

## **Senate Community Affairs Committee into Commonwealth Funding and Administration of Mental Health Services**

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I welcome the opportunity to make a submission to the **Senate Community Affairs Committee into Commonwealth funding and administration of mental health services**. I make this submission as a private citizen based on my professional experiences as a psychiatrist working with adults with intellectual disabilities as well as in mainstream services for aged persons mental health.

All too often the unmet health and mental health needs of Australians with intellectual disabilities are overlooked in the policies on disability and the policies in mental health. I would like to draw to the attention of the Committee Article 25 of the United Nations Convention on the Rights of People with Disabilities which requires that Australia, as a signatory state, provides for equal access and quality of health care (which would include mental health care) as is provided to any other Australian citizen or resident. In addition Australia is required to meet the health needs that are specific to the intellectual disability. It is my opinion that Australia falls far short of these standards in practice in providing equitable access and quality of care in general and in particular fails to meet the health needs specific to the intellectual disability, especially in the adult population.

The National Standards for Mental Health Services (2010) are a most welcome development, in that there is a specific requirement to identify and take into account the needs diverse groups (and their carers), including people with intellectual disabilities, throughout all phases of care. This is an important first step, which needs to be underpinned by programs and resourcing. This should be a restated requirement for all federally funded mental health programs eg HeadSpace. So that these standards are not merely aspirational, the next step is monitoring and ensuring that these standards are actually met for people with intellectual disabilities and their carers.

Aspirational statements and indeed legislation against discrimination have not been sufficient to prevent blatant discrimination against people with intellectual

disabilities seeking mental health services. I draw your attention to the case in Western Australia where an adolescent male with Down syndrome and a serious mental illness requiring a long inpatient admission was refused follow up care by the regional Child and Adolescent Mental Health Service, because it was their policy and practice to not provide services to young people with intellectual disabilities and mental illness. This was an unforgivable and unlawful act of discrimination on the grounds that this young person had Down syndrome. Ministerial intervention was required before a service was provided. His mother lodged a complaint with the Equal Opportunity Commission which found that the service had discriminated against the young person. This is not an isolated act of systemic discrimination. In addition to blatant discrimination, there is an insidious form of discrimination in which a person's mental illness is denied, even when diagnosed by experts in intellectual disability psychiatry, and therefore service need not then be given.

In addition to requiring mainstream mental health services to "step up", there also needs to be specific provision of specialist mental health and health services for people with intellectual disabilities who have exceedingly high rates of mental ill health (point prevalence is 40% (Cooper, et al. 2007) as well as high rates of physical ill health, sensory and motor impairments, and premature death. Specialist health and mental health services for people with intellectual disabilities are needed to address the difficulties in assessment and diagnosis, the multiple morbidities, the clinical complexity and the presence of rare and syndrome specific disorders. Specialist services also provide opportunities for clinical training, as well as support for mainstream services providing generic health care to people with intellectual disabilities. There needs to be consideration of the pathways to specialist services for people with intellectual disabilities. The provision of specialist services should in no way be an excuse for mainstream services to then discriminate against people with intellectual disabilities and not provide the service on the grounds that a person has a intellectual disabilities and should just go to the disability health service. For example not all people with a criminal record as provided mental health care by forensic mental health services. The creation of ghetto services is not the solution, and the specialist ID health services must be embedded firmly within the mainstream health services.

So don't mainstream mental health services meet the mental health needs of people with intellectual disabilities? In many cases "yes", but the answer is "no" in too many. Australian general practitioners (Phillips, et al. 2004) and psychiatrists admit that they are poorly trained, and that services are not equipped to meet the health and mental health needs of Australians with intellectual disabilities (Jess, et al. 2008; Torr, et al. 2008). The comparison of generally trained Australian psychiatrists with specialist learning disability psychiatrists in the UK (Jess, et al. 2008), found that general psychiatrists felt poor trained, tended to treat symptoms rather than diagnose and were limited in practice settings and treatment modalities. and comparing changes in views over decade. A repeat survey of Victorian psychiatrists after decade of statewide consultation intellectual disability services, found a small increase in confidence but a more clear cut view that mainstream

services were not suitable for people with moderate to severe intellectual disabilities. But overall the views of psychiatrists had not changed. These papers support the establishment of specialist intellectual disability psychiatry capacity within Australian mental health services. I am not necessarily advocating an exact copy of the UK system, but there does need to be specialized care available, especially in the acute settings. Current consultation only models in operation in Victoria generally have long waiting times, and hence are not responsive to people with immediate need to expert assessment and care.

In my work as a psychiatrist in a mainstream aged persons' mental health service I have witnessed the missed diagnosis of mental illness and misdiagnosis of organic brain syndrome in older adults with mild intellectual disabilities. For the examples that follow, all of the individuals have conversational level of language development. Psychiatric diagnosis is more challenging in people with limited or no language development. These cases illustrate the lack of diagnostic expertise in mainstream adult mental health services.

Mr DD, a man in his late 50s, with a mild intellectual disability. He has been homeless and itinerant at times in his life. He has schizophrenia, and had been treated long term with a typical antipsychotic medication. For reasons that have not been available to me, this treatment was ceased. Over the course of a few months Mr DD became very disturbed, incontinent and was unable to self care. He remained in a deeply disturbed state for many months. He was diagnosed as having a "dementia", despite the rapid onset of functional decline over only a few months. He was sent to the aged persons inpatient unit, where he was diagnosed as being psychotic and treated with a typical antipsychotic medication and made a full recovery. One year later he remains well. He does not have a dementia and there is no functional decline from former baseline. He is now a resident in an aged care facility because he requires support because of his intellectual disability and mental illness. Not because he has an aged related disorder.

Mr EE lives in the same aged care facility. He too is in his late 50s and has a mild intellectual disability and bipolar disorder. He became hypomanic and was diagnosed with delirium, and was sent to aged persons mental health inpatient unit and from there to the aged care facility with the current relapse undiagnosed and untreated. Now that he has appropriate treatment for the bipolar disorder he is doing very well.

Ms FF, another older but not elderly woman, who has a mild intellectual disability, was incorrectly diagnosed as having a frontotemporal dementia when she was in an episode of a recurrent mental illness. And then she was placed in the same aged care facility as Mr EE and Mr DD.

The other issue that I wish to raise is that mainstream mental health services provide assessment and management of mental illnesses such as psychoses and mood disorders. They are not set up to assess and manage the behaviour disorders

that are common in people with intellectual disabilities. Perhaps they should be. It is well established that adults with intellectual disabilities are subjected to chemical restraint, ie the prescription of psychotropic medications to control behaviour, rather than to treat a diagnosed disorder (D'Abera 2008). The presenting behaviour disorder could indeed be due to medical illness, pain, other physical ailments, mental illness, a neurobehavioural syndrome, or a reaction to life circumstances. This requires careful assessment to make the right diagnosis and to provide the right treatment and management. Australian psychiatrists agree that they tend to treat symptoms and not make psychiatric diagnoses in people with intellectual disabilities (Torr, et al. 2008). Hence medical or psychiatric illnesses may remain undiagnosed and untreated or mistreated. I ask the members of the Committee, how is it acceptable that Australian citizens, are denied access to informed assessment and care. Indeed there is a lack of multidisciplinary services to enable medical, psychiatric, and psychological assessments of behaviour disorder. It took a judicial enquiry in Queensland before such a service was established in that state. Other states have yet to establish such services. Personally I think this is to Australia's great shame that as a wealthy nation we leave some of the most vulnerable members of the community to uninformed assessment and a questionable standard of care that would not be tolerated by the general community if such standards applied to them.

## References

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