

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

Organisation Name

N/A

Name

Mr Dean Barton-Smith AM OLY

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

"Overarching trend: Discrimination towards Deaf and Hard of Hearing people who also have mental health is rampant. Many reported cases and stories from Deaf and HoH consumers cite that hospital admission was akin to being sent to a jail cell' and left to their own devices adding another level of trauma onto them. Existing hospital/clinical procedures fail to realise that by ignoring, neglecting a deaf / hard of hearing person human right to have equal communication access and to be actively engaged in any recovery programs but not providing let alone avoiding any provision of interpreters etc is deemed as seclusion practice' which also goes against UN convention. 1) Current and existing (plus emerging) clinical support services (eg hospital, clinical wards, recovery centres) do not meet basic accessibility standards. More often D/HoH patients feel they are being punished and traumatised' further for being denied let alone have same equal access as their hearing consumers' hence adds another layer of trauma in the process. 2) CEO and business owned Psychiatrist who run clinical inpatient/out patient services have been known to challenge accessibility request raised by consumers and their families creating further tension and fear of poor quality service and victimization as result. To them its about money not patient first interest despite financial reports showing a healthy financial return 3) Information, education and awareness of MH related information are more often not accessible for D/HOH people. D/HOH have had to remind or chase up these organisations to make this happen and subsequently it can take weeks or months before a satisfactory access' is achieved. This also need to be taken into consideration that such action actually agitates a D/HOH Consumer health and well being and is known to further delay their recovery process. 4) United Nation Convention of the Rights of Persons with Disability (UNCRPD) are not acknowledge or respected let alone understood within the psychiatry fraternity alone. More often it is left for peak advocacy groups to raise and 'educate' this component of human rights and often times professional clinicians are not able to devote time and attention on this due to their nature of work 5) Whilst there is a National Mental Health Commission that is responsible for developing a national framework, however when raising their work plan priorities let alone strategic plan they continue to not factor D/HOH consumer (and carers) into their strategy. They continue to remain silent on not acknowledging this issue and this also despite request for such spotlight' to be focused by having appropriate representative and/or Commissioner appointed. Mental Health Australia has a National MH Consumer and Carer Reference Group which, despite repeated request and recommendations from past consumer experts who are not D/HOH themselves, to have D/HOH consumer experts with lived experience on this group ignored. For reasons unexplained the vast majority of those who are Deaf/Hard of Hearing in Australia are more often an 'after thought'. (There are an estimated 4 million Australians with a hearing loss - one in six and will soon be one in four in ten years time) 6) Recent reports re suicide prevention fails to factor the barriers Deaf and Hard of Hearing Victorians experience (and we shouldn't just be saying Victorians as anyone entering into this state will be exposed to the existing MH landscape.) 7)

Lack of consultation has been evident that engages Deaf and Hard of Hearing Victorians (let alone Australians) in virtually all dialogue with state and federal government. 8) We have a new Mental Health Act however no effort has been made to ensure the Deaf and HoH are made aware of their rights and obligations of such act including Advance Statements' and what this means. This is currently done in a reactive rather than proactive manner. 9) There are no Mental Health Advocates sought and provided to Deaf and Hard of Hearing consumers especially when in period of crisis. 10) Whilst some progress has been made to educate and train sign language interpreters re MH terminologies and overall language use, there is no central oversight to ensure development of appropriate signs and new terms are given the quality assurance process and integrity it deserves. 11) Hospital and clinics that are deemed to be specialist in this area of mental health are not accessible or factors the need of D/HoH consumers. As a consequence their family/partners are left to fight against administrators to ensure consumers are getting equal support and services as others within. More often this adds to the trauma of their recovery experiences and further prolongs their recovery process significantly. 12) Access to Mental Health nurses are determined only if Auslan (Australian sign language Interpreters) interpreters can be afforded'. CAT Teams are able to call upon any interpreters of any language during event of crisis and follow up sessions with consumers however this is not the same in the MH setting whether private or public. More often MH consumers are made to wait in excess of four months before they can access mental health nurses due to ongoing internal bureaucracy conflict as to who should be paying for this service (which is to also provide sign language interpreters) at the expense of the MH consumer whereas if this MH consumer was not deaf - such service is provided promptly and efficiently within a couple of weeks. 13) Medication prescribed to D/HOH consumers when in state of distress are rarely ever properly communicated as to why they are taking them let alone the side effects and long term impact of their health properly explained. More often it is years later that when the D/HOH becomes well that they become more aware of what and why these medications are necessary. 14) Clinical experts' today have little to no experience with D/HOH consumers and are making quality of life decisions that are based on medical model not the functional model. Professional clinical experts have requested (read begged') for better accessible education and awareness sound managing and supporting Deaf/Hoh consumers and their family. The above can be further explained during the hearing with real case examples especially from my own personal experience which will help shed light of the clear imbalance provided to Deaf and Hard of hearing consumers who are experiencing MH challenges."

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?

"In the area of support towards Deaf and hard of hearing consumers who are experiencing MH, refer to previous question. The current system is designed for 'able bodied patients who do not have a degree hearing loss'. When support and recovery services rely predominantly on 'communication' this is being done without foresight and consideration for the growing group of Deaf and Hard of Hearing people. It is only when the issues and awareness of Mental Health in the public space is being regularly talked up that countless numbers of Deaf and Hard of Hearing people have only started to come forward to share their stories. In the first ever National Deaf Mental Health Conference in November 2015 (which I was a convenor), common stories as shown above were very common and the traumatic impact associated as a result of 'fighting to have equal access' was so profound it was identified as being a national crisis. "

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

"Very little in the area of knowledge, education and awareness affecting those who have a degree hearing loss. Whilst some online resources have 'progressively' made itself 'accessible', it is more often after a complaint has been made by a deaf person to be able to access to these resources. The awareness and education of suicide itself in the public domain should be commended however it need to go much further into the growing issues affecting Victorians who have a hearing loss and how inaccessible and extremely difficult for them to access information about suicide and suicide prevention. The need to have appropriate people who are Deaf / Hard of Hearing appointed in high level roles including advisory roles to ensure that any plans factors whether it meets UNCRPD expectations and are accessible in various forms. Currently there are NO person with such expertise on any advisory roles in Australia. This is done more often in a reactive rather than proactive manner."

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.

Please refer to the list of examples provided above - which is only a tip of the ice berg. I would gratefully welcome the opportunity to share real case examples during the Commission hearing sessions whereby I can assisting providing and shaping the steps and challenges any person with hearing loss experience in the current MH landscape today.

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

"Lack of consultation and engagement of experienced consumer experts especially those who have a disability such as a hearing loss. We are more often left to fend for ourselves and to work it out without quality qualified support provided. More often this is left to the consumer's partner, family to 'deal with it' which further creates unnecessary stress, trauma and health issues"

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

"If the MH landscape met the minimum standard of 'access' for people with disabilities, we would not have to see our partners and family having to fight / advocate to ensure their family member with a MH crisis is left treated worse and neglected by the the key MH professionals that are suppose to help them. I am reminded that when a person with a hearing loss is battling and fighting with their Mental illness, they are made to fight even more within the MH landscape to get the basic support and services they critically need and it is only the very very few who have the capacity and energy left to do so are able to survive - just. More often these consumers are made to feel much worse and it is no surprise that they end up contemplating their 'life worthiness' and consider darker options to avoid further burdening their partner, families and friends."

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

Good governance and oversight to ensure quality and experienced peer workers would do wonder for those who are Deaf and Hard of hearing. This can only be done via appropriate co-design / co-production methods with great care and attention. Currently there are NO deaf peer workers and despite a market of around 4 million Australians with a hearing loss (and growing) I can personally count about 6 professional clinical psychologist who have some direct face to face experience with consumers with hearing loss across the entire country. There are two qualified psychologist in

Australia who have a hearing loss themselves. Therefore the chance for a consumer with hearing loss being able to first identify and then being able to access such qualified and experienced psychologist (note there are no known 'deaf' psychiatrist in Australia) is very slim to none. This consumer is then at the beg and mercy of being diagnose and treated by psychiatrists who do not have any appreciation of the personal and health (and life) challenges that a deaf person endures every..single...day. More often the medical model approach is undertaken that focus on the persons disability rather than the functional of the person that needs help and support towards effective recovery.

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?

"Simply put, real opportunities can only happen if the community (and the profession) ensures it is accessible to them. If those experiencing MH knows that they can access to quality support and understanding this can be a major step forward towards accepting their illness and also help their families towards full recovery. As such if these MH consumers who are Deaf and Hard of hearing experiencing a very positive recovery pathway, they will then become exceptional advocate / peers to others - which in turn reduces the level of anxiety, fear and trauma that many are experiencing today. In addition, the issue around stigma - or in my view ' discriminatory conducts - will reduce and people become less judgmental and more emphatic towards people like us. "

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?

"1) All leading government body /department are to be governed by a board/council that represents at least 50% of the make up of this board/council who have a lived experience with MH of which at least 20% of this are people with disabilities - in which at least one is Deaf / Hard of Hearing. (The currently ABC figures shows at least 20% Australian population have a disability and growing due to the ageing population arising in coming years. As such ensuring appropriate representations at any high level areas will prevent 'afterthought / oversights' to this growing disability sector) and; 2) That the National Mental Health Commission (and also Victorian Mental Health Commission) appoints a Mental Health Commissioner who have a lived experience with a disability (ideally a person who is Deaf/Heard of Hearing) to undertake a national consultation process to identify and propose global best practiced toward support and treatment for those with a hearing loss within Australia.This is to happen immediately to prevent further loss of life and; 3) Develop high quality, fully accessible educational and awareness resources that supports BOTH the professional clinical sector AND for the consumers that meets the needs of those who have a disability and; 4) The Commission recognizes and fully supports the importance of adhering to the UN Convention of Rights of Persons with Disability that provides the foundation of minimum level of support and services expected to those who have a disability and also have mental health issues and; 5) A 'near enough if good enough' mentality / approach is NOT acceptable in today standard. MH consumer have the right to have access to full quality care, supporter and recovery services without any limitations to access - as to do otherwise - is deemed an act of gross neglect to the person concerned and; 6) That the education / professional fraternity that provides, recognizes and graduates students who wishes to become a qualified Psychiatrist, Psychologist, Forensic and any within the mental health sector, are to undergo mandatory minimum training, education and qualification of identify, understanding and treating MH consumers who are Deaf/Hard of Hearing and undergo regular proficiency development and assessments so to

ensure high quality of care is maintained and; 7) In the area of psychology, mental health and sport/recreation, that leadership, governance and oversight is also undertaken to ensure those athletes are also able to receive quality care and support (including exposure to elite athletes / peer role models who themselves have a disability) form part of the essential minimum requirements across all sports including governing bodies and Government departments such as Sport Australia. 8) That a 'Center of Excellence type model' towards ongoing research, development and leading edge resources that focus on MH consumers who have a disability whereby ongoing practice of continuous improvement ensures those operating within and those who are in receipt of MH support and services are able to be regularly informed of best practice guidelines towards exceptional recovery. "

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

"Undertake bold commitment to go further and deeper by undergoing consultations with people with disabilities to develop a national (and globally leading) guidelines that ensure the the future generations of those who have a disability (and their family/carers) do not experience the fractured, inequitable and discriminatory experiences that current and past consumers have endured thus far."

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

"As a person who is Deaf since birth, and a lived experience with mental health, and also one of the National Mental Health Leaders (graduated in 2013 by the National Mental Health Commission), my submissions provides a snapshot of the current state of play and the current and emerging issues identified to date. I would very much welcome the opportunity to speak/sign in person during one of the hearing dates to further outline and provide greater insights of the journey a Deaf person experience within the existing MH landscape today. My story has been often regarded as profound, insightful and provides the listen with a greater understanding of what actually happens and the many gaps, barriers and inequities that a general able bodied person would not have realized are happening unless they acquired the same disability themselves. As a elite athlete too, I can also bring considerable insight as to how an elite athlete journey looks when faces with mental health challenges."