Senate Select Committee on Mental Health 2005

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Summary

Psychiatric disorders in people with intellectual disability are 3-5 times more common than in the general population but are frequently not recognized or misdiagnosed and therefore not appropriately treated. There a many barriers to people with intellectual disability accessing mental health services or receiving informed and appropriate care in Australia. There is little opportunity for Australian mental health clinicians to train in the assessment and care of people with intellectual disability and mental illnesses. Australian psychiatrists report that they do not have the training or confidence to assess and manage people with intellectual disability.

Victoria has some specialist mental health services for people with intellectual disabilities. However these services cannot meet the demand and high levels of unmet need continue. Indeed denial of access, delays in access to care and mismanagement of mental health problems is of serious concern.

Specialist services in other states either don't exist or are extremely limited.

Recommendations

1. ***An enquiry be commissioned into the barriers to accessing psychiatric services for people with disabilities and the consequent impact on their lives.***
2. ***A review of international models for delivery of psychiatric services for this population be conducted with a view to the development of appropriate services in Australia.***
3. ***A process of accountability be established to ensure the rights of people with intellectual disability to access appropriate services.***
4. ***Gaps between the services provided by Disability Services and Mental Health Services and by Commonwealth and State departments be explored with view to improving accessibility to services where these gaps exist eg autistic spectrum disorders.***
5. ***Restructuring of medicare rebates to adequately remunerate general practitioners and psychiatrists for the work involved in assessment and management of people with dual disability.***
6. ***Training needs for medical practitioners and psychiatrists be serviced by appropriate academic activity.***
7. ***Recurrent funding be provided for psychiatry training positions***
8. ***Recurrent funding be provided for academic psychiatry of intellectual disability to maintain and develop evidence based knowledge***
9. ***Funding be provided for research into improving psychiatric services for people with intellectual disability.***

Mental Illness in People with Intellectual Disability

Mental disorders in people with intellectual disability are 3-5 times more common than in the general population (Cooper 1997; Gustafsson 1997) but are frequently not recognised or are misdiagnosed and therefore not treated or inappropriately treated (Reiss 1990; Torr 1999). Costs in terms of individual suffering, carer and peer burden and costs to the community are enormous.

> "Mental illness in people with intellectual disability often presents with nonspecifc behavioural disturbance, but then so does physical illness, pain, adverse medication effects, and reactions to life circumstances and life events. The phenomena of `diagnostic overshadowing' results in the behavioural disturbance being ascribed to

> the intellectual disability and the possibility of a mental or other disorder being discounted. Other barriers to diagnosis include impaired verbal communication and cognitive abilities of people with intellectual disabilities impeding history giving and verbal self report of internal phenomena; incontinuities of care and difficulties in obtaining reliable current and longitudinal history; atypical presentations of common psychiatric disorders; minimal research into the presentation, phenomenology and treatment of mental disorders in people with intellectual disabilities; lack of valid and reliable diagnostic systems for use in people with intellectual disabilities; difficulties in accessing mental health services including reliance on others for referral, lack of specialized services and generic services not being receptive to people with intellectual disabilities; and last but not least inadequate training of psychiatrists and mental health professionals.
>
> The evidence base for psychiatry in intellectual disability is extremely limited. Research in people with intellectual disabilities is fraught with difficulties. Overall numbers of this most heterogeneous population are small and subgroupings, such as Down's syndrome, are even smaller. To enroll sufficient numbers of people in clinical trials of sufficient power will require multi-centre research. Comorbid conditions may mean exclusion from trials. Consent to participate is a challenging ethical consideration. Methodological problems abound with lack of standardized, valid and reliable diagnostic criteria and sensitive diagnostic and rating instruments."(Torr and Chiu 2002)

Improvements in the social care of people with intellectual disabilities in Australia have not been matched by improvements in mental health care. Indeed the mental health care of people with intellectual disabilities has been characterised by denial, neglect and discrimination.

Parmenter (Parmenter 1988) identified a dearth of services and trained mental health professionals in Australia in the 1980s. In 1993 the Human Rights and Equal Opportunity Commission concluded that

> "there is an urgent need for academic research, increased clinical expertise and substantial increased resources in the much neglected area of dual disability"(Burdekin 1993).

Subsequently, in 1998, Australian Health Ministers in The Second National Mental Health Plan (Australian Health Ministers July 1998) identified people with intellectual disabilities and mental illness as one of the target groups with high level needs and called for improved treatment and care, improved access to and response by services; however this was to be achieved using current resources.

The Steering Committee for the Evaluation of the Second National Mental Health Plan (Steering Committee for the Evaluation of the Second National Mental Health Plan 1998-2003 2003) stated:

> "The development and implementation of effective service models for other groups with complex needs, such as people with mental disorder and intellectual disability, are yet to be realised and need to be afforded higher priority."

The National Mental Health Plan 2003-2008 refers to people with complex needs and comorbidities including people with intellectual disabilities.

The National Mental Health Report 2004 (Department of Health and Ageing Commonwealth of Australia 2003) failed to identify the few mental health services that do exist for people with intellectual disability. Simply identifying in a few sentences a need does little to advance outcomes.

Progress in mental health care of Australians with intellectual disability has been driven by a small number of committed individuals. Currently there is not a critical mass of psychiatrists specializing in the psychiatry of intellectual disability in Australia.

The terms of reference for this Senate Select Committee fail to specifically identify people with intellectual disabilities for consideration, although people with complex and co-morbid conditions are acknowledged. (Senate Select Committee on Mental Health. 2005) How can the mental health needs of people with intellectual disabilities be met when people with intellectual disabilities when they don't show up on the radar.

The federal Disability Discrimination Act 1992 (Commonwealth Government of Australia 2005) makes discrimination against people with disabilities illegal. Victorian government policy is clear that people with disabilities have the same rights and responsibilities as anyone else in the community. (State Government of Victoria Department of Human Services 2002) Mental health services should make reasonable adjustments so that people with disabilities have equal access. Despite the stated aims of legislation and policy, Australians with intellectual disabilities experience excess unmet mental health need and discrimination contributes to this.

Services and Training in the United Kingdom

The United Kingdom is the only country in the world to have adequately addressed the mental health needs of people with intellectual disabilities. There is an active and influential faculty of Learning Disability Psychiatry in the Royal College of Psychiatrists that has lead the way in advocacy, policy and service development. Localised services of various configurations provide access to community based specialist psychiatric care. These services provide Royal College of Psychiatrist accredited training posts for specialist registrars who will become certified learning disability psychiatry consultants after 2 years of supervised specialist training. These services also provide training posts for basic trainees who have to complete a 6 month term in either Child and Adolescent Psychiatry or Learning Disability Psychiatry.

Services in Australia

Specialist Services

Until recently there were no specialist psychiatric services for people with intellectual disabilities in Australia. Victoria has lead the way with university based specialist psychiatric clinics, local service initiatives in Gippsland and the Northern metropolitan regions and the statewide Victorian Dual Disability Service. However these initiatives still fail to meet the substantial mental health needs of many people with intellectual disabilities.

The Centre for Developmental Disability Health Victoria (CDDHV), a joint initiative of Monash University and the University of Melbourne, receives core funding from the Department of Human Services. The CDDHV aims to improve health outcomes for people with intellectual and developmental disabilities in Victoria through clinical, educational, research and advocacy initiatives. The psychiatric clinics conducted at the CDDHV are extremely limited in their capacity (0.5 EFT clinical), and although statewide in scope were never intended to be the primary service provider. The role of these clinics is to support general practitioners, train health professionals and to provide a base for clinical research. The clinics at CDDHV are office based, without a multidisciplinary team and are outside the mainstream service system. These clinics see patients referred by local general practitioners for a broad range of health problems; 70% of referrals have a behavioural or psychiatric component.

Together with other academic units in New South Wales and Queensland the CDDHV has provided the academic foundations, training opportunities for health care professionals, and limited clinical services. These units are generally funded by state disability services, not health departments. A unit has recently been opened in South Australia.

The Northern Dual Disability Program (NDDP) is a joint project of Mental Health Branch and Northern region of the Department of Human Services. The service model is proactive, the senior clinicians advocate for people with intellectual disabilities and suspected mental health problems, conduct comprehensive assessments and broker and coordinate a range of tailored disability and mental health services. The NDDP has now been incorporated into the Victorian Dual Disability Service.

The Victorian Dual Disability Service is a statewide service under the umbrella of public mental health services. The VDDS responds to requests from clinicians in area mental health services for assistance in the assessment of clients with intellectual disability. These assessments are conducted by senior clinicians and a psychiatrist. A comprehensive report is completed. The problem with the current model of operation is that it limits the capacity of the VDDS to undertake an advocacy role for particular clients as it can only respond to requests or referrals from area mental health services (AMHSs). My experience and understanding is that VDDS does not assist with access to area mental health

services and does not offer their services to people who are not receiving services from area mental health services. Where the main barrier to appropriate management is proper diagnosis and familiarity with this group it makes little sense to that people with intellectual disability and mental illness have to negotiate the AMHS gatekeepers who may fail to recognise the mental illness, before they can access an assessment by the VDDS. The VDDS does not provide clinical follow up and is not involved in any primary care of patients with intellectual disabilities.

Forensic psychiatric services for individuals with intellectual disability are limited. Individuals with dangerous behaviour are particularly disadvantaged. In Victoria there are a limited number of psychiatrists in the private sector who provide services. The Department of Human Services provides public funding for inpatient rehabilitation of a small number of dangerous offenders with intellectual disability. This service offers limited outpatient consultation to community clients who need more specialised services than area mental health services can provided. It is staffed by 0.2 EFT psychiatrist and 1.0 EFT mental retardation nurse. Clearly this service can only cater for a tiny fraction of the demand.

Mainstream Services

It is Victorian government policy that people with intellectual disabilities are to access mainstream health and mental health services. The role of the specialist services are to provide clinic support and training to mental health clinicians.

Public mental health services in Victoria tend to focus on “serious mental illness”, generally psychotic disorders, serious mood disorders and some personality disorders. AMHS in Victoria are under resourced and struggling to meet the enormous unmet mental health needs of the population. AMHSs do assess and care for people with intellectual disability, usually those people with a mild intellectual disability who are living independently/semi-independently in the community or those who were long stay patients in the psychiatric institutions. The clinical issues tend to be more or less the same as for the general population.

However some people with mild intellectual disability with a clear need for service from an AMHS are denied assessment and care seemingly on the basis that they have an intellectual disability and not on the basis of the actual mental health need or the mental health need is overlooked, redefined or minimised. More serious problems of access apply to people with greater levels of intellectual disability.

Patients seen at the CDDHV generally have greater levels of intellectual disability, and are often in residential care. Clinicians at the CDDHV seldom make referrals to AMHSs and do so only when it is considered necessary for safety reasons or the seriousness of and difficulty in treating the mental illness.

The response to such referrals is depressingly predictable, disappointing and often blatantly discriminatory.

My experience is that carers in disability services are not “antipsychiatry” but that mental health is “antidisability” and that mental health clinicians will find a myriad of excuses as to why they cannot see a person with an intellectual disability and suspected mental illness. Five years ago I would be regularly told that it was the policy of the particular AMHS not to see people with intellectual disabilities and that Disability Services were responsible. I have not been given this excuse for some time now. It now seems that AMHSs realise that they do have a responsibility however the denial of services continue.

Examples of what clinicians at the CDDHV have been told have been;

1. The problem is “behavioural” and not psychiatric (even when the person is referred by a psychiatrist specialising in intellectual disability psychiatry), and therefore the problem is the responsibility of disability services. This may happen without the person even being assessed.
2. The clinicians in the AMHS don’t have training in intellectual disabilities and therefore can’t help the person.
3. The acute psychiatric ward is no place for a vulnerable person with intellectual disability. However a community based service is not provided.
4. ‘Referral by Disability services is an attempt to “dump” the person with intellectual disability’
5. We will see the person when the VDDS have time. That may be 3 months hence for a person with acute mania.

Mental health clinicians often fail to appreciate the degree of disturbance and individual distress, the risk to the person, carers and peers as well as the sheer burden of care. People with serious mental illnesses, such as mania, who may be extremely violent with serious assaults on staff and other residents in community residential units (CRUs), and destructive, for example from hurling furniture and dismantling of built structures, are denied access to appropriate and informed care.

Mental health clinicians appear to have a mistaken view that CRUs are wards in the community, staffed by nursing staff who are trained in the mental health care of people with intellectual disability and who can give prn medications whenever required. CRUs are essentially private homes for a group of people with intellectual disabilities. Carers in (CRUs) usually receive limited if any training in health and psychiatric problems and the use of medications. They are not nurses, they are not health professionals. Mental retardation nursing has been abolished. Carers are expected to seek appropriate services for the people that they care for. Referrals to AMHSs are often met with refusal, or if the person is assessed the problem is dismissed, even when the carers and other residents are being assaulted, property is being destroyed and people cannot get adequate

sleep. The myth that CRUs are mini psychiatric wards in the community needs to exposed.

Other Unmet Mental Health Needs

People with intellectual disability who have “less serious” mood and anxiety disorders are also not having their mental health needs met. General practitioners don’t have the training and are also not remunerated to spend the required time it takes to make an assessment and diagnosis. In a retrospective review of 70 consecutive patients at dual disability clinic, only 20% of those diagnosed with depression were treated with an antidepressant. 80% were treated with an antipsychotic (incl. 100% of those being treated with an antidepressant) and 20% were on no psychotropic medication. Similarly only 20% of those diagnosed with bipolar disorder were treated with a mood stabilizer and 80% were on antipsychotic medication. (Torr 1999) Generally no formal psychiatric diagnosis had been made. Essentially people were being chemically restrained not treated.

People with intellectual disabilities and neuropsychiatric disorders resulting in high levels of disturbed/challenging behaviours are often treated with antipsychotic medications, and often at high doses. Some people with autism who have a history of serious aggressive or self injurious behaviour are currently being treated with multiple psychotropic medications at doses above recommended limits. In some situations over $500,000 a year is spent on accommodation support for one person because of these behaviours. There is precious little public medical care for adults with intellectual disability and frontal lobe problems or autistic spectrum disorders or behavioural phenotypes related to genetic disorders. The limited neuropsychiatric services in Victoria do see people with intellectual disabilities. However these services are not in a position to provide the ongoing care that is required

Inappropriate use of antipsychotic medications, often in high doses can result in serious side effects including lassitude and loss of participation in life enriching activities, blunting of personality, cognitive impairment, weight gain and diabetes, amenorrhoea, osteoporosis, akathisia, distressing extrapyramidal side effects and dystonia, and tardive dyskinesia (an involuntary movement disorder).

General Practitioners

General practitioners are the primary health care providers for people with intellectual disabilities. Proper assessment of mental health problems takes time that the average general practitioner does not have. Such assessments also require specialist knowledge. They report difficulty in accessing public mental health services for their patients with intellectual disabilities and a mental health crisis.

Private Psychiatrists

Private psychiatrists provide an essential service to people with intellectual disability. Most operate in isolation, with little peer support and often have had not training. To complete an adequate assessment substantial non face to face time is required (how long does it take to review 15 volumes of history?) which is not remunerated. People with intellectual disabilities are usually in receipt of a disability support pension and finding a psychiatrist who bulk bills is difficult.

Training in Australia

Victorian General Practitioners

General practitioners have identified mental health as the number one training need in the intellectual disabilities. (Phillips, Morrison et al. 2004). The expectation that general practitioners will be able to assess, diagnose and manage mental disorders in their patients with intellectual disability is unrealistic, especially when the majority of psychiatrists do not feel adequately trained for the task.

Victorian Psychiatrists and Trainees

A survey of Victorian psychiatrists (Lennox and Chaplin 1995; Lennox and Chaplin 1996) found that:

1. 85% agreed with the proposition that clients with dual disability received a relatively poor standard of care
2. 70% believed the general acute admission ward was not adequately suited to the needs of people with dual disability
3. 90% agreed that a higher standard of care would be delivered in specialist units
4. Most respondents agreed that inadequate community resources lead to the over-prescription of drugs and that liaison with intellectual disability services is not easy
5. 75% felt they had not had adequate training in dual disability and there was almost universal support that registrars should have the opportunity to train in dual disability.
6. 39% said they personally would rather not treat people with a dual disability.
7. 71% made comments on how psychiatric and community services could be improved.
8. 28% were interested in further training
9. 10% had developed a special interest in dual disability.

Specialist services were strongly supported and it was envisaged that they would become centres of excellence and provide training opportunities, support to generic services and undertake research.

Common themes related to training of all professionals caring for people with dual disability, reduction in 'anti-psychiatric' attitude of non-psychiatric staff, increased liaison between psychiatric and intellectual services, development of specialised services for dual disability clients, and sufficient funding to attract specialists into dual disability.

It was emphasised that residential care staff needed training in identification and management of psychiatric disorders, and the use of medication with clients with dual disability. It was felt that there was a distinctly anti-psychiatric feeling coming from some service providers particularly with the introduction of the non-medical normalisation movement. There was a call to support residential staff more to improve morale and decrease staff turnover. There was support expressed for higher staff to client ratios, a greater range of residential options for dual disability clients, and increase in the vocational or recreational activities offered.

A more recent survey comparing the attitudes of Victorian psychiatrists and trainees with their counterparts in learning disability psychiatry in the UK (Torr, Jess et al. 2004; Jess, Torr et al. 2005) concluded:

> **"**The specialist model of training and service provision (U.K. model) results in psychiatrists/psychiatric trainees who hold positive views about the services they work within and between, who are flexible in their approach to service delivery, and in the range of mental health needs and population needs they address, and the range of treatment approaches they endorse. They are knowledgeable, experienced and consider themselves to be well trained, competent and confident in their work. They want to work with people with intellectual disabilities. The generic model of training and service provision (Australian model) results in psychiatrist/psychiatric trainees who believe a different model (specialist model) of services should be provided, are more restrictive (compared with the U.K.) in their approach to service delivery, the range of mental health needs they address and the treatment approaches they endorse. They believe themselves to be unskilled, undertrained and unconfident when working with people with intellectual disabilities. They lack experience in such work and continue to be under exposed to such work (compared with the U.K.). Addressing these issues is a challenge, as the lack of specialist intellectual disabilities services and psychiatrists with specialist skills in this area results in difficulties for trainees in accessing training opportunities. Australian psychiatrists as a group were ambivalent regarding working with adults with intellectual disabilities."

Royal Australian and New Zealand College of Psychiatrists

The RANZCP now recognizes the need for trainees to have some expertise and skills in the Psychiatry of Intellectual Disability, however training experiences in this area are not compulsory.

> "The Fellowships Board recognises that it is not possible to mandate training in all areas of psychiatry before completion of basic training. You are encouraged to develop skills in such other areas, such as psychiatry of intellectual disability and

> forensic psychiatry, when appropriate opportunities are available. "(Royal Australian and New Zealand College of Psychiatrist 2003)

Accredited training positions for psychiatry registrars remain limited and funding is precarious. Without a critical mass of suitably trained fellows of the RANZCP training in the psychiatry of intellectual disability cannot be made mandatory.

Training Opportunities

Academic Programs

The Victorian Postgraduate Psychiatry Program (Monash University and University of Melbourne) masters program has offered candidates an elective subject in the psychiatry of intellectual disability since 2003. Although enrolments are at a sustainable level, candidates generally opt for subjects in areas that will be examined the RANZCP. Feedback from candidates who have completed the subject is positive and candidates report increased confidence in assessing people with intellectual disabilities and in formulating management plans. However this academic subject is no substitute for supervised clinical training.

The Institute of Psychiatry in New South Wales now also offers an elective subject in the psychiatry of intellectual disability.

Clinical Training Positions

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Disability services in Victoria provided pilot funding for 3x0.5x12 months psychiatry trainee posts in, one each at the CDDHV, VDDS, and
Forensicare for 2004. Unfortunately this funding has not been ongoing. The training posts were supported by Mental Health Branch but no funding has been provided. My understanding is that VDDS discontinued a previous training position due to funding restraints. The Forensicare outpatient service has closed limiting future training in this forensic intellectual disability psychiatry.

While the primary aim of the CDDHV is to provide a broad based clinical service there is a continuing high demand for psychiatric expertise from GPs and service providers. The CDDHV has continued with providing a 0.5 EFT psychiatry training position but this is not sustainable because the salaries to date have been cobbled together from non recurrent external sources. The CDDHV still does not have the capacity or the resources to provide ongoing psychiatric care

The funding required for 2x0.5EFTx12 month psychiatry training positions in Victoria would be of the order of $100 000 per annum. Two full time training positions would cost around $200 000. This would a small investment for an ongoing return in training a steadily increasing pool of psychiatrists who would have fundamental skills in the assessment and management of people with intellectual disability and mental illness.

I am aware of only one other psychiatry training position in intellectual disability in Australia and that is in Queensland. The Institute of Psychiatry provided a 12 month fellowship to one trainee who developed her own program in the psychiatry of intellectual disability.

Failure of care and to care: Case Histories

AA

A single woman in her late 40s living in a community residential unit. AA had previously lived an isolated existence with her mother who was now living in an aged care facility.

AA had a past history of ad hoc treatment with conventional antipsychotic medications with no formal diagnosis of psychiatric disorder. However AA had a well documented recent history of a major depressive episode diagnosed by a specialist learning disability psychiatrist from the United Kingdom. AA was successfully treated with a standard antidepressant medication which was later ceased.

Sometime later AA was assessed by private psychiatrist who diagnosed a major depressive disorder and recommended recommencing treatment with an antidepressant. This did not happen.

Almost a year later AA was assessed by another psychiatrist experienced in the assessment and treatment of psychiatric disorders in people with intellectual disability. AA had presented with a 6 month history of increasingly agitated and disturbed behaviour with weight loss of 20 kg. Over the 6 months carers had taken AA to the local emergency department on a number of occasions and she was always sent home inspite of a history of extremely disturbed behaviour, delusional thought, poor oral intake and significant weight loss. On mental state examination AA was extremely agitated, incoherent and delusional. A diagnosis of psychotic depression made. AA was recommended and sent to the area mental health service.

AA remained an inpatient for 3 months. Documented past and current diagnosis of serious depressive disorder made by psychiatrists experienced in intellectual disability were ignored. A diagnosis of autistic spectrum disorder was made by a psychiatry registrar with no reference to a developmental history, no reference to carers and family regarding adult social functioning and no reference to the detailed history of presentation provided by the referring psychiatrist. Treatment consisted predominantly of high dose benzodiazepines and low dose atypical antipsychotic. Outpatient follow up was promised but did not occur.

A month after discharge AA was taken the local emergency department. She was dehydrated and anuric (no longer passing urine). She received intravenous rehydration and the plan was for discharge back to the community residential

unit. Her carers refused to take her home and she was readmitted to psychiatric inpatient unit. AA was finally treated with ECT and recovered.

AA was seriously ill. AA could have died if her carers had not refused to take her home. The AMHS demonstrated good faith in admitting AA, however the treating clinicians ignored the detailed prior assessments, made an inaccurate diagnosis and therefore failed to provide appropriate treatment. The service also failed to provide follow up in the community.

BB

A 55 year old man with mild intellectual disability who had lived in institutional settings most of his life who continually "sabotaged" efforts to place him in community based accommodation with supported employment. He was reinstitutionalised. He had an undiagnosed and untreated bipolar disorder. He had never received treatment with a mood stabilizer (lithium remains the most effective mood stabilizer – the irony is that its use in bipolar disorder was discovered by a Melbourne psychiatrist John Cade in the early 1950s) and had long term side effects from high dose antipsychotic treatment. He also had to pay for all the damage done when he was in a manic phase.

CC

A 25 year old man with mild intellectual disability and good communication skills. He was responding to command auditory hallucinations and inserting wires into his penis. The voices were also telling him to cut off his penis and to cut his throat. The crisis assessment and treatment team (CATT) clinicians asked care staff to keep a behaviour chart for 2 weeks. This man was clearly psychotic and posed a serious risk to himself and probably to others. People with psychosis who are responding to command auditory hallucinations have been known to seriously mutilate themselves by cutting off their penis or pulling out an eye. This man should have been recommended, admitted to hospital and treated, not left at home with untrained carers. Fortunately he did not do himself any serious harm.

This is an example of diagnostic overshadowing, where the presenting problems are ascribed to the intellectual disability and other diagnoses are overlooked, even when the diagnosis is seemingly obvious. Mental health clinicians don't have the training, experience or confidence to manage people with intellectual disability and mental illness.

DD

A man with mild intellectual disability in his 30s, living independently with outreach support who had supported mainstream employment. He was referred to the AMHS by his outreach worker after he stopped attending work and was found in a self neglected state, refusing to get out of bed. The diagnosis given by the CATT was "behavioural". This man was deeply depressed.

This case again underscores the inadequate training of mental health clinicians and the tendency for diagnostic overshadowing.

EE
A woman in her late 20s, with mild intellectual disability, living in a country town. She was manic, aggressive and absconding at night. AMHS refused to assess on a number of occasions. When AMHS did assess a psychiatric diagnosis was not made and there was no follow up. After a complaint to the Office of the Chief Psychiatrist she was finally admitted to hospital.

FF
A woman in her 20s, with moderate intellectual disability, living in a CRU. FF had a history of bipolar disorder. She had had a previous psychiatric inpatient admission. Follow up had been limited. Her carers were struggling to care for her during a manic relapse. AMHS would not assess without the VDDS. An appointment could not be made for months.

GG
A man in his 20s, with mild intellectual disability, with psychotic symptoms. He was judged to be a risk to himself and others. An urgent referral was made to the AMHS. Two weeks later he still had not been seen.

HH
39 year old man with moderate intellectual disability due to a chromosomal abnormality, living in country town, with a history of rapid cycling bipolar disorder treated with a mood stabilizer and an antipsychotic. No psychiatric follow up in local area. The bipolar disorder was reasonably controlled however he was to have his salivary glands removed because of excessive salivation. This is a not so common side effect of the particular antipsychotic he was prescribed. What was required was a change of antipsychotic medication not a surgical procedure with permanent consequences.

Denial of access to mental health services to, prolonged delays in the assessment of, or the mismanagement of Australians with intellectual disabilities and acute serious mental illnesses is of major concern. Perhaps such problems exist for all Australians with mental illnesses. Maybe there is a misunderstanding about the training disability care staff or the capabilities and responsibilities of the disability services. Or perhaps Australians with intellectual disabilities are subjected to unlawful discrimination. In documenting these cases I have no issue with the individual clinicians involved. They have not been adequately trained, the services in which they work are under-resourced and there has been a failure by the system as whole to address these problems.

It is important to note that these cases occurred in Victoria which has the best mental health services for people with intellectual disabilities in Australia. I cannot

account for the circumstances of people with intellectual disabilities living in other states of Australia where specialist services are extremely limited or do not exist.

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