

Inquiry into equity, accessibility and appropriate delivery of outpatient and community mental health care in New South Wales

Hearing – Friday 22nd September

Supplementary Questions

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Supplementary questions:

1. Is there a centralised pathway that is integrated with both State and federally funded services that enables people to access the care they need at the time they want it?

We are not aware of a centralised pathway that is integrated with both State and federally funded services.

2. How would the people you represent e.g. consumers and mental health carers describe their ability to navigate the system and its varied pathways to service access?

People with intellectual disability and their support networks describe a range of challenges when trying to navigate the mental health system. The key challenges that they face include:

- Unclear referral pathways to mental health services and supports.
- Denial of access to mental health services on the basis of having an intellectual disability. At times, this is overtly represented as an exclusionary criterion for acceptance into mental health services. At other times, there is a more subtle but equally detrimental culture of rejection from services.
- Low levels of health literacy among people with intellectual disability and their support networks to identify and know when and where to seek help for mental health problems.
- A lack of accessible information provided by mental health services.
- Inflexible services that do not routinely provide 'reasonable adjustments' to allow people with intellectual disability to access, engage with or move between services.
- Services that are slow to respond, with long wait times to enter and to progress between services.
- Diagnostic overshadowing (where signs of a mental health condition are incorrectly misattributed to the diagnosis of intellectual disability) and misidentification of mental health conditions.
- Mental health clinicians poorly equipped to meet the mental health needs of people with intellectual disability – this includes low levels of knowledge and skills regarding the needs of people with intellectual disability and stigmatising attitudes.
- Fragmented services with poor co-ordination or communication. This includes:
 - When patients present with a combination of mental health and physical health care needs. This is a common occurrence for people with intellectual disability given the underlying medical complexity.
 - When transitioning from child and young person to adult mental health services.
- A lack of funding from the National Disability Insurance Scheme and shared ways of working across sectors in an integrated way to facilitate their access to mental health services, treatment, and recovery.
- A tendency for specialised services and clinicians to be based in the private sector – this presents as a financial barrier to many.
- A lack of specialised services, especially for those living in rural and remote areas.
- A lack of services when transitioning from child and young person to adult mental health services.
- A lack of services equipped to meet the mental health needs of ageing people with intellectual disability.



- A paucity of mental health services that are equipped to provide ongoing care. Many of the services that have skills in the area of intellectual disability mental health are provided under a consultation-liaison model of care.
3. Do any of these challenges or enablers extend to when a carer or consumer is wanting to escalate their concerns when health is deteriorating in the community?
- a. Can you tell us about their experience of this?

Yes, these challenges extend to when a person or their support network is wanting to escalate their concerns when health is deteriorating in the community.

There are also additional challenges including:

- Accessing emergency helplines as these are often not accessible to people with intellectual disability.
- Emergency services and emergency departments are not adequately equipped to respond to deterioration in mental health.
- The inappropriate use of psychotropic medications as a form of restraint during an acute mental health crisis.
- The availability of support staff to respond in a timely manner.
- There is a paucity of referral pathways and limited capacity available for emergency or escalation when people with intellectual disability are deteriorating or need additional supports. This often leads to worsening mental health before presentation to acute services, and more complex, extended admissions to emergency departments or inpatient units.
- A lack of training for first responders when people with intellectual disability have deteriorations in mental health.

There are some 'islands of excellence' where individuals with experience or training in caring for people with intellectual disability are involved in the care journey for the patient. The specialist intellectual disability health teams and the intellectual disability mental health hubs are examples of these and are very progressive relative to other states.

4. Does your organisation have a direct line of contact to the NSW Department of Health?
- a. If so, what division/section is your direct line of contact?

Yes, we have a direct line of contact to the NSW Department of Health.

Our contact is:

Mr Vincent Ponzio
 Director | Disability and Social Policy
 Acting Director | Priority Programs
 Mental Health Branch, NSW Ministry of Health
 L8, 1 Reserve Road, St Leonards, NSW 2065
 Locked Bag 2030, St Leonards NSW 1590



5. How many people (measured as full-time equivalents) work for your organisation on either a paid or voluntary basis? 30 FTE
6. Does your organisation receive any funding or support, in any form, from the Commonwealth Government?
 - a. If so, what was the amount in the 2021/2022 financial year?
 - b. If so, what was the amount in the 2022/2023 financial year?

Yes, our organisation has received base funding from the NSW and Australian Government. In 2021/22 FY we received approximately \$500,000 in base funding from the NSW Government, and in 2022/23 we received \$500,000 in base funding from the NSW Government and \$500,000 in base funding from the Australian Government. We also received income from research and project income of approximately \$2.5M for each financial year specified.

Questions of notice:

1. The final report for the Intellectual Disability Mental Health National Disability Insurance Scheme Residual Functions Program Evaluation can be found here:
<https://www.unsw.edu.au/research/sprc/our-projects/idmh-ndis-program-evaluation>
2. The final report for the Intellectual Disability Mental Health Hubs is currently under review by NSW Health. We can share this report with you when it has been finalised. A copy of the formative evaluation of the Intellectual Disability Mental Health Hubs can be found here:
<https://www.unsw.edu.au/research/sprc/our-projects/evaluation-the-hubs>

We thank the Committee for this opportunity for input into this important issue. Should you have any further questions please do not hesitate to contact us.

Sincerely,

Professor Julian Trollor

Dr Janelle Weise

Dr Rachael Cvejic

Dr Pramudie Gunaratne

