Submission
No 49

PREVENTION OF YOUTH SUICIDE IN NEW SOUTH WALES

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MHCN mental health carers nsw

Submission to the NSW Parliamentary Inquiry into Youth Suicide 2017

Introduction

This submission is from Mental Health Carers NSW. Mental Health Carers NSW is the peak body in NSW representing the interests of the carers of people with a mental illness. Our vision is for an inclusive community and connected carers; and our mission is to empower carers for mental health. With Being and Way Ahead, our organisations are part of Collective Purpose and share a vision of a community that embraces and maintains mental, social and emotional wellbeing for all people and a society which is free from prejudice and discrimination against people living with a mental illness.

This submission is based on information we have received from members, advocates and stakeholders. In the process of writing this submission we have consulted with our Mental Health Carer Peak Advisory Committee and Young Carers Peak Advisory Committee and undertook two public surveys. The first survey sought feedback and information from young carers about their experiences and the challenges of their caring role and the second survey was targeted towards parents and carers of young people.

Suicide is the most common killer for young people up to the age of 44. It is a function of extreme psychological distress and can be strongly related to experience of mental ill health. However, not everyone who ends their own life would qualify for a diagnosis of mental illness; it is also a function of an inability to cope with distress or difficulty due to social isolation, lack of support, lack of psychological skills, lack of opportunities and social and economic disadvantage. Like mental illness generally its incidence is worsened by inequality and by the stigma still displayed by some elements of the community to other parts of it, including people with experience of mental illness and their families and carers.

An adequately funded health system, with the scale to deal with the scope of mental illness in NSW, is a key part of the response needed, as well as close cooperation between health and educational authorities to enhance the support and the psychological skills and resilience of young people in Australia. This can only be achieved by robust, ongoing planning between state and federal authorities.

Gaps in mental health interventions for youth

Gaps in Policy

The current National Suicide Prevention Strategy is vague in detail regarding the actions that will be implemented in regards to Youth Suicide Prevention. Even more problematic, is the fact that it is not governed by any Act or overarching government policy. Suicide is not just a social issue but also a serious and complex health problem (Anton et al. 2016), and therefore it must be carefully addressed with detailed, evidence based policies and accountable national leadership. There is a need for the government to introduce a 'National Suicide Prevention Plan' that will form the policy basis of this nation-wide initiative.

As mentioned, the activities in relation to Youth suicide prevention set out in the National Suicide Prevention Strategy are not clear in what they entail. Budget, responsibilities, deliverables and timelines seem to be missing from this 'plan'. We do not believe that developing further clarification of these plans will offer a drastic change in outcomes either. Instead, we suggest that a separate strategy that specifically focuses on youth suicide prevention is developed - a National Youth Suicide Prevention Strategy. From this, smaller state-wide policies and programs that facilitate youth suicide prevention should be aligned and implemented. We are aware that Tasmania has adopted this approach and strongly believe that the same should happen in NSW. The reason why this is important is not only because of the high incidence of suicide amongst this specific group, but because the mental health needs of young people are complex in the way they are influenced by a multitude of different factors (Lynch 1998).

Furthermore, we are not aware of a current framework or system underway that is designed to monitor the success rate of the National Suicide Prevention Strategy. Without this measure in place, it will be difficult to evaluate the effectiveness of the proposed activities, and determine where future adjustments will need to be made if the aims and objectives are not fulfilled; which in reality defeats the main purpose of this initiative which is to provide effective ongoing support for young people. We strongly advise that such a framework is established as soon as possible.

Recommendations

- To develop a separate response for youth suicide prevention. This will be known as the National Youth Suicide Prevention Strategy. The initiative will set out a clear plan for tackling the specific mental health needs of youth with the intention of reducing suicide rates for this population. It is required that this initiative is developed in partnership with young people, their carers and families, who will co-design the activities to ensure that they are reflective of their needs and have potential to achieve good outcomes.
- To urgently develop a national framework that monitors and evaluates the progress and outcomes of the National Suicide Prevention Strategy that supports the implementation of the state plans and the Youth Plan under it.

Lack of specialised mental health care for youth at most risk of suicide

Despite a growth in government initiatives aimed at tackling the issue of youth suicide in the last decade, there still remains a high level of inadequacy in addressing the mental health needs of the population including the younger generation. Too many distressed young people and others are still turned away, usually after hours of waiting, from state hospital Emergency Departments ('ED'), with no follow up and poor access to mental health services in the community. This notion is particularly prominent when looking at the gaps in mental health support services targeted at youth, and to be even more specific, those youth that are deemed to be most at risk of suicide. We have identified that these are: young Indigenous Australians, young people of culturally and linguistically diverse (CALD) backgrounds, and young people belonging to the LGBTI community. Young people who also provide significant amounts of care for their family members, particularly for mental health issues, can also experience the social isolation, lack of support and potential for stigma and trauma which heightens suicide risk.

Young Carers

Young carers make up approximately 4.4% of all young people under the age of 25 (Hill, Smyth, Thomson & Cass, 2009). Young carers are a disadvantaged group who face significant challenges in balancing caring responsibilities with education, employment, friendships and self-care with many young carers reporting that they experience stress and mental ill health as a result. In our survey of young carers a majority of respondents (70%) reported that their mental health and wellbeing had been affected by their caring role. As one young carer described; *"I think my biggest thing is that when* *you do all the running around and getting this and that job done, it's hard to take note of your own mental health. Even when you get down time you're just tired. It's only when something major occurs do you start to realise the stress of the situation and that's when the mental health things kick in."*

Young carers typically experience numerous risk factors which are associated with an increased risk of suicide;

- Mental ill health
- Difficulties in education
- Difficulties in employment
- Adverse socio-economic background
- Experience of stressful life events
- Parental disharmony or divorce (Cass et al., 2009; Cass et al., 2011)

Current suicide prevention programs that address youth resilience, self-esteem, belonging and positive mental health and wellbeing are commended for their efforts in reducing suicide rates of the younger population. However, the underlying issue is that most of these programs are often applied with a 'one size fits all' approach, and essentially only cater to the general population. Very few of them address the different needs, different starting points, and levels of risk that are experienced by young people of Indigenous, CALD, and LGBTI backgrounds or young carers.

This is also the case for many other mental health initiatives which may not necessarily only focus on suicide prevention. There is a need for change in this space that will see more culturally sensitive, person-centred support, and specialised mental health care that is government funded, offered to young people from these categories. Additionally, we need increased community-level initiatives that are operated by qualified and experienced professionals and are specifically designed to reduce the suicide rates of young groups at risk. The allocated funding will also enable a multi-systems approach to care that considers the active involvement of family in the care and decision making process.

Recommendations:

LGBTI Youth

- To increase the level of government-funded LGBTI youth suicide prevention initiatives across NSW. There is a need to develop more mental health programs and services that are designed to address stigma, discrimination, bullying, violence and other forms of marginalisation experienced by young LGBTI people which are known to increase the risk of suicide. Young transgender people especially have high rates of suicidality. Additionally, there is a specific need for more mental health crisis intervention services for this group that offer face-to-face service delivery as the majority of crisis services for young LGBTI people currently only offer assistance through telephone hotlines or online chats and forums.

Aboriginal and Torres Strait Islander Youth

- To increase the level of government-funded youth suicide prevention initiatives that are specifically designed to target Indigenous youth across NSW. These initiatives must incorporate both a person-centred approach as well as an ecosystems approach in delivering care. This means that they must not only address mental health promotion, self-esteem and resilience but must also implement strategies that target the social, cultural and economic conditions that are known to affect young Aboriginal and Torres Strait Islander people and their families. The goal here is to improve the well-being of Indigenous youth by reducing the life stresses experienced by their families which are likely to also play a significant role in their mental health. This includes but is not limited to housing, socioeconomic and community-level disadvantage. Additionally these services need to be sensitive to the needs of Indigenous youth and must be operated by staff who are qualified and experienced in Indigenous mental health, and co-facilitated by Indigenous people.

CALD Youth

- To develop more government-funded suicide prevention initiatives across NSW which are specifically targeted towards young people of culturally and linguistically diverse backgrounds. These initiatives must combine both culture-informed and trauma-informed care and must be facilitated by qualified counsellors and psychologists who are dedicated to the past and present narratives and experiences of young refugees and CALD youth. Essentially these services must also aim to address the factors that are known to contribute to poor mental health for CALD youth including migration issues, housing issues, and educational issues through working closely with the families of young CALD people to help reduce if not eliminate these barriers.

Young Carers

- Funding to support Young Carers in the Family and Carer Mental Health Program be expanded and the program work with Education to maximise impact.
- Parent and teacher literacy in mental health and suicide prevention be developed by dedicated training and education programs.

Gaps in existing mental health and suicide prevention initiatives

Specialised mental health care

Specialised mental health services for young people from CALD, Indigenous or LGBTI backgrounds do exist, however in very small numbers compared to the size of this population and those that are available face many challenges. The biggest challenge for these initiatives has been the lack of funding they receive. A great number of services operate solely off their own fund raising, like local club grants and gold-coin donations. This is a common dilemma for a vast majority of services that offer specialised care for the groups mentioned but is especially prominent amongst LGBTI youth mental health services (The Australian Research Centre in Sex, Health and Society 2006).

With this lack of resources, comes a limited capacity to meet suicide prevention needs of target groups not only because of the insufficient funding but also because of the additional issues that stem from this such as issues surrounding continuity of staffing, training and the overall quality of service delivery. The issue of limited resources and funding also impacts the ability of the services to engage with the family unit as a whole in the provision of care which creates many barriers for achieving positive outcomes for young people. Furthermore, the reduced capacity of these existing initiatives means they have limited ability to develop a greater systemic approach that goes beyond the daily face to face interactions with young consumers. There is a need for the NSW government to invest adequate funding and support into current services and programs that offer specialised care for young people who are at risk of suicide. This will support services in being able to employ qualified staff, adopt volunteer programs, and offer opportunities for staff development and training that is response-focused and supports the needs of target groups.

Recommendation

- That adequate government funding is allocated to current services and initiatives that are specifically targeted at mental health promotion and youth suicide prevention for CALD youth, Indigenous youth, and LGBTI youth. This will go towards reducing the common issues faced by these services that are known to be a result of insufficient funding such as staffing, the inability to run effective volunteer programs, the limited opportunities for professional development and training, and the lack of skill in promoting family engagement in the care of young people. Additionally it will improve the quality of service delivery for young people and assist them in getting the appropriate care they need.

General mental health care

We are aware that youth workers and other staff working in youth mental health services are not always required to have any formal training or experience in youth suicide prevention. Whilst it may be encouraged, it is not mandatory. This stimulates a lack of awareness and competence in the identification of suicidal behaviour such as the inability to recognise signs and symptoms, and therefore prevents any early referral for intervention to occur if a young person does present to have suicidal tendencies. Additionally the lack of staff expertise means there is a potential for staff to not apply appropriate and effective measures during crisis situations; increasing the likelihood for further harm or damage to be done.

We believe that it is of significant importance that mental health services have ongoing access to staff who know how to therapeutically intervene when a young person is suicidal as this essentially determines whether or not the consumer gets the help they need. In saying this we believe it is important to make it a mandatory requirement for all youth workers and other professionals working in youth mental health services to undergo a youth suicide prevention first aid training course prior to their employment, and in addition, be assessed on these skills upon their employment interview.

It is also entirely unsatisfactory that any person presenting to a clinical mental health service or Emergency Department with suicidality who cannot be seen by that service at the time, will routinely receive no further contact at all from the services they attended after leaving them and will not be followed up by any other service in the community either. Proving mental health services or ensuring referrals make contact with the person subsequently with people in such circumstances should be a mandatory requirement on all hospitals and General Practitioners who see such people.

Recommendation

- That it is made a requirement for all individuals applying for positions in youth organisations or youth mental health organisations to undertake a first aid training course in youth suicide prevention prior to their employment. In addition, potential employees should also be assessed on their skills and knowledge of effective intervention strategies upon their initial employment interview.
- That the Triage Policy Directive for NSW hospitals ED's be amended by the Health Ministry to prioritise and divert mental health crisis presentations to urgent support instead of putting them behind any urgent physical problem, meaning the often spend hours waiting for support before leaving without having received any.
- That state mental health services are funded to provide follow up to people who attend ED or other mental health services with suicidality, who can't be supported by that service at the time, creating a specialist community service to do so if necessary.

Gaps in research and literature

There is a lack of adequate and accurate data collection regarding early-intervention and suicide prevention work with young people, and even less for young groups most at risk of suicide. This is despite recent findings that suggest a current and expected increase in suicide rates amongst the younger population (Orygen, The National Centre of Excellence in Youth Mental Health; 2016). Additionally, there is limited research on the cost effectiveness of suicide prevention strategies as well as a lack of reporting on positive suicide prevention outcomes in interventions targeting other mental health areas such as anxiety, depression, etc. This has resulted in a lack of recognition of the need for this work, as well as a lack of understanding of the need to resource successful interventions.

In responding to these gaps, we believe that it is essential for the NSW government to invest more funding into improving the evidence base for youth suicide prevention. We additionally think that it is important that there is an increase in the level of partnerships and collaborations between mental health, youth, and research organisations so that emerging issues are identified, the demand for this work is made evident, and so that best practice outcomes can be monitored. This is not limited to the need for these organisations to work alongside young people, their carers, and their families in consistent data collection and evaluation.

Recommendations

- That the NSW government allocates more funding towards the establishment of increased state-wide evidence based research on youth suicide prevention. This will support research organisations in the development of both qualitative and quantitative research that explores service outcomes, best practice interventions for at risk groups and other young people, and develops evidence on the cost-effectiveness of implementing prevention strategies. The funding will also go towards the resources needed for youth organisations and youth mental health organisations to establish a framework for the adequate and consistent collection of data and information
- That research organisations, youth organisations, youth mental health organisations and specialised mental health services work in partnership in informing research on emerging trends and patterns, groups at risk, service outcomes, the level of demand for services, and best practice approaches. Such organisations will additionally be expected to closely work with young people in producing these data.

The Role of Carers and Families in Youth Suicide Prevention

Educate Parents as Gatekeepers

Although adolescence and early adulthood is a time of increasing independence, the role of families and carers in supporting young people's wellbeing is important and should be valued. Families and carers have a significant impact on the wellbeing and mental health of the young people in their care (Robinson, Power & Allan, 2011) and family environment impacts upon young people’s suicide risk (Fergusson, Woodward & Horwood, 2000; Goud, Greenberg, Velting & Shaffer, 2003). As such carers and family members should be recognised as gatekeepers and a Youth Suicide Prevention Strategy should deliver gatekeeper training to parents. Schools should be utilized as a platform to deliver mental health education and gatekeeper training to families and carers.

Gatekeeper training for parents should include mental health first aid as young people tend to seek help from parents in relation to mental health and suicidal thoughts (Mission Australia, 2016; yourtown, 2016). Based on carer’s experiences, crises involving a young person are often very distressing and in many cases carers are not equipped with knowledge about available services and skills to know how to effectively respond to their loved one, especially during the first onset of acute mental illness where people are less likely to be linked in with supports. A Kids-Helpline survey of young people who reported experiencing suicidal thoughts found that 60% of respondents who had received help sought it from a parent or carer, however 44% of respondents reported that their parent was 'not at all helpful' and only 22% found their parent 'very helpful' (yourtown, 2016).

The attitudes of parents and families to mental health services can significantly affect young peoples' access to services, as young people are often dependent on their parents cooperation in order to access psychological supports (e.g. consent to treatment, access to Medicare cards, transport and financial recourses) (yourtown, 2016). Parents can actively discourage young people from accessing help due to concern around the stigma attached to mental health services or because they underestimate the significance of physiological distress experienced by their child (AHRC, 2014).

The impact of past negative experiences with mental health or emergency services (including practices that cause trauma such as seclusion and restraint) does significant damage to the reputation of mental health and emergency services in the community. Carers and family members sometimes attempt to 'protect' young people and hinder access to crucial services because they believe that emergency and health services will do harm. Gatekeeper training should educate carers and family members about the benefits of accessing help from mental health services and the potential risks of untreated mental illness.

Recommendation:

- The NSW Government allocate funding to wellbeing initiatives for education based settings that can deliver mental health education and gatekeeper training to Emergency Department staff, Ambulance and Police as well as teachers, carers and families of young people through partnerships with educational institutions.

Information Sharing

Information sharing is crucial to ensure successful transition from mental health inpatient services to community based care. This is a critical period of time as suicide risk is particularly elevated in the weeks after discharge from an inpatient facility and it is essential that consumers have continual access to supports. Family involvement is important to contain suicide risk in high risk young people (Robinson, Power & Allan, 2011), so it is essential that mental health services value and strengthen the enduring relationships that young people have with their families and carers. Poor practices in information sharing frequently damage consumer-carer relationships and disrupt informal support networks, thus undermining the recovery process (NMHCCF, 2011). Conversely good practice in information sharing strengthens carer-consumer relationships, improves the quality of care and equips carers with information and skills relevant to their caring role. We suggest that protocols around information sharing should be developed via a co-design process that involves both consumers and carers. Separate protocols should be developed for adolescents and adults as needs in regards to information sharing differ between the two populations.

The Mental Health Act (NSW) 2007 stipulates that professionals must consider information provided by carers in determining whether a person is mentally ill and in determining whether to discharge a patient s72A). However, with the exception of discharge planning, (s79) mental health services are not explicitly required to seek information from carers and some carers have reported that in practice the information they provide is disregarded without clinical judgement being carefully applied. Carers often have the advantage of the experience derived from a long-lasting relationship with the person that they care for and can therefore provide insight that cannot be garnered from the short time that professionals have to interact with a consumer.

Information from carers is especially important where a consumer is experiencing significant illness and as a result lacks insight or the capacity to provide information that would be relevant to their care. While we are not asserting that carers' views will always be a perfectly accurate, it is important that mental health professionals both seek and consider information provided by both consumers and carers in making a professional judgment. Such information can be crucial for adequate assessments of risk.

The experience of being excluded from receiving basic information about the care of a loved one while they are in a critical state of mental ill health is distressing and isolating for carers. Based on carers experiences the onus is often on the carer to assert their rights by proactively requesting and providing information. Carers who are unfamiliar with the mental health system often lack awareness around their rights and the rights of consumers and may not have the capacity to advocate for themselves or the person they care for in a distressing situation where there loved one is seriously unwell. It is our opinion that mental health inpatient services need to be proactive in seeking to identify and consult with carers and in informing carers about their rights and the rights of consumers.

One possibility is to develop a statement of rights for carers based on the Mental Health Act and relevant Health policy directives. The statement could be given to carers when a loved one is detained in a mental health inpatient facility and included into protocol around information sharing. We also suggest that funding organisations that can deliver training for carers and consumers around their rights in the mental health system. Carer Survey respondents wrote about the need for additional support for carers, especially where a loved one is hospitalized due to mental ill health. There are few services which can provide individual advocacy for carers within the mental health system. Increasing the availability of individual advocacy services for carers would likely improve the capacity of carers to advocate for both consumer and carer rights.

Given that carer involvement in mental health care typically improves outcomes it is important that mental health services do not alienate carers but value them as key supports. Mental health services should use a supportive and reassuring approach when working with carers and develop lines of communication with carers. By excluding carers, mental health services miss the opportunity to equip carers with skills and knowledge that is useful to them in caring for their loved one. A number of carer survey respondents felt that mental health services had treated them as "the enemy" and spoke about how this had undermined relationships.

As one carer described; "*Adolescent services vilified the parents and encouraged the teenager to live with grandparents and not parents…. This situation was disgraceful and parents were cut out of the relationship. It has taken a great deal of graciousness and forgiveness for relationships to be healed. Parents are back now being primary carers of a still very sick (now 22) year old, and parents are now supporting the grandparents as well due to age related issues."* Importantly services should take care to do no harm by damaging existing relationships with carers and families unless they are determined to be harmful or inappropriate by thorough investigation.

Recommendations:

- The NSW Ministry of Health develop protocols around information sharing for mental health inpatient services via a process of co-design with input from consumers and carers. The co-design process should seek to;
    - Define consumer's and carer's rights to confidentiality, identify how confidentiality must be limited by considerations of safety and define what information should be shared and what should be kept confidential when consent may not be provided but risks are acute.
    - Develop strategies to inform and educate carers about their rights
    - Develop strategies to support carer involvement (excepting relationships are not harmful or inappropriate)

- The NSW government allocate additional funding for services to deliver advocacy training to carers which equips carers with knowledge of consumer and rights in the mental health system
- The NSW government allocate additional funding to services that can provide individualized advocacy in the mental health system for carers as clients

Suicide Prevention Strategy in Education Based Settings

Suicide Prevention Strategies in Education Based Settings

Given that nearly 90% of all attempts at suicides are associated with a diagnosable mental health or substance abuse issue (Glorioso et al. 2012), it is crucial that schools implement universal strategies to improve the mental health and wellbeing of all students. As recent research suggests that suicide prevention education programs can be delivered safely and effectively (Robinson et al., 2016), evidence-based suicide prevention education programs should be trailed and incorporated into wellbeing initiatives. While we acknowledge that government has funded a number of excellent initiatives around wellbeing in schools such as got-it! and school-link and developed the Wellbeing Framework for Schools, implementation of wellbeing programs is dependent on the resources available to the school and the willingness and cooperation of principals, teachers and staff.

In MHCNs Parent and Carer Survey, responses on questions around school reflected a large variety in experiences. A number of parents/carers reported positive experiences where schools had played an integral role in supporting the wellbeing of the young person they cared for. For example; *'my sons school (Catholic) supported mental health with time for reflection and retreats where students could focus on their wellbeing and mindfulness. Yes, they call me when concerned, have updated his risk and health care plan and involve the school counsellor when my son is distressed. They have also applied for reduced hours so that he can cope better and recover.'* However many parents/carers reported that they had negative experiences where schools had not been supportive of their child's mental health. For example; *'the teachers and deputy principal do not listen to me when I try and discuss my children's mental health.* Another carer reported that '*general teaching staff have very little training in the signs and behaviours of students who are distressed.'*

Post-vention strategies are particularly important, as suicides are more likely to occur in clusters in young people (Robinson et al., 2016). Although schools are encouraged to develop suicide prevention and post-vention strategies, additional policy guidelines are needed to ensure systematic implementation of post-vention strategies. While post-vention strategies should be adaptable for the varying needs of schools and communities, there should be a minimum standard for schools to comply with in responding to the suicide of a student or community member. The NSW Department of Education has guidelines for public schools in responding to the suicide of a student are only available internally which limits feedback. We see no need for these guidelines not to be accessible to the public and would encourage transparency. While NSW Public Schools must comply with these guidelines they do not apply to independent and Catholic schools. There is a need for a national response, with cooperation from states, to ensure that there is a standardized approach to post-vention strategies in schools.

Adequate funding to ensure that all schools have regular access to quality school counsellors and support staff is a critical issue as they are integral to student support strategies (Wallace, Holloway, Woods, Lucinda & Rose, 2011; Parliament of NSW Committee on Children and Young People, 2009). School counsellors are the most commonly used type of school service for emotional or behavioural issues with 8% of students accessing a school counsellor between 2013-14 (Lawrence, Johnson, Hafekost, Boterhoven, Sawyer, Ainley & Zubrick, 2015).

A significant number of schools either do not have access to a school counsellor or have limited access to part time counsellors. Principals have reported that lack of access to counsellors interferes with the ability of schools to promote students wellbeing (NSW Commission for Children and Young People; 2016). While additional funding to school counselling and wellbeing services through the "supported students, successful students" initiative is a positive step in the right direction, more funding is needed to ensure that public schools across NSW have regular access to counselling staff.

We are also very impressed with the work done by 'special schools' such as Coreen High School in supporting kids with complex needs and the excellent results achieved in terms of dealing with trauma and building wellbeing and call upon the state government to expand access to these schools to all who need them.

Recommendations:

- The NSW government allocate additional funding for schools to employ counselling staff.
- As a part of a National Youth Suicide Prevention Strategy, develop standardized protocol for post-vention responses in schools. While the protocol should be adaptable to the needs of individual schools it should also define minimum standards in implementing post-vention responses. It should also establish a method of evaluating the effectiveness of post-vention responses and compliance to the policy.
- Expand access to special schools supporting kids with complex needs toi the whole population requiring such support.

Young mental health carers are likely an at risk group

Young carers who have parents with a mental illness maybe especially at risk as parental ill mental health, parental substance abuse and a family history of suicidal behaviour have been found to increase the risk of suicide in young people (Fergusson et al., 2000; Goud et al., 2003). These risks are only worsened by destruction of the family unit, making provision of appropriate support to such families crucial. The fact that young carers are more likely to experience numerous risk factors for suicide is concerning because risk of suicidal behaviour increases dramatically with young people's exposure to multiple risk factors (Fergusson et al., 2000). Research into other groups of carers has found a correlation between being a carer and an increased likelihood of experiencing suicidal thoughts (e.g. O'Dwyer, Moyle, Pachana, Sung & Barrett, 2014; O'Dwyer, Moyle, Zimmer-Gembeck & De Leo, 2013). This suggests that suicidality in young carers is an area for future attention and research.

When asked about what they needed to support them in their caring role young carer survey respondents identified that services which are targeted towards young carers are important. Young carers, particularly those in rural areas, lack access to specialised supports. As one young carer describes "*We need more support for young carers. Kookaburra Kids camp is awesome but once a year is not often enough.*" Access to respite services for young carers is of particular concern as the NDIS is expected to be the sole avenue for young carers to access respite services. Young carers of people who do not qualify for the NDIS will not have access to respite supports which is particularly problematic for young carers of people with a mental illness who do not meet the permanency requirements for the NDIS.

A number of young carer survey respondents also commented that people lack understanding around their caring role. For example *"People don't take my role seriously, they just think of me as my sister's sister, they don't see all the other things I do for her and my family."* Similarly members of the young carers' panel at the Carer Forums reported that schools, health services and employers often lacked awareness about young carers and this made it more difficult to find and access supports. Given the disadvantages experienced by many young carers it is important that youth services, disability services, health services and schools are aware of young carers. Schools and services should have strategies in place to identify young carers, provide referrals to young carer services and provide additional support and accommodations to young carers if they request them.

There are many reasons why young carers may go unnoticed by schools and other services. Young people in a caring role may view their responsibilities as a normal part of family relationships and thus they may not recognise that they are a carer or ask for support (Cass et al., 2011). Additionally, young people often choose not to disclose their caring role for several reasons including concern that they will experience stigma, fear of intervention by child protection services and concern that they could be treated differently by teachers or peers if they knew about their carer status (Cass et al., 2011). Young carers at MHCN's Carers Forum reported that access to supports is delayed until they 'identify' as a carer. The young carers reported experiencing stigma as a result of their caring role, particularly from peers and employees. Improving public awareness of young carers by educating families and youth about young carers will help to reduce stigma around this caring and inform young carers about their caring role and avenues to seek help. Training for professionals and teachers can improve knowledge and awareness.

Young Carers at the Carer Forums felt that due to their daily contact with young people schools and teachers were perfectly positioned to identify young carers and act as a link to resources and support but commented that in their experience many teachers lacked knowledge about young carers and the supports that are available to them. Young carers often experience difficulties in education, especially where schools do not provide the flexibility that they require. Caring responsibilities can mean that young carers miss school, need to use their mobile phone at school or take time out of classes, have less time to complete schoolwork, and sometimes have to hand in assignments or homework late (Cass et al., 2009; Cass et al., 2011).

Young carers at the Carer Forums and survey respondents identified that they would benefit from greater flexibility from schools. Schools can support young carers by providing extensions and informing students about flexible options for study. Examples of strategies developed for schools to support young carers include the 'young carer aware schools criteria' (Young Carers WA, 2017) or the 'YSCI Young Carers Support Toolkit' (YSCI, 2017).

However, in implementing strategies to support young carers, schools should keep in mind that young carers may not want to be singled out, or treated differently to other children. Many young carers view school as kind of respite where they are away from caring responsibilities (Cass et al., 2011). The type and level of support that young carers will find useful will vary between individuals and schools should ask young carers what will be useful to them.

The disadvantages young carers experience in education coupled with a lack of awareness on the part of education staff, points to the need to include young carers as a priority group in education strategies and policy. While the NSW Carers Strategy identified that the wellbeing framework for schools would play an important role in supporting young carers' mental health, young carers are not actually mentioned in the wellbeing framework which means that an opportunity to educate schools and teachers about young carers has been lost. Young carers should be included particularly where it comes to wellbeing policies as they are impacted by them. This will help to ensure that education staff have knowledge around young carers.

Recommendations:

- Young carer status should be considered for identification in the data collection around youth suicide. Data collection should take into account issues with identifying young carers by considering young people who live with someone who has a disability as potential young carers.

- The NSW government allocates more funding to specialised services that support young carers in their caring role, including respite services.
- The NSW Department of Education includes young carers as a priority group in education strategies and policies

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Appendix 1

Summary of Carer Survey Results

Parent/Carer Survey Results:

School

Carers have a broad variety of experiences around how effectively schools have supported the mental health of the young person they care for and students in general. Positive experiences included:

- Invitations to mental health seminars
- Schools listened to guidance of parents and professionals
- Time for reflection and retreats where students could focus on wellbeing and mindfulness
- Flexibility
- Calling or updating parents where they are concerned
- Updating risk and health care plan
- Positive experiences with school counsellors

Positive Experiences:

Invitations to mental health seminars, being available for discussions when initiated by parents, following up at home by phone calls on occasion. Following up equity ATAR points with HSC candidate when family affected by mental health issues. Creating an understanding and working relationship with parents

They did not identify or do anything, however in one of my children's schools they have at least been very flexible and willing help as directed by parents and professionals.

My sons school (catholic) supported mental health with time for reflection and retreats where students could focus on their wellbeing and mindfulness. Yes, they call me when concerned, have updated his risk and health care plan and involve the school counsellor when my son is distressed. They have also applied for reduced hours so that he can cope better and recover.

Yes, they call me when concerned, have updated his risk and health care plan and involve the school counsellor when my son is distressed. They have also applied for reduced hours so that he can cope better and recover.

One of the schools my children attended started the day with a period of aerobic exercise to great music. There was a marked difference in the school environment and it was a happier place.

Negative experiences have included:

- Teachers/principals not listening when carers try to discuss mental health of their children
- No available counsellors
- Teachers/staff lack awareness about mental health
- School did not respond to bullying and other inappropriate behaviours
- Punishing a young person for behaviours associated with their mental illness
    - Threats of expulsion
    - Caused a young person to become disengaged

Negative Experiences:

No. We withdrew our child from preschool when their unsupportive practices started to have a mental health impact on our child.

The teachers and deputy principal do not listen to me when I try and discuss my children's mental health

Nothing. They don't have counselors available (time shared, part-time, over booked, inaccessible or not fit to speak to children) and general teaching staff have very little training in the signs and behaviours of students who are distressed

Not much at all except telling us he would be expelled if he didn't stop his elusive attitude and day dream / falling asleep in class and being late .

My daughters school (public) did nothing to support her mental health and actually inflamed her situation by not responding to her reports of bullying and making stereotypical judgements in favour of the bully who appeared little and cute and knew how to manipulate that to her advantage.

My son has had depression for over 10 years. When he was at school, it became worse because some teachers did not know how to support or handle him. He was not violent or aggressive just argumentative and disinterested and sad. They just seemed to punish him for that. He became suicidal, smoked a lot of marijuana and has isolated himself since. Left school at the end of year ten and done a bit of work here and there but mostly sat in his room

We removed one of our children from school and started homeschooling because the local public high handled sexually predatory behaviour (from other students towards our child) so badly. We were not even given a phone call in response to complaints by our child. Our child has autism.

I approached school counselor for some support and directly asked her not to speak to my son at this point. She stood outside his classroom and approached him as he left the class to ask him what was going on for him. His reply "nothing" and I was roasted when he came home from school. I have never fully regained my sons trust.

In general carers would like to see more support for their children’s mental health in schools.

Suggestions:

They need more training. They need help identifying behaviours, a better understanding of mental health but they also need more counsellors or mental health professionals - OT's, nurses etc who can actually work therapeutically with the kids - not just fulfil the administration and referral part of the job.

more on support, caring and compassion. Less on discipline and authority. Engage and bring the kids along with you not alienate them

Actively listen to concerns raised by parents. Look at ways to support the children and parents Children with mental health issues should not be further discriminated against

Educate all students to identify first symptoms and give them the tools to face the challenge and mainly seek help without fear. They should discuss with the family some concerning signs and follow the child up closely in his evolution .

Listen when students make reports of bullying and harassment and not make judgements based on size, sex, race or any other discriminatory factor. They should inform parents when punishments are being handed out so parents can investigate the situation. They could support students by encouraging them to work from their strengths and values. They should never tell a child they are stupid or use offensive language. They should never use humiliation as a punishment. They should never withhold school reports because a parent cannot meet school "contributions". Students should be allowed to access areas like the library or art rooms in their lunch breaks so they can avoid being bullied or being left isolated in the playground by themselves. Art or quiet reading or mindful activities can benefit their mental health immensely.

Involve the parent, listen and believe them. Collaborate with services already involved. Keep the communication timely and relevant. Educate themselves further regarding symptoms of mental illness and strategies to support the child.

Mental health education in all high schools (as part of their curriculum vitae) is so important , just as important as any other health science / discipline. Anti bullying campaigns are influential in that adolescence stage too.

Parents should be able to access support and parenting guidance at their local school. Workshops and parenting groups could be offered at local schools after hours by this. These services should be available at large... Not only for affluent communities, but also for those that are of lower socio-economic development. Parents of children with psychological and psychiatric disorders should be able to receive free support and training... During the school holidays, all schools should provide social skills training workshops and leisure and recreational opportunities for communities of lower socio-economic backgrounds.

With so many accidents in schools; diseases and conditions that are prevalent in any school I believe there is a place for a 'school nurse' to attend to the medical needs of the children and trained to detect early signs of mental distress in children. Detection and preventive measures/education taken early enough could make a world of difference to children, parents and communities.

Impact of Bullying:

he trauma she experienced at high school which has added to her mental health issues was increased by the fact that she is very tall and looks strong and confident and nobody believed she was being bullied, in fact the bully was often able to lie and have her punished when she was is fact the victim.

At one school my youngest daughter suffered horrendous bullying by her teacher and other students due to her skin condition and at such a young age she was suicidal.

Mental Health Services

- Carers reported many positive experiences with MH services
- Mixed experiences in being included in care

Yes to a degree but felt neglected as a parent when child would not engage.

Yes... But mainly because I was assertive and proactive in ok involving myself with their care...

Equine therapy with Bushbred was Amazing but we couldn't afford to keep it up

Yes - he has see professionals since the age of 3. The professionals that work with families, respect their input etc have been more successful. DIR Floortime model of therapy worked well for us. Psychology - we have seen 5 and counting - all seem to use CBT approach. Very prescriptive, just has not worked well for us.

Yes, I was included as a carer but because I am assertive.

As parent we were often assumed to be the problem when our daughter was admitted to hospital and treated as the enemy.

I believe the situation is quite different now but at that time I was totally excluded from my child's treatment. When I requested participation I was rudely refused.

yes they did but they would not release a report on my son to me due to him asking them not to (he is 17)

Adolescent services (especially X Children's hospital) vilified the parents and encouraged the teenager to live with grandparents and not parents. The suicidal behaviour impacted terribly upon the health of the grandparents, and in many ways they never recovered. They also had to go back into the work force and move cities to be able to be primary carers of such a sick adolescent. This situation was disgraceful and parents were cut out of the relationship. It has taken a great deal of graciousness and forgiveness for relationships to be healed. Parents are back now being primary carers of a still very sick (now 2X) year old, and parents are now supporting the grandparents as well due to age related issues.

The parent must be consulted, included at all stages and believed. They know their child best. Also ensure enough support is made available to the parent.

- Difficulties in accessing services that cater to children with complex needs
    - E.g one carer reported that her child was admitted to an adult unit even though she was under age. According to the carer no other unit in NSW would take her.
- Some carers reported traumatic/negative experiences with hospitals.

Issues were accessing in patient care given very complex medical and psychiatric needs of our child. X adult unit opened one month after our child turned 18. For months she was cared for in X LM unit, a rundown place, designed for adults. Her teenage brothers were not permitted inside because they were under age, even though she was under age herself and was admitted there. No other unit in NSW would take her.

No the public hospital tried to exclude me because my daughter was 2X. They treated her like a criminal and the facilities in emergency for the mentally ill are very confronting. If I hadn't been with my daughter which I insisted on the whole time she would have been in a worse state. The overnight facilities in the pecc Ward were disgusting. 6 in a room males and females in together and the toilet/bathroom Doors didn't lock properly. The staff were wonderful especially having to work under such conditions

- Regional Access

It is really hard to access a good team of professionals to assist with mental health in this area, we do not have a youth impatient unit here, the nearest is a good way away up the coast.

- Mental Health Care can be inaccessible because it is expensive

Yes, actual access to Psychiatrists you can prescribe medications and review them. CBT and talking is great but sometimes chemical interventions are required and if you are low socio economic you can not afford the fee for service

private services are generally excellent and consult regularly with parents - but not all parents can afford them.

We are in our sixties and have no idea how or who will look after her when we are gone. Our daughter has attempted suicide 3 times. The voices tell her to kill herself because she is not worthy to be alive. We have no help from anyone except the private psychiatrist and psychologist that we pay for. We have top hospital and top extras but even the very top extras only gives $300 per visit to a psychologist and the ones that are under the free 10 visits are no where near qualified to deal with my daughter.

There is so much information but once you attempt to get real practical help, there is nothing available, only inaccessible fee for service professionals

- Transfer of Care:

The issue we constantly face is at discharge, the community team is too slow and made various mistakes one of which very serious costing my son to decline tremendously .

I think the gap coming out of hospital, waiting to see a psychiatrist or case manager etc is crucial . An elaborate plan should be in place on a daily basis if possible right from discharge. That first week is " make it or lose it " .. this is when most suicides occur I believe . Facing loneliness and being independent after being taken care off.

Linkages to Other HealthCare

Most recent suicide attempt for our child was July this year. In RNS, and had been for several weeks with impacted bowel. "Threatened" by psychiatrist with going back to X AMH, so our child ran away, caught the train to our home, took ropes from our shed and attempted a suicide attempt in local bush and was prevented by passing resident. ended up scheduled in X AMH. Our family did warn that our child was most at risk when threatened like this. We very nearly lost our child.

GP

Almost 80% had used GP for mental health related issues

The GP was great, my son is in denial and wont get help

Yes, I believe my daughter has often been overlooked as having serious mental health issues because she appears to be very high functioning. Our own GP often says to her how well she looks on a day where she is on the verge of breaking down and experiencing suicidal ideation, or manic highs/lows. She looks well, therefore people think she is well.

Emergency Services:

My child was pepper sprayed by police at 13, due to their lack of understanding of MH.

Supporting Families:

Parents need to be educated on how to parent. With our nuclear family; society and family breakdown young people are not learning how to parent or how to live in a caring, loving community with rights and responsibilities.

My daughter, husband and I have completed Acceptance, Commitment Therapy Courses and I believe the three of us can communicate better and use the strategies taught in the course to reduce contagious conflict and lead us to contagious caring. The three of us think differently and our communication skills reflected this, however, the course gave us a common language and skills/strategies to use. A willingness to learn created a bridge for us.

Employment Services:

The system is a mess. The public system treats the mentally ill like criminals. Centrelink treat you like you should just get a job. My daughter tried to get disability pension but they said she wasn't stable. My daughter has scizoeffective bipolar 1 disorder with auditory hallucinations. The drug she is on at the moment is keeping her stable but we do not know for how long. Bipolar is a lifetime illness and although she wants to work there are many times that my daughter can't. We fully support our daughter both financially and emotionally. We are in our sixties and have no idea how or who will look after her when we are gone. Our daughter has attempted suicide 3 times. The voices tell her to kill herself because she is not worthy to be alive.

When my daughter applied for disability centrelink said she didn't qualify so they put her on new start. This was a lot of stress for my daughter trying to find jobs and having to go to interviews. The service provider that centrelink nominated for her case kept calling her telling her that she needed to look for more jobs and then when we did find a job for her they said she wasn't doing enough hours. This led to a complete break down and my daughter was in hospital (private Hospital) for 3 weeks. We took her off new start but the service provider kept calling even after we asked them not to. They even called me. Young people with anxiety/depression do not need that kind of pressure. It is enough to push them further into depression and suicidal thoughts. They need someone to try and understand what they are going through. Also the people in centrelink are not qualified to understand mental illness. They put the details into a computer and if you can't tick all the boxes then you do not get disability assistance. We need real people having an interview with the person and the carer of the person. The system is too complicated for people with a mental illness. It is confusing and heartless.

Yes, disability employment services need to be trained in mental health. Again because my daughter looks high functioning there are expectations placed on her constantly which she cannot manage. Despite written confirmation form her psychiatrist Centrelink and the Job Agency continue to pressure her to do thing she cannot do at this point in her recovery.

Insights from Young Carers:

Mental Health:

The majority of young carers reported that their caring role had impacted their mental health.

I get emotionally exhausted. My anxiety levels have increased. I sometimes find it hard to sleep.

I think my biggest thing is that when you do all the running around and getting this and that job done, it's hard to take note of your own mental health. Even when you get down time you're just tired. It's *only when something major occurs do you start to realise the stress of the situation and that's when the mental health things kick in.*

It is frustrating to have to worry about my brothers all the time.

Caring is a huge task for a young person. A lot of young carers lack time for themselves and want a space where they can be treated as just a normal kid:

When asked about challenges of their caring role:

- *Cooking, cleaning, doing everything on your own and being relied on*
- *Balancing work and other commitments around my sibling. Yes I am a carer but I also need time to do things that contribute to my future as well.*
- *Understanding what my mum is trying to deal with*
- *Can't do or go things like normal children do*

Recognition and awareness:

People don't take my role seriously, they just think of me as my sister's sister, they don't see all the other things I do for her and my family.

When asked what are the challenges of their caring role: *not being taken seriously in the Community*

When asked what they needed to better supported in their caring role*:*

- *A therapist of my own who understands what being a young carer involves and can teach and support me.*
- *People to understand and school to be more flexible*

School:

Of the 10 young carers; 5 felt that school did not support them in their caring role, 3 were unsure and 2 felt that they are supported by schools

More services for young carers and improving access to them:

When asked what they needed to be better supported in their caring role:

- *More support services*
- *Either easier access and awareness about services I can access or for other services that have hours that fit with a 8-6 job.*
- *A therapist of my own who understands what being a young carer involves and can teach and support me. I'm 11 and there's a shortage of child psychologists*
- *More activities or support available in the regional towns where we live.*

We need more support for young carers. Kookaburra Kids camp is awesome but once a year is not often enough.

I think more awareness for young carer group meets (if there are any) could be really beneficial.

Access in regional areas: *Need more support especially regional remote areas. We are very isolated.*