

SUB.0002.0032.0002

5 July, 2019

Submission to the Royal Commission into Victoria's Mental Health System

We are parents of a 32 year old daughter with moderate intellectual disability (ID) due to Down syndrome, who, about a decade ago developed a treatment resistant psychotic illness. While diagnosis was readily established through the good diagnostic services of the State-wide Centre for Developmental Disability Health at Monash University after a GP referral, finding treatment services was an enormous challenge.

We both work in the health and mental health sectors and are very familiar with provision of services across these sectors. But finding a psychiatrist willing to take on treatment of a person with an ID, who has a chronic mental health condition was staggeringly difficult. Only because of our personal, professional networks were we able to find a psychiatrist who both professed confidence in treating the kind of dual disability experienced by our daughter and who exhibited empathy and responsiveness to our family needs.

In the process we approached various public and private sector services including psychiatrists in high profile positions and psychiatrists who were recommended as having expertise in the treatment of this kind of disability and we found that most of the psychiatrists we initially approached either lacked confidence in dealing with such comorbidities or admitted to lacking the relevant expertise.

Lack of training in psychiatry in particular but also in clinical psychology on the comorbidity between ID and major mental health conditions makes finding competent clinicians almost impossible. It was evident to us that there is a very low standard of professional skill amongst Australian psychiatrists in the treatment of patients with intellectual disability. In the end we secured the services of one psychiatrist who has made a career-interest of treating patients with these comorbidities. Only because of our personal connections and knowledge of a wide network of colleagues were we eventually able to find this psychiatrist. This psychiatrist is also exceptional in that they bulk-bill. While we are able to pay gap fees, many clients would not be able to afford these services if not bulk-billed. This psychiatrist also has 'closed-books' meaning they won't take new patients because of their heavy patient load, and we were only able to access their services because of personal recommendations from colleagues.

Overall, our impression is that psychiatrists and clinical psychologists in Victoria are woefully undertrained in the treatment of serious mental health conditions in people with intellectual disability. Is there a higher needs group in the community, in terms of mental health vulnerabilities? We live in dread of the day our daughter's psychiatrist retires, as they must. From whom will she then receive competent, compassionate treatment?

As another general comment on the provision of mental health services, it is difficult or impossible to find a private psychiatrist or clinical psychologist who does not charge a gap fee, on top of the Medicare rebate, typically in the vicinity of \$100 or more. We have paid gap-fees of \$300 for one consultation with a prominent psychiatrist. Despite Medicare funding for mental health services, the gap fees make these services accessible only to the wealthy. Many years ago, Brian Burdekin identified the lack of access, particularly by poor people, to mental health services in Australia, as a denial of human rights. What has changed in Australia?

Sincerely,

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2019 Submission - Royal Commission into Victoria's Mental Health System

Submission: 0002.0032.0001

What are your suggestions to improve the Victorian community's understanding of mental illness and reduce stigma and discrimination?

"Improve education for the community and mental-health service providers, particularly psychiatrists and clinical psychologists regarding the nature of dual disability in people with intellectual disability (ID)."

What is already working well and what can be done better to prevent mental illness and to support people to get early treatment and support?

State-wide services such as the Monash University Center for Developmental Disability Health provides a good diagnostic services. Yawning gaps in treatment services for people with ID.

What is already working well and what can be done better to prevent suicide?

I don't know that anything is working well. Access to psychiatrists and psychologists without long waiting lists in the public sector and unaffordable gap fees in the private sector would help to provide early intervention and prevention.

What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.

See above.

What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?

See above.

What are the needs of family members and carers and what can be done better to support them?

Access to affordable services.

What can be done to attract, retain and better support the mental health workforce, including peer support workers?

better training and funding of services to people with dual disabilities.

What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?

N/A

Thinking about what Victorias mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?
better funding and training of mental-health professionals.

What can be done now to prepare for changes to Victorias mental health system and support improvements to last?
better funding.

Is there anything else you would like to share with the Royal Commission?
"yes, a personal submission"