creating a better life for children and young people in care

Submission to the Royal Commission into Victoria's Mental Health System

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About CREATE Foundation

CREATE Foundation is the national consumer body representing the voices of almost 46,000 children and young people in the out-of-home care system, as well as those who have transitioned from care up to the age of 25.

Our vision is that all children and young people with a care experience reach their full potential, in line with our mission to:

- CONNECT children and young people to each other, CREATE and their community; to
- EMPOWER children and young people to build self-confidence, self-esteem, and skills that enable them to have a voice and be heard; to
- CHANGE the care system, in consultation with children and young people, through advocacy to improve policies, practices and services and increase community awareness.

At CREATE, we believe that to improve the care system, we need to listen to the people who have experienced the system firsthand. This is why youth participation is the foundation of our advocacy. Everything we do is shaped by the voices of children and young people with a care experience.

Introduction

Submission to the Royal Commission into Victoria's Mental Health System

CREATE Foundation welcomes the opportunity to make a formal submission to the Royal Commission into Victoria's mental health system (the Commission). An accessible, flexible, responsive and effective mental health system is of particular interest to us because the young people we work with often self-report challenges with mental health, as well as experiencing the out-of-home care system as being inadequate in its support of their mental health needs. Additionally, many identify particular shortcomings of the mental health services which are available to them.

As with all of CREATE's work, this submission is shaped by the voices of children and young people with a care experience. Specifically, the voices of 14 young people, aged 14 to 25, residing in Victoria, were documented. The views of the young people were recorded at two separate events: the first being CREATE's Election Hour of Power (HOP) youth forum on October 11, 2018, where five young people delivered a group presentation on "Mental Health and Out of Home Care"; and the second a CREATE Youth Advisory Group meeting on the topic of mental health, convened on May 14, 2019. The latter event, which saw nine young Victorians participate, was facilitated by CREATE for the express purpose of informing this submission.

In this submission, we will address five of the Commission's eleven formal submission questions (specifically, question numbers 1, 2, 4, 5 and 9), as it is these on which we are most informed by young people and/or which are of most pertinence to them, as opposed to the questions relating to suicide prevention, attracting and retaining mental health workforce and improving economic participation of people living with a mental illness. Each of our responses will address "*Experience*" where we share the lived experiences of young people in relation to mental health; as well as "*Ideas for Change*", which will include suggested reform. All quotes used are from the young Victorians with an out-of-home care experience who participated in the above mentioned events. We trust that the Commission will value

the candour of the young peoples' responses, and their insightful suggestions for system improvement.

The Out-of-Home Care Context

While all sections of society are impacted by mental health issues, the mental health support needs of children and young people with a care experience are recognised as being greater, and often more complex, than that of the general population (Baidawi, Mendes, & Snow, 2014; Fergeus, Humphries, Harvey, & Herman, 2019; Tarren-Sweeney, 2017). When the state intervenes to remove children from the care of their birth parents, it is because the safety risks of the children remaining with their parents are considered to be unacceptable. As a result, young people typically enter care having experienced serious trauma (e.g., abuse, neglect, and/or grief and loss), and sadly they often go on to experience additional trauma and loss while in the care system, such as being separated from their siblings. Sawyer, Carbone, Searle and Robinson (2007) for example has found evidence for increased rates of depression and suicidal ideation in young people in care compared to their peers not in care, while other research has found high incidence of conduct problems, attention-deficit disorder, and trauma related anxiety (Centre for Parenting and Research, 2007).

Experiences in care can further complicate psychopathology; placement instability for example reduces young people's opportunities to form secure, supportive attachments with carers, and are separated from siblings who may otherwise be a protective factor against developmental of mental disorders. Accessing support services for this group can be difficult, considering placement instability and turnover of caseworkers which can hinder identification and communication of the young person's needs, and reduce timeliness of accessing specialist support.

In recent research conducted by CREATE Foundation, of 182 children and young people in Victoria, over 55% had experienced more than two placements (the recommendation articulated in the *National Standards for Out-of-Home Care),* and over 40% have between three and six caseworkers (McDowall, 2018). Further, 40% of participants in Victoria stated they had no caseworker presently at the time of surveying. While problematic for several reasons, in the context of mental health it contributes to difficulties of accessing support if the young person is not aware of their worker from whom they can seek assistance in obtaining specialist support. As well as the specific recommendations young people raise below, addressing the mental health needs of young people in out-of-home care requires commitment to improving systemic issues of placement and caseworker instability.

Response to the questions

Responses the questions posed by the Commission have been addressed with reference to quotes obtained from children and young people who have been involved in CREATE events in Victoria, including a focus group run for the purpose of this submission. Identifying details are not included for the purpose of maintaining young people's right to privacy, but quotes were transcribed verbatim by staff members.

QUESTION 1: What are your suggestions to improve the Victorian community's understanding of mental illness and reduce stigma and discrimination?

Experience

Children and young people in care often experience stigma in relation to being in care (CREATE Foundation, 2017). This stigma often intersects with other stigmas, for example, the racism experienced by Aboriginal and Torres Strait Islanders who are over-represented in out-of-home care. The negative impact of stigmas is then compounded by stigma regarding any mental health issues.

> *Stigma can make you afraid to speak up and say what is happening to you. You worry people won't believe you.* (Female, 15)

One effect of stigma around mental health is that it becomes a barrier to people seeking support and treatment.

> *There was a lot of stigma around going to mental health support services, or struggling mentally, especially when I was around 14, 15, 16 and in residential care and the other kids would ask where I had been. Even in my mid 20's, there is stigma connected with accessing mental health support.* (Male, 24)

Young people with a care experience see a need for raising public awareness in order to challenge stigma and "breakdown the stereotypes". One young person commented that:

> *Ads are powerful. Issues need to be advertised more widely, including on social media.* (Male, 22)

There is concern too for how stigma around mental health issues permeates the health system itself.

> *Bulk billed doctors and hospitals need to have more understanding when dealing with mental health patients.* (Female, 19)

> *Sometimes doctors and nurses talk down to you. I'm not stupid.* (Female, 19)

> *There is a stigma around medication. I know that they are hesitant to put kids on medication, but sometimes we need it to be able to move forward.* (Female, 15)

Young people shared feeling discriminated against because of their mental health concerns, with reports of being misunderstood, judged, and blamed for their mental health problem not uncommon:

> *People think we have problems due to our own decisions. Our decisions can sometimes seem wrong, but that just reflects how terrible we feel sometimes.* (Female, 15)

> *Sometimes people say "why are you depressed, your life isn't that bad?" This just makes you feel worse. People need to understand that not all depression is situational.* (Female, 16)

> *Mental health can be as debilitating as physical illness.* (Female, 19)

Young people believe there is an urgent need for greater public awareness of complex mental health disorders.

We need to break down stigma regarding a broader range of mental health problems. Depression and anxiety are more understood, but not more complex things like PTSD. (Female, 19)

Some people think PTSD only happens in wars. (Female, 15)

Train our carers to understand our conditions more. Even good carers can assume we don't need help when we do. (Male, 17)

Ideas for change (based on the comments from young people, and strongly supported through CREATE's experience):

- Stigma of more complex and disorders such as Post Traumatic Stress Disorder and Borderline Personality Disorder needs particular addressing, such as through public health campaigning, use of social media, advertising and inclusion in school curricula.
- Need for carers to have trauma informed training and psycho-education if they care for a child or young person with a provisional diagnosis of mental illness.
- Employ people with a lived experience of mental illness in governance and policy roles within the mental health system;
- Make sure mental health services are respectful of diversity, and actively inclusive of communities such as Aboriginal and Torres Strait Islanders and LGBTIQ+ people;

QUESTION 2: 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?

Experience

Young people were not able to identify any aspects of the mental health system that they considered were working well. Their comments focussed on deficits in support. For example, several reported that the services they have attempted to access often avoid providing them with treatment. They feel that it can be a battle to get help.

Services need to be responsive when we first ask for help. This is a huge issue in Emergency Departments. They have so few beds, that they leave you for waiting for a long time, and then determine that your problems is not severe enough to qualify for support. Being turned away from EDs just encourages us to ramp up dangerous behaviours so that we will eventually be listened to and helped. (Female, 16)

I waited a long time to get mental health support, and in the meantime my mental health became much worse. I saw it as being a part of dealing with the system that I had to get worse before I could access support. I reached psychosis and I was then admitted after waiting at the Emergency Department. I had not been sleeping for ten days. I asked my doctors and supports if I could have medication, however they kept saying that my mental health was not severe enough. I learned that it is only if I was in crisis that I would be able to access help. Only if I said that I was suicidal would the mental health services do much to help. (Female 19)

While young people in the Melbourne metropolitan area spoke of an insufficient number of beds for young people experiencing mental health crises, it was noted that the paucity of resources in regional areas is even more severe.

In Ballarat there are no psychiatric beds for young people. We are in the catchment area for the Royal Children's [Hospital in inner city Melbourne]. (Male, 17)

Young people expressed that the lack of services willing to provide treatment for complex or acute mental health disorders could result in young people entering the criminal justice system unnecessarily.

> *The lack of appropriate help when we first ask for it means that people end up in justice system due to mental breakdowns.* (Female, 15)

> *They are putting AOD [alcohol and drug] services and psych beds in the new youth justice centre in Cherry Creek, but how about giving young people these services before they end up locked up. It angers me that the justice system is used to plug holes in the mental health and AOD systems.* (Female, 16)

In addition to experiencing a lack of resources, young people report that their age can be a barrier to accessing responsive treatment. One 15 year old girl stated that:

> *There is a huge problem with provisional diagnoses. It is wrong that they can't diagnose us with conditions when we strongly present with all of the symptoms, just because of our age. That means we cannot get treated for our condition. Things unfolded and I've ended up with criminal charges when I lashed out because I wasn't getting the help I needed. They refused me help because of my age. I have been having these problems since I was seven years old.*

The same young person acknowledged how mental health professionals can be hesitant to label or over-medicate children, but experienced firsthand how such reluctance and/or refusal to provide sufficient treatment, without adequate explanation, can have serious and long term consequences. Similarly, another young person shared that:

> *I have a friend who also ended up with a criminal record before he got a diagnosis. There must be a better way to deal with this, without ruining peoples' future employment and housing chances.* (Male, 16)

CREATE acknowledges that the hesitation to use diagnostic labels can be an important step towards mitigating negative effects, such as internalisation of stigma associated with labels or medicalising issues which may be part of a normative adolescent experience (e.g., low self-esteem as opposed to an anxiety disorder). Medical professionals may be advised to avoid the use of labelling or using pharmacological treatments for young people of certain age. However, the responses of young people indicate a need to improve communication and explanation of treatment decisions and courses of action.

Ideas for change

- More youth justice diversions. Wherever possible, provide appropriate mental health services *instead of* recorded convictions and custodial sentences. In extreme cases, where this is not possible, provide mental health support in tandem with youth justice;
- Raise the age of criminal responsibility from 10 to 14. Restore access to the dual track system (where young people aged 18-20 can be sentenced to a *youth* detention facility if the court believes they are particularly vulnerable, or if this may assist their rehabilitation) and extend age eligibility for this system to 24 years
- Better understanding of how to access both support and information. Targeted advertising around services available can help, as can campaigns in schools and providing increased access to mental health support and counselling in schools

- Organise expert panels to consider offering more significant treatment earlier for children and young people under the age of 18 who have provisional diagnoses. The views of the child and young person to be given serious consideration in this process;
- More psychiatric beds for children and young people, especially in Regional areas;
- Out-of-home care case workers (DHHS or contracted community services organisations) to provide detailed information to young people about how to access mental health support;
- DHHS to publish a booklet or other form of communication specific to young people in out-of-home care on accessing mental health services.

QUESTION 4: 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.

Experience

Children and young people in care face a host of barriers to meaningful engagement with mental health treatment and support. Young people report that they often have "trust issues".

> *We have been let down by so many adults. We have had so many workers come and go and not really help us. Why would we think that a mental health service would treat us any differently?* (Female 16)

A recent survey showed that more than a quarter of a sample of 182 children and young people in care in Victoria reported having had seven or more case workers, and 9% reported having had 15 or more (McDowall, 2018). This high turnover of caseworkers has the potential to further compromise a young person in care's mental health, with one young person sharing:

> *We change workers all the time, and sometimes our information doesn't get passed on to the new workers. It can be annoying to have to keep telling our stories over and over and again. It can actually be re-traumatising.* (Male, 16)

Young people also find the attitude of caseworkers can be a barrier to their ability to obtain mental health treatment and support:

> *Some workers don't understand the importance of psych services.* (Female 19)

> *DHHS would wait until I had a crisis to find mental health support for me, whereas we really need support when we are doing well, so that we don't reach crisis point as readily.* (Male, 24)

> *Sometimes our transport to mental health appointments falls through. Workers need to prioritise this.* (Female 19)

Moving homes is a frequent occurrence for many young people in care. Some are removed from the care of their parents, but are later returned, only to again be placed back in the care system at a later date. Young people are also often moved between different care "placements." This can cause multiple disruptions in a young person's life and relationships, including interrupting their relationship with mental health services.

> *When you're in care your living arrangements are so unstable, you move so much. Sometimes when you move, you fall outside of a catchment area, and can't stay with a service. Or we move too far away from the psych we are seeing.* (Female, 16)

Young people perceive most youth mental health services to lack a specialised understanding of the types of trauma that young people in care can experience, as well as having little awareness of the out-of-home care system itself. This can affect young people's willingness to engage, as well as their experience of any mental health support and treatment that they do receive.

One young person living in kinship care expressed frustration at a lack of understanding among mental health professionals about children in care.

> *In my family we have been to lots of psychologists and counsellors, and lots of them did not understand us and couldn't help us. Most of them have looked at us like we are weird species.* (Female 17)

Additionally, young people complain of the public mental health system being too "rigid" in relation to the types of therapy offered.

> *I was not a fan of working one on one in a room with a therapist. I was lucky to go to a private hospital where they had a number of alternative therapies available, which suited me better. I was able to do art, music, and to work out, which worked for me. I felt more comfortable as I felt that the services got me more. They were willing to use what worked for the individual and they connected my therapy to my hobbies and interests.* (Male, 24)

Ideas for change

- Young people need support from those they trust to access mental health service while in care and when transitioning from care to independence. Efforts should be made to ensure that children and young people with a care experience are connected with support people who have the skills and capacity to refer them to appropriate mental health services if and when required. Trials of personal advisory models have found to be successful in supporting young people leaving care in Victoria address complex issues, including mental health and homelessness, through the development of a trusting relationships with a worker, and learnings from these trials should inform the Commission's recommendations;
- Given the relationship instability and attachment insecurity which many young people in care have sustained, and the impact of this on mental health outcomes, mental health services should pay particular attention to how service staff engage with young people, as well as their diagnosis and treatment. Rapport and relationship building cannot be overlooked, especially for this cohort for whom trust can be difficult and who may be wary of services, based on previous experiences;
- Ensure that the DHHS Child Protection and contracted community service organisations view connecting children and young people in care to trauma-informed mental health services as a crucial component of their core-business;
- Increase efforts at staff retention for out-of-home care case workers. As noted earlier, addressing the mental health needs of young people in out-of-home care requires commitment to improving systemic issues of placement and caseworker instability.

Further, CREATE commends the commitments made by the Royal Australian and New Zealand College of Psychiatrists (2015), which (a) undertakes to include the mental health needs of children in OOHC as part of the core curriculum for specialist training of child and adolescent psychiatrists; (b) supports the initiation of research opportunities in collaboration with other disciplines and agencies which expand current knowledge and skills in intervention with this

population; and (c) encourages collaboration with state, territory, and regional health departments and child welfare agencies in their efforts to establish or enhance systems to ensure all children in OOHC are assessed for mental health problems and receive effective mental health treatment. CREATE suggests that the provision for such training, research, and cross-sector collaboration, *along with* adequate resourcing for dedicated and ongoing rollout, is prioritised for all practitioners within the mental health system (e.g., GP's, psychologists, counsellors, social workers, nursing staff) working with children and young people in out-of-home care.

QUESTION 5: What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?

Experience

Ten young people with a care experience were asked "Do you think that young people with a care experience would generally have a greater need in relation to mental health than people who have not been in care?" Their responses varied from screams of "YES", to laughter at how obviously true the statement is. The reasons young people gave for this being the case included:

> *We have generally suffered trauma and neglect. These are usually the reasons we come into care.* (Female, 16)

> *Even when we are in care, we still have a relationship with our birth family, and their behaviours still have an impact on us.* (Male 17)

> *We witness a lot of conflicts.* (Male, 21)

> *We have so much instability in housing and the area we live in, lots of changes. Sometimes we are moved without warning. We have workers and carers in our lives and then out again. How can we feel secure?* (Female, 16)

> *The trauma and uncertainty can cause extra difficulties in developing our identities and defining morality for us as young people.* (Male, 20)

> *Disproportionately we have early access to drugs and alcohol.* (Female, 16)

> *We grow up feeling a lack of love and support* (Male, 20)

Problems experienced while in the care system often result in additional risks to mental wellbeing.

> *We often experience more traumas in care. It's not always safe for us in care, especially resi* [Residential Care]. (Female 15)

Concerns around safety can be prevalent in OOHC and young people recognise that such concerns have a deleterious impact on their mental health. Indeed, concerns with safety in residential care have been widely reported (e.g. Commission for Children and Young People, 2015). Despite recent reforms to residential care in Victoria, CREATE continues to hear concerns from young people:

> *Resi units are a problem. They put a lot of people with struggles together. Young people can then feed off each other. These young people need help, but it is such a difficult environment.*

> *So one problem is that there are not enough foster families. There needs to be more funding for foster carers. After all, better payments for carers saves money on resi staff.* (Female 15)

Similar issues can, however, occur when several young people live together in foster care, as with this young person's experience:

> *I have often raised that I am unhappy living in my placement because of one of the other young people there, but it gets ignored. This impacts my mental wellbeing.* (Male, 16)

Ideas for change

- Systematic prioritisation of care-experienced children and young people in developing and allocating resources in the mental health system;
- Increased funding and training for home-based carers (foster and kinship carers) as an alternative to residential care for young people with complex needs and behaviours;
- Ensure residential care has a truly therapeutic focus, rather than being a "last resort" for young people without other accommodation options.

QUESTION 9: Thinking about what Victoria's mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?

Experience

As per the responses recorded above for question 5, there are significant reasons children and young people could be expected to have greater needs in relation to mental health services than that of the general population. These relate principally to the experiences of profound trauma and loss in childhood that typify this particular population subset. It follows that the needs of children and young people should be a priority area in the provision of mental health services.

Young people in care report having caseworkers refer them to *Headspace*. While acknowledging that the *Headspace* model may be beneficial for many other young people, these young people had histories of serious trauma and complex mental health concerns that they felt a "mainstream" primary youth mental health service such as *Headspace* could not appropriately address.

Several of the young people were aware of other services that do provide different types of trauma-informed mental health services, that could be better suited to the needs of children and young people in care. These include the Australian Childhood Foundation, Berry Street Victoria's *Take Two* program, and some initiatives of the Lighthouse Foundation. However, all of these services have very limited capacities, meaning that many children and young people in care are missing out.

The experience of one 15 old girl is an alarming example:

> *I went without mental health support for two years, as DHHS weren't able to get funding for counselling. I was lucky to eventually get it, otherwise my carer would have had to find the money for private counselling. DHHS viewed that my mental health was not an urgent issue and that it was ok. I am able to access Victim of Crime funding when I am 21 years old, and I was told that I could not access this funding earlier to use it now for my mental health support.*

If the Victorian Government is to be a good "corporate parent", it needs to provide suitable trauma-informed mental health services to all of the trauma-affected children and young people in its care – and to the young adults adjusting to the difficulties of life post-care.

A young person who was previously in care in Queensland described a mental health service in that state specifically for children and young people in out-of-home care. The service is called *Evolve*.

> *I did not have to attend a GP first, there was no waiting list, it was my case worker who did the referral. I was given the choice about whether I would like to see the service weekly, fortnightly or monthly. I also had the choice of where I would like to meet, so long as it was a safe space. I was able to use the service until I was 18 years old. It didn't matter if I went into a Psychiatric Hospital, as I still had the same worker and I was not handballed to anyone else. I felt comfortable using the service. It felt like it was suited to me and it felt like the workers understood what it was like to be in care as they were specifically trained in out-of-home care.* (Male, 20)

At present, Victoria has no equivalent service. As one young person explained:

> *It would be great to have a specialist service that understands kids in care. It would save so much time and hassle for us. You feel like giving up on getting help when you have to tell your story over and over again to people who don't seem to get it.* (Female 17)

Ideas for change

- Increase the provision of trauma-informed youth mental health services;
- Provide unlimited access to mental health services for all young people with a care experience, up to the age of 25, in recognition of the impact of childhood trauma. A maximum of ten psychologist's sessions may not be sufficient
- Ensure that all children and young people in care have access to a broad and flexible range of treatment options. Enable young people to access the types of support suited to their individual needs
- Support mental health practitioners with training in issues that impact children and young people in out-of-home care
- Establish a state-wide mental health service specifically for children and young people with a care experience to fulfil the previously stated goals.

Conclusion

Young people in out-of-home care in Victoria are not adequately supported in regards to their mental health needs. Barriers prevent young people seeking support, such as the influence of stigma, the perceived lack of willingness of services to provide treatment for complex and acute disorders, and the belief that mental health services lack an understanding of the care system and impact of trauma. Addressing the needs of these young people ultimately requires a multi-system approach, addressing issues that exist in care systems (including placement instability and improving carer and caseworker therapeutic training), youth justice systems, and the health system.

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