumstances. This act does not apply to people receiving care under the Mental Health Act 2015. Under this legislation all uses of restrictive practices must be reported to the senior practitioner. Use of a restrictive practice by a service provider is only permissible if used in a way that is consistent with a positive behaviour support plan for the person. This framework highlights the need for increased access to expertise in positive behavioural support in disability and mental health services.

Creating a More Effective System

Too often, people with ID and ASD are not afforded the same access to mental health promotion activities and low intensity mental health supports as the rest of the community. The provision of GP Mental Health Care Plans and access to mental health treatment through Better Access programs or Primary Health Network funded mental health programs is limited due to lack of specialisation available in these pathways. Work is required to ensure people have access to the right service at the right time. This means the full range of services are available to people with ID and ASD across the lifespan and spectrum of mental health care.

A collaborative, cross-agency approach to early intervention and mental wellbeing, before a person's mental health deteriorates, could result in improved outcomes for the person, their family and the community, with the added benefit of reducing demand on specialist and acute mental health services or justice services. Better integration between primary care, general health, specialist developmental services, general and specialist mental health services, social services, disability services and education would ensure each service is playing to its strengths and promote better outcomes.

While targeted services are important, understanding of the needs of people with ID and ASD should also be developed in mainstream health services so that they are able to make the necessary accommodations to make these services inclusive and staff are equipped to meet the needs of these populations where appropriate. Improving environmental and operational accommodations for people with ID and ASD such as allocation of extra time for appointments, enabling key stakeholders to attend specialist appointments and stakeholder meetings or providing access to spaces that meet sensory or behavioural needs should be routinely embedded in the way services operate.

The Communique from the National Roundtable on the Mental Health of People with Intellectual Disability (Attachment A) provides recommendations against eight elements:

1) Inclusion

2) Prevention and timely intervention

3) Access to skilled services

4) Specialist services support mainstream mental health services

5) Collaboration

6) Workforce development and support

7) Data

8) Multiple disadvantage

A commitment to prevention and timely intervention through cross-sector action, in partnership with people and their families/carers, to improve access to, and expertise of, mental health services and supports is required. (Department of Developmental Disability Neuropsychiatry , 2018)

Questions/Points for Discussion

1. How can mainstream health and social services become more inclusive of people with ID and ASD? What are the barriers to accessing mainstream services?

2. What is working well in services and between services?

3. Is there a clear picture of the service system and demand? Where are the gaps in services? What are the referral pathways? How can these be developed/improved?

4. What is the impact (risks and costs) where there are gaps or things are not working well?

5. Do we collect the right data? How can we measure current and future demand, monitor and communicate wait times? What is useful data to share between NDIS and Health? Useful links between federal and local data?

6. How do we build workforce capacity? Increasing understanding, expertise and inclusion in primary care, mainstream health and other mental health services as well as ensure adequate capacity and expertise through specialist mental health (e.g. MHS-IDS) and positive behavioural support services?

7. What considerations are there in implementing a competency framework for the health, education and disability workforce? For example, coordinated implementation of specific tools for evidence based assessment and management of mental illness in people with ID and ASD, especially recognition of early signs of mental health issues and identification of borderline and mild intellectual disability and associated support needs.

8. What is provided to people with ID and ASD in relation to mental health promotion, are tools already available? Is there a need for further research/ development of these?

9. What needs to be done to achieve better outcomes for people with ID and ASD in contact with the Justice System?

10. What exists or should be established to facilitate mechanisms for consumer input into the design of systems?

11. Are there other strategies to build capacity across mainstream mental health services as well as the MHS-ID Team?

12. How do we ensure specialist teams can be accessed by mainstream mental health services and have the resources to meet the demand for their clinical and consult liaison services?

13. Identification and/or development of adjunct behavioural specialist teams to work collaboratively with specialist MH services.

14. Improving the engagement of mainstream services with pre-planning and planning processes of the NDIS (e.g. consider NDIA pathway work).

15. Support and capacity to allow collaboration. Development and/or access to guidelines and tools for cross-agency collaboration

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COMMUNIQUÉ

Recommendations from the National
Roundtable on the Mental Health of
People with Intellectual Disability 2018

UNSW
SYDNEY

3DN
DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

cid
Council for
Intellectual Disability

ACI NSW Agency for Clinical Innovation

Centre for
Applied Disability
Research

Inclusion Australia

Mental
Health
Commission

Mental Health
Review Tribunal

NSW
GOVERNMENT

Ombudsman
New South Wales

CONTENTS

FOREWORD

"We aren't nobodies. We are someone important, just like you."

"It would be a very different world if we put the lived experience and health
of people with intellectual disability at the centre of our discussions."

"Please take today seriously as a chance to make a difference
in the lives of people with intellectual disability."

Excerpts from keynote address
Mr Michael Sullivan,
Vice Chair, Council for Intellectual Disability

Australians with intellectual disability experience very high rates of mental ill-health,
and multiple barriers to effective mental health care. Definitive action is required to address
this issue. Doing so will help realise the right of people with intellectual disability to the
enjoyment of the highest attainable standard of mental health. This Communiqué represents
the response of sector leaders to the mental health needs of people with intellectual
disability. It contains a series of practical Recommendations for improving the mental health
system for people with intellectual disability. As such, these Recommendations represent
the current thinking about how to improve the situation in Australia. Implementation of
the Recommendations is a corporate responsibility. We encourage you and other sector
representatives to engage with the Recommendations and to actively seek opportunities
to lead initiatives as outlined in this Communiqué.

Julian Trollor
Professor and Head, Department of Developmental Disability Neuropsychiatry
Chair of Intellectual Disability Mental Health
School of Psychiatry, UNSW Sydney, Australia

INTRODUCTION

This document presents a series of Recommendations under eight Elements of an effective mental health system for people with intellectual disability. These Recommendations were collated from the responses of sector leaders to the mental health needs of people with intellectual disability. The responses were articulated at the second National Roundtable on Intellectual Disability Mental Health held on 27 March 2018 at UNSW Sydney.
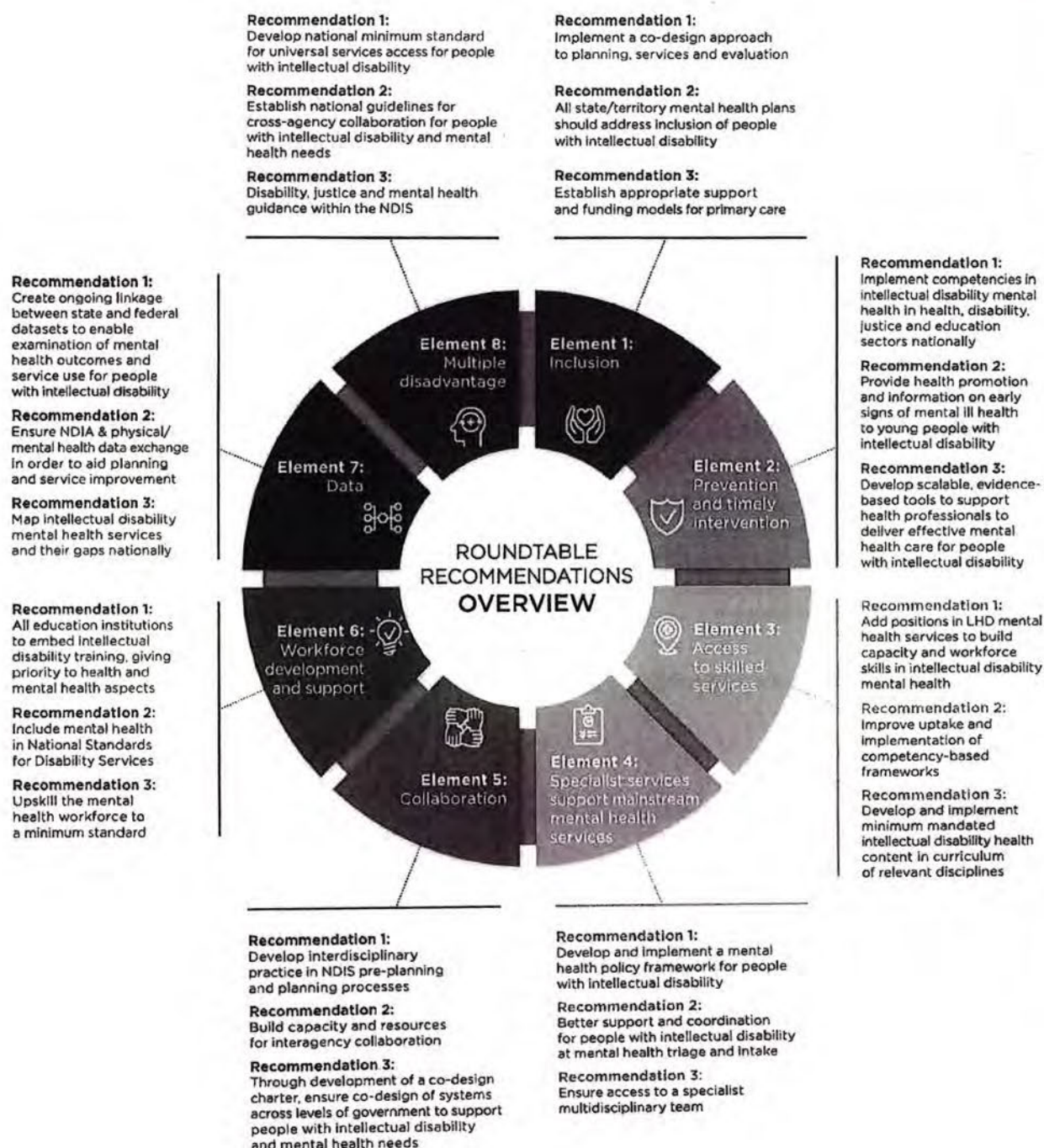
Eight Elements of an effective mental health system for people with intellectual disability were agreed at the first Roundtable event in 2013. These Elements were used as a framework for generation of Recommendations for further action at the second National Roundtable. The current communiqué presents a summary of each of the top three Recommendations developed by 2018 Roundtable participants for action within each Element. A more detailed description of each Recommendation is presented in Appendix 1, together with suggested pathways to assist stakeholder implementation.

The second National Roundtable on Intellectual Disability Mental Health was a major research translation event of a National Health and Medical Research Council (NHMRC) funded Partnerships for Better Health Project "Improving the mental health outcomes of people with intellectual disability" (APP 1056128). It brought together 130 lead clinicians, academics and sector representatives from around Australia (see Appendix 2 for a list of attendees). The Roundtable sought to engage sector leads at a national and state level to raise awareness of the mental health needs of people with intellectual disability, generate a set of clear and actionable Recommendations for the sector, and to act as a catalyst for ongoing improvement in mental health services and outcomes for people with intellectual disability.

This National Roundtable was organised by the Department of Developmental Disability Neuropsychiatry, UNSW Sydney in collaboration with the Council for Intellectual Disability and research partners. Important background about intellectual disability mental health, the NHMRC research partnership which informed the 2018 Roundtable, the eight Elements, and the National Roundtable methodology is presented on pages 3-13. Further detail about the Roundtable, NHMRC Partnerships Project and results of the pre-roundtable survey are included in Appendix 2.

OVERVIEW

The following diagram summarises the three top Recommendations in each of the eight Elements of an effective mental health system for people with intellectual disability. Each Recommendation is briefly described on pages 4–11 and in more detail in Appendix 1.

Recommendation 1:
Develop national minimum standard for universal services access for people with intellectual disability

Recommendation 2:
Establish national guidelines for cross-agency collaboration for people with intellectual disability and mental health needs

Recommendation 3:
Disability, justice and mental health guidance within the NDIS

Recommendation 1:
Implement a co-design approach to planning, services and evaluation

Recommendation 2:
All state/territory mental health plans should address inclusion of people with intellectual disability

Recommendation 3:
Establish appropriate support and funding models for primary care

Recommendation 1:
Create ongoing linkage between state and federal datasets to enable examination of mental health outcomes and service use for people with intellectual disability

Recommendation 2:
Ensure NDIA & physical/mental health data exchange in order to aid planning and service improvement

Recommendation 3:
Map intellectual disability mental health services and their gaps nationally

Recommendation 1:
Implement competencies in intellectual disability mental health in health, disability, justice and education sectors nationally

Recommendation 2:
Provide health promotion and information on early signs of mental ill health to young people with intellectual disability

Recommendation 3:
Develop scalable, evidence-based tools to support health professionals to deliver effective mental health care for people with intellectual disability

Recommendation 1:
All education institutions to embed intellectual disability training, giving priority to health and mental health aspects

Recommendation 2:
Include mental health in National Standards for Disability Services

Recommendation 3:
Upskill the mental health workforce to a minimum standard

Recommendation 1:
Add positions in LHD mental health services to build capacity and workforce skills in intellectual disability mental health

Recommendation 2:
Improve uptake and implementation of competency-based frameworks

Recommendation 3:
Develop and implement minimum mandated intellectual disability health content in curriculum of relevant disciplines

ROUNDTABLE RECOMMENDATIONS OVERVIEW

Element 8: Multiple disadvantage
Element 1: Inclusion
Element 7: Data
Element 2: Prevention and timely intervention
Element 6: Workforce development and support
Element 3: Access to skilled services
Element 5: Collaboration
Element 4: Specialist services support mainstream mental health services

Recommendation 1:
Develop interdisciplinary practice in NDIS pre-planning and planning processes

Recommendation 2:
Build capacity and resources for interagency collaboration

Recommendation 3:
Through development of a co-design charter, ensure co-design of systems across levels of government to support people with intellectual disability and mental health needs

Recommendation 1:
Develop and implement a mental health policy framework for people with intellectual disability

Recommendation 2:
Better support and coordination for people with intellectual disability at mental health triage and intake

Recommendation 3:
Ensure access to a specialist multidisciplinary team

Element 1: INCLUSION

The mental health needs of people with intellectual disability are specifically considered and accommodated in all mental health initiatives.

Recommendation 1:
Implement a co-design approach to planning, services and evaluation

$$ · 🏛️💼👪 · ⏱️ 2020

A National Guide to Co-design would enable the development of mental health services that are responsive to people with intellectual disability. Its development and implementation should be led or supported by key national bodies such as the National Mental Health Commission, the Mental Health Stakeholder Group to the Australian Government Department of Health, and the Mental Health Principal Committee of COAG. The guide should be developed with people with intellectual disability, family members, advocates, and intellectual disability mental health professionals.

Roundtable participants suggested a strategy for development of the guide.

Recommendation 2:
All state/territory mental health plans should address inclusion of people with intellectual disability

$ · 🏛️💼📁 · ⏱️ 2019

Specific inclusion of people with intellectual disability in state/territory mental health plans is necessary to ensure their distinct mental health needs are acknowledged and met. Where this has occurred to date, the inclusion of action items on intellectual disability mental health has been a driver for key initiatives and enhancements. All state/territory plans should therefore include a section on intellectual disability, and/or have specific references and actions throughout the plan.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 3:
Establish appropriate support and funding models for primary care

$ · 🏛️💼🌐 · ⏱️ 2018

The primary health sector currently struggles to respond adequately to the needs of people with intellectual disability and mental health problems. Development and incremental refining of models of care would lead to improvements in care. Primary Health Networks (PHNs) could lead enhancement of capacity and skills in primary care. Medicare Benefits Schedule (MBS) items could be revised to recognise the complexity of diagnosis and treatment, and the time health professionals need to spend with a person with intellectual disability and other informants; the current MBS review may provide scope to address this issue. With appropriate resourcing, the Health Care Homes model also has substantial potential for people with intellectual disability.

Roundtable participants suggested a strategy for implementation of this Recommendation.

🏛️ Government agencies (departments, offices, agencies, commissions, etc.) | 📁 Peak & professional bodies
👪 Advocates & people with intellectual disability | 🌐 Services (human, health, education) | 🎓 Academics

Element 2: PREVENTION AND TIMELY INTERVENTION

People with intellectual disability and their families receive education and support to prevent, and to obtain early and timely assistance for mental illness.

Recommendation 1:
Implement competencies in intellectual disability mental health in health, disability, justice and education sectors nationally

$ | 🏛 | Staged 2019-2021

Competencies in intellectual disability mental health describe core attributes of professionals and provide roadmaps and tools for professional development in this field. Lack of skills and confidence has been repeatedly demonstrated in key professional groups and contributes to an inability to meet the mental health needs of people with intellectual disability. Competencies should be developed and implemented for each of the above sectors by adapting existing competency frameworks and toolkits.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 2:
Provide health promotion and information on early signs of mental ill-health to young people with intellectual disability

$$ | Staged 2019-2020
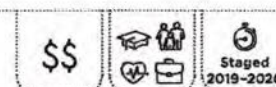
Presently, people with intellectual disability are not specifically included in health promotion. Information on early signs of mental ill-health and what to do about them is not readily accessible to people with intellectual disability. People with intellectual disability should specifically be included in health promotion initiatives, and accessible information about early signs should be developed for people with intellectual disability in order to support this group to improve their mental health. Roundtable participants recommended that this work is undertaken in partnership between consumers, advocates, disability and health service providers, and academic leads.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 3:
Develop scalable, evidence-based tools to support health professionals to deliver effective mental health care for people with intellectual disability
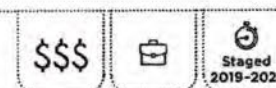
$$$ | Staged 2019-2021

Clinicians lack awareness of available evidence-based tools to assist assessment and management of mental illness and related disorders in people with intellectual disability. Whilst many tools and links to resources have been developed, these need organisation and coordinated promotion. A web-based clearing house is required to disseminate information to enable professionals to deliver more effective mental health care to people with intellectual disability.

Roundtable participants suggested a strategy for implementation of this Recommendation.

🏛 Government agencies (departments, offices, agencies, commissions, etc.) | 🖿 Peak & professional bodies
👥 Advocates & people with intellectual disability | ⊕ Services (human, health, education) | 🎓 Academics

Element 3: ACCESS TO SKILLED SERVICES

All mental health services provide equitable access and appropriately skilled treatment to people with intellectual disability.

Recommendation 1:
Add positions in Local Health District (LHD) mental health services to build capacity and workforce skills in intellectual disability mental health

$$$ | 🏛 🏥 | Staged 2019-2021

People with intellectual disability are frequent users of mental health services but available evidence indicates poorly coordinated and inefficient care. Recently established clinical positions (including coordinator or clinical nurse consultant) have been pivotal in building workforce capacity and improving practice in intellectual disability mental health within LHD mental health services. Positions should be implemented in a coordinated manner, embrace principles of co-design, and be subject to strong evaluation.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 2:
Improve uptake and implementation of competency-based frameworks

$ | 🏛 💼 🏥 | Staged 2019-2021
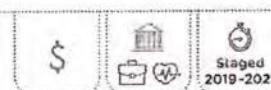
Element 3 work groups recognised the value of strong uptake and implementation of competency frameworks to improve clinical practice in intellectual disability mental health.

The strategy for implementation of this Recommendation was covered under 🛡 Element 2, Recommendation 1.

Recommendation 3:
Develop and implement minimum mandated intellectual disability health content in curriculum of relevant disciplines

$$ | 🎓 | Staged 2019-2021

Exposure to people with intellectual disability and their health needs during training will improve professionals' attitudes and capacity to address the mental health needs of this group. A striking deficit in this area is apparent in medical, nursing and psychology training, and should be addressed by adopting a co-production approach to the development of minimum mandated intellectual disability health content with a strong mental health focus in each discipline.

Roundtable participants suggested a strategy for implementation of this Recommendation.

🏛 Government agencies (departments, offices, agencies, commissions, etc.) | 💼 Peak & professional bodies
👥 Advocates & people with intellectual disability | 🏥 Services (human, health, education) | 🎓 Academics

Element 4: SPECIALIST SERVICES SUPPORT MAINSTREAM MENTAL HEALTH SERVICES

A national network of specialist intellectual disability mental health professionals is available to support mainstream mental health services – by provision of consultancy and training, and through research.

Recommendation 1:
Develop and implement a mental health policy framework for people with intellectual disability

$ | 🏛 💼 | ⏱ Staged 2018-2019

Reliable inclusion of people with intellectual disability in national and state mental health policy is lacking. Urgent work is required to develop and implement a national mental health policy framework. This will ensure meaningful inclusion of people with intellectual disability within all state and national mental health policies.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 2:
Better support and coordination for people with intellectual disability at mental health triage and intake

$$$ | ♿ 🏛 | ⏱ 2020

Access to mental health services for people with intellectual disability should be improved by ensuring that each component of mental health services has a defined clinical pathway and capacity to respond to the needs of people with intellectual disability. Arguably the greatest need is within entry points to mental health services. The development of robust clinical pathways will require mapping of the clinical journey for a person with intellectual disability, awareness of clinical resources and supports, and the implementation of reasonable adjustments.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 3:
Ensure access to a specialist multidisciplinary team
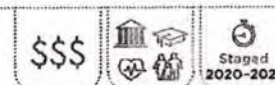
$$$ | 🏛 🎓 ♿ 👥 | ⏱ Staged 2020-2021

Specialist multidisciplinary health teams are required for some people with intellectual disability because of their more complex mental health needs. Specialist multidisciplinary teams with a strong mental health component should be established. Uniformly available state and territory working groups, which include support for representation by consumers, carers and advocates, are necessary for the development of models and business cases for funding enhancements.

Roundtable participants suggested a strategy for implementation of this Recommendation.

🏛 Government agencies (departments, offices, agencies, commissions, etc.) | 💼 Peak & professional bodies
👥 Advocates & people with intellectual disability | ♿ Services (human, health, education) | 🎓 Academics

Element 5: **COLLABORATION**

Ongoing joint planning by disability services, schools and mental health and other relevant services including (a) identification of referral and treatment pathways; and (b) a framework and capacity for collaborative responses where intellectual disability and mental health needs co-exist.

Recommendation 1:
Develop interdisciplinary practice in National Disability Insurance Scheme (NDIS) pre-planning and planning processes

$ | 🏛 | Staged 2018-2019

Interdisciplinary practice in the pre-planning and planning of NDIS applications and supports is critical to ensuring cohesive supports for a person with intellectual disability. Interdisciplinary practice, particularly that which engages health or mental health professionals, has been limited by historical 'silos' between services. However, exemplars of good practice can be seen within highly specialised health and disability services, which offer either a multi- or interdisciplinary approach. Interdisciplinary practice is particularly important for people with complex support needs, including those with intellectual disability and co-occurring mental illness or challenging behaviour. Interdisciplinary practice frameworks and support must be developed to support interdisciplinary approaches by practitioners in the pre-planning and planning for NDIS participants. A key opportunity to get this right is within the National Disability Insurance Agency's (NDIA's) pathway for people with complex needs that is currently under development.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 2:
Build capacity and resources for interagency collaboration

$ | 🏛♡ | 2019

Interagency collaboration benefits people with intellectual disability, professionals and services. However, there are currently limited resources to support and grow these collaborations. Lack of leadership due to devolution of state-based disability services risks regression of capacity in this area. Leadership is required in key agencies including NDIA, lead disability service providers, LHDs, PHNs, education, community services, and corrections to drive interagency resource development and implementation.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 3:
Through development of a co-design charter, ensure co-design of systems across levels of government to support people with intellectual disability and mental health needs

$ | 🏛💼👪 | Staged 2019-2020

Adoption of co-design approaches across government and other agencies will ensure consumer input into services and systems development, in a way that better meets the mental health needs of people with intellectual disability. The development of a co-design charter would be strengthened if led by key national leads such as the National Mental Health Commission, which has led the development of similar charters in the past, as well as input from the Department of Social Services, Department of Health, people with intellectual disability and their families and advocates.

Roundtable participants suggested a strategy for implementation of this Recommendation.

🏛 Government agencies (departments, offices, agencies, commissions, etc.) | 🗂 Peak & professional bodies
👪 Advocates & people with intellectual disability | ♨ Services (human, health, education) | 🎓 Academics

Element 6: WORKFORCE DEVELOPMENT AND SUPPORT

Training in intellectual disability mental health to minimum standards for front-line and other professional staff in disability services, schools and health services, particularly including primary health and mental health services.

Recommendation 1:
All education institutions to embed intellectual disability training, giving priority to health and mental health aspects

$$ ⚕👪 Staged 2019-2021

(See also Element 3: Recommendation 3)

Roundtable participants working on Element 6 suggested a broad strategy for implementation of this Recommendation involving a larger number of educational institutions.

Recommendation 2:
Include mental health in national standards for disability services

$$ 🏛 2019

National standards relating to disability services (as have been articulated in the National Standards for Disability Services) specify what is expected of disability services. Yet, the specific obligations for disability services in interaction with other support systems such as health, is lacking. The current and future standards, in particular those developed by the NDIS Quality and Safeguards Commission, should specifically outline health-related aspects in such a way that the responsibility of disability services in this area is clear, and in a manner that strengthens the interagency imperative between disability and health services.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 3:
Upskill the mental health workforce to a minimum standard

$$$ 💼🏛 2019

(See also Element 2: Recommendation 1, Element 3: Recommendations 1-3; Element 6: Recommendation 1)

A broad range of professionals constitute the mental health workforce, with available evidence indicating lack of skill and experience in intellectual disability mental health in multiple sectors and professional groups. Opportunities should therefore be sought to develop minimum workforce training across multiple groups.

Roundtable participants suggested a broad strategy for implementation of this Recommendation.

🏛 Government agencies (departments, offices, agencies, commissions, etc.) | 💼 Peak & professional bodies
👪 Advocates & people with intellectual disability | ⚕ Services (human, health, education) | 🎓 Academics

Element 7: **DATA**

Collection and analysis of data that measures mental health needs, access to services, and outcomes of people with intellectual disability.

Recommendation 1:

Create ongoing linkage between state and federal datasets to enable examination of mental health outcomes and service use for people with intellectual disability

$$ 🏛 🎓 | Staged 2019-2021

and

Recommendation 2:

Ensure NDIA & physical /mental health data exchange in order to aid planning and service improvement

$$ 🏛 🎓 | Staged 2019-2021

Historical and current linkage projects in this area highlight the value of big data in understanding the health needs of, and informing service responses to, people with intellectual disability. High level leadership through COAG and agreement between NDIA, Australian Department of Health, the Australian Institute of Health and Welfare, and state and territory health counterparts will be required to ensure that appropriate data linkage capacity and interrogation of linked data is supported.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 3:
**Map intellectual disability mental health services and their gaps nationally**

$$$ 🏛 🎓 | Staged 2019-2020

Service mapping will assist the identification of gaps in intellectual disability health and mental health services. A dedicated project would be required to develop this map.

Roundtable participants suggested a strategy for implementation of this Recommendation.

🏛 Government agencies (departments, offices, agencies, commissions, etc.) | 🗂 Peak & professional bodies
🏠 Advocates & people with intellectual disability | 🏥 Services (human, health, education) | 🎓 Academics

Element 8: MULTIPLE DISADVANTAGE

All Elements include specific focus on contributors to multiple disadvantage including poverty, isolated lives, alcohol and other drugs misuse, Indigenous status, culturally and linguistically diverse (CALD) background, and contact with the criminal justice system.

Recommendation 1:
Develop national minimum standard for universal services access for people with intellectual disability

$$ | 👥🏛💼 | Staged 2019–2025

A national minimum standard for access to health and human services for people with intellectual disability would reduce key barriers to accessing services.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 2:
Establish national guidelines for cross-agency collaboration for people with intellectual disability and mental health needs

$$ | ⚕🏛 | Staged 2019–2020

(See also 🔲 Element 5: Recommendations 1–3)

Cross-agency collaboration is recognised as critical to the provision of integrated supports for a person with intellectual disability and multiple disadvantage. The final goal of this Recommendation is the production and implementation of national guidelines for cross-agency collaboration at local, state and commonwealth levels.

Roundtable participants suggested a strategy for implementation of this Recommendation.

Recommendation 3:
Disability, justice and mental health guidance within the NDIS

$$ | 🏛🎓 | Staged 2018–2020

(See also 🔲 Element 5: Recommendation 2)

A greater understanding is required of the needs and factors that influence outcomes for people with intellectual disability who have contact with the justice system. Interagency collaboration is a concrete step likely to underpin quality service provision to people with intellectual disability who have contact with the justice system. An important initial step is to ensure that the NDIS pathway for people with complex needs has the capacity to cater to the needs of people who have contact with the justice system.

Roundtable participants suggested a strategy for implementation of this Recommendation.

🏛 Government agencies (departments, offices, agencies, commissions, etc.) | 🗄 Peak & professional bodies
👥 Advocates & people with intellectual disability | ⚕ Services (human, health, education) | 🎓 Academics

BACKGROUND

Intellectual Disability Mental Health

People with intellectual disability represent about 1.8% of the Australian population, or approximately 450,000 individuals[1]. The prevalence of mental ill-health is at least two to three times higher in people with intellectual disability compared to the general population[2]. People with intellectual disability are more vulnerable to mental ill-health due to complex interrelationships between disability and other medical, social and psychological factors[3].

Many people with intellectual disability experience a high degree of complexity and an atypical profile and presentation of mental illness[4], thus requiring a high level of psychiatric expertise, and coordinated approaches between services. The poor health and mental health status of people with intellectual disability, and commitments to address these problems, have been clearly articulated in the National Disability Strategy[5]. Further priorities to address the mental health needs of people with intellectual disability were determined at the National Roundtable on the Mental Health of People with Intellectual Disability in 2013[6], and in progressive documents such as the NSW Mental Health Commission's ten-year strategic plan[7] and the Fifth National Mental Health and Suicide Prevention Plan[8].

Australian intellectual disability mental health policy and services fall short of obligations under the United Nations Convention on the Rights of Persons with Disabilities, and lag behind leading international standards[9]. This affects the way that services support this group and means that people with intellectual disability and mental ill-health often receive limited or inappropriate mental health care. Access to treatment is poor and highly variable, and illnesses are often misdiagnosed, unrecognised, and poorly managed. A number of barriers and enablers have been identified across all aspects of both the mental health and disability sectors. These range from systemic and organisational barriers, to a lack of services and poor-quality services related to deficits in knowledge[3].

NHMRC Partnership Project

The National Health and Medical Research Council (NHMRC) funded Partnerships for Better Health Project "Improving the mental health outcomes of people with intellectual disability" (APP 1056128) brings together leading academics and representatives from health, disability, advocacy, education and supporting sectors to improve access to mental health services and quality of mental health services for people with intellectual disability (see Appendix 2 for a list of all investigators and partners). The project uses large scale data linkage, comprehensive policy analysis and qualitative methodologies to establish an evidence base from which to guide the development of targeted, appropriate services for people with intellectual disability. The project is inclusive and a consumer representative group oversees and provides research and dissemination advice for the life of the project. The focus of this body of work is on prevention and equipping of the services sector to respond to the needs of people with intellectual disability. Findings underscore the need for cross-sector action, in partnership with people with intellectual disability and their carers to identify and deliver means of improving access to mental health services and supports. A summary of the key findings was presented at the Roundtable.

[1] Australian Institute of Health and Welfare. Disability Prevalence and Trends Canberra: AIHW; 2003.
[2] Cooper, SA et al. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *The British Journal of Psychiatry*, 2007, 190(1): 27-35.
[3] Whittle, EL et al. Barriers and Enablers to Accessing Mental Health Services for People with Intellectual Disability: A Scoping Review. *Journal of Mental Health Research in Intellectual Disabilities*, 2018, 11(1), 69-102.
[4] Fuller, CG & Sabatino DA. Diagnosis and treatment considerations with comorbid developmentally disabled populations. *Journal of Clinical Psychology*, 1998, 54(1): 1-10.
[5] Council of Australian Governments. National Disability Strategy 2010-2020. Canberra: Commonwealth of Australia.
[6] NSW Council for Intellectual Disability. National Roundtable on the Mental Health of People with Intellectual Disability – Communique. 2013.
[7] NSW Mental Health Commission. Living Well: A Strategic Plan for Mental Health in NSW. Sydney, NSW Mental Health Commission, 2014.
[8] Department of Health. The Fifth National Mental Health and Suicide Prevention Plan. Canberra: Commonwealth of Australia, 2017.
[9] Evans, E et al. Service development for intellectual disability mental health: a human rights approach. *Journal of Intellectual Disability Research*, 2012, 56(11), 1098-1109.

Eight Elements of an Effective System

At the 2013 National Roundtable on the Mental Health of People with Intellectual Disability, participants considered and supported eight key Elements of an effective system of mental health care for people with intellectual disability. They were asked to develop a set of priorities for action for each Element. The resulting Communiqué and subsequent audit report, and the pre-roundtable survey for the 2018 Roundtable, are structured around these Elements of an effective system.

NATIONAL ROUNDTABLE 2018

Roundtable Methodology

Preparation for the 2018 National Roundtable involved a number of steps. Consultation with investigators and partners enabled the development of key aims and objectives for the Roundtable. Pre-roundtable "roadshows" with relevant government agencies in all states and territories were conducted by Professor Trollor, to engage and set the scene for the Roundtable. This also assisted the identification of senior representatives from key agencies within the advocacy, disability, health, criminal justice and education sectors to be invited as attendees. A pre-survey was developed and disseminated to prospective attendees to identify progress, barriers and enablers in agency and sector work in intellectual disability mental health. The survey informed the Roundtable background paper which summarised the pre-survey data and communicated important background information. The key barriers to delivering quality mental health care, as well as key enabling factors are summarised in Appendix 2. The development of an innovative and engaging format for the Roundtable was a key priority. This included the identification and testing of appropriate software and hardware for live collation of the perspectives of Roundtable participants, including electronic voting on priorities for action.

The Event

The event was co-chaired by Ms Alanna Julian from the Council for Intellectual Disability and Professor Julian Trollor from UNSW Sydney. The event took place at Leighton Hall, The John Niland Scientia Building, UNSW Sydney. Following the Welcome to Country by Aunty Maxine Ryan, the day was officially opened by the Hon. Brad Hazzard, Minister for Health and Minister for Medical Research. Following contextualisation by experts, the latest evidence of the gap in mental health care for people with intellectual disability was explored. Subsequently, participants were engaged in brainstorming new potential priorities for action under each Element to close this gap. Using innovative technology, these priorities were ranked by attendees using a live mobile voting system. Subsequently, two table groups per Element worked to develop a set of SMART (specific, measurable, attainable, relevant, time-bound) Recommendations for the top 3 priorities within each of the eight Elements. A summation of the day was given at the conclusion of the event by Australia's Disability Discrimination Commissioner, Mr Alastair McEwin.

Post Roundtable Consultation

Subsequent to the Roundtable, leads for each table had the opportunity to provide further information regarding the Recommendations arising from their work on their assigned Element. A draft version of the Recommendations was derived by integrating the outputs from each of the two working groups for each Element. This draft was circulated to table leads for final comments and approval.

ACKNOWLEDGEMENTS

APPENDIX 1

Detailed Recommendations from SMART groups

The SMART Recommendations developed at the Roundtable are outlined on the following pages. They represent consensus on priorities for specific and appropriate action in key areas.

Element 1: **INCLUSION**

The mental health needs of people with intellectual disability are specifically considered and accommodated in all mental health initiatives.

Recommendation 1:
Implement a co-design approach to planning, services and evaluation

A National Guide to Co-design would enable the development of mental health services that are responsive to people with intellectual disability. Its development and implementation should be led or supported by key national bodies such as the National Mental Health Commission, the Mental Health Stakeholder Group to the Australian Government Department of Health, and the Mental Health Principal Committee (MHPC) of COAG. The guide should be developed with people with intellectual disability, family members, advocates, and intellectual disability mental health professionals.

Recommendations for governance and review of the co-design approach must be established. High level support for the development and monitoring of a national co-design approach is necessary. The scope of work should either encompass whole of health with a strong mental health focus, or mental health alone.

The current work by the National Mental Health Commission on consumer and carer engagement and participation, and the NSW Mental Health Commission's work on developing co-design guide are potential templates or background for the national intellectual disability mental health co-design guide.

Suggested pathways

1. Initiate discussions on the development of a national guide to intellectual disability mental health co-design with the Department of Health, to develop a project plan
2. Identify and engage key stakeholders
3. Commission a National Guide to intellectual disability mental health co-design through lead national agencies
4. Seek high level endorsement, with targets determined by the scope of the guide. This could include endorsement from relevant state and national leads, or the MHPC of COAG.

Potential timeline

Suggestions 1–4 complete by 2020, with a report on progress and outcomes being determined by emerging governance and reporting framework.

Element 1: **INCLUSION**

Continued...

Recommendation 2:
All state/territory mental health plans should address inclusion of people with intellectual disability

Specific inclusion of people with intellectual disability in state/territory mental health plans is necessary to ensure their distinct mental health needs are acknowledged and met. Where this has occurred to date, the inclusion of action items on intellectual disability mental health has been a driver for key initiatives and enhancements. All state/territory plans should therefore include a section on intellectual disability, and/or have specific references and actions throughout the plan.

Suggested pathways

1. Raise the issue of inclusion of people with intellectual disability in state plans with the Mental Health Principal Committee of Australian Health Ministers Advisory Council (AHMAC)

2. Seek inclusion of an agenda item on the Council of Australian Governments Disability Reform Council

3. Raise the issue of inclusion of people with intellectual disability in state plans with peak bodies and advocacy groups

4. Initiate advocacy through agencies to mobilise sufficient ministerial and political support for this issue

5. Raise the issue of inclusion of people with intellectual disability in state plans with all mental health commissions through the joint Mental Health Commissions meeting to the end goal of developing a plan to incorporate intellectual disability in all future strategic plans and work plans of the various state and national commissions

6. Provide input into draft plans as needed.

Potential timeline
Suggestions 1–5 by the end of 2019; suggestion 6 as per revision of state plans.

Element 1: **INCLUSION**

Continued...

Recommendation 3:
Establish appropriate support and funding models for primary care

The primary health sector currently struggles to respond adequately to the needs of people with intellectual disability and mental health problems. Factors contributing to the shortfall in primary care provision to people with intellectual disability and mental health needs are manifold, and arise through a combination of policy, services and provider factors. This Recommendation included several steps to improve the ability of the primary care system and primary care providers to meet the needs of people with intellectual disability and mental health needs.

Development and incremental refining of models of care would lead to improvements in care. PHNs could lead enhancement of capacity and skills in primary care. MBS items could be revised to recognise the complexity of diagnosis and treatment, and the time health professionals need to spend with a person with intellectual disability and other informants; the current MBS review may provide scope to address this issue. With appropriate resourcing, the Health Care Homes model also has substantial potential for people with intellectual disability.

Suggested pathways

1. Deliver submissions to the current MBS review that seeks representation of the needs of people with intellectual disability. This could be led by the National Mental Health Commission and others.

2. Seek a joint planning and commissioning approach for people with intellectual disability and mental health needs. The mental health needs of people with intellectual disability should be raised with the Department of Health through the Primary Health Network Advisory Panel on Mental Health, for consideration in the 5-year Horizon document that is currently under development. Senior representatives from the National Mental Health Commission and Mental Health Australia have a leadership role in this context.

3. People with intellectual disability and mental health issues should be included in the Health Care Homes trials. Whilst there are several competing priorities for the Health Care Homes trials, the complexity of health-related needs experienced by people with intellectual disability makes this group one of particular importance. Formal representation should be made to the Department of Health to this end.

4. Use the research findings presented at the Roundtable relating to primary care data to inform submissions for MBS item reform.

Potential timeline

Suggestions 1–4 initiated by the end of 2018.

Element 2: PREVENTION AND TIMELY INTERVENTION

People with intellectual disability and their families receive education and support to prevent, and to obtain early and timely assistance, for mental illness.

Recommendation 1:
Implement competencies in intellectual disability mental health in health, disability, justice and education sectors nationally

Competencies in intellectual disability mental health describe core attributes of professionals, and provide roadmaps and tools for professional development in this field. Lack of skills and confidence has been repeatedly demonstrated in key professional groups and contributes to an inability to meet the mental health needs of people with intellectual disability. Competencies should be developed and implemented for each of the above sectors by adapting existing competency frameworks and toolkits such as those produced by 3DN, UNSW Sydney, or those in development for both disability and health professionals in Western Australia. An enabler is that 3DN's Competency Framework maps onto 3DN's IDMH e-learning which currently targets health professionals, disability professionals, and carers.

Suggested pathways

1. Building on existing work, seek support from the Mental Health Principal Committee of Australian Health Ministers Advisory Council (AHMAC) for uniform development and implementation of competencies in intellectual disability mental health for mental health services, including forensic services, nationally

2. Develop strategy with NDIS for the development of competencies in intellectual disability mental health for the disability sector nationally

3. Develop a strategy for the development of competencies in intellectual disability mental health for the education sector nationally.

Potential timeline

Suggestion 1 by the end of 2019; suggestion 2 by the end of 2020; suggestion 3 by the end of 2021.

Element 2: PREVENTION AND TIMELY INTERVENTION

Continued...

Recommendation 2:
Provide health promotion and information on early signs of mental ill-health to young people with intellectual disability

Presently, people with intellectual disability are not specifically included in health promotion. Information on early signs of mental ill-health and what to do about them is not readily accessible to people with intellectual disability. To achieve improved inclusion in health promotion and awareness in this area, a broad-based strategy is required, underpinned by inclusive design. People with intellectual disability should be specifically included in health promotion initiatives, and accessible information about early signs should be developed for people with intellectual disability in order to support this group to improve their mental health. Roundtable participants recommended that this work is undertaken in partnership between consumers, advocates, disability and health service providers, and academic leads. Use of internet and social media platforms has gained traction in the general population. The potential of this medium should also be explored for people with intellectual disability.

Suggested pathways

1. Measure the current level of knowledge and attitudes about mental health in people with intellectual disability, and the current level of engagement with the internet and social media platforms

2. Scope evidence and review evidence-based models of improving health literacy

3. Approach the Department of Health to request inclusion of the needs of people with intellectual disability in all aspects of health promotion and prevention

4. In partnership with people with intellectual disability, co-design tools and information that are accessible to people with intellectual disability, and increase promotion in mainstream health channels.

Potential timeline

Suggestions 1–3 by the end of 2019; suggestion 4 by the end of 2020.

Element 2: PREVENTION AND TIMELY INTERVENTION

Continued...

**Recommendation 3:
Develop scalable, evidence-based tools to support health professionals to deliver effective mental health care for people with intellectual disability**

Clinicians lack awareness of available evidence-based tools to assist assessment and management of people with intellectual disability and mental illness and related disorders. Whilst many tools and links to resources have been developed, these need organisation and coordinated promotion. A web-based portal is required to disseminate information to enable professionals to deliver more effective mental health care to people with intellectual disability. A clearing house model catering to key professional groups (general practitioners, developmental paediatricians, psychiatrists, mental health nurses, registered psychologists, etc.) was identified as the preferred option for hosting and dissemination of material.

Suggested pathways

1. Seek funding for the development of a clearing house for intellectual disability mental health resources
2. Liaise with relevant colleges and professional bodies to establish needs and mechanisms for uptake of materials, and for the embedding of resources in continuing professional development programs
3. Establish an online clearing house
4. Embed training materials in CPD programs of all relevant professional bodies.

Potential timeline

Suggestions 1–2 by the end of 2019; suggestion 3 by the end of 2020; suggestion 4 by the end of 2021.

Element 3: ACCESS TO SKILLED SERVICES

All mental health services provide equitable access and appropriately skilled treatment to people with intellectual disability.

Recommendation 1:
Add positions in LHD mental health services to build capacity and workforce skills in intellectual disability mental health

People with intellectual disability are frequent users of mental health services but available evidence indicates poorly coordinated and inefficient care. Recently established clinical positions (including coordinator or clinical nurse consultant) have been pivotal in building workforce capacity and improving practice in intellectual disability mental health within LHD mental health services. Positions should be implemented in a coordinated manner at a whole of state level in each jurisdiction. The funding and establishment of such positions could be sought through either a coordinated state/territory budget enhancement, or as an initiative of an individual LHD. Coordinated implementation (embracing principles of co-design), core performance indicators, and strong evaluation of these positions was recommended.

Suggested pathways

1. State and territory leads to partner with national advocacy leads to determine strategy for development of this approach in each jurisdiction

2. State and territory leads to seek support within corresponding health departments for funding to support the establishment of intellectual disability mental health clinical coordinator type positions and their evaluation

3. Using co-design principles, evaluate the impact and outcomes of positions.

Potential timeline

Suggestions 1–2 by the end of 2019; suggestion 3 by the end of 2021.

Recommendation 2:
Improve uptake and implementation of competency-based frameworks

Element 3 work groups acknowledged the value of competency-based frameworks to improve clinical practice in intellectual disability mental health. This Recommendation was covered under ♡ Element 2, Recommendation 1.

Element 3: ACCESS TO SKILLED SERVICES

Continued...

Recommendation 3:
Develop and implement minimum mandated **intellectual disability health content in curriculum of relevant** disciplines

Exposure to people with intellectual disability and their health needs during training will improve professionals' attitudes and capacity to address the mental health needs of this group. A striking deficit in this area is apparent in medical, nursing and psychology training, and should be addressed by adopting a co-production approach to the development of minimum mandated intellectual disability health content in each discipline. Extensive intellectual disability mental health content should be a core part of this material.

Suggested pathways

1. Determine target disciplines, establish a working group, and identify champions in each key discipline by the end of 2018
2. Approach Dean's governing bodies for discipline-specific support by mid-2019
3. Secure funding for curriculum projects, either individually or as a collective
4. Develop curriculum toolkits in key disciplines with minimum specified content
5. Trial curriculum toolkits across each of the core disciplines
6. Refine curriculum toolkits and seek national roll out.

Potential timeline

Suggestions 1–2 by mid-2019; suggestions 3–5 by the end of 2020; suggestion 6 by the end of 2021.

Element 4: SPECIALIST SERVICES SUPPORT MAINSTREAM MENTAL HEALTH SERVICES

A national network of specialist intellectual disability mental health professionals is available to support mainstream mental health services – by provision of consultancy and training, and through research.

Recommendation 1: Develop and implement a mental health policy framework for people with intellectual disability

The development and implementation of a national mental health policy framework was the lead Recommendation for Element 4. As featured at the Roundtable, reliable inclusion of people with intellectual disability in national and state mental health policy is lacking. Urgent work is required to develop and implement a national mental health policy framework. This will ensure meaningful inclusion of people with intellectual disability within all state and national mental health policies.

Suggested pathways

1. Identify state/territory and national mechanisms by which this issue could be raised
2. Seek high level support from Ministers and departmental leads at state and national levels
3. Brief the Mental Health Principal Committee on this and other relevant issues
4. Develop a framework for policy inclusion and seek high level sector endorsement.

Potential timeline

Suggestion 1 by the end of 2018; suggestions 2–4 by the end of 2019.

Element 4: SPECIALIST SERVICES SUPPORT MAINSTREAM MENTAL HEALTH SERVICES

Continued...

Recommendation 2:
Better support and coordination for people with intellectual disability at mental health triage and intake

Access to mental health services for people with intellectual disability should be improved by ensuring that each component of mental health services has a defined clinical pathway and capacity to respond to the needs of people with intellectual disability. Arguably the greatest need is within entry points to mental health services. The development of robust clinical pathways will require mapping of the clinical journey for a person with intellectual disability, awareness of clinical resources and supports, and the implementation of reasonable adjustments. A number of issues arise including:

- the importance of implementation of adjustments to practice at every stage of the health care journey, to allow the mental health needs of a person with intellectual disability to be met

- the value of having well defined clinical pathways for people with intellectual disability developed in each core component of mental health services

- the importance of mapping and documenting available services and supports across all elements of health and disability, at a local, regional and state level.

Suggested pathways

1. Linking clinical pathway components to a database of resources for clinicians at each phase of the clinical journey, including triage and intake

2. The funding, development, and trial of a clinical pathways toolkit to enable services to map clinical pathways for each core component of their mental health service, which can ultimately be widely adopted

3. The funding, development, and trial of a service mapping tool to enable services to map available services and supports across all Elements of health and disability, at a local, regional and state level.

Potential timeline
Suggestions 1-3 by the end of 2020.

Element 4: SPECIALIST SERVICES SUPPORT MAINSTREAM MENTAL HEALTH SERVICES

Continued...

Recommendation 3: Ensure access to a specialist multidisciplinary team

Specialist multidisciplinary health teams are required for some people with intellectual disability because of their more complex mental health needs. The establishment and embedding of specialist multidisciplinary teams was viewed as highly desirable by the working groups. Specialist multidisciplinary health teams for people with intellectual disability provide higher level care and consultation for people with more complex needs. Multidisciplinary teams can either have a whole of health focus (including mental health) or a specific mental health focus. Each state and territory is at a different phase of development of such services. Leadership at a national, state and territory level is required to ensure uniform access to multidisciplinary teams for people with intellectual disability and mental health needs. State and territory working groups, which include support for representation by consumers, carers and advocates, are necessary for the development of models and business cases for funding enhancements and should be instituted in each state and territory.

Suggested pathways

1. Following principles of co-design and in partnership with intellectual disability health leads in academia, government, services, and advocacy:
   a. Perform a national gap analysis
   b. Review and scope preferred model of care
2. Develop health economic modelling to support state-wide networks of multidisciplinary health care across all ages
3. Seek state-based funding enhancements to support the development of multidisciplinary specialist teams in each state and territory.

Potential timeline

Suggestions 1a and 1b by the end of 2020; suggestions 2 and 3 by the end of 2021.

Element 5: **COLLABORATION**

Ongoing joint planning by disability services, schools and mental health and other relevant services including (a) identification of referral and treatment pathways, and (b) a framework and capacity for collaborative responses where intellectual disability and mental health needs co-exist.

Recommendation 1:
Develop interdisciplinary practice in NDIS pre-planning and planning processes

Interdisciplinary practice in the pre-planning and planning of NDIS applications and supports is critical to ensuring cohesive supports for a person with intellectual disability. Interdisciplinary practice, particularly that which engages health or mental health professionals, has been limited by historical 'silos' between services. However, exemplars of good practice can be seen within highly specialised health and disability services, which offer either a multi- or interdisciplinary approach. Interdisciplinary practice is particularly important for people with complex support needs, including those with intellectual disability and co-occurring mental illness or challenging behaviour. Interdisciplinary practice frameworks and support must be developed to support interdisciplinary approaches by practitioners in the pre-planning and planning for NDIS participants. A key opportunity to get this right is within the NDIA's complex needs pathway that is currently under development.

Suggested pathways

1. Within the current pilot for people with complex needs the NDIS should develop a systematic process of interdisciplinary input including:
   a. Guidelines for practitioner input to pre-planning, including format and content template
   b. Guidelines for collation, evaluation and integration of advice from subject matter experts and external stakeholders
   c. Formal provisions for involving practitioners in planning meetings and processes, including via email, telephone, and videoconferencing
   d. Routinely providing feedback on outcomes of the planning process
2. Develop mechanisms to routinely identify and support participants with intellectual disability and mental health needs
3. Use identification to trigger and support interdisciplinary input into the planning process
4. Planners to seek interdisciplinary sources of information before the planning meeting
5. Ensure support for the NDIS participant with intellectual disability and mental health needs by:
   a. Automatically allocating an NDIS specialist support coordinator for pre-planning
   b. Supporting participant choice regarding who should provide information for NDIS planning; ensuring that interdisciplinary input is sought where appropriate
   c. Identifying a mechanism for NDIS or participant to seek new or additional assessments or reports if needed to inform planning.

Potential timeline

Suggestion 1 by the end of 2018; suggestions 2–5 by the end of 2019.

Element 5: COLLABORATION

Continued...

Recommendation 2:
Build capacity and resources for interagency collaboration

Resources are required to enhance interagency collaboration. This is particularly important as in many jurisdictions connectivity between agencies has been challenged by the implementation of the NDIS. Interagency collaboration benefits people with intellectual disability, professionals and services. However, there are currently limited resources to support and grow these collaborations. Lack of leadership due to devolution of state-based disability services risks regression of capacity in this area. Leadership is required in key agencies including NDIS, lead disability service providers, LHDs, PHNs, education, community services, and corrections to drive interagency resource development and implementation.

Suggested pathways

1. Lead commonwealth, state and territory agencies to consider development of an overarching collaborative charter for supporting people with intellectual disability and mental health needs

2. At a local level (e.g. NDIS, lead disability service providers, local health networks, PHNs, education, community services, corrections), ensure strong consumer and carer input by identifying and engaging locally relevant carer and consumer networks

3. At a local level, foster collaborative practice by forming joint working groups, communities of practice, and formal collaborative charters

4. Local leads to drive the development of resources. For example, consider services and interagency mapping, establish mechanisms for collaboration and resolution of disputes, establish shared training and education initiatives.

Potential timeline

Suggestions 1–4 by the end of 2019.

Element 5: **COLLABORATION**

Continued...

Recommendation 3:
Through development of a co-design charter, ensure co-design of systems across levels of government, to support people with intellectual disability and mental health needs

Adoption of co-design approaches across government and other agencies will ensure consumer input into services and systems development, in a way that better meets the mental health needs of people with intellectual disability. The development of a co-design charter would be strengthened if led by key national leads such as the National Mental Health Commission, which has led the development of similar charters in the past. Key partners include people with intellectual disability and their families and advocates, the Department of Social Services, and the Department of Health.

Suggested pathways

1. Develop, through audit, a list of stakeholders nationally
2. Agree with stakeholders on a common understanding of, and framework for, co-design
   a. Lead a consultation and development process
   b. Develop draft charter; associated deliverables; accountability; reporting requirements and mechanism; implementation strategy
3. Agreed draft Charter and associated documents to be submitted to COAG
4. Through a COAG commitment to the Charter, seek formal sign up by all agencies at high level and agree to a set of deliverables, accountability, and reporting
5. Roll out to include strategy for raising awareness of obligations under Charter, and for building capacity and improving collaborative practice under the Charter.

Potential timeline

Suggestions 1–3 by the end of 2019; suggestions 4–5 by end of 2020.

Element 6: WORKFORCE DEVELOPMENT AND SUPPORT

Training in intellectual disability mental health to minimum standards for front-line and other professional staff in disability services, schools and health services, particularly including primary health and mental health services.

Recommendation 1:
All education institutions to embed intellectual disability training, giving priority to health and mental health aspects

This Recommendation also links strategically to Element 3, Recommendation 3. Roundtable participants working on Element 6 suggested a broad strategy for implementation of this Recommendation involving a larger number of educational institutions.

Suggested Pathways

1. Identify key stakeholders: Universities, TAFE, private colleges, accrediting bodies, NDIS Quality and Safeguards Commission, peak consumer and carer groups
2. Determine priorities for audits and develop audit tools and methodology
3. Audit curriculum content in key priority sectors, disciplines and courses
4. Work with accrediting bodies or equivalent to gain support, agree to minimum content and set overall targets for inclusion
5. Develop and test 'minimum standards' curriculum toolkits for specific stakeholder groups
6. Advocate for local adoption of toolkit content to augment course content to meet standards.

Potential timeline

Suggestions 1–3 by the end of 2019; suggestions 4–6 by the end of 2021.

Element 6: **WORKFORCE DEVELOPMENT AND SUPPORT**

Continued...

Recommendation 2:
Include mental health in National Standards for Disability Services

National standards relating to the provision of disability services (currently articulated in the National Standards for Disability Services) specify what is expected of disability services. Yet, the specific obligations for disability services in interaction with other support systems such as health, is lacking. The current and future standards should specifically outline health-related aspects in such a way that the responsibility of disability services in this area is clear, and in a manner that strengthens the interagency imperative between disability and health services.

Inclusion of health and mental health related aspects in the National Standards for Disability Services and future relevant standards documents will ensure that the responsibility of disability services in this area is clear.

Suggested pathways
1. Broaden approach to include both Health and Mental Health domains in the Standards
2. Lobby for inclusion of health aspects in National Standards for Disability Services when next reviewed, or in superseding documents
3. Evaluate existing Standards document for opportunities and leveraged e.g. around human rights and inclusion
4. Develop a working group with appropriate inclusive representation
5. Prepare and provide supportive evidence from Partnership Research to policy makers
6. Develop draft submission with suggested wording to cover both Health and Mental Health domains.

Potential timeline
Suggestions 1–5 by the end of 2019; suggestion 6 at next review of National Standards for Disability Services.

Element 6: WORKFORCE DEVELOPMENT AND SUPPORT

Continued...

Recommendation 3:
Upskill the mental health workforce to a minimum standard

(See also:
Element 2,
Recommendation 1;
Element 3,
Recommendations 1-3;
Element 6,
Recommendation 1)

A broad range of professionals constitute the mental health workforce, with available evidence indicating a lack of skill and experience in intellectual disability mental health in multiple sectors and professional groups. Opportunities should therefore be sought to develop minimum workforce training across multiple groups. Professional bodies and specific service compartments need to be engaged in efforts and initiatives to address this Recommendation. Champions within each sector or professional group could link with existing expertise within specialised services to lead initiatives. Roundtable participants recognised the breadth of services and professional groups who provide mental health supports to people with intellectual disability, and this presents a challenge for this broad Recommendation.

Suggested pathways:

1. Identify key components of mental health workforce, from primary care, acute care, community mental health, and non-hospital specialists in relevant disciplines

2. Determine current knowledge and training needs in each component

3. Determine the potential for inclusion of minimum mandated content

4. Design tiered approach to training that progressively builds competencies; harnesses existing learning opportunities such as in-service education, grand rounds, and video resources that can promote reflective discussion

5. Develop marketing and promotion approach for available resources - e.g. competency frameworks, e-learning, existing specialist services and other resources

6. Collate and promote a national web-based clearing house of information about intellectual disability mental health for service providers, modelled on existing websites about defined mental health problems.

Potential timeline

Suggestions 1-5 dependent on sector or professional group but achievable within 24 months; suggestion 6 by the end of 2019.

Element 7: **DATA**

Collection and analysis of data which measures mental health needs, access to services, and outcomes of people with intellectual disability.

Recommendation 1:
Create ongoing linkage between state and federal datasets to enable examination of mental health outcomes and service use for people with intellectual disability

Recommendation 2:
Ensure NDIA & health/ mental health data exchange in order to aid planning and service improvement

Recommendations 1 and 2 for Element 7 are conceptually linked and have been presented as a united series of actions.

Historical and current linkage projects in this area highlight the value of big data in understanding the health needs of, and informing service responses to, people with intellectual disability. Big Data has the potential to answer key questions regarding the mental health status, service use and outcomes of people with intellectual disability, and has the capacity to inform improvements in service provision. High level leadership through COAG and agreement between NDIA, Australian Department of Health, the Australian Institute of Health and Welfare (AIHW), and state and territory health counterparts will be required to ensure that appropriate data linkage capacity and interrogation of linked data is supported.

Suggested pathways

1. Seek in-principle agreement from the NDIA, Department of Health, AIHW, and state and territory health counterparts. It is likely that COAG agreement through the relevant group will be necessary to achieve this. Consider including the NDIS Quality and Safeguards Commission in this process

2. Agree to the scope and terms of reference for work. This will require a commitment to an ongoing linkage and the engagement of content and process experts as well as academics active in this field

3. Work through legislative, ethical and technical issues associated with data sharing/matching. Existing data linkage processes at a commonwealth and state level, and current research linkages provide guidance

4. Identify mechanism for linkage and for data to be made available for analysis

5. Analyse data according to priority; ensure data is used to examine outcomes, interrogate service gaps, examine marked development and opportunities, inform the development of improved models for care and evaluate participant pathways

6. Utilise analysis to inform service and policy planning across NDIA, commonwealth health, state and territory health. This should be a collaborative process, with a cross-agency perspective

7. Use experience of data process to inform potential future improvements to data sets and data capture.

Potential timeline

Suggestions 1–4 by the end of 2019; suggestions 5–7 by the end of 2021.

Element 7: **DATA**

Continued...

Recommendation 3:
Map intellectual disability mental health services and their gaps nationally

Service mapping will assist the identification of gaps in intellectual disability health and mental health services. Documenting service models and their development may assist other jurisdictions to embark on services development in this area and may showcase exemplars of best practice. Methodological approaches with other populations in several states have demonstrated the feasibility of this approach. A dedicated project would be required to develop this map.

Suggested pathways

1. Using co-design principles, engage states and territories in this initiative
2. Establish resource that documents current available qualitative and quantitative data
3. Identify key research methodology for service mapping and key research questions to be addressed
4. Collect data from each state and territory in a uniform way, ensuring attention to specific groups for example, people with complex needs, CALD groups, LGBTIQ, Aboriginal and Torres Strait Islander people, and people in contact with the criminal justice system
5. Analyse data and identify key strengths, gaps and vulnerabilities in service provision
6. Report national snapshot and use data to lobby for funding enhancements in jurisdictions where necessary.

Potential timeline

Suggestions 1–3 by the end of 2019; suggestions 4–6 by the end of 2020.