Royal Commission into
Victoria's Mental Health System

WITNESS STATEMENT OF ROSE CUFF

I, Rose Cuff, say as follows

1 I make this statement on the basis of my own knowledge, save where otherwise stated. Where I make statements based on information provided by others, I believe such information to be true.

What is your background and experience?

2 I am trained in occupational therapy and Brief Family Therapy.

3 I started working in youth mental health/high risk settings in 1987 and have worked in adult psychiatric settings since 1994. I have been working specifically in the area of children and families where a parent has a mental illness since 1995.

4 I have been involved in developing a range of programs relating to children in families where a parent has a mental illness. I developed a peer support program for children aged 8 -12 in 1995. I was involved in writing the strategy for Families where a Parent has a Mental Illness (**FaPMI**) during a secondment to the Department of Health and Human Services in 2007.

5 I am presently the state-wide coordinator for the FaPMI program. I am based at the Bouverie Centre, an integrated practice research centre of La Trobe University. The Bouverie Centre is the state-wide coordination body for FaPMI. In my role as the state-wide coordinator, I am responsible for overseeing, co-ordinating and implementing the FaPMI program, with the regional FaPMI coordinators, across services and sectors in the State of Victoria.

6 Separately, I hold the voluntary role of Executive Director and co-founder of Satellite Foundation (**Satellite**). Satellite is a not for profit community-based organisation that aims to provide a voice and creative space for children and young people living in families where a parent has mental health challenges.

The FaPMI program

7 FaPMI is a service development, capacity building program that aims to reduce the impact of parental mental illness on all family members through timely, coordinated, preventative and supportive action within Area Mental Health Services (**AMHS**).

8 FaPMI launched in 2007. Since 2016, it receives full and recurrent funding from the Victorian State Government. This funding includes brokerage funding of $16,000 for each AMHS which can be used for the purchase and provision of goods and services to address a need and/or for the prevention of an emerging situation for which no alternative response is available.

9 The FaPMI Program is locally implemented by the work of FaPMI coordinators who are employed by and embedded in each of the 21 adult mental health services. Funding provided by the Victorian state government enables one effective full-time position to be employed in each of these adult mental health services. These roles work with their AMHS, specialist initiatives such as the Family Violence Capacity Building Program, networked partner services, the peer workforce and the statewide FaPMI coordinator to build structures and processes which aim to improve service's responses to children, young people and their families where a parent has a mental illness. FaPMI co-ordinators offer a range of services including secondary consultations, and joint consultations with the parent/family to role model and enable conversations with clients and families about the potential impact of mental illness especially on children. They are also involved in building resources, workforce development initiatives at adult mental health services and network partner organisations and building collaborative practices between sectors.

10 Importantly, the FaPMI program works with services to utilise a strength-vulnerability framework rather than a risk oriented one. Whilst some children and young people are at risk and appropriate action needs to be taken, not all are. The FaPMI program is building capacity to promote such a framework by developing relevant practice models, structures, and resources.

11 Local FaPMI co-ordinators also support specific peer support programs such as CHAMPS and Space4Us, and the mental health promotion program SKIPS (Supporting Kids in Primary Schools) These programs are discussed in more detail in the attachment RC - 1.

What are the potential impacts on families living with a parent with a serious or recurring mental illness? What are the possible risks to children in those families?

12 In my view, it is important to take a systemic, broad view concerning the potential impacts on families where a parent has a mental illness, to fully understand the implications. This enables us to better understand the possible risks to children in those families in the context of all their familial and community relationships, as well as their resourcefulness.

13 We should remember that the potential impact can change with the episodic nature of mental illness, the changing developmental needs of children and young people and other 'everyday' life challenges.

14 Mental illness can have negative effects on families and can contribute to families being fractured and experiencing significant trauma and grief, which in turn impacts on the wellbeing and overall development of children in those families.

15 Research tells us that children are twice as likely to develop their own mental health issues when a parent has a significant mental illness themselves.

16 This potential risk to children in families where a parent has a serious and/or recurring mental illness can be reduced to a significant extent by effective early intervention. However, there are not enough easy-to-access programs that focus in particular on young and primary school aged children with anxiety, attachment disorders, behavioural difficulties and their own emerging mental health issues. Unless they come to the attention of a specialist mental health service such as Child and Adolescent Mental Health Services (CAMHS), they and their family may not receive the help they need.

17 Without early support and intervention, some children can be exposed to cumulative harm and trauma which is preventable, and further embeds the trajectories of intergenerational disadvantage.

18 Very young children in families where a parent has multiple challenges including a parent with mental health illness, do not have a voice to express their feelings and in particular their fears and an increasing absorbing and cumulative burden of worry and responsibility depending on family circumstance. These children can and do, consistently 'fly under the radar' of services.

Why is it that children become carers for a parent with a mental illness? Are there particular groups within the community who are more susceptible to a child having a caring role?

19 Children who have a parent with a mental illness can become carers for many reasons. *First,* they become carers because there is no adult in the family to shoulder the caring responsibilities. This is particularly so in single parent families. *Secondly,* children become carers because it becomes routinised and normal for them to be the carers. Children are loyal and protective, and they want to look after their parents and siblings. *Thirdly,* children become carers because there is no other support or alternative outside the family. They may not know who they can contact for support or what to do and therefore, they shoulder the caring responsibilities themselves.

20 Cultures within families and cultural background of families have an impact on whether a child is more likely to take on a caring role. If the culture within the family is such that everyone steps up to look after the family, then the children will likely step up as well. In families where there are multiple complex problems such as substance use, family violence, poverty etc in addition to mental health issues, the children have to step up constantly. The children may not even realise that they are carers – they step up because they need to and have always done so.

21 The cultural background of families also impacts whether the child takes on the caring role themselves or shares it with others in the family or community. For many families, caring roles are seen as part of caring ABOUT a loved one, and not as a separate delineated role.

22 Mental illness is not a term always used by families, including Aboriginal families and communities. Great care needs to be taken with language and that assumptions are not made about concepts of caring in families where mental illness is understood and spoken about differently, and where what might be called ‘caring roles’, are family and community working together.

What are the main challenges young carers face in their caring role?

23 There are many challenges that young people who take on caring responsibilities face in that role.

24 Access to school and support services is a big problem for young people who cannot drive or afford public transport, or whose parent/s cannot drive for a number of reasons. Most volunteer transport schemes will not take children by themselves. Therefore, young people who have caring responsibilities need access to a safe, free mode of transport in order to reach school or other services. This could be funded by Government.

25 Many young people who take on caring responsibilities struggle to keep up with the requirements for school along with their caring responsibilities. There are often adverse financial impacts on the family when a parent has a mental illness. The flow on effect of this is that young people with caring responsibilities often struggle to manage their social activities as they do not have sufficient means.

26 Children and young people in caring roles can be viewed with pity, and easily feel patronised. In reality many of them are extremely capable, resourceful and skilled at navigating the health care systems, at the same time as feeling overwhelmed and burdened at times.

27 I also understand that young people who take on caring responsibilities often experience a plethora of emotions related to that caring role. These range from being very worried about their family to feeling very angry at missing out on their childhood. In families where there is no adult to help shoulder the caring role, it can be hard for children to manage their emotions or speak to services seeking support, in a way that they feel is loyal to their family.

28 Children, including young children, may very often stay at home from school because they are worried about their parent and feel the need to keep an eye on them

29 Children and young people in families with complex challenges including having a parent with a mental illness, can feel extremely isolated as can their families. They often feel as if they are the only ones in this situation, assuming that no-one will understand their experience and anticipate a response infused with stigma, especially if their parent has a serious mental illness such as a psychotic illness. Schools can be lonely places.

30 A separate challenge can arise in cases where young people step into a caring role for a short period when a parent is away (for instance, in a hospital). In many cases, when the parent comes back home, the parent may understandably wish to resume their parenting role and this can cause conflict with the young person who had taken on the caring role and responsibilities in their absence.

31 All the above challenges can contribute to young people who take on caring responsibilities not having hopes and dreams for their future. These young people need experiences other than their caring role and need to feel supported and connected in order for them to be optimistic for their future – to see a ‘solution enabled’ future for themselves.

In what ways does the FaPMI program / Satellite seek to reduce those impacts?

32 FaPMI is working on establishing routine and systematic responses from adult mental health services and network partners organisations (e.g. family services) so that parents and children who are in need of support are identified early and offered that support. FaPMI is working on promoting sensitive engagement approaches with these families as early as possible, so that parents can feel more confident about seeking that support and talking about their children and family. Parents’ fear of being judged is a very significant barrier to help seeking. The FaPMI program is also working to support better connections between services so that access for families is more easily understood and less confusing.

33 Satellite develops programs that enable children and young people to focus on their hopes and dreams for their future whilst connecting them with others who may have similar experiences. It takes a position of valuing the strengths and potential of these

young people and offers opportunities for growth and transformation. The programs tap into the belief that through living and learning to navigate life around mental illness, they carry deep wisdoms and knowledge around self, survival and family. For instance, Satellite is trialling a leadership program where it trains young people who have taken on a caring role in their families, in leadership, telling their story, group facilitation and mentoring. For young children, spending time with someone older than them and who is achieving their goals and dreams gives hope to the younger children that they can do so as well.

What is the importance of specific peer support programs for young carers?

34 There are a number of peer support programs that focus on children and young adults with caring responsibilities such as CHAMPS, Space4Us and Mi.Spot. Additionally, there are mental health promotion programs such as SKIPS. See attachment RC-1 for a summary of these programs.

35 Although the objectives of these peer support programs vary depending on their focus and their target population, they are important for young people with caring responsibilities as they aim to:

(a) promote open communication about mental health and wellbeing and family relationships;

(b) improve the participant's knowledge about mental health and wellbeing;

(c) improve and promote healthy coping strategies for the participant;

(d) reduce the isolation that the participants may feel by connecting them to their peers, families and their community;

(e) provide opportunities to engage the families and carers of participants in order to better support the participants.

36 These programs offer a broad range of supports for young people with caring responsibilities of different ages. The flexible nature of the CHAMPS and Space4Us programs mean they can be run as an after-school program in the community or in a school, as a holiday program or as a camp. Mi.spot has the potential for much greater 'reach' as an online program and for some young people who don't wish to engage in a face to face program, this gives them opportunity to connect with others who may have similar experiences.

37 For young children (8-12), CHAMPS can provide a relational context in which children and parents/carers can find ways to connect and better understand the ways in which the mental illness may be impacting on their lives.

In what ways can the mental health system change to better support young carers and families?

38 The mental health system broadly needs to routinely and sensitively identify children of parents with mental health challenges (and often other complex issues) and who may have caring responsibilities, in all adult focused services. The mental health workforce should be equipped, and the workforces trained to have such conversations with families in a way that is curious, respectful and non-judgmental. The system should be structured such that it gives them time to have potentially difficult conversations with children and families.

39 Planned respite opportunities for children, young people, parents and families should be provided where a parent or parents have a mental illness.

40 There should be targeted online supports for young people with caring responsibilities including a peer support online model such as Mi.spot. Programs such as eheadspace and Kids helpline would benefit from a deeper understanding of the experiences of young people in caring roles, of how diverse the role can be, and the perspectives of family members. Online programs for younger children and their parents/family should be considered.

41 At present, the mental health system is disconnected, particularly for young people with caring responsibilities. The current system provides services for children and young people experiencing their own mental health problems OR some recognition and support for children and young people who have caring responsibilities. It is not clearly evident from a Google search (for instance) what 'in place' programs are available to support these young people. The support needs of these young people and their families can range from needing every day, practical support, to counselling and specialist mental health advice. A community-based hub/place could provide scaffolded, targeted, and accessible support for young people whose families are struggling with mental illnesses. This place could be led by peer leaders and include peer support and connection, drop in facilities, practical advice and assistance for everyday tasks such as transport, grocery shopping, career advice, psycho-education, arts and creative activities, access to respite and camps, counselling and therapeutic spaces, leadership opportunities, mentoring of younger children. Any such facility should integrate supports for the whole family.

42 Any community-based place should integrate support for children young people and their families so that people have choices about what type/level of support they want to access.

43 Children and young people need to be given a stronger voice in the planning and delivery of mental health support services including how key messages about what they might be experiencing and where they can seek support are provided – what, where and when. Messages for example should be provided in schools, on social media and in public spaces where young people gather.

44 Any support provided to children and young people with caring responsibilities should include universal messages of recovery and possibility as well as messages validating their challenges and their triumphs over adversity. We should enable and encourage these young people (and their families) to have hopes and dreams for their future and provide them with the support that enables them to achieve those dreams.

Attached to this statement and marked 'RC-1' is a summary of peer support and mental health promotion programs.

sign here ► RA Cuff

print name Rose Cuff

date 02/07/2019

Royal Commission into
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ATTACHMENT RC-1

SUMMARY OF PEER SUPPORT AND MENTAL HEALTH PROMOTION PROGRAMS

SKIPS

1 SKIPS is a mental health promotion project for primary schools. It aims to:

(a) increase teachers' understanding of mental illness and their confidence in supporting children who live with a parent with a mental illness; and

(b) provide students in grade 5 and 6 appropriate language for talking about mental illness and increases their understanding of people who live with mental illness.

2 SKIPS is a joint project of Eastern Access Community Health (EACH) and Eastern Health. The SKIPS program has been supported by EACH without any allocated funding and this funding source is no longer available with changes to funding streams and the NDIS. The SKIPS program is not currently formally supported by the FaPMI Program other than that the FaPMI coordinators have promoted the program to be delivered in their regions. They are potentially very well placed to support the statewide implementation of the SKIPS program if this was funded given the embedded nature of their roles.

CHAMPS

3 CHAMPS (Children and Mentally Ill Parents) is a peer support program primarily designed for children (between 8 and 12 years of age) of parents living with a mental illness. The content of the program can also be adapted for children who have a sibling or other family member living with a mental illness. It can include a concurrent parent peer support program which is open to any significant adult in the child's life. The programs are designed to facilitate discussions on mental illness and wellbeing within families, to strengthen and build protective factors and address the impacts on families using creative and activity-based formats that are appealing to children and adults. CHAMPS is co-ordinated by the FaPMI program.

Space4Us

4 Space4Us is a peer-support program for young people between 13 and 18 years of age who have a parent, sibling or other family member with a mental illness. With a focus on early intervention and prevention, the aim of Space4Us is to reduce the likelihood of the development of mental health difficulties in young people who have been identified as

increased risk by providing them with an opportunity to share their experience and be supported by other young people in a situation similar to their own. Space4Us was developed through a partnership of Carers Victoria, Satellite, Wellways Australia and FaPMI and is currently being further developed and implemented by the FaPMI Program.

Mi.Spot

5 Mi.Spot (Mental Illness supportive preventative online targeted) is an online program aimed at young adults between 18 and 25 years of age who have (or have had) a parent with a mental illness or substance abuse disorder. It is an online 6-week voluntary intervention for young adults which offers real time and anonymous online peer networking opportunities and individually tailored, interactive and professionally led intervention. Mi.spot was developed and is currently provided by Monash University and partners and is undergoing a proof of concept phase with a view to being fully funded and implemented. FaPMI and Satellite support this programme by promoting it.