Response to the Royal Commission into Victoria's Mental Health System: Peer Support Interventions for Mental Health Carers and Families

Attention: Penny Armytage Chairperson Royal Commission into Victoria's Mental Health System

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Details:

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Tandem is proud to be the trusted voice of family and friends in mental health in Victoria. As the Victorian peak body with a sole focus on the needs and interests of mental health carers, Tandem's role is to provide leadership, coordination and knowledge for the organisations and individuals advocating for family and friends of people living with mental health issues. Tandem is committed to ensuring that the importance of the contribution, expertise, experiences and needs of family, friends and other carers is recognised and addressed, through a whole of family, whole of lifespan approach.

Tandem would like to thank the Commission for their invitation for a response and for the opportunity to provide further detail to support our initial recommendations for the investment in family/carer peer support interventions. Tandem would like to acknowledge the valuable contributions of Caroline Walters and Dr Melissa Petrakis to this report. We also acknowledge Ballarat Mental Health Carers Circle for their contributions from a regional community-based carer support group perspective.

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About Tandem

Who we are

Tandem is the peak Victorian not-for-profit body for carers of people with mental health issues and organisations with a carer-support focus.

What we do

- Tandem helps raise community awareness about mental health issues and the challenges faced by carers of people with mental health issues;
- provides information, education and training to Members and others involved in caring for people with mental health issues;
- ensures state and federal governments recognise the role, contribution and needs of the carers of people with mental health issues;
- facilitates communication between carers, government and other stakeholders in the mental health system;
- advocates for policy changes and improved services to address carer needs;
- supports carer participation in the planning, delivery and evaluation of services for people with mental health issues and their carers;
- facilitates the development of relationships between carers and carer-focussed organisations and other stakeholders in the mental health service system, and facilitate the establishment of partnerships between carers and service providers; and
- encourages research on best practice in carer support.

Who is a mental health carer?

a) a family member, partner, friend or other person;

b) of any age;

who will commonly:

c) be actively involved in caring for and supporting a person with mental health issues, with this role not necessarily a static role, but rather a role that is capable of fluctuation over time according to the needs of the person with mental health issues and the carer;

d) have their life impacted by the wellbeing of the person with mental health issues; and

e) undertake for the care of and support of a person with mental health from *Tandem's Rules of Association, 2019 p.2*

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Tandem Recommendations: Family and Carer Peer Support

In this report, we have provided further evidence to support the Tandem recommendations in our July 2019 submission, for the:

- **Benefits of investment in support for the Family/Carer Lived Experience Workforce**
- **Benefits of investment in peer support interventions that are family/carer peer-led and delivered**
- **Benefits of investment in stage of life appropriate peer supports for mental health carers and families**

Within this report Tandem makes 9 additional recommendations regarding family and carer peer support and the carer lived experience workforce.

Tandem's 4 recommendations: Addressing the urgent need for investment in the family/carer workforce

Tandem R1: **Provide resourcing for research to support understanding and development of the family/carer lived experience discipline**, including roles, responsibilities and support structures of the family/carer lived experience workforce. This will allow for critical knowledge needed to develop training for the workforce, and their co-workers and employers.

Tandem R2: **Establish principles, policies and guidance material to guide support for carers and families in mental health service settings** (inclusive of template position descriptions, core principles and practices, generic information sharing and documentation protocols).

Tandem R3: **Co-produce specialised training for the family/carer peer workforce.**

Tandem R4: **Establish minimum EFT of family/carer peer support workers and consultants.**

Tandem's 5 further recommendations: The benefits of investment in peer support across the life span, including interventions that are family/carer peer-led for mental health carers and families

Tandem R5: **Mandate a significant state-wide investment in the Family Carer workforce as 'core business'** as part of holistic multidisciplinary teams

Tandem R6: **Recurrent funding state-wide of family/carer peer support programs**, tailored to the needs of mental health carers and families and delivered across locations, including in regional and remote areas

Tandem R7: **Provide for flexibility through a range of access options**, including in clinical and community settings, afterhours access, online, phone, as well as in-person supports

Tandem R8: **Support recurrent investment in a range of interventions**, including individual and group, more intensive support options for carers and families who need the additional support, age appropriate programs to support young carers, diagnosis-specific interventions, and early intervention programs for families at the beginning of the mental health caring and recovery journey

Tandem R9: **Support recurrent investment in family/carer peer navigators** to support connection and access

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Tandem's Response: Peer Support Interventions for Mental Health Carers and Families

Tandem welcomes the request from the Royal Commission to elaborate on the recommendations noted below provided on page 11 of **Tandem's 2019 Submission to the Royal Commission into Victoria's Mental Health System.**

Recommendation: Mandate investment in peer support interventions that are family/carer peer-led and delivered

Recommendation: Mandate investment in stage of life appropriate peer supports for mental health carers and families

Interventions for mental health carers and families are diverse, including where they occur, if they are an individual or group approach, the duration of the intervention, and whether they are conducted by a professional or a person with lived experience of supporting someone with mental health issues (Ewertzon & Hanson, 2019). But, increasingly, support programs are being led by mental health carer peers (Farhall et al., 2020; Lobban et al., 2020; Zhou et al., 2020), with multiple studies evidencing many benefits to participants that go beyond the acquisition of knowledge.

Before we provide more detail on the recommendations above, we must alert the Commission to the fact that neither of these recommendations can be addressed without reference to the below recommendations also made in our initial submission on pages 11 and 12, as they are closely interconnected.

Recommendation: Mandate investment in workforce, in staff training and staff support so that consumers, families and carers receive therapeutic and compassionate care.

Recommendation: Mandate a significant investment in Family Carer workers across Victoria as part of holistic multidisciplinary teams. Currently, the Family Carer workforce is grossly over extended and under resourced to meet demand

In recognition that the Commission has had extensive evidence provided on the need to expand, support and provide appropriate training to the entire mental health workforce to ensure therapeutic, family inclusive relational and compassionate care, we will focus on the need to grow, support and invest in the family/carer lived experience workforce as a non-negotiable if any investment in peer support and peer led supports for mental health carers and families is to be effective and sustainable.

We also suggest this report is considered alongside 'A briefing note for the Royal Commission into Victoria's Mental Health System on implementation and sustainability of Family-Inclusive Practices (FIPs)' prepared by Petrakis et al 2020.

The Benefit of Investment in Support for the Family/Carer Lived Experience Workforce

Underpinning the delivery of family/carer peer-led programs and supports in a future Victorian mental health system is the need for investment in the development of the carer lived experience workforce.

Tandem recommends the development of a range of measures that will assist in attracting, retaining and better supporting carer/family lived experience workers in the mental health workforce, in order to see the full benefits for carers and families of peer-led interventions.

Current Issues & Challenges with the Family/Carer Lived Experience Workforce

- Inconsistent role definition and role clarity
- A poorly resourced workforce with limited career progression opportunities and pathways
- A lack of training and supervision that reflects the role
- Issues regarding documentation of carer contacts in consumer files

Inconsistent role definition and role clarity

Family/carer, as with consumer, lived experience roles in mental health services are often inconsistently defined, which contributes to role confusion, role creep, and worker burnout (Centre for Mental Health Learning Victoria, 2019, p. 16).

Family/carer lived experience workers, in consultant and peer support roles, have expressed pressure to respond to system demands and service culture issues at the expense of their core work role responsibilities (p. 16). In particular, there is a need for clarification around the difference in the work undertaken by family/carer consultants and carer/family peer support workers.

Whilst consumer and family/carer peer workforce guidelines are due to be completed sometime in 2021, led by the National Mental Health Commission, in the interim, there are no agreed principles or guidelines for family/carer or consumer work (p. 16).

Importantly, family/carer lived experience workers experience additional challenges with role clarity in working with carers and families within a system oriented around the consumer. The family/carer workforce express that support for carers and families often seems to be a 'tack on', or afterthought, rather than a central focus (p. 17).

A poorly resourced workforce with limited career progression opportunities and pathways

The family/carer, and consumer, lived experience workforce remains proportionally small in number of EFT. A survey conducted by DHHS in 2017 identified 341 lived experience workforce positions in Victoria, totalling 187 EFT: 238 consumer positions, and 104 carer/family positions (p. 17). These roles were employed 3 days or less per week (84 consumer, and 72 family/carer) (p. 17). Recent data, of the carer/family lived experience workforce, has shown a much further decrease.

Increasing demands on both workforces has been highlighted, lived experience staff report feeling pressured to prioritise other system demands, rather than their core role responsibilities (p. 17). Furthermore, workload demand impacts on their ability to access training and professional development opportunities.

A lack of training and supervision that reflects the role

Broadly, sufficient training and supervision is not easily accessible for lived experience workers. There is a lack of specific training designed by and for the lived experience workforce, which compounds the issues of poorly and inconsistently defined roles (p. 17). Carer and consumer consultants, particularly, describe working for years without access to training that supports them to understand and be effective in their role, and there is no designated, ongoing funding for peer support worker training (pp. 17-18). Furthermore, the personal cost of training is a significant barrier for lived experience workers, who typically are low paid (p. 18).

Opportunities for learning and development varies service to service and is often dependent on the value manager's place on the lived experience workforce. However, there is currently no specialised training about family/carer consultant work and no training for family/carer peer support workers, or in lived experience leadership (p. 18). IPS (Intentional Peer Support) training is written by and for consumer peer support workers, and does not speak to the family/carer peer role.

There are also challenges accessing effective supervision from management who understands the lived experience role and perspective. Discipline-specific supervision remains difficult to access, with insufficiently skilled family/carer perspective supervisor's available and limited training specific to this type of supervision (p. 18).

Issues regarding documentation of carer contacts in consumer files

A lack of clarity and consistency across services with documentation of family/carer contacts in consumer files is another challenge for the family/carer peer workforce in operating in consumer-centred practice environments (p. 17). The family/carer lived experience workforce express concerns that this compromises the carer or family member's privacy and could pose a risk to their relationship with the consumer (p. 17). Some workers keep a separate file for the carer/family member; however, this is performed on an ad hoc, inconsistent and unreliable basis. Standard guidelines and procedures are needed to support effective family/carer peer support documentation in mental health service settings.

What is needed to Support the Family/Carer Lived Experience Workforce

A stable, sufficiently resourced and supported family/carer peer workforce is needed in order to realise the benefits of peer support interventions for carers and families. As previously stated, Tandem makes 4 recommendations addressing the urgency for investment in the family/carer workforce**:**

Tandem R1: Provide resourcing to research to support understanding and development of the family/carer lived experience discipline, including roles, responsibilities and support structures of the family/carer lived experience workforce. This will allow for critical knowledge needed to develop training for the workforce, and their co-workers and employers

Tandem R2: Establish principles, policies and guidance material (inclusive of template position descriptions, core principles and practices, generic information sharing and documentation protocols) to guide support for carers and families in mental health service settings

Tandem R3: Co-produce specialised training for the family/carer peer workforce

Tandem R4: Establish minimum EFT of family/carer peer support workers and consultants

The Benefits of Investment in Peer Support Interventions that are Family/Carer Peer-led and Delivered

Extensive research shows multiple benefits for mental health carers and families, and consumers, of family/carer peer-led support interventions. They indicate what is possible, what needs to be considered, and what to strive for in future funded programs and supports.

Benefits for Consumers

Studies that have looked at carer peer-led family support groups have identified significant and consistent improvements in consumer's psychosocial functioning, psychotic symptoms and number of re-hospitalisations (Chien, Bressington & Chan, 2018). This in addition to improved consumer engagement in treatment and improved employment outcomes (Visa & Harvey, 2019), indicating that supporting family caregivers is beneficial to consumer recovery. Furthermore, the reduction in carer distress and improved communication serves to strengthen the relationship with the relative or supported person (Farhall et al., 2020).

The dual benefits for consumers and families by way of reduction in consumer risk of relapse and improved social functioning, along with reduction in family trauma and improved consumer and family/carer relationships, indicate the ultimate cost-effectiveness of such interventions and highlight the argument for investment.

Benefits for Carers & Families

The benefits for mental health carers, families specifically, who require support in their own right as well as for the health of the whole family, are varied and many. Extensive research demonstrates the following benefits for mental health carers and families:

Alleviates psychological distress: Peer work has been seen as particularly beneficial in reducing stigma and psychological distress. Of particular note are studies where participants are long-term carers, of 10+ years, in which results showed significant reductions in their distress. These participants may have knowledge of treatment practices; however, family/carer peer-led groups provide a dimension that raises their emotional experiences that has possibly not been apparent in other aspects of encounters with the health system (Farhall et al., 2020).

Increases hope and optimism: Witnessing someone who has had similar experiences but is now thriving, or managing well, gives carers and families an increased sense of hope and optimism (Fox, Roman & Morant, 2015).

Increases feelings of empowerment: Family/carer participants experience greater improvements in problem-focused coping and feelings of empowerment (Dixon et al., 2011; Shor & Birnbaum, 2012). Carers and families also feel more able to converse with care professionals and have a growing sense of expertise (Fox, Ramon & Morant, 2015).

Improves communication and family functioning: Studies have found improved communication and family functioning longer-term from family/carer peer-led interventions, such as the family-led Mutual Support Group (Chien, Bressington & Chan, 2018).

Reduces self-stigma and secrecy: Peer-led group interventions have shown significant reductions in self-stigma and secrecy, and may be more effective than clinician-led education (Perlick et al., 2011). The availability of even brief interventions that can help reverse the internalization of mental health stigma for

families is important as self-stigma adversely affects the self-esteem, social lives, and psychological health and wellbeing of families of persons with mental health issues that can lead to families being less likely to take constructive actions.

Provides practical assistance and support: Family/carer peer leaders are able to share relatable experiences of disorder management and coping strategies, including practical solutions, support and advice (Bademli & Duman, 2016).

Provides comfort and relatability: Carer participants feel more comfortable and less judged in the presence of the family/carer peer (Shor & Birnbaum, 2012).

Convenience and flexibility with access: Many family/carer peer-led support groups are able to occur at locations and times that are convenient to carers. Furthermore, some family/carer peer interventions provide services that can be accessed when required via internet or telephone support lines. These have been identified as useful for providing support when needed but also fitting in around other caring activities or work (Foster, 2011; Lobban et al., 2020; Shor & Birnbaum, 2012).

Access in remote and poorly serviced areas: Participants in studies where they were able to access family/carer peer-led support outside normal work hours were especially appreciative of this support, particularly for carers and families in rural or remote, or poorly serviced areas (Foster, 2011).

Growth of the family/carer peer worker: Becoming a carer peer facilitator promotes understanding and acceptance of the carer experience, where carer peer facilitators see positive changes in participants over time. The experience of helping others establishes unique new social roles and creates lives with a new sense of value (Kageyama et al., 2017).

Effective Carer/Family Peer Support Interventions

Benefits arising from carer peer-to-peer interactions have been suggested to occur through a number of mechanisms, including:

- Receival of support from others who have a similar lived experience
- An ‘all in the same boat’ feeling and shared belief among group members, which induces strong commonality and a sense of coherence, providing effective social learning and practical advice on effective caring strategies
- Improved mental health knowledge through shared language and understanding, and
- Enhanced knowledge, skills and social support for illness management, resulting in better perceived controls over family relationships and caregiving

Farhall et al. (2020) suggest a critical element for the effectiveness of family/carer education programs is the learning in small groups of peers with trained peer leaders who have also supported relatives with mental health issues. The stress buffering occurs through the social support gained from someone with similar experiences who is not distressed and perceived as capable of greater empathic understanding. The empathic understanding reduces the caregiver’s feelings of shame through normalisation by social comparison, enabling increased reception to informational support to alter the nature of the stressor or stress reaction (Farhall et al., 2020). Notably, long-term carers, of 10+ years, experienced reductions in carer burden, psychological distress and stigma through carer peer-to-peer support interventions.

As abovementioned, the cost-effectiveness of family/carer peer interventions is demonstrated through multiple benefits, immediate and long-term, for carers/family members and consumers (the whole family).

Effective models and interventions, nationally and internationally, exist for mental health carers and families and are described at length in ***Appendix 1: Table of Family/Carer Peer Support Interventions*.** This document outlines various programs and interventions shown to produce positive and lasting benefits for families in a range of settings and modes.

Considering Peer Support with Children and Young People in Families Effected by Mental Health Issues

While peer-led peer support interventions may not always be appropriate for children and young people, there are examples of alternative peer support models globally, as well as within Australia, that have been shown to significantly benefit children and young people in families impacted by mental health issues (Purcal et al., 2012; Stamatopoulos, 2016). Peer support has been identified by young people and professionals alike, as a necessary and helpful form of support, with a 2002 report highlighting increased peer support options for young carers as a Commonwealth identified need and goal (Foster, K, Lewis, P, McCloughen, A., 2014; Noble-Carr, 2002; Purcal et al., 2012). Within studies of children and young people who have participated in peer support programs or groups for children of parents with mental health issues (COPMI), participants expressed consistent themes of the power of shared experiences, recognising that you are not alone, and building social connections with peers (Grove et al., 2015; Floor van Stantvoort et al., 2014; Purcal et al., 2012).

When considering potential supports for children and young people in families impacted by mental health issues, it is important to remain conscious of the fact that although they are young, they may already have significant caring responsibilities that constrain aspects of their lives, in particular social outlets (Purcal et al., 2012). While many young people are proud of their roles as young carers, the ultimate aim of child and young carer supports should be to enable the young person to have agency and to shift the focus from 'care-giving' to 'caring about', so as to support the child/young person's right to a childhood and ensure their own needs as children and young people are being met (Diminic et al., 2016; Purcal et al., 2012). Ideally, the mental health system should function, so that children and young people are not placed in the position where they are compelled to provide care in order to keep their family member safe and their family together. However, fixing the system and providing supports to children/young people should go hand-in-hand, not be an either or. Peer support is just one aspect of a suite of supports that should be widely available and accessible to children and young people across Victoria.

Conceptualising Peer Support for Children and Young People

Peer support with children and young people often looks different to the carer and peer-led peer support interventions offered to adults. Programs incorporating peer support often cater to developmental age groups such as 4-8 years, 8-12 years, 12-18 years and 18-23 years (Reupert, A., Maybery, D., 2009). While the definition of 'young carers' is now widely accepted to include young people up to the age of 25, it is important to note the dearth of peer support options and literature on peer support for young carers in the 18-25 year age group. This presents an interesting area of consideration, as there are substantial opportunities for peer-led peer support interventions with the young adult age group, and indeed an expressed need as witnessed in our direct engagement with young adult mental health carers.

Typically, peer support programs for children and young people are framed around time-limited group-based leisure activities that are facilitated by professionals in the youth or mental health workforce. These professionals may have lived experience as carers, however it is rarely a requirement for facilitators of child and youth peer support interventions. While young people may not view adults with carer lived experience

as direct 'peers', adults such as those within the Carer Lived Experience Workforce may have an important role to play in the provision of peer support for children and young people in families where there are mental health issues.

Peer support interventions for children/young people often incorporate peer support and connection components into a broader framework of leisure, respite and psychoeducation activities and programs (Stamatopoulos, 2016). Peer support groups and programs are typically marketed at COPMI, however many are beginning to expand their definitions to include any children whose' families are impacted by mental health and/or addiction issues, such as those with siblings or close relatives experiencing mental health issues. Some peer support programs for older children, have evolved to incorporate peer-led co-facilitation by those who have 'graduated' from the programs, providing 'older' young carers the opportunity to be a role model for younger generations, whilst also building their leadership skills and capabilities. Certainly, we have heard anecdotal evidence from several young people who have participated in programs such as SKIPS, Space4Us and CHAMPS, where they spoke of the significant benefits and sense of pride they experienced after completing the programs; then going on to complete training to co-facilitate sessions for young generations of mental health carers and family members. While child and youth peer support models may not always be able to be peer-led, interventions that integrate peer support have been shown to be effective in:

- Supporting healthy connections and communication
- Increasing socialisation to combat isolation
- Reducing stigma through shared understandings
- Increasing resilience and hope
- Increasing understanding of mental health issues
- Increasing help-seeking behaviours
- Improving family connection and communication

Appendix 1: Table of Family/Carer Peer Support Interventions includes a summary of peer support interventions with children and young people, outlining several models and significant benefits they have for children/young people, parents and families as a whole.

Barriers to Peer Support for Children and Young People

Research has highlighted that children and young people in families where there are mental health issues can experience additional barriers to participation that may differ to those experienced by adult carers and family members (Price-Robertson, R, et al., 2019; Smyth & Michail, 2010). It is important to consider these barriers when making recommendations for peer support interventions, to ensure that children and young people across Victoria have the opportunity to engage meaningfully in peer support programs and groups. The most commonly reported barriers to children and young people participating in peer support programs are:

- **Access** – including transport, geographical location and internet/devices
- **Time pressures** – including juggling caring responsibilities, school, employment or extra-curricular activities (as often face-to-face programs are only offered at specific time/day)
- **Lack of referrals** – siloed service sectors such as mental health and child/youth services means that few professionals are aware of the programs available that they can refer young people to
- **Limited resources** – programs often exist under precarious conditions, propped up by inconsistent funding and often relying on the passion of professionals who go above and beyond in their roles in

order to provide peer groups as part of their service. When those staff move on, the programs can cease to exist in those catchment areas

- **Parental consent** – where the parent does not recognise they have a mental health issue, or where there are fears of social services intervening, it can be difficult for the child or young person to participate, this is of particular concern for children under the age of 16

The majority of peer support interventions for children and young people are offered in a face-to-face format, as this has been evidenced to support greater trust building and accountability, two aspects which are important for meaningful peer connections (Price-Robertson et al., 2019). More recently however, online peer support interventions have been trialled to resolve accessibility issues that many children and young mental health carers experience. Children and young people in regional areas, those with disabilities, highly stigmatised children/young people, and those without access to consistent transport, are often unable to take part in face-to-face peer support programs. Online peer support programs offer a solution to these issues. Additionally, some studies have suggested that online peer support options appeal to young people as 'digital natives', provide greater flexibility in delivery and may increase the reach for services, in terms of the distribution of resources and how many young people that can engage with over a period of time (Price-Robertson et al., 2019).

Notably, these studies have also advised of the shortcomings of only providing online peer support interventions, with many professionals raising concerns around the lack of connection and possibility of inappropriate and unsafe online interactions between participants (Price-Robertson et al., 2019). Integrally, the existing evidence-base endorses a combined approach of initial face-to-face peer support followed by options for online interventions. The provision of online peer support options as a follow-on to face-to-face interventions may also address a common criticism of child and youth peer support models, which is that they are frequently short-term and time-limited (Foster et al., 2016; Purcal et al., 2012). There is a need for further exploration of ongoing peer support interventions for children and young people, as research suggests that interventions provided over a longer period of time result in more substantial and enduring benefits (Foster et al., 2016).

The cost-benefit argument for investing in consistent peer support interventions for children and young people is most eloquently expressed by the programme director of a Canadian Young Carer Program:

> *"If we continue to look the other way and not address the impact caregiving has on these youth now, we will have to deal with it down the road as secondary users of a physical or mental health care system. It is crucial, therefore, that efforts at promoting recognition for these youth continue and that better methods at identifying, supporting and ultimately preventing their entrenchment in substantial caring roles are implemented" (Stamatopoulos, 2016, p 191).*

The Benefits of Investment in Stage of Life Appropriate Peer Supports for Mental Health Carers and Families

The benefits of family/carer peer support interventions for mental health carers and families, as described here, are clear and compelling; not just for carers and families themselves, but for consumers and the health of the relationship/s.

Tandem recommends investment in family/carer peer support interventions be implemented in a future Victorian mental health system, supported by recurrent funding and continued investment to meet the needs of families and carers across locations (particularly considering the needs of carers and families in regional and remote areas), the age span, and the stage of recovery in which families sit at any given time.

Where mental health family/carer peer programs have been implemented, they have been sporadic, with minimal funding to reach the need and be effective. Sustained state-wide investment needs to occur to support these programs to fully realise the positive outcomes for mental health carers and families that evidence demonstrates.

Ideally, investment would encompass a range of peer intervention types and modes of delivery, including one-on-one supports as well as group programs, online in addition to face-to-face sessions, diagnosis-specific peer support groups, and early intervention programs for families experiencing the onset of their family member's mental health issues, and targeted programs for young carers.

Supports should be accessible in a range of community settings as well as in clinical settings, but with consideration to flexibility for carers and families to access, including afterhours access, central locations, and online and phone options. Continued investment in family/carer peer navigators should also occur to support connection and referral pathways to family/carer peer supports and other supports for families in the community.

Tandem provides 5 further recommendations to the Royal Commission:

Tandem R5: **Mandate a significant state-wide investment in the Family Carer workforce as 'core business'** as part of holistic multidisciplinary teams

Tandem R6: **Recurrent funding state-wide of family/carer peer support programs**, tailored to the needs of mental health carers and families and delivered across locations, including in regional and remote areas

Tandem R7: **Provide for flexibility through a range of access options**, including in clinical and community settings, afterhours access, online, phone, as well as in-person supports

Tandem R8: **Support recurrent investment in a range of interventions**, including individual and group, more intensive support options for carers and families who need the additional support, age appropriate programs to support young carers, diagnosis-specific interventions, and early intervention programs for families at the beginning of the mental health caring and recovery journey

Tandem R9: **Support recurrent investment in family/carer peer navigators** to support connection and access

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Appendix 1: Table of Interventions for Family/Carer Peers Providing Support

Intervention	Description	Noted Benefits
Tandem Support and Referral Service (funded to July 2021) Tailored for family and friends in mental health, carers of those with mental health challenges and psychosocial disability.	State-wide short term service providing peer support, general advice, advocacy and information on services to meet needs, including: • Advocacy support and information on the Mental Health Act. • Identifying and supporting self-advocacy in navigation of complaints pathways. • Assistance in navigating and communicating with mental health services. • Assistance with referral to community and government agencies and supports. • NDIS support and advice on access and plan issues. • COVID-19 support for families and friends, wellbeing activities, and links to official information about the Pandemic.	• Carer peer support staff provide an understanding of people's journey, work with carers and families to build resilience and advocate for themselves. • Carer peer support staff include subject matter experts including regarding the NDIS and mental health related legal expertise. • Carers and families report feelings of being supported and their roles being validated and understood. • Carer/family members report feeling connected to others, feel informed and that they belong to a community.
Family Education Program (Peer Led) Known as: • Wellways' Building-a-Future program • Family-Led Mutual Support Group • Peer-to-Peer • Family-to-Family • Family Link Educational Program (FLEP) Peer workers are trained in facilitation skills, psychoeducation and support skills.	A flexible interactive client-directed approach for family caregivers which involves supportive sharing and information exchanges, problem-solving and caregiving skill practices during and after sessions. Content suggestions cover symptom recognition and treatment, crisis intervention from carer perspective, communication skills and coping strategies. Groups may decide to have ongoing meetings.	Participants: • Have lower levels of psychological distress and enhanced self-identity. • Feel better able to manage their situation through identification of practical caring options. • Feel socially supported. • Gain both theoretical and practical knowledge of illness, treatment and care practices. • Adopt new coping skills. • Increased hope and optimism for the future. • The first time for some carers they have felt able to tell their story • Additional benefit to carers who become peer workers (gain an added dimension with establishing unique new social roles and created lives with new sense of value).

Source: Walters, C. & Petrakis, M. (2020). A systematic mapping review of family carer perspectives about interventions designed to respond to their needs while supporting people with mental health challenges. Unpublished manuscript.

Intervention	Description	Noted Benefits
Remote Wellways Programme and Individual Emotional Support	Wellways is a group-based, family-to-family, education programme for family carers or friends of mental health consumers that aims to increase carer capacity to care effectively for themselves, their family, and the consumer. The 12-month programme comprises an initial 8 weeks of group education and discussion sessions with four follow-up sessions throughout the year. The emotional support offered to participants during the Well Ways programme aimed to provide individual emotional support in addition to the education provided by the weekly programme. The emotional support ranged from one-off sessions to intermittent or regular support over weeks to months, and was face-to-face, by phone, and/or by email.	• Few other options for help; appreciated opportunity to be heard; chance to experience unresolved loss and suppressed emotions; health professionals perceived as more interested in assisting family member; rural setting very challenging. • Strong connection and feeling well understood; a shared language (different to non-carers); acceptance; individual support outside sessions greatest appreciation; not alone in carer role. • Chance to explore different options: practical suggestions such as writing to people or taking notes to appointments; self-care strategies.
Family Psychoeducation with Carer Peer and User Peer Leaders (Qualified Social Workers)	The training programme was designed to focus on personal, practical and policy aspects of recovery. Participants were introduced to recovery, and invited to consider how a service user's recovery journey might relate to the carer's journey, and what recovery might mean in practice. Training covered how service users might develop their own wellbeing strategies, and introduced the WRAP tool (Wellness Recovery Action Planning).	• Carers moved to a model of enabling recognising the need for the service user to become independent. • Gained a sense of hope for their own and relative's future. • Gaining an understanding of recovery helped carers to feel more confident, have power and able to use the language of recovery. • Carers had raised expectations of their role and how to interact with professionals.
Carer Support Group with Early Intervention Program	Peer led support group held weekly over a 2-year period whilst also accessing early intervention program. During the support group, families share experiences and insights about caring for a person with psychosis.	• **Sharing with peers:** increased knowledge about navigating health care, identifying resources and understanding treatments. • **A time 'for them':** The carers group enabled space to acknowledge the need for self-care and the importance of hope. • **Gaining emotional support**: Compassion and empathy were identified as underpinning meetings.

Source: Walters, C. & Petrakis, M. (2020). A systematic mapping review of family carer perspectives about interventions designed to respond to their needs while supporting people with mental health challenges. Unpublished manuscript.

Intervention	Description	Noted Benefits
Web-based Peer Support	Online: The Relatives Education And Coping Toolkit (REACT) was developed with extensive input from relatives and clinicians. Peer support was provided through a moderated forum.	• Participants able to use when needed or at a time that suits their availability. • Appreciated the anonymous support.
Telephone Peer Support	A family peer support helpline designed to help family members of persons with mental illness was established by a self-advocacy organisation of persons with mental illness or family members of persons with mental illness. The organisation is operated by them without any professional involvement, and it provides a number of other services to its recipients of help (such as supplying written information needed for coping with mental illness).	**Key features of assistance:** Immediacy and accessibility of help • Understanding expressed by staff. • Not being left alone in a crisis: family peer provided support. • Practical guidance on how to interact with the health system. • Confidence to be an advocate for self and user. • Catalyst to connect to services. • Advice on coping strategies.
Carer Peer Support Worker Program	Designed to provide one-on-one emotional support, advice about financial support, practical strategies, information, advocacy and referral to other services through face-to-face or via the telephone.	• CPSW beneficial and valued emotional and practical support through mutual understanding and experience. • Able to tailor responses to need of carer with consideration for stage of caring and previous experiences. • Shared lived experience provided comfort, hope and empowerment; helped carers feel comfortable and less judged; felt less alone. • Practical advice and referrals to support measures such as vouchers and financial services especially valued.
The Family Community Navigation Specialist	They helped connect families to family-focused interventions (for example, family psychoeducation) and answered questions about service referrals. They bridged relationships between the consumer, family members, the community, and the treatment team. The F-CNSs also engaged in “resource mapping” of community resources for participants and their families.	• The Community Navigator provides support and advocacy and can identify and direct resources within the community.
Family Psychoeducation Intervention with Co-facilitated Carer Peer	Parallel clinician and peer-led information programmes for people with enduring mental health problems and for their family members and significant others. Programs have been co-produced, co-delivered and co-managed by users (service users	• Valued the opportunity to meet others in similar circumstances, share their experiences, learn from each other and provide mutual support. • Expressed feeling empowered.

Source: Walters, C. & Petrakis, M. (2020). A systematic mapping review of family carer perspectives about interventions designed to respond to their needs while supporting people with mental health challenges. Unpublished manuscript.

Intervention	Description	Noted Benefits
	and family members) in conjunction with mental health practitioners.	• Family member participants went on to form two separate peer support groups, as a follow-up to their experience of the programme.

Source: Walters, C. & Petrakis, M. (2020). A systematic mapping review of family carer perspectives about interventions designed to respond to their needs while supporting people with mental health challenges. Unpublished manuscript.

Peer Support Interventions for Children & Young Carers

Intervention	Description	Noted Benefits
ON FIRE peer support programme for children and adolescents in families with mental health problems Previously run by volunteers in NSW, a significant funding increase allowed for expansion across metro and regional sites, with an evaluation conducted in its first year of multi-site pilot implementation.	Peer support programme, consisting of fun-days and camps for children and adolescents aged 8–17 years living in families affected by sibling or parental mental health problems. Informed by positive psychology coaching philosophy, the programme has a strengths-based framework that aims to increase positive emotions; to enhance social belonging; to strengthen social–emotional life skills such as hope, positivity, resilience and positive coping; and to improve well-being literacy and build social capital. ON FIRE is not time limited. Children can enter the programme at any point during the year. Children are referred by schools, health services, Department of Community Services, women's refuges, non-government organizations and self and family/friends referrals. Core programme components are fun days and camps which are offered ongoing throughout the year. Fun days are day-long social outings (once every 4–6 weeks) at different venues. Camps were run over 2–3 days (twice per site). Camps included fun and leisure activities, combined with group work including peer support groups, mental health literacy groups and life skills coaching groups. 'Chat groups' (face-to-face peer support groups) were	• Connections with peers fostered resilience and helped alleviate feelings of stigma, isolation, and loneliness. • ON FIRE is distinct from other peer support programmes in that it is offered to a broad range of age groups (8–17 years); includes siblings as well as parents with mental health problems; and is ongoing rather than time limited (i.e. does not have a beginning and end point to the programme structure) • Participants developed personal strengths, and learned how to contribute to others' wellbeing. • Findings indicate that young people's abilities and perspectives of themselves and their situations have potential to be transformed by participating in peer support and to build resilience. • At baseline, adolescents in the ON FIRE programme were found to have significantly more difficulties on the SDQ scale compared to Australian averages. At 4 months follow-up, adolescents reported a reduction of the impact of these difficulties on their lives. • There was a statistically significant increase in 'hope' between baseline and 4 months in the programme. Importantly, 'hope' has been identified as a protective resilience factor for at-risk children. • An increase in positive affect was identified by trained observers.

Intervention	Description	Noted Benefits
	conducted at camps or fun days, providing the opportunity for small groups of children and a facilitator to discuss particular conversation themes relating to children/ adolescents in families affected by mental health issues.	
Kookaburra Kids Camp, developed by the Australian Kookaburra Kids Foundation	The two-day programme aims to i) provide respite, ii) provide psychoeducation, iii) promote help seeking and iv) facilitate connection to similar youth (Kookaburra Kids Foundation, 2014). Four overnight programmes occur yearly for different age groups: age's 8 to 10, 11 to 12, 12 to 14, and 15 to 17 years old. Educational activity booklets are provided which include developmental and age appropriate information about parental mental illness, how to access support, available supporting organisations, and healthy lifestyles (i.e. self-care). The programme was developed by mental health professionals and based on research outlining children's needs. The programme is delivered by volunteers trained by the Kookaburra Kids Foundation. Delivery and content of the programme is similar across ages and programmes. Youth are self-referred via their parent or through health care professionals (family doctor or mental health clinician). Mental illness diagnoses are self-reported by the parent. Parents with a mental illness are or have been in a treatment or recovery programme.	• Participants expressed an increased connection with peers where they felt a shared understanding and reduced stigma to share their experiences. • There was also an increased connection at home, as children felt more comfortable discussing their parent's mental illness with them. • Children noted that the programme was a form of respite for them, and some commented that it was important that their parents did not attend so that the young person did not have to think about their caring role and could focus on enjoying the camp. • Attendance at the camp lead to an increase in the child's mental health literacy, their understanding of their parent's mental illness and the episodic nature of mental health issues. • Increased understanding of their parent's mental health issue in combination with peer support connections assisted with negating feelings of blame or guilt many young people had before attending the camp. • After attending the peer support programme, participants commented on 'seeing their parents differently', understanding that it is not the child or parent's fault when they experience episodic mental health issues. • After attending the psychoeducation peer support group, participants felt more comfortable to share that their parent had a mental illness with others outside of the program, such as a close friend or calling Kids Helpline. Though several were still concerned about bullying at school if they shared their story with their peers.
PIEP said the mouse – A Dutch Peer Support Programme for Young Children	'PIEP said the mouse' is a preventive intervention for children aged 4 to 8 who live with a lot of tension and stress at home (defined as psychological problems or addiction in the family, family breakdown or family violence).	• Children have fun and socialise whilst developing protective factors enabling them to express emotions and ask for help when needed. • Parents develop understanding of the impact on the child, connect with other parents, with the option for further tailor-made support

Intervention	Description	Noted Benefits
(The name of the program is taken from the hand puppet PIEP the mouse, which is used to talk to the children)	The goal is to support these children and to strengthen protective factors to promote healthy development. The program includes parent meetings with the option to organise tailor-made support for parents. The intervention consists of four parts: • Informing the network • Children's group of 14 meetings • 4 parent meetings • Tailor-made support from a family counsellor 'PIEP said the mouse' is free for the children and parents. Children's group: The children come to a weekly children's group 14 times, where they play, craft and sing. Every week they learn in conversation with the hand puppet 'PIEP the mouse' to express their feelings and to talk about what they are experiencing at home on the basis of themes such as being afraid, happy or feeling strong. The goal is for them to better understand and deal with events at home. In addition to support, there is also room for relaxation. Parent meetings: Parents learn what their child does during the children's group and why. During these meetings, the possibility of tailor-made support can be presented to the parents by a family counsellor.	• Group facilitators work together with welfare work, mental health care prevention and public health services (this may vary per municipality). • The approach is low-threshold and therefore also suitable for low SES families, which are poorly reached by regular preventive assistance. The intervention is also suitable for families with diverse cultural backgrounds.
'Do-support group'– A Dutch peer support group programme for	The 'Do-support group' is a safe meeting group for children between 8 and 12 years old, who grow up in a family with at least one parent with psychological or addiction problems, which discusses in a playful way how you can as a child cope with your parent(s) problems. The aim is to prevent the child from developing psychological problems themselves.	• Gives children an opportunity to relax and play with like-minded people outside of the family in a safe environment. • Children experience a sense of not being 'alone' or 'othered' as they meet children with similar experiences and home lives.

Intervention	Description	Noted Benefits
primary school aged children	The 'Do-support group' consists of 8 meetings of one and a half hours for the children and 2 parent meetings of one and a half hours. There is also a workbook for parents. The children are working on: • reduce feelings of guilt, shame and loneliness • improving the sense of competence and coping skills • become aware and use the social network Work is being done with parents to raise awareness of the consequences of their problems for their child and to improve the interaction with their child.	• Children develop an understanding of what is going on in their family/for their parents and develop skills and strategies to express their emotions. • The program also supports psychoeducation for parents, where they too have an opportunity to connect with parents with mental health and/or addition issues which helps reduce stigma. • An evaluation using a control group where children only participated in group-based leisure activities, demonstrated the specific benefits of peer support and psychoeducation. When children in the control group began discussing their parent's mental health, the group leader spoke with the child separately to the rest of the group, a very different approach to that of the peer support groups. Notably, the control group did not experience the same benefits overtime as the intervention group, who received specific peer support interventions in conjunction with leisure based activities. • Children experienced a greater decrease in negative cognitions and sought more social support immediately after participation and 3 months later, compared to children who engaged in three leisure activities instead (control group). • One year after attending the peer support group, emotional and behavioural problems of children in the group had declined to just below the sub-clinical threshold level.
Talk-Link – telephone group counselling for young carers **Young Carers NSW**	Sessions are provided free of charge, one hour a week for 6 to 8 weeks, with young carers linking up from their homes. Talk-Link offers participants 'the chance to talk to other young carers who are in a similar situation', whilst having the professional support of a trained counsellor. Two trained counsellors and six young people can participate. Counselling has been organized for three different age groups: 8–12, 13–17 and 18–25 year olds.	• Helps young carers make new friends, share their feelings, enhance their coping skills, talk with people who understand them and reduce their feelings of isolation. • In offering these types of assistance over the phone, the programme responds to widely acknowledged constraints faced by young carers, such as transport restrictions, and difficulties attending meetings outside their home due to caring responsibilities.

Intervention	Description	Noted Benefits
	Talk-Link is provided on a short-term basis and is aimed at helping young carers cope with their caring. It provides counselling, access to peers and the opportunity to share helpful information, for example on other services.	
CHAMPS (Children and Mentally Ill Parents) – A psychoeducation peer support program for children	CHAMPS is a peer support program for children of parents who have a mental illness or mental health issues. The CHAMPS programs are for children aged between 8 and 12 years, although there is flexibility depending on their developmental maturity. CHAMPS programs can run in various formats: • After-school programs. • School holiday programs. • Camps. and may be supplemented by specialist programs such as Martial Arts as Therapy (MAT) program and graduate groups offering ongoing support and connection such as 'Kids Club'. Parent groups are also run in more recent versions of CHAMPS, and it is recommended these are held concurrently with the children's groups. The aim of CHAMPS is to give children and parents opportunities to spend time with others who may have had similar experiences to gain support and age-appropriate information about mental health and illness. These programs compliment the support provided by other workers who support families affected by parental mental illness.	• Enables families to have open conversations about mental health • Provides children with age appropriate information and support and the opportunity to form social connections with peers. • In the 2019 evaluation, over 90% of the children said that they had learned things at CHAMPS; most common was that they had learned about different types of and the effects of mental illness. • Children reported that they learned what to do if their parent is unwell. • Children felt more confident to talk about mental illness in the home and have an increased confidence to ask for help after completing the program. • Many children said they had fun with activities, and enjoyed sharing food with peers. • All parents said the program had assisted their child in some way and that they would recommend the program to other parents. • Parents reported that peer support for their child (the child learning that they were not the only one with a parent with a mental illness) was significant. • 2019 evaluation found that peer support is the most important component of the program. Supporting peer connections should not be limited by adherence to content.
Cowichan Young Carers Program – A Canadian peer programme	The Cowichan Young Carers Program combines aspects of peer support with other modes of assistance, with the aim of involving young people in a leadership capacity to build awareness on young carer issues, particularly within schools.	• A collaborative approach with the school board district allowed for a 'volunteer course credit' to be applied for all students, supporting many young carers to be able to graduate and acknowledging the additional skills and knowledge their young carer experience brings. • Builds on young carers existing skills, developing further leadership capabilities and empowering them to share their experiences to educate their peers.

Intervention	Description	Noted Benefits
	The program developed a 'Youth Resource Team' (YRT) comprised of the programme director, local youth (both young carers and non-carers) and a handful of adult volunteers. They held bi-weekly meetings which resulted in: • The creation of a documentary film (Ending the Silence) • A curriculum guide for educators, both of which are available for purchase by schools and community organisations; • More than 80 presentations made to various local schools, community organisations and public officials; • The design and execution of an annual youth-based conference (with young caring being the underlying theme) drawing in an average of 100 students from 10 neighbouring schools; • A consultative role in the Action Canada Task Force (2013) dedicated solely to raising awareness for this 'invisible population'.	• Utilises aspects of peer support to generate awareness raising and educational resources. • Enables stronger peer-to-peer connections between young carers and non-carers, breaking down stigma and the feelings of isolation.