YACVic's Youth Reference Group's

Submission to the Senate Select Inquiry into Mental Health

Youth Reference Group
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Who are YACVic and the YRG?

This submission was prepared by members of the Youth Affairs Council's (YACVic) Youth Reference Group. The Youth Reference Group (YRG) is a working group of ten young people, two of whom have formed a 'Mental Health Working Group'. Their thoughts, perspectives and experiences as young people drive this submission. The opinions expressed in this submission reflect those of members of YACVic's youth reference group, and do not necessarily reflect YACVic policy. The Youth Affairs Council's policy response is being delivered it submission titled *YACVic's response to the Senate Select Committee Inquiry into Mental Health*.

The Youth Affairs Council of Victoria (YACVic) is the peak body representing the youth sector. YACVic provides a means through which the youth sector and young people voice their opinions and concerns in regards to policy issues affecting them. YACVic works with and makes representations to government and serves as an advocate for the interests of young people, workers with young people and organisations that provide direct services to young people. The Youth Reference Group is a constitutionally enshrined, discrete organisational structure within YACVic.

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The Senate Select Committee Inquiry into Mental Health

The Mental Health Working Group of YACVic's Youth Reference Group welcomes the opportunity to respond to the Inquiry into Mental Health and to ensure that young people had the opportunity to engage with the debate, have prepared this submission. We recognise that our perspective and experiences will not be representative of the experience of all young people with mental health concerns, but believe that our individual experiences are valuable in illuminating the lived experience of the issue. The views and perspectives are

very much our own, and reflect the thoughts of two young people with a passionate concern for the issue, and the brief amount of anecdotal evidence we have gathered.

The Mental Health Working group has chosen to focus on the facets of this issue on which we felt that our experience and knowledge were greatest. These relate in part to the terms of reference 1. b), e), g), h), l) and p). As such, we have identified three key issues; surrounding service gaps, stigma and community awareness and the impact of mental illness on family, friends and partners. These concerns are broadly addressed by the Working Group in this submission. Throughout this document, names and details have been changed to protect the privacy of the young people who provided their stories.

Concerns

Service Gaps

Young people need youth specific services and government commitment to providing for the future of their young people. If young people can access appropriate treatment and early intervention, the potential for young people to make a full recovery is quite high. By treating young people early, the potential drain on public health resources later in life is nipped in the bud. Treating a chronically unwell adult who has entrenched mental illness and needs a high level of support for the rest of their life (perhaps even to the point where they are unable to gain or sustain employment) is significantly higher than the costs involved in providing funding to run an early intervention/prevention program for young people.

This section focuses on two case studies; two different experiences of the mental health system that we feel highlight the often insidious impact mental illness can have on young people particularly in the older age bracket. Although they each raise their own specific issues, there are also common threads. The

conclusions that we have drawn from them are the dot points in the 'Policy Recommendation' section further on in the document.

Seamus' Story

Seamus is a 20-year-old young person who has not been formally diagnosed with, but has the symptoms of depression, anxiety and adult ADD. Many of the issues he is now experiencing have their roots in childhood, but the impact has not been apparent until recently. He began experiencing the symptoms of depression (including self-harming behaviour) whilst still living with his custodial parent at 14 years of age. The symptoms of ADD became more prevalent when Seamus was 18 and attempting to complete the final year of his first post-secondary qualification. Anxiety became most noticeable when Seamus began working in his first full-time job.

The first time he cut his wrists he was 15. "Ironically, that was the first year at school I can clearly remember developing positive peer relationships, but being in an abusive relationship with your parent can somewhat delay your social development", Seamus said. Depression worsened when Seamus was 16 as he moved from his state capital to a major rural centre. Consequentially he was cut off from any social support he had known and by necessity was forced into an even more enmeshed relationship with his custodial parent. Fortunately, the school that he was attending offered counselling services that he was able to access, quite convenient when he cut his wrists again towards the end of the year.

Over the course of that year his relationship with his parent worsened significantly to the point where after the school year had finished, he spent some time in crisis accommodation before staying with various family members while something more permanent was worked out. Not long after this, it was decided that the most safe and healthy option would be to move in with a relative at the other end of the country, just in time for year 12.

He has just got out of an abusive relationship and is living in a new state, having to find a new school, living with a relative he did not know very well and has worsening depression. At the most academically important time of his life, Seamus was struggling to get out of bed in the morning. Senators, it makes for fantastic academic results…So, Seamus did not get into university, he went to TAFE, graduated and has yet to find employment in the area he studied.

Recently, Seamus cut his wrists again which he has not done for about five years. It certainly wasn't a suicide attempt. "The type of pain caused by cutting your wrists is quite sharp and intense. It gives you something to focus on and for those moments you can feel." Seamus explained. As with many people who self harm, Seamus covered it up and most people were none the wiser.

Now, he has the challenge of trying to find an adult psychiatrist who has evening appointments, can treat anxiety and depression but has an interest in adult ADD and preferably bulk-bills. Any savings he has will be eaten up by weekly appointments costing $250-$300 per session. Seamus feels that the only reason he is still alive today that he was fortunate enough to be treated at the Older Adolescent Service within Orygen Youth Health. It was during year 12 when he was diagnosed with dysthymic disorder while being treated at Orygen Youth Health.

The skills learnt while a client at Orygen Youth Health have helped him so far, but are no longer enough and what is most difficult of all, is that the only help he is likely to receive is from psychiatrists who are used to treating older adults. The one youth specific mental health service in the country, he can no longer access because he has used up his quota of sessions. "Mentally ill young people are often shunted into child or adult services and are not given the specific, specialised treatment they need and deserve", he says. "I would much prefer to be treated with people my own age by a psychiatrist that is used to treating young people and facilities are there in the event of a relapse".

So there you have it. The 'high-level' snapshot of a 20 year old's life to date. Would you like to swap?

Service gaps are endemic in youth mental health service provision and many of the service gaps are unique to young people. Issues such as access, resources, youth specific services, over-medication and access to information are widespread amongst young people attempting to access a mental health service.

It could be argued that access, resources and youth specific services are interrelated. There are components of these issues, which bureaucrats often overlook that are young people specific.

Did I feel isolated? It went beyond that

Access is most definitely about geographical location but it is also about youth specific services (15-25 years olds). There is only one publicly funded specialist mental health service for young people (15-25) in Australia, Orygen Youth Health. The services' catchment area is the North West region of metropolitan Melbourne and not all of the people who need access to the service can be assisted, because there are insufficient resources to treat them all. There are many factors relating to the geographical location that we hope will be taken into account in any future planning of mental health services for young people because they are often young person specific.

Regarding access, the biggest of these in the location of services on or near main roads/ major urban hubs and within close walking distance of regularly functioning public transport. Many young people, not just adolescents, do not drive or do not have regular access to a car. There is also no guarantee that the forms of public transport required to get somewhere function on a frequent,

regular timetable. A phone call to the appropriate transport information line that takes five minutes to ascertain what is the nearest form of public transport, how frequently it operates and what connecting services that are appropriately timed exist (i.e. also run after 7pm) is an inexpensive and efficient way to access information on what should be a vital consideration in the planning stages of any publicly funded service.

Given that people in regional communities are often overrepresented in suicide statistics, it makes sense to attempt to address the service gaps within these communities and again this issue particularly affects young people who live in regional/ rural areas. Seamus pointed out; “from my experience, although my major rural centre had about 100,000 people, understanding of mental health issues was not widespread and although there were some publicly funded resources available, without being driven to them accessing them was difficult to near impossible”.

They will have no access to resources, because they are too far away

Consideration must be given to young people in the urban fringe areas of capital cities. If you have a difficult relationship with your parent/s for instance and it’s a one and half hour drive to the nearest capital city to get treatment, they can’t or won’t take time off work and you can’t afford the time off school because it’s all too difficult anyway, what do you think is going to happen to that young person? They will have no access to services, because they are too far away. Thus the mental illness gets more entrenched due to the lack of treatment, and potentially costs to the health system later on are high. As a young person, the most striking aspect of this scenario is that the young person’s sense of isolation in more ingrained and it has been proven that a feeling of connection with one’s community is significant in improving mental health. Connection to one’s community in itself improves outcomes for those with mental illness – think of the benefits of having access to appropriate treatment! For the other likely outcome to the above scenario is that the young person gets ‘fitted in’ to the nearest child or adult service. These services do the best they can for young people, in spite of the fact that they are not really a youth specific service.

The age bracket a service will treat is a component of both access and resources. Sometimes there seems to be a heavy focus on adolescents and the 18-25 year old bracket of the youth 'market' gets well and truly lost in the shuffle. It is more than a little ironic that when a young person can vote, pay tax, gain full time employment or study intensely (working towards getting full time employment and paying taxes) that the services available for mentally ill young people are almost non-existent. Furthermore, the impact an illness such as depression or anxiety has on someone working full time for instance is viewed quite differently by a KRA (Key Result Area) focussed boss that a somewhat harassed, overworked but caring high school teacher. The sense of isolation felt by a young person working full time and lacking access to services is different from being in high school. In the words of Seamus "try being on reception at work having about 3 panic attacks in just over an hour while dealing with clients, contractors and senior management with no-one noticing anything was wrong; or if they did, not even asking 'are you ok?' Did I feel isolated? It went beyond that".

The most common reason for calling was difficulty finding treatment

Just because a young person has more opportunities to become independent, it doesn't necessarily mean any mental health issues automatically disappear, if anything they just become harder to see and treat. Young people need youth specific services that are publicly funded, easily accessible and are not solely focussed on psychoses. Yes, schizophrenia is an issue, but a recent report showed a large number of people present with depression and anxiety disorders. The 2004 Sane Helpline Report observed that "depression and mood disorders were the most common diagnoses given by callers, followed by schizophrenia and anxiety disorders, while the most common reason for calling was difficulty finding treatment". In fact, the authors of this submission were not aware of the existence of such a helpline until the middle of their research. Given that Orygen Youth Health is the only publicly funded specialist mental health service of its kind, to say young people in particular could have difficulty accessing appropriate treatment is rather an understatement. Even accessing child and adolescent mental health services can be very difficult. These issues are compounded when one considers that much of the funding given is

directed towards psychoses treatment and illnesses such as depression, which affects more people, are often ignored.

Services such as Kids Helpline (which assists young people up to 18 years of age) are free to use, widely publicised and relatively easily accessible. Unfortunately at present only half of the attempted calls placed with the service are answered. Although Kids Helpline does not have the capacity to provide ongoing case management, there is no ceiling on the number of times a young person can access the service. Also, it is important to realise that one of the unique aspects of the service is that young people can access it when they want and speak to professionally trained paid counsellors. So for the younger end of the youth market, there is a service that can provide as needed support. Unfortunately for the older young people there is no similar service that is equally as well publicised and accessible.

Dave's Story

As an eighteen-year-old University student, being able to wake-up and study, walk to Uni, eat and function as a normal human being remain novelties. In January 2005, lying in a hospital bed, ripping at a drip, being threatened with Sectioning[1], alone and in agony, the sedatives seeping in to my veins, screaming, I did not think 'life' was possible.

Following a failed suicide attempt in early October 2004, I was admitted into the Marion Drummond Adolescent Inpatient Unit at the Austin Hospital. I have no doubt that together with the staff, we saved my life. The dedication, determination and quality of care given in the Unit is exemplary, with many adolescents experiencing their first encounters of care. The 'Unit' provides intensive inpatient support to young people in extreme distress and helps to contain and manage mental illness. I am truly thank-full for the immense support given by the unit to myself and friends.

As an eighteen-year-old, it is a rude shock to realize that there is only one – private- 'adolescent' unit (Albert Rd) catering for people from 18-23, and that CAMHS (the Child Adolescent Mental Health Service) no longer has a duty of care. As a young adult, especially when first receiving treatment for mental illness, it is terrifying to be threatened with adult unit hospitalisation and the absence of a recently formed support structure – CAMHS. Many young adults, who only gain sufficient confidence, independence and support later in their teens, bravely seek support only to have it revoked once they reach 18 and find themselves in an entirely new, less supportive, often threatening set of circumstances. Mental illnesses rarely peter-out after birthdays and circumstances change little in 24 hours. In the opinion of myself and others, CAMHS needs to be expanded to encompass the 18-23 year olds, with special consideration given to making CAMHS interlinked nationally, with close links between services, to ensure that young-adults moving

[1] Sectioning is where a person is detained against their will to receive treatment

interstate or out of home, have immediate contact with support services. At present, there is a large group of individuals from 18-23 years, leaving home and finding themselves without support services, unable to access information and without referrals or follow ups. The expansion of CAMHS would improve treatment of adolescents nationally and provide more consistent, extended care, to completely treat mental illness in the critical period, when positive changes in behaviour can occur, reducing the numbers of chronic adults. CAMHS expansion would also benefit from a huge boost in funding to expand the size and number of Inpatient Services, whereby in both rural and city settings, there is an ever increasing number of beds, which would be further increased by including 18-23 year olds. Subdivision of Inpatient wards into younger and older sections could ease insecurities and provide more independence for young-adults. As mental illness and suicide rates continue to increase at an alarming rate, more funding is needed to provide prevention treatment for children and adolescents, rather than being forced to wait until crisis situations. More beds would greatly benefit and induce suicide prevention programs and more intensive management of 'at risk' young people.

Stigma and community awareness

Unfortunately people with a mental illness still experience stigma and misunderstanding about their illness. Seamus recalls, 'I can remember working in reception and trying to explain delicately to my boss that I suffered from anxiety and depression with the unspoken implication being that although sometimes I might appear to be disproportionately anxious and this did not necessarily indicate a lack of professionalism. His response was to inform me that if I had not have told him he would not have known anything was wrong, which basically had the effect of killing any chance of dialogue and from there understanding". From this example it can be inferred that awareness amongst employers does need to be addressed and efforts to de-stigmatise mental illness need to be continued. There is still a perception that symptoms of mental illness are nothing more than a badly behaved young person.

One of the major reasons for the high level of use a service such as Kids Helpline has is that there is significant community awareness of the charity. To the best of the authors' knowledge, the only service to have similar awareness amongst the general public is Beyond Blue. The consistent use of prime-time television advertising was a significant strategy to raise the general community's awareness of mental health issues and in particular depression. Gregory commented; "the ad campaign by Beyond Blue was the first of its kind in that it seemed to have a real impact in raising community awareness of

mental illness. Most people I know had at least seen the ads, and this meant that at the very least they now recognised that depression was an important health issue. Before, even that level awareness didn't exist". Awareness of an issue is often the first step on the path to acceptance, understanding and active assistance and the advertisements by Beyond Blue certainly helped to facilitate awareness amongst the general community.

Impact of mental illness on family, friends and partners

In many cases of mental illness, there is a need for timely, age appropriate and practical professional and medical support, as has been outlined above. However, there is a further dimension to this issue; the way in which mental illness impacts on the family, friends and partners of the mentally ill.

Firstly, due to the fact that the general public is largely ignorant about mental illness, identifying certain behaviours of a close friend or family member as symptoms of a mental illness is next to impossible.

Evan's Story

I had no idea what was going on with Josie. We'd have long phone calls, and she'd say the scariest things – her outlook on life was so bleak. But I knew that she always worried about things too much, and god knows she had a lot of horrible things to deal with from her past. For ages I thought she'd work through it herself and she'd be fine. But then things got worse. She started hitting out at people that were trying to help her; she'd undermine them and fill their heads with negative ideas that weren't true. Looking back I know she didn't mean it, but you'd get off the phone to her and feel as if you were crazy.

If a young person doesn't know much about mental illness, then they cannot recognise behaviour as being part of a mental illness and thus are incapable of helping their friend of family member. Furthermore, they become vulnerable themselves because they don't know how to cope with the behaviour of some one they're really close to. The mental illness of their friend, family member or partner may then start affecting them in an adverse way – they might worry incessantly about the person, or blame themselves for the problems they

witness. If the person is especially close to them and/or is an authoritative figure they might become influenced by what they're hearing and start to have a negative worldview themselves.

Even when a diagnosis is made, the support available to the family and friends of mentally ill young people are limited. Friends in particular are often kept in the dark by the young person with a mental illness or their parents, because of the fear of being stigmatised. Unaware of what their friend is experiencing and without any professional support, friends sometimes take on the role of carers, especially when the mentally ill young person's relationship with their parents has deteriorated. They may spend long periods of time staying with the families of their friends, sometimes going from house to house and leaving when they feel that they have exhausted their welcome. Such situations have a huge impact on every one in the house and force friends into difficult situations; do they contact their friend's parents or is this a betrayal? "I knew that Adam hadn't been home for weeks, that he'd been staying with other friends because he felt threatened and misunderstood at home. But his parents said that everything was ok. When he asked to stay with me I didn't know who to believe. And I thought that it would be the end of our friendship if I helped his parents find him".

Each week, more than 30,000 kids attempt to call kids help line. Sadly, due to lack of funds, more than half these calls will go un-answered

This is just one of the ways that the families and friends of mentally ill young people fill the shoes of trained professionals when professional help is not available or when they are not properly supported to deal with the impact of the illness. They take on the role of counsellors, psychiatrists, psychologists, psychiatric nurses, crisis accommodation providers and much more with little or none of the training and experience given to the professionals in these roles.

Unsupported, many people cannot deal with the behaviour of the mentally ill person and the task of caring for them. As mentioned earlier, others will not even understand what is happening to their friend, family member or partner. The consequence is that many people choose to disassociate themselves; to end their relationship with the person. This cuts off the mentally ill young person's natural support network, damages their self esteem and leaves them

severely isolated – which is bad enough in itself without the added consequence that this can contribute to the deterioration of that person's mental health

Policy Recommendations

Service Gaps

- A renewed focus on the provision of services for sufferers of depression and anxiety, (not just sufferers of psychoses) as these are the illnesses that are the most insidious – that is hardest to detect, most frequently untreated and possibly the most widespread.

- The location of services on or near main roads/ major urban hubs and within close walking distance of regularly functioning public transport. Furthermore, there is a need for new policy initiatives to ensure that young people who live in rural Australia are not effectively cut of from treatment if they cannot get to it by car.

- Subdivision of Inpatient wards into younger and older sections to ease insecurities and provide more independence for young-adults. This would ensure the care that is given is appropriate and would also prevent placing young-adults who have just begun to experience problems into a volatile environment with older patients who have been chronically ill over an extended period.

- More funding for the Kids' Helpline, to enable it to take every call, not just 1 in 2. Also, the establishment of a similar service that is equally as well-publicised and accessible, for young adults.

- CAMHS (the Child Adolescent Mental Health Service) needs to be expanded to encompass the 18-23 year olds, and should be linked nationally, to ensure that young-adults moving interstate or out of home, have immediate contact with support services.

- More beds created in suicide prevention programs and more intensive management of 'at risk' young people.

- More funding is needed for day programs, specially designed for depression and eating disorder patients. At present very few day-programs exist except for Inpatient programs, which do not benefit the increasing numbers of young-people seeking assistance as outpatients.

- The creation of outpatient day-programs, which use a combination of education, fun, excursions, and case management.

-Widespread national roll-out of a service that is young person specific in both capital cities and major rural areas based on Orygen Youth Health

- A national service that is for mentally ill young people and has an employment focus, without the requirement to be psychiatrically disabled and on Centrelink benefits before you can access it.

Stigma and community awareness

- The creation of new policy initiatives that communicate effectively with young people through a variety of channels, to educate them about mental illnesses. Furthermore, the creation of campaigns to target stigma and deficiencies in community awareness of mental illnesses.

- Support for and expansion of the activities undertaken by Beyond Blue, as it is has been successful and effective in targeting stigma and deficiencies in community awareness of depression on a grass roots level. This model could be extended to other mental illnesses or to the topic of mental health as a whole.

Impact of mental illness on family, friends and partners

- The investigation of cutting edge technologies that communicate in a youth friendly way such as ‘Txter Assist’. Txter is an instant referral system by which young people message a keyword (such as ‘depression’) to certain number for free, and are sent a text message in response with the details of the services they can contact for help.
See http://www.txterassist.com/index.html.

- Education and support groups could help reduce hospital admissions and teach carers to cope with crisis situations as well as providing counselling support.

- Education programs and support groups for carers and friends, not exclusively parents, would greatly reduce anxiety in home situations and ease feelings of helplessness in carers who are often greatly affected by the mental illness.