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

Organisation Name
N/A

Name
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What are your suggestions to improve the Victorian communitys understanding of mental illness and reduce stigma and discrimination?
"We need to have an ongoing conversation about mental health, mental ill health and mental illness. And we need to be mindful about the words we use. Words underpin our world view. If we use derogatory words, or words of exclusion then mental ill heath and illness will be hidden. We will deny it in ourselves, and not seek help. Othering is the foundation of discrimination. Defining someone by a characteristic, or an illness or condition to refer to someone as a schizophrenic is to diminish them as human being. But stigma and discrimination begins with the individual and collective attitudes in parliament, public service, health services, and the health professions. This is reflected in policy, funding, diversion of resources and delivery of services. "

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?
N/A

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

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.
People with intellectual disabilities with serious mental illness attending emergency departments are often deemed to have problem behaviour and are denies mental health care. They are vulnerable on inpatient units.

What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?
"The focus of this submission is the provision of mental health care for people with intellectual disability, and mental ill health/mental illness. For more than 2 decades I have provided psychiatric care to people with intellectual disabilities. I have also taught students and health professionals, been involved in clinical research and scholarship, and have been an advocate for improved training of health professionals, and for improved mental health services for people with intellectual disability. This is an individual submission. Any reference to my experiences in working in services are my personal views. I listened to Professor McGorry on Radio National on 5/7/19. He noted that currently Victorian public mental health services provide for 1% of the population. His view is that mental health services should provided for 3% of the population. I would add another 1%. The point prevalence of significant mental ill health in people with intellectual disability (IQ<70), from childhood to old age is 30-40% [1-6]. This translates to 1% of the population, equivalent to the prevalence of schizophrenia. If people with borderline intellectual

disability (IQ,75), the point prevalence of mental ill health increases to 2%. The United Nations Convention of the Rights of Persons with Disability Article 25 Health States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall: a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes; b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons; c) Provide these health services as close as possible to people's own communities, including in rural areas; d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care; e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner; f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability. Mental ill health in people with intellectual disability is too often overlooked, undiagnosed, denied and characterised as behavioural, or misdiagnosed. The barriers to accessing mental health care are too often insurmountable. Surveys of Australian psychiatrists have highlighted the limited if any training and training opportunities, scarce expertise, use of psychotropic medications to manage symptoms and behaviour rather than treating diagnosed mental illness, and concerns about the standard of care, the lack of specialist services, and the difficulties in cross sector interactions and cooperation. [7-12] Equity in care is not achieved with equal care. Reasonable adjustments are required. How is this possible in a broken system? Over the last 2 decades of working with people with intellectual disability there has been an improvement in the provision of mental health care. My impression is that Mental Health Services do recognise that the responsibility to all Victorians, including Victorians with intellectual disability and mental ill health. There are many examples of very good care. Treating teams aim to do their best, but often do have the expertise, training, or expert clinical support to provide effective care. And then there are examples of refusal to provide care or failure of care, and failure to care. I am still shocked by the attitudes expressed by some mental health professionals, of the blaming disability support workers for not knowing how to manage the person they are supporting when in fact that person has a serious mental illness and should be receiving inpatient mental health care. People may be on high dose polypharmacy, a potent mix of multiple antipsychotic medications, benzodiazepines, anticonvulsant medications, and yet the issue is defined behavioural and not mental ill health. If that is so, then why is the person on such cocktail of medications. I am though sympathetic to my colleagues. Assessment of someone with an intellectual disability is often extremely challenging. For the last 2 decades this population has been served by the statewide Victorian Dual Disability Service, which is a consultation service, not a treatment or management service. The university based Centre for Developmental Disability Health Victoria provided assessment and limited psychiatric intervention to support general private practitioners. This service is now within Monash Health but with reduced psychiatrist hours. Two Mental Health in Intellectual Disability Initiatives (MHIDI) have been operational for about 18 months. MHIDI-Adult offers mental health assessments and interventions for adults with an intellectual disability, aged 16 years plus, with a known, or suspected mental illness, in the Monash Health catchment. The multidisciplinary team is funded for of a psychiatrist 0.5 EFT, psychiatry registrar 0.5 EFT, and a psychologist, social worker, occupational therapist, registered nurse and [part time speech and language therapist. The MHIDI services are an important step forward. I have worked at MHIDI-A for 8 months. The challenge is how can a small team address the unmet mental health needs catchment population. For example, should the service be limited to people with an IQ <70, or about 1% of the population. Or should the service be open to people with an IQ >75, or 2% of the population. There is a potential for the service to be swamped, especially given the challenges in assessment, diagnosis and intervention. The presentation of mental illness is atypical. Standard diagnostic criteria are not valid for people with more severe intellectual disability and mental state examination is difficult because of cognitive and communication impairments. This is one reason why mental illness is often not diagnosed in mainstream mental health services. And then the clinical presentation is so often complex, and complicated by the specific neurodevelopmental disorder resulting in the intellectual disability, the high rates of comorbid disorders, and polypharmacy. Intellectual disability is secondary to a myriad of neurodevelopmental disorders. Each disorder has typical cognitive profiles, behavioural profiles, risks for psychiatric disorders and autism spectrum disorders. Comorbid physical conditions are common. Neurodevelpmental disorders have associated physical health conditions including but not limited to sensory and motor disorders, congenital heart disorders, epilepsy, immune system disorders. Aspiration pneumonia is common and a leading cause of death. And then there are general health conditions, metabolic ill health and diabetes, and the effects of being on a mix of antidepressant, antipsychotics, anticonvulsants, anxiolytics. It takes time to assess, to provide diagnostic'' clarification, or conduct a medication review, and it takes time for effective intervention, which often involves a gradual reduction in medications. Assessment involves taking detail history from family and support providers; locating medical, disability, educational, and pharmacy records, constructing time lines, designing data collection, and then collecting and analysing behaviour data, and testing clinical hypotheses with clinical interventions and monitoring. Review of a medication regime requires an understanding of presentation, diagnosis and how the person came to be on the medications. This takes a lot of time. Much of this work is considered to be administrative and therefore cannot be claimed as a CMI contact. I consider the assessment to be a major diagnostic investigation. Getting the assessment right, means the right intervention and often profound life changing improvements. Sometimes an intervention can be quick and effective and sometimes it can take years to sort someone out, especially when you have to unwind years of adding one medication after another. Diagnostic overshadowing is unfortunately common, and serious mental illness is not recognised and the disturbances in mental state and behaviour are deemed to be behavioural and the responsibility of the disability sector. A typical scenario is when some with an intellectual disability, and often but not necessarily, autism spectrum disorder is prescribed an SSRI antidepressant for depression, or anxiety and obsessive behaviours, all valid indications. This is reported to be effective for a time. And then there is a switch, to what I consider to be a manic state characterised by a highly volative mood state, extreme irritability, frequent violence, property destruction, other hyperactive driven behaviours, loud vocalisations, screaming, limited sleep etc. I have collected and graphed data on my patients, demonstrated clusters of behaviour, and tracked treatment outcomes. I have construted visual medication time lines, and time and time again see the same pattern. An antidepressant usually an SSRI, sometimes venlafaxine, less often other antidepressants - is commenced for anxiety, or obsessive behaviours, or some depressive symptoms, or some other reason. Sometime later the dose is increased. Why? My guess is that obsessive behaviours have escalated in the elevated or behaviourally activated state, which then escalates again. At the next review valproate is added, or olanzapine, and there is another dose in the antidepressant. The result is that the person is left, sometimes for many, many years, in extremely agitated energised, destructive, and aggressive state. High doses of antipsychotics, anticonvulsants, and benzodiazepines, are not enough. I have learnt this from my unique experience. This is not in the literature. The classification systems don't include extreme irritability, anger, destructive behaviour, and menacing, threating behaviour and actual violence as a manifestation of mania. But the evidence base, and knowledge base, is missing, and people are diagnosed as behavioural. People get hurt, some people end up in prison with an iatrogenic condition, and the costs to the person, family, carers, disability services, health services, and the PBS are yet to be counted. Consider the costs of -Ambulance and police involvement -Recurrent emergency department attendances -Inpatient admissions, which might be prolonged eg 6 months, or repeated, and require one one specialling -Justice system costs including imprisonment -Behaviour support services -Disability support services -Work cover costs What about the human costs of the person who is mentally ill for years, sometimes decades, the toll on families, on support services, and direct support workers etc. And the stress and burnout on clinicians. Specialist services with a mandate to treat are a recent addition to Victorian Mental Health Services. But these services are too small in scale for the unmet need. The upskilling mandate is going to take time. Mental health clinicians are too overwhelmed. The system is under resourced and run down. There is no time to think. When you have to manage a ward, with so many people with ICE induced or exacerbated psychosis, and high turnover, contemplating the validity of DSM criteria is not even on the list, nether lone the slog of teasing apart symptoms of mental illness from cognitively based impairments in coping, from illness, pain, medications, or of identifying syndromal clusters of behavioural equivalents from reactive behaviours. Psychiatrists are expensive, and there are not enough to provide the quality of care we would like to provide. It is soul destroying. In community teams you might see a person you are clinically responsible for every 3 months, even in the subacute phase post discharge for an inpatient unit, without the case manager. There is no time to do a real file review, or to provide genuine multidisciplinary care. We are forced to guess. In community teams the KPIs penalise file reviews (deemed administrative), working together, travelling to someone's home. The online medical records are mind numbing to navigate 3-4 clicks per page, an undated page, with generic label eg progress note. It takes hours if not days to complete interviews, a file review and medication time line. I have made many submissions to state and federal inquires of the last 2 decades. It has been demoralising. There is much more that I could say. You will hear from people with mental illness, their families, clinicians, and health, disability, emergency services about the mental health system as a whole. The challenges are compounded for people with intellectual and related disabilities. It seems to me that policy makers and the designers of the monitoring systems do not understand what is required to provide humanised and effective mental health care. Yes, it will cost what does it cost to get care wrong, or to not care. What does 10 years of 24 hour one on one disability support cost? In 1993 Brian Burdekin [13] concluded there is an urgent need for academic research, increased clinical expertise and substantial increased resources in the much neglected area of dual disability A quarter of a century later, there have been some real gains, but the urgent need remains much the same. If the Commission considers it worthwhile to further explore these issues I would welcome the opportunity to talk with the Commission.

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

Families and carers are defacto mental health care providers because serious mental health is not so often recognised and is deemed to be a behaviour issue and therefore not the responsibility of mental health services.

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

N/A

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?

"I would like to see the Mental Health Intellectual Disability Initiatives rolled out across the state, with a substantial increase in clinician time, including psychiatrist and psychiatry EFT. Multidisciplinary care will be ineffective in the presence of undiagnosed and untreated mental illness. "

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

"Mental health clinicians would like to be able to provide good care but the under resourcing, and the model of accountability is counterproductive. Throughput counts. Quality and outcomes do not. "

Is there anything else you would like to share with the Royal Commission?

N/A