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CIRCLE OF SUPPORT

SUPPORTING FAMILIES
AND THEIR INVOLVEMENT
IN YOUTH MENTAL HEALTH

ACKNOWLEDGEMENTS

This policy paper was developed by Orygen.

Orygen acknowledges the families of young people who have or continue to experience mental ill-health for participating in focus groups for this project. Family members participated in two focus groups in January 2020, generously sharing their experiences and providing insights into how families could be better supported and involved in the mental health journey of their young person.

Orygen also acknowledges the provision of information, advice, peer-review and feedback from colleagues. The final report reflects Orygen's analysis and independent conclusions. It may not necessarily reflect all the opinions or conclusions of key contributors.

Orygen recognises the significant role that friends can play in supporting young people. The focus of this policy paper, however, is limited to families. For the purposes of this project, the term 'family' includes parents, extended family members, adult support people, siblings and partners.

ACRONYMS

ASIST	Applied Suicide Intervention Skills Training
FFT	Functional Family Therapy
FPSW	Family peer support worker
GP	General practitioner
MBS	Medicare Benefits Schedule
MST	Multi-Systemic Therapy
NMHC	National Mental Health Commission

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ISBN 978-1-920718-55-8

Suggested citation Baker, D. Circle of support: Supporting families and their involvement in youth mental health. Melbourne: Orygen 2020.

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Orygen acknowledges the traditional custodians of the lands we are on and pays respect to their Elders past and present. Orygen recognises and respects their cultural heritage, beliefs and relationships to their ancestral lands, which continue to be important to First Nations people living today.

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EXECUTIVE SUMMARY

The experience of mental ill-health impacts young people and their family. Implementing family inclusive practice orientates clinicians and services to the supportive role families can play in a young person's engagement with services and treatment adherence. Family members can also have a need for their own support. Developing peer support roles for siblings is an opportunity to improve support for families.

Family involvement in treatment can also be beneficial and there are therapeutic approaches that can support improved relationships within families. Guidelines for family involvement in treatment decision-making would enable improved family inclusion.

Two complementary roles support family inclusive practice in clinical services (family workers) and lived experience support (family peer support worker). Service coordination of these roles will optimise the provision of support for families.

Policy solutions to improve support for families were developed through focus groups with families, consultation with Orygen staff working in peer support, clinical practice and research, and analysis of current evidence.

PATHWAYS FOR FAMILIES TO SEEK HELP

Family members involved in caring for a young person experiencing mental ill-health are at risk of a variety of negative outcomes. Family relationships, work and finances and friendships can all be points of strain. Family members need to be supported to identify their need for support. The focus of family support is often centred on parents, more attention is needed in developing and implementing support services for siblings and partners.

As mental health symptoms emerge, family members may have to deal with challenging behaviours and increasing symptom severity. The demands of supporting a young person can result in family members needing personal and therapeutic support for themselves. Support for families includes learning about mental ill-

health, social and emotional support, therapeutic support for themselves and instrumental and crisis support for their role as a support person.

POLICY SOLUTIONS

- Family informed development of support resources.
- Enhanced roles for family workers to support implementation of family inclusive practice.
- Developing peer support for siblings.
- Trial a centralised sibling peer support model.
- Evaluate the provision of training for families through the National Suicide Prevention Trial.

STRENGTHENING OPPORTUNITIES TO INCLUDE FAMILIES

For many young people experiencing mental ill-health, family members are their primary support people and they need to be supported to fulfil this role. Family members can be included in a young person's mental health treatment in different ways. Clinicians and family workers can support young people to identify how their families can be included. While families can often provide insights into their young person's experiences, they are sometimes frustrated by not being engaged. Involving families in care can be enabled through dedicated staff roles and programs, and through interventions that have been developed with a role for family.

POLICY SOLUTIONS

- Practice guidelines for family inclusion in treatment decisions.
 - Develop the evidence base for interventions that include families.
 - Involving families in making successful transition to adult services.
-

IMPLEMENTING FAMILY PEER SUPPORT WORKER ROLES

Family Peer Support Workers (FPSW) generally have a lived experience of a similar caring role from which they can draw to support the families of young people receiving mental health care. The support FPSWs can provide is varied and can include: information and access to support services, support when families feel socially isolated and contribute to delivery of family inclusive practice.

Implementation of FPSW roles in mental health services can face barriers. A service preparing to implement FPSW need to consider what organisational change may be required, develop training and support for staff to prepare them for working with the new role, and defining the role and identifying how it fits into a service.

Program logic to guide implementation of FPSW roles in mental health services is appended to this policy paper.



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For many young people experiencing mental ill-health, family members are their primary support people”

SUPPORTING FAMILIES

Family members can play an important role in supporting young people experiencing mental ill-health. For many young people it is their family who provides a pathway to mental health services and supports help-seeking.(1) Reflecting this, greater family connectedness was adopted as an item for measuring improved outcomes in the Fifth National Mental Health and Suicide Prevention Plan.(2) The Productivity Commission draft mental health report estimated the cost of informal care provided by family and friends to be \$15 billion per year (2018-19).(3) An over-reliance on family for support, however, can come at a personal cost.

While the influence of family lessens as a young person grows older and their circle of support widens (4, 5), there remain support opportunities at every stage from help-seeking, through engagement and understanding mental ill-health to implementing treatment plans. Engaging family members to be involved can support a young person's treatment attendance and adherence.(6)

A young person's experience of mental ill-health, service access and participation in treatment can sometimes place considerable pressure and strain on other members of the family. This strain can negatively affect family relationships and wider social supports, family member's capacity to work or study and their capacity to support their young person. Despite the possible need for support themselves, anecdotally family members are less likely to seek support.(7) Supporting families to care for themselves and other family members also puts them in a better position to support their young person, including the opportunity, if appropriate to be involved in their treatment.

FAMILY INCLUSIVE PRACTICE

Family inclusive practice involves orientating mental health services and clinical practice to include families in a young person's care. Engaging family members can support a young person's treatment attendance and adherence in many ways, such as providing transport to

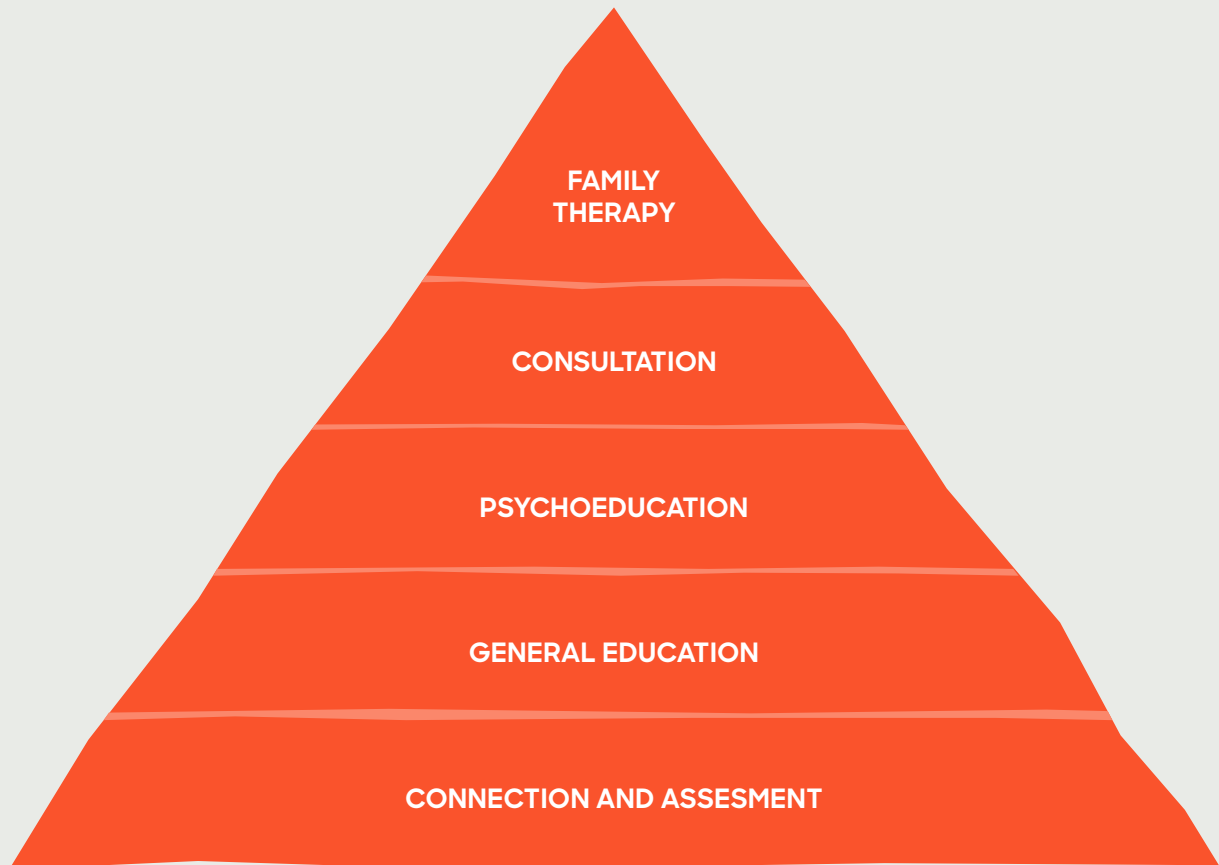
appointments, supporting ongoing participation and reinforcing psychoeducation.(6) Family inclusive practice begins with a service wide approach through which structured practices can be implemented.(8) Structured family inclusive practices include engaging families together with a young person to understand their experience, determining the direction that treatment may take and the relevance of involving family in treatment or providing family-based interventions. The transition to family inclusive practice is also an opportunity to increase the support provided to families.

The mental health staging model sets out the potential range of experience from emerging risk to recurrent and persistent illness. How a family can be supported to access support for themselves and be involved in supporting a young person differs at the stage of mental ill-health: from initially not knowing where to access information, to the risk of dislocation if a young person is hospitalised or experiences the effects of a persistent disorder. Services and clinicians need to adapt the level of support for families to the reflect the stage of symptomology and associated level of service involvement and types of treatment.

At every stage there is an opportunity to engage families and provide avenues for support and involvement. How families can be included and the type of support they themselves may need will shaped by the type and severity of disorder a young person is experiencing and the level of service and treatment they receive.

How a family can be supported to access support for themselves and be involved in supporting a young person differs at different stages of illness and engagement with a service. The pyramid of family care (see Figure 1) provides an example for how the level of support changes as severity increases.(9) Specific roles have been developed to provide support to parents (family peer support workers) and facilitate their inclusion in a young person's treatment (family workers).

FIGURE 1 PYRAMID OF FAMILY CARE



IN THIS POLICY PAPER

The importance of supporting families and involving them in a young person's care is widely recognised. This recognition is reflected in government strategies, service and practice guidelines and resource material for families. For example, in Victoria, the Chief Psychiatrist has published guidelines for working together with families and carers that addresses their involvement, communication, responding to their needs and inclusion in governance. The document includes a self-assessment tool for services to measure compliance with the guidelines.⁽⁷⁾ Mind Australia and Helping Minds have developed six partnership standards for family engagement that provide a framework applicable at an organisational, service and individual clinician and staff level.⁽¹⁰⁾

There are barriers to the implementation and practice of family inclusion. These barriers are structural (i.e., service system models, resource constraints) and cultural (i.e., entrenched attitudes and practices, family expectations) and require policy solutions that enable support for families and their inclusion in care of their young person.

This policy paper explores further opportunities to build on family inclusive practices policies developed in the 2019 Orygen policy paper *We're in this together: Family inclusive practice in mental health services for young people*.⁽¹¹⁾

PATHWAYS FOR FAMILIES TO SEEK HELP

For many families help-seeking is a reoccurring challenge. At the outset they need to learn about mental ill-health, then navigate services as well as supporting their young person to seek help. Once their young person is receiving treatment families and individual family members themselves will likely need some form of support. Understanding their own needs and where to find support can present further challenges. Pathways for families to seek help need to be promoted by mental health services and where missing pathways need to be laid.

NEED FOR SUPPORT

Family members involved in caring for a young person experiencing mental ill-health are at risk of a variety of negative outcomes. Increased levels of stress and strain on families is widely recognised.(12, 13) Potential consequences from the strain include; increased risk of relationship discord,(14) missed workdays, reduced hours and productivity(15) and financial problems.(16) The negative impact on family relationships and available social support in particular was raised by parents Orygen spoke to for this project. The impact of these stressors can result in reduced access to support services.(17) There is a role for mental health services to provide support for families or regularly inform them of the available options. When caregivers are supported they are better able to cope with the challenges of providing care.(18) Family members need to be supported to identify what support they need and how to access it.

Despite the need for help families often feel unsupported. The Productivity Commission draft mental health report found that a quarter of primary carers, caring for someone (not just young people) experiencing mental ill-health, have unmet needs for carer support services. (3) In England, the Association for Young People's Health have identified that parents of adolescents are the most unsupported parent group, with those caring for a young person experiencing mental ill-health particularly isolated.(19) While there is awareness of the

WHAT FAMILIES TOLD US

ADVICE

- Family peer support workers can provide knowledge when a family is overwhelmed, but that there is no one to connect with siblings.
- Parental advice services were helpful, but need to be available around the clock. It was suggested that having someone visit the home to provide advice would be helpful.

SUPPORT

- A family's need for support fluctuates and does not always align with what support is provided.
- There is a need for ongoing support during treatment including safety. The idea of home visits from a mental health equivalent to the maternal health nurse was popular.
- The discharge process can be traumatic, the potential for brief Prevention and Recovery Care stays and the importance of referral to mental health knowledgeable GPs were discussed.
- Family therapy is needed once a young person's mental health begins to improve because the family may continue to struggle or at this point the impact of the strain becomes apparent.

TRAINING

- Suicide awareness training was helpful for one parent who found it strengthened the relationship with their young person.
- Ideas for training included; options for shorter courses, flexible delivery and tailoring courses to diagnosis.

pressures faced by families it has not been a consistent feature of mental health studies with young people(20) highlighting a need to routinely include families in research. When families are supported they are better able to cope with the challenges of providing care.(18)

Where recognised, the need to support families has tended to focus on parents or adult support people leaving siblings and partners with fewer formal support options.

SIBLINGS

While there is emerging recognition of the need to support the families of young people experiencing mental ill-health, this support is often focused on parents or caregivers. The experience of siblings includes mixed emotions of resentment and guilt stemming from reduced parental focus, the need to be more self-reliant, overcompensating for their own behaviour and unmet needs for parental support. Alongside this experience they can also feel as if they have 'lost' their sibling.(11) To better support siblings through these experiences there are opportunities to:

- Provide appropriate information about what is happening for their sibling and reassurance that they are not alone, not to blame and not responsible for 'curing' their sibling.
- Allow a sibling the freedom to grieve their sense of loss and to have their own time and space, and own time with friends and extended family.
- Establish and maintain structure and routine in their daily lives and maintain a line of open communication that works for them.
- Provide opportunities to connect with other siblings in a similar situation.(21)

It is particularly important to understand the experience of young siblings who are also in the age range (12–25 years) during which the onset of mental ill-health is greatest. Existing supports for siblings provide direction for the development of sibling support in youth mental health services. For example, family functioning interventions have shown promise with children and could be adapted for adolescent and young adult siblings(22) and positive psychological outcomes from wellbeing interventions with siblings of young people with chronic physical and/or mental health illness.(23)

Siblings Australia provide resources and host a social media platform to provide support for young people who have a sibling with a disability. There is an opportunity to develop specific resources for siblings of young people experiencing mental ill-health.

Age and gender are factors in the level of impact a young person's mental ill-health has on a sibling. Female siblings are at higher risk of negative outcomes with younger sisters reporting the highest level of negative experience and older brothers the lowest. These differences can inform how clinicians identify need for support and the level of intervention that may be required.(24)

Approaches to engaging and supporting siblings need more attention and will be influenced by the mental health symptoms a young person experiences. Supporting sibling relationships provides a chance to enhance understanding and empathy, support sibling-parent relationships and provide opportunities for help-seeking by siblings.

PARTNERS

Some young people experiencing mental ill-health and receiving treatment will have partners. A partner may need their own support as well as wanting to be part of caring for a young person. Where a partner is also a young person clinicians, youth peer workers and services will be well placed to adapt information and support to inform and meet their support needs. Supporting communication between a partner and family of a young person is also important. The foundation for this communication during a mental health episode or treatment will be the pre-existing relationship between a young person's partner and their family.

The emergence and role of romantic relationships in a young person's development is a complex field of study and will not be covered here. What needs to be noted, however, is that developmental stage, wellbeing and the functioning of relationships are interlinked. Positive family climate, competent parenting and engagement have been found to inform young adult romantic relationship functioning.(25)

While many of the avenues for involving families in care are suited to also including partners the potential for competition around who has the primary support role, especially during a time of crisis may need to be managed by clinicians and family workers. Similarly, peer support for family members may need to be offered separately to partners and parents.

POLICY SOLUTION	EVIDENCE AND RATIONALE	OUTCOME	MECHANISM
PROVIDING INDIVIDUAL SUPPORT NEEDS FOR FAMILY MEMBERS			
<p>Service approaches to family inclusive practice recognise the potential need for different types of support for individual family members.</p> <p>Roles and programs need to be tailored to the types and stage of illness treated in a service.</p> <p>Novel approaches informed by consultations with families about what they would find helpful need to be explored.</p> <p>Dedicated family program funding is required for family support services and transition to family inclusive practice.</p>	<p>Family members involved in caring for a young person experiencing mental ill-health are at risk of a variety of negative outcomes. Despite the need for help families often feel unsupported and what support is available is often focused on parents or adult support person.</p> <p>Families suggested that home visits from a mental health (similar to the maternal health nurse) and that brief stays in Prevention and Recovery Care following discharge would be helpful.</p> <p>Approaches to engaging and supporting siblings need more attention.</p> <p>Some young people experiencing mental ill-health and receiving treatment will have partners. A partner may need their own support as well as wanting to be part of caring for a young person.</p>	<p>Individual family members have access to appropriate support.</p>	<p>Commonwealth Department of Health, state and territory health departments, mental health services.</p>

TYPES OF SUPPORT

A range of supports can be needed by families for themselves and in caring for their young person. This variation will be informed by the personal circumstances, the stage of illness their young person is experiencing and their own experiences. Support for families includes learning about mental ill-health, social and emotional support, therapeutic support for themselves and instrumental and crisis support for their role as support person.

As mental health symptoms emerge family members may have to deal with challenging behaviours and increasing symptom severity. Caregivers are required to balance the home environment with arranging for and coordinating appropriate treatment, educational, and recreational opportunities.(26, 27) If a young person's symptoms become more severe, reoccur or persist families will need a level of support that reflects this advanced stage of ill-health. This support may include more practical, clinically informed advice, having a service contact they can go to for help to support their young person and access to crisis support. Parents engaged for this project described for Orygen their need for short/medium respite periods to enable them to run errands and

take time to look after their own wellbeing and relationships. They also identified the importance of being able to contact clinical services for information and support in responding to an issue or crisis.

The demands of supporting a young person can result in family members needing personal and therapeutic support for themselves. These differing needs, personal and therapeutic, align with the different roles within mental health services. Family Peer Support Workers (FPSW) can provide support from a shared or similar experience and family workers can provide therapeutic support through family therapy.

PSYCHOEDUCATIONAL SUPPORT

During the early stages of a young person's experience of mental ill-health families will require knowledge about mental health and available service options. Families who do not have access to education and support services have been found to have higher levels of strain related to this role, lower family functioning and higher levels of internalising and externalising symptoms.(28) Psychoeducation for family members can give them confidence in their supportive role for a young person.(29) Once their young person is accessing care, family

members can find themselves recognising their own need for social and emotional support. For others they will need to be supported to recognise this opportunity.

For most young people and their families, a general practitioner (GP) is the first health professional they turn to for help. The level of knowledge and expertise a GP has in treating a young person will vary. The stage of illness and presenting symptoms will also be a determining factor in the level of care a GP can provide and the support they can offer a young person and their family. GPs need information about mental health services in their vicinity and access to psychiatric advice to inform the care they can provide.⁽³⁾ Families need concise, accurate advice about mental disorders and available support services.

Support resources from youth mental health services provide information and guidance for families about treatment and answer common questions about mental ill-health and young peoples' experience. Family self-care and recovery from mental illness, is a detailed guide to family support from Canada.⁽²¹⁾ With the input of family members (including siblings) the guide is intended to support the families of people experiencing mental ill-health to be informed caregivers as well as to care for themselves and other family members. Similar guides are available in Australia from state and territory health services. For example, the Mental Health and Carer Information Guide in New South Wales. The quantity and quality of resources varies. Developing resources in conjunction with families will enable resource material to address the questions families have and the avenues to seeking support they find helpful.

POLICY SOLUTION	EVIDENCE AND RATIONALE	OUTCOME	MECHANISM
FAMILY INFORMED DEVELOPMENT OF SUPPORT RESOURCES			
<p>Service providers undertake a three-year development, evaluation and renewal cycle of support materials for families that incorporate family input and review.</p> <p>Co-design principles be employed to place family members at the centre of the process.</p> <p>Distribution strategies also be developed to ensure relevant and acceptable formats and distribution channels are used.</p>	<p>To be prepared for a supportive role and self-care for themselves and each other family members need information and education about mental ill-health, support options and self-care.</p> <p>Developing resources in collaboration with families will enable resource material to address the questions families have and the avenues to seeking support they find helpful.</p> <p>There is a need to evaluate the effectiveness of communication and distribution of support resources.</p>	<p>Families are better informed about available support.</p>	<p>Primary Health Networks, lead agencies and mental health services.</p>

ONLINE INFORMATION

Online information resources are readily available to families with internet access. In addition to the Australian Government's Head to Health website are other websites provide by mental health organisations such as Orygen, Beyond Blue, headspace and ReachOut.

ReachOut has reported that one-in-two parents are be likely or extremely likely to use an online search as part of informal support.⁽³⁰⁾ Among health and education professionals working with young people, there is broad demand for online information and guidelines they can provide for parents to assist them in supporting their young person with their mental health.⁽³¹⁾ Online resources are widely accessible by a majority of families and there has been an emphasis on

ensuring that evidence based information is provided and the presentation is accessible to the intended audience. There is, however, a need to evaluate the effectiveness of communication and comprehension of information.

SOCIAL AND EMOTIONAL

Families and individual family members have their own need for social and emotional support. The need for support can continue and sometimes increase after a young person's mental health begins to improve. There is a role for mental health services in providing social and emotional support for families or referral to relevant services. Where support cannot be provided within a service, a warm referral in which staff

or clinicians assist family members to make an appointment with a support service is advised.

Caring for a young person experiencing mental ill-health can result in social isolation. Stigma and judgement can mean family members establish a protective distance between themselves and family, friends, and the wider community. (32, 33) Family members told Orygen about their experience of they and their young person's friends withdrawing from friendships during mental health crisis and treatment. This is a common experience for families.(34) Families that are socially isolated need access to formal and informal support networks and support to maintain their own friendships and social support.

Face-to-face groups and online forums can provide emotional support for families. Face-to-face groups (facilitated by FPSWs where available) can provide mutual support for families and a forum for sharing experiences. Online forums (such as that hosted by Beyond Blue) can provide a safe environment to ask questions and also find support. Siblings also have a need for social support and a chance to ask questions as well as a need for respite, education support and diversion activities.(35) More effort is required to develop support services for siblings (discussed further in the peer support section below).

Maintaining contact with friends and making time to spend time together can be an important support for family members in debriefing their experience or providing respite.(21) Family members engaged for this project and in the literature report social isolation due to stigma and a lack of understanding undermined their ability to call on their own circles of support.(34) Time with one friend might be a chance to talk through what is going on, while time with another might be limited to only discussing shared interests. Social contact or support is also available through going to work or volunteering (if either is possible), attending family support groups and continuing to attend a sporting club, faith based group, choir, book club or other hobby group. Families that are socially isolated need access to formal and informal support networks and strategies to maintain friendships and social support.

Practical resources are another way families can be supported to care for their wellbeing and ensure they practice healthy habits. A simple example is a self-care chart. Similar to a weekly planner or timetable, people identify activities that are socially and emotionally beneficial. The chart helps a person identify how often, with who and ways to maintain activities.(21)

Families also need to remember to continue to do what is important for them. For example, ensuring family celebrations and rituals are maintained. Locking in some time each week

to spend together that everyone has a part in organising (i.e. watching a movie, going out for a casual dinner) will help maintain family relations and support everyone.(21) While 'fun' or 'play' will be different for each family the need is similar.

FAMILY RELATIONSHIPS

A young person's experience of mental ill-health can place families and their relationships under strain. This can affect their ability to achieve tasks and perform roles, communicate and express feelings, be involved in one another's lives and a shared family life.(36) Recognising how a young person's changing contexts can impact receptiveness to treatment (37) is an opportunity to minimise those impacts, including enlisting family support for a young person's engagement. Family work and therapy are components of family inclusive practice that can support families and young people.

FAMILY WORKERS

Family workers work alongside clinicians to involve family members in the care their young person is receiving. Time is a primary barrier to clinicians providing support to families to enable them to support their young person. This role includes helping to create a caring, non-blaming and respectful environment. They may provide brief interventions for the family in supporting the recovery of the young person.(38) Through integration into the treatment team a family worker can support a clinician (including the development of their skills in this area) to involve families in the treatment of their young person. (39) The inclusion of family workers in treatment teams can build more effective family inclusive services.(40, 41) It cannot, however, be left to clinicians to involve families, all staff at a service or on a ward need to be actively engaged.(42) Family workers are an enabler of family inclusive practice in youth mental health and for access to more structured family support and inclusion.

The emergence of youth mental health services has been premised on the needs of young people between childhood and adulthood. While most young people individuate from their family during this developmental stage and treatment responses respect this process families are still a recognised source of support for many young people experiencing mental ill-health. Family workers can facilitate this process by enabling supportive and understanding family relationships.

POLICY SOLUTION	EVIDENCE AND RATIONALE	OUTCOME	MECHANISM
ENHANCED ROLES FOR FAMILY WORKERS TO SUPPORT IMPLEMENTATION OF FAMILY INCLUSIVE PRACTICE			
<p>Family workers enable family involvement in a young person's treatment decisions, planning and implementation. An enhanced family worker model to support family inclusive practice balances:</p> <ul style="list-style-type: none"> • Direct services for a family and young person. • Capacity building for clinicians in family inclusive practice. • Develop and trial a family inclusive practice implementation role for family workers in youth mental health services. 	<p>Family work and therapy are components of family orientated support that can support families and young people. Family workers support family relations and opportunities for family involvement at each stage of their young person's clinical treatment.</p> <p>Family workers can also support capacity building for clinicians in family inclusive practice.</p>	<p>Increased opportunities for family inclusion in treatment.</p>	<p>National Mental Health Commission, Orygen.</p>

FAMILY THERAPY

Family therapy can provide relational support and strategies for families. The foundation for strengthening family relationships involves clear communication and a recognition that each family member will have their own experience of their young person's experience mental ill-health.(21) Single session family consultations is a model for engaging families in the early stages of service access to identify how they may be involved and support needs they may have that has been successfully trialled in headspace centres.(43, 44) Families can be supported to reflect together on how they want to relate as a family following their shared experience of treatment.(45)

Family therapy supports a young person and their family to share and understand each other's experiences of mental ill-health and treatment. From this discussion a family can be supported to reflect on their individual and shared relationships and how they want to function as a family following their shared experience of treatment.(45) Family therapy supports a family to identify processes that enable or act as a barrier to change.(46) Family therapy can also include a focus on supporting a young person's engagement with their treatment.(47) While family therapy is widely used in child mental health services, examples of application in youth mental health services need to be developed into models that can be readily implemented.

Family functioning is a complex, multidimensional construct, encompassing several conceptual domains. Dimensions of family functioning include the ability of a family and individual members to achieve tasks and perform roles, communicate and express feelings, involvement in both shared family life and each other's

lives and a family's values and norms around participation.(36) Poor family functioning can negatively affect a young person's mental health. Correspondingly, improved family functioning can have positive benefits for a young person experiencing mental ill-health. For example, improvement in family functioning and a reduction in care giver strain has been found to positively influence treatment outcomes for young people experiencing anxiety, depression and comorbid symptoms.(48, 49)

MULTI-SYSTEMIC THERAPY AND FUNCTIONAL FAMILY THERAPY

Multi-Systemic Therapy (MST) and Functional Family Therapy (FFT) are two evidence based therapeutic systems used to support young people and their families. Both therapies have been manualised which enables training, practice and fidelity. MST is a combination of therapeutic approaches, including structural family therapy, social learning theory, and cognitive behavioural therapy. MST has been found to improve family relations and reduce mental health symptoms for young people and parents/caregivers.(50) FFT also combines behavioural and cognitive interventions to address family relational functioning. The general focus of the two interventions can be differentiated as providing relationship skills and changing relationship behaviours.

While there are family therapy training centres across Australia, the practice of family therapy has fallen away in recent years with fewer people training and practicing in this field.(46) Orygen heard from parents of young people who had experienced moderate to serious mental ill-health that family therapy was something they needed to support their family as a young person's mental ill-health improved. Family therapy has been identified as a therapy that young people and their families would like to see available through headspace.(51) Access to family therapy is dependent upon there being identified therapeutic benefits for the young person(17) and the availability of a qualified clinician or family worker.

Family therapy programs are a large part of child mental health services where the role of family is central to the treatment approaches and service models. As such, state and territory funded child and adolescent mental health services widely employ family therapists. Family therapy is also provided by private providers and not-for-profit organisations such as Relationships Australia.

PEER SUPPORT WORKERS

Peer support workers have a lived experience that enables them to provide support for families engaged with a mental health service. Peer support programs can be individual or group based. Workshop-based programs involve structured content delivered in a group setting, whereas individually-delivered programs are provided on a needs basis to individual caregivers. Support can include information about mental health and services, coping mechanisms and self-care and social connections with other families in a similar position.



FAMILIES

The role of a FPSW is to support the family of a young person receiving mental health care. People employed in this role generally have a lived experience of a similar caring role. This experience gives the support they offer credibility with families.(52, 53)

Families engaged for this project identified that FPSW can help inform families about mental health services and a young person and families journey through treatment. There is evidence the role can improve family inclusive practice(54) and enable access to information and support services.(55) Available evidence indicates that parent satisfaction with existing FPSW services or interventions tends to be high.(52)

Peer support can assist family members to make and maintain connections within their own social network.(56) FPSWs can also assist parents in becoming more actively engaged with their young person's treatment and mental health service.(57, 58) The focus of FPSW is supporting individual families overcome barriers rather than removing systemic barriers.(59) The FPSW role is different to a family worker who is part of a treatment team, working with both families and clinicians to support a young person.(38, 39)

Evidence for the important role FPSWs can play in youth mental health services and the need for funding for these positions was a key policy solution identified in the 2019 Orygen policy paper *We're in this together: Family inclusive practice in mental health services for young people*. Implementation of FPSW roles in youth mental health is addressed in the final section of this policy paper.

SIBLINGS

Peer support services for siblings are not as advanced as they are for parents or young people experiencing mental ill-health. While FPSW and youth peer support workers would be able to provide some level of support for a sibling they would do so from their particular perspective and not that of a sibling. The need for peer support for siblings is recognised, both in the literature (11) and among family members engaged for this policy project.

As a less developed aspect of the peer work field the current development of peer workforce guidelines by the National Mental Health Commission (NMHC) provides an opportunity for advancing development of this role. A pilot trial of a sibling peer role across multiple youth mental health services would require centralised resourcing through a Primary Health Network or Local Health District/Network. Evaluation of the trial and service demand would inform the feasibility and scale of a national sibling peer worker program. Supported recruitment of young people with a lived experience of a sibling with mental ill-health into these roles be modelled on existing youth peer support roles.

POLICY SOLUTION	EVIDENCE AND RATIONALE	OUTCOME	MECHANISM
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DEVELOPING PEER SUPPORT FOR SIBLINGS

<p>Peer workforce guidelines under development by the NMHC identify the need for peer support resources for siblings. Guidelines to include:</p> <ul style="list-style-type: none"> • Identification of the particular experiences of siblings. • Definition of the specific attributes of this role. • Processes and practices to support a sibling peer workforce. • Supported recruitment of young people with a lived experience of a sibling with mental ill-health into these roles. 	<p>Siblings of young people with mental ill-health experience a range of emotions and need for support. Family inclusive approaches need to be developed and implemented to include appropriate support for siblings.</p> <p>Peer support provides an avenue for delivering tailored support for siblings.</p>	<p>Implementation of sibling peer support.</p>	<p>National Mental Health Commission.</p>
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TRIAL A CENTRALISED SIBLING PEER SUPPORT MODEL

<p>Trial a centralised flexible sibling peer support worker model. Primary Health Networks commission a sibling peer support worker who is available to youth mental health services according to service demand.</p> <p>Four PHNs be selected to trial and evaluate a central sibling peer support worker role. The role would be:</p> <ul style="list-style-type: none"> • Based on NMHC guidelines (underdevelopment). • Coordinated with youth mental health services and Local Health Districts/ Networks. 	<p>Family inclusive approaches need to be extend to siblings.</p> <p>As a less developed aspect of the peer work field a centralised or shared service would provide an implementation model for delivering sibling support until service uptake justified an individual service model.</p>	<p>Development of sibling peer support services.</p>	<p>Primary Health Networks, Local Health Districts/ Networks.</p>
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INSTRUMENTAL AND CRISIS SUPPORT

Family members may require instrumental and crisis support for their role in supporting and caring for their young person. This includes practical advice in navigating crises and managing a young person at home.⁽¹⁹⁾ Instrumental support can provide practical resources for families and develop skills to enhance their capacity to care for themselves and their young person. When families do not feel they are coping, the sense of frustration and powerless can lead them to start questioning their role as a caregiver.⁽⁶⁰⁻⁶²⁾ Examples of instrumental support include respite services and skills to support their young person.

Respite services that provide caregivers a break from responsibilities are an important form of instrumental support.⁽¹⁸⁾ Parents told Orygen about having to rely on friends to help when there were signs of increased suicide risk. The option of short-term residential respite was a service option raised by parents engaged for this project.

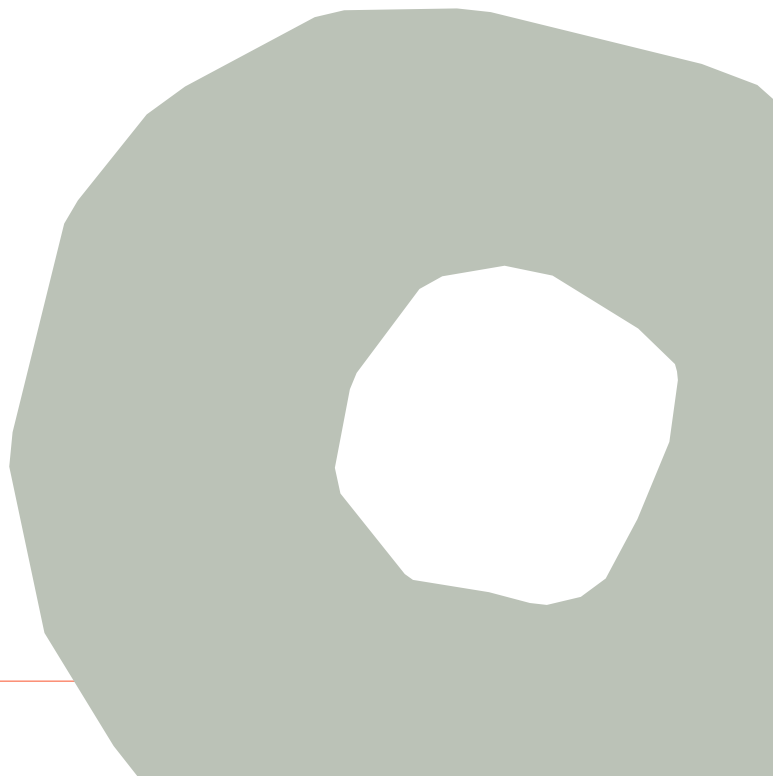
Families told Orygen that programs such as Applied Suicide Intervention Skills Training can increase parent confidence, but that for some the two-day format can be a barrier to participation. safeTALK, an alternate half-day alertness workshop that teaches suicide risk signs to look for and steps to take to support people that could be offered to family members. Increased access to these programs will support families in caring for their young person. Funding increased access needs to be based on evaluation of training as part of the National Suicide Prevention Trial.

APPLIED SUICIDE INTERVENTION SKILLS TRAINING

Applied Suicide Intervention Skills Training (ASIST) is a two-day workshop that teaches people how to recognise when someone may be at risk of suicide and how to support them with their immediate safety. The training focuses on understanding attitudes towards suicide, providing guidance for an individual, effective suicide safety plans, the value of community awareness and self-care. The ASIST program is evidence based and has been evaluated internationally.^(63, 64)

POLICY SOLUTION	EVIDENCE AND RATIONALE	OUTCOME	MECHANISM
EVALUATE THE PROVISION OF TRAINING FOR FAMILIES THROUGH THE NATIONAL SUICIDE PREVENTION TRIAL			
<p>Evaluation of existing family training initiatives included in the National Suicide Prevention Trial be collated to inform the expansion of training available to families accessing youth mental health services. Evaluation should identify:</p> <ul style="list-style-type: none"> • available training programs and delivery models; • range of family needs and ability to participate; and • resource requirements to ensure equitable access. 	<p>Families want to support their young people and keep them safe. Evidence based suicide prevention training programs are available for families. Twelve National Suicide Prevention Trial sites are funded by the Commonwealth with evaluation due by the end of 2020 or later. The Fifth National Mental Health and Suicide Prevention Plan supports a nationally consistent approach to suicide prevention.(2) This policy solution supports the National Suicide Prevention Adviser's recommendation (2.1).(65)</p>	<p>Increased family members confidence in their capacity to provide suicide prevention support.</p>	<p>Commonwealth Department of Health.</p>

Experiences of moderate and severe mental health symptoms can sometimes be acute and families may need access to crisis support. Families also spoke of needing a phone line to mental health services that can provide advice and support. Expectations of such services are varied and will be dependent upon the particular experience is family is having. A 24-hour hotline may be called upon to provide information or listen when a family member needs to express their frustrations.(47) Crisis assessment and treatment teams are available to families caring for a young person. These crisis services operate out of hospitals and can call on a range of mental health professionals appropriate to a crisis. While these services exist, families' report that they are not as available as they need.



SUMMARY

Families, including siblings and partners of young people experiencing mental ill-health can also have a need for support.

The types of support families may need include psychoeducational, social and emotional, relational and instrumental or crisis support.

Peer support for siblings is an area of support needing development.



“

Family therapy supports a young person and their family to share and understand each other's experiences of mental ill-health and treatment.”



STRENGTHENING OPPORTUNITIES TO INCLUDE FAMILIES

Families, in most instances are the primary support people for a young person experiencing mental ill-health. As primary support people families need to be equipped to support their young person. Mental health services have a responsibility to include families, set out in legislation and practice guidelines. For example: in Victoria, the Chief Psychiatrist has produced guidelines for involving families and support people in the treatment and care of an individual; and nationally, Orygen's Engaging young people and their families in youth mental health provides an accessible guide for mental health professionals. The service context (i.e. community based, hospital in-patient) dictates the extent and ways in which families can be included.

Family members can be included in a young person's mental health treatment in different ways. For example, they can have knowledge to inform a clinician's understanding of a young person's experience and environment and inform treatment planning. While most parents see themselves as an important emotional support for their young person, not all of them will be prepared for providing support in a way that corresponds to their young person's needs.⁽¹⁸⁾ It is important to acknowledge that in some individual circumstances the role of family in supporting a young person might be limited or potentially unhelpful. Clinicians and family workers are in a position to assess this resistance and support a young person to consider how their family could be involved.

Families need practical advice in navigating crises and managing a young person at home.⁽¹⁹⁾ What a family needs to support their young person will differ depending on the stage of illness. It is important that families have a sense of hope in relation to their young person's mental health and recovery.

WHAT FAMILIES TOLD US

ENGAGEMENT

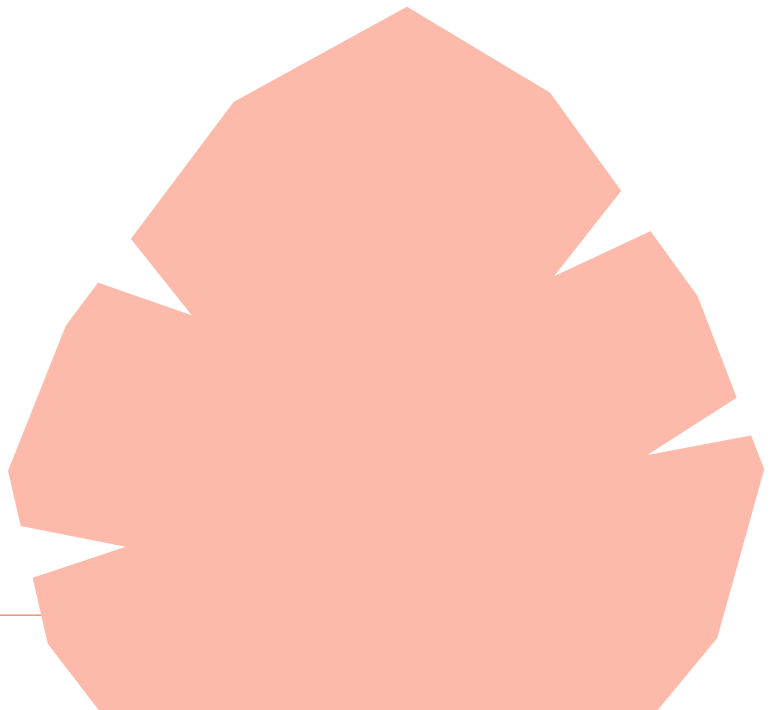
- Provide time for clinicians to see families; want the ability to be able to call up their young person's case manager.

PERSONAL EXPERIENCE

- Families do not always feel they are listened to or considered a resource to inform a young person's care needs.

RELATIONSHIP WITH YOUNG PERSON

- Staff can come between a young person and their family.
- If parents leave when a young person refuses to see them, it may reinforce their narrative about their family.



MENTAL HEALTH SERVICES

Engaging with family members can be helpful in understanding a young person's home and social situation and any fluctuations in their mental health. While recognising the importance of consulting a young person about family involvement, clinicians and services should try and engage with family members from the initial point of contact. Clinicians and services should take time to understand their perspective.(6)

BENEFITS OF INVOLVING FAMILIES

Placing families at the centre of care with a young person recognises the circle of support they can provide. Families of young people experiencing mental ill-health want to be recognised that they can be partners in their young person's care.(19) When family risk factors are a contributing factor to a young person's experience and symptomatic behaviours the potential benefits of involving family in an intervention should be considered.(66) While many clinicians recognise and rate highly the benefit of family engagement for young people(67), there remains opportunities to improve levels of engagement and best practice approaches in support of family inclusive practice.

Family engagement has been identified as a common principle in integrated community based youth mental health service hubs.(68) Recognising the benefits of family involvement in a young person's care and the role of clinicians to enable this involvement has seen the development of resources and processes to enable this. The Parent Participation Engagement Measure is an example of a tool developed to inform and support clinicians in engaging families.(69) Including family members in a young person's care is not limited to improved medical outcomes, but also includes care in which the individualised needs of young people and families were addressed in a way that they felt worked for them.(70)

Involving families in a young person's care builds on the patient-centred model of care. Patient-centred models of care locate the patient as the primary individual responsible for decision-making and the receiver of information.(70) The advantage of patient-centred care is that it can increase engagement in health services by providing a sense of ownership over their own care.(71) However, a patient-centred care model in youth mental health may not always be appropriate due to the potential challenge of having complex conversations with vulnerable young people.(72) Accordingly, medical professionals may utilise what is often called 'family-centred care' which emphasises the role of family/caregivers in communication, support and decision-making.(70) Three key themes for providing family-centred care have been

developed; emotional and social engagement, empowerment and individually effective care. (70, 73, 74)

Families can provide valuable insights about their young person that may be beneficial for a clinician. Families engaged for this project recalled the frustration of not having their input sought. In other research, parents report understanding the need to balance their desire to be involved and privacy considerations, but felt that their potential to help was underplayed. (19) While understanding a service and the treatment provided is the largest factor on parent experiences of child and adolescent mental health services in Norway, their experience is also strongly shaped by the perception of accessibility and involvement.(75) Families also want to be involved in decisions about their young person's care.(76) Balance is required between the wishes of family and where made, a young person's request for privacy or independence in their treatment and therapeutic relationship.

headspace, for example has a family inclusive approach that starts with the young person and extends to engagement, communication and collaboration with a young person's support network. As part of its approach to family inclusive practice headspace asks family and friends, through the headspace Family and Friends Satisfaction Scale about their experience of being involved in care and decision-making and provided with supportive information. A pilot study recorded a high number of "don't know/ NA" for the "Satisfaction with your involvement" item.(77) This suggests that family expectations of the level of involvement was unclear. Asking about family and friends' experiences may identify more constructive data for improving service involvement and engagement with a young person's family and support network.

ACCEPTABILITY OF FAMILY INVOLVEMENT AMONG YOUNG PEOPLE

Young people are generally open to their families being involved in their care. The following extracts are from Orygen's previous family focused policy paper, *We're in this together: Family inclusive practice in mental health services for young people* illustrate young people's openness to family involvement along with potential barriers to involvement and how this can be addressed.

A majority of young people accessing mental health services identified the value of family support(78) and reported being interested in family-centred care, open to their parents' involvement and to discussing their concerns. (79) (pp. 10-11)

In some cases, there may be factors that mean a young person may be resistant to involving their family.

These factors include a desire for privacy, concerns about how their family (or friends) will react (stigma), not wanting to burden them and conflict or misunderstanding within family relationships.(80) (p. 11)

Clinicians, including family workers are in a position to assess this resistance and support a young person to consider how their family could be involved. It is important that consent is obtained and only appropriate information is shared.

Respectfully negotiating partial consent to family involvement with a young person expressing reluctance can open the way to greater family engagement.(81) Respecting a young person's privacy and wishes needs to be balanced with the potential benefits of family support. (p. 11)

The evidence base for family-centred care is predominantly qualitative.(70, 82) There is, however, some emerging quantitative evidence for this approach in youth mental health, including with families of young people hospitalised for bi-polar disorder.(83)

HOW TO INVOLVE FAMILIES

Family involvement in treatment includes supporting a young person to attend appointments and adhere to treatment. The Fifth National Mental Health and Suicide Prevention Plan recognised that families contribute to the care and support for people experiencing mental ill-health. As part of this, the plan included family connectedness as a measure of improved mental health.(2) This involves seeing a young person and their family as experts and involving them in all aspects of treatment and wider service provision.(74) Clinicians can support young people's sense of personal empowerment by believing their reported level of symptom severity and sharing information about treatment, symptoms and services. (84) Empowerment can also be enhanced by increasing a young person and their family's ability to use their own informal support systems in addition to professional services.(74, 85)

Families are diverse and family inclusive practice needs to reflect this. Communication is the basis for family involvement in the support of a young person. While research with specific groups is limited there is evidence of the potential benefits of clinician communication with families. For examples, small studies have identified benefits for young people from migrant families and those living with foster families.(86, 87) Overcoming barriers based on past experiences

requires frequent reminding of the benefit of family involvement, 'at a greater frequency than clinicians might expect'.(87)

Involving families in care can be enabled through dedicated staff roles and programs. Families told Orygen during consultations for this project that having a consistent contact person within a service that family members could talk too would be a good model. Implementation of family inclusive practice requires service wide support and resourcing.

The *We're in this together policy paper* (2018) identified dedicated staff roles and programs to engage and support families will further enable inclusive practice. These included:

- Family workers enable family involvement in treatment and can support capacity building for clinicians in family inclusive practice.
- FPSWs provide support from a shared or similar experience, assisting parents to be more informed and engaged.
- Single session family consultations are conducted in the early stages of treatment to establish with a young person and their family how they will be involved and enable family members to identify support needs they may have.

Opportunities to strengthen family participation include funding constraints on family engagement and inclusion; shared decision-making; family involvement in treatment; and the transition to adult services.

ADDRESSING FUNDING CONSTRAINTS

Mental health clinicians and primary health practitioners can be a source of information for family members who may need their own mental health help or support. There are limits, however, on how much support can be provided around treatment being provided for a young person. Answering questions from family members at the reception desk or doorway is in most cases the extent of 'extra' service available.

Service funding models are a determining factor in the avenues available for implementing roles and programs to support families. While a block funded service has discretion on budget allocation the competing demands for resources and primacy of clinical services can be a barrier to apportioning funding to support for families. The Productivity Commission draft mental health report proposed the NMHC trial and evaluate the efficacy of a dedicated role in state and territory mental health services to facilitate family focused practice.(3)

Services based on a Medicare Benefits Schedule (MBS) funding model (i.e. headspace) are constrained by the limits of MBS items. For example, there is provision within the MBS for

psychiatrists to consult a support person (within the same category as multidisciplinary clinicians) but this avenue is not available to allied health professionals. The Productivity Commission draft mental health report has proposed amending the current MBS model for psychiatrists to four sessions per year and extending this to allied health professionals.⁽³⁾ Providing family support services requires a commitment from service management to prioritise resourcing for roles and programs.

SHARED DECISION-MAKING

In youth mental health, shared decision-making allows clinicians to collaboratively involve young people in decisions about their healthcare by exchanging information about options, evidence, risks and benefits, as well as understanding a young person's values and preferences. Shared decision-making may also involve multiple health professionals or family members. As involving family members often requires the consent of young people (the age varies between jurisdictions) clinicians have to negotiate and support involvement where it would be beneficial. Where a young person is attending adult mental health services there will likely be lower rates of facilitation of family involvement in treatment decision-making (see Transition to adult services below). This is evident in the consistent message the Royal Commission heard from families and support people (of people of all ages) that 'they often felt excluded from care and treatment decisions'.⁽⁷⁾ Despite service barriers and lower use of shared decision-making in youth mental health contexts than for chronic physical conditions, there is promising, emergent evidence for shared decision-making in mental health care.^(88, 89)

A systematic review of 148 collaborative mental health care programs found that only 22 programs provided support for families of people with depression or anxiety disorders, and only five of those programs involved shared decision-making with families.⁽⁹⁰⁾ Experiences of decision-making for young people with depressive disorders and caregivers found that caregivers had a critical role in practical supports and managing medication. While all were asked to provide information, very few were involved in treatment decision-making.⁽⁷¹⁾ Desire for involvement varied, which was influenced by their trust in the care provided and the perceived capacity of the young person to engage in care and decision-making.⁽⁷¹⁾ Caregivers reported that the main barrier to their involvement in decision-making relating to services and clinicians, while some were excluded by the young person.⁽⁷¹⁾ Families have expressed not feeling invited to engage in care and perceived negative attitudes towards their involvement by mental health professionals.⁽⁹¹⁾

Conflicts involving families in decision-making need to be addressed. Very active family members may be excluded by either people using services or health professionals.⁽⁹¹⁾ Their involvement may cause issues if they do not agree with treatment approaches, or difficulties may arise if they agree with the health professional in a way that does not align with a young person's preferences.⁽⁹¹⁾ The involvement of caregivers should be explicitly negotiated on an individual basis.⁽⁷¹⁾

A range of enablers and barriers exist in involving parents and young people in shared decision-making in youth mental health. These include:

- capability (e.g. awareness of shared decision-making and communications skills);
- opportunity (e.g. availability of treatment options and staff shortages); and
- motivation (e.g. whether they believed that shared decision-making led to better outcomes).⁽⁹²⁾

Implementation of shared decision-making with young people and their families requires clinician training, supported involvement of young people and their families with clear definitions of decision-making roles, clear guidelines for consent and confidentiality, service delivery issues (e.g. finding and appointment times), and identifying appropriate outcome measures.⁽⁹³⁾

Decision guides and aids have been developed to involve families in health-related and social decisions.⁽⁹⁴⁾ While decision aids are the most common facilitator of shared decision-making, it can also be facilitated through therapeutic techniques, psychoeducational information, goal setting and mobilising service users and their families to engage.⁽⁹⁵⁾ There is a need to better understand best-practices for involving families, as well as resolving conflicts between a young person and their family.⁽⁹¹⁾

It may not always be possible to include families at every stage of decision-making. Stages of potential engagement with family include:

- pre-selection (information gathering and deliberation);
- selection (treatment choice); and
- post-selection (explaining to families the rationale for a decision if they have not been involved, need clarification, or to enable ongoing involvement).

POLICY SOLUTION	EVIDENCE AND RATIONALE	OUTCOME	MECHANISM
PRACTICE GUIDELINES FOR FAMILY INCLUSION IN TREATMENT DECISIONS			
<p>Practice guidelines for including family members in shared decision-making be developed to support implementation at a service level.</p> <p>There are opportunities at varying stages of the treatment decision-making process for a young person and clinician to include family members.</p> <p>Guidelines for family involvement in shared decision-making supports family inclusive practices.</p>	<p>Shared decision-making allows clinicians to collaboratively involve young people in the initial and ongoing decisions about their treatment.</p> <p>While it may not always be possible to include families at every stage of decision-making, there are different points where inclusion can be facilitated.</p>	<p>Better decision-making, improved communication and understanding about the scope for family involvement.</p>	<p>Commonwealth Department of Health, state and territory health departments, PHNs, youth mental health services.</p>

INTERVENTIONS THAT INCLUDE FAMILY

The supportive role that families can play for a young person experiencing mental ill-health supports exploration of how they can be involved in treatment interventions. There is evidence for family interventions (broadly defined) in treating mental ill-health in young people, but some interventions are limited to particular disorders. (96) Eating disorders in one area in which family involvement is well established.(97)

There is emerging evidence of the benefits of family involvement in other disorders. For example, a review of the impact of family intervention for bi-polar disorder found improvements in illness outcomes and caregiver

burden(98) and reduced relapse in young adults at risk of psychosis.(20) The duration of an intervention has been found to be a factor in the effectiveness of interventions for families of young people and self-harm. While there was some benefit from all interventions, effectiveness increased with the intensity of an intervention.(99) A need to develop guidance in treatment direction in the implementation of family interventions have been identified in the treatment of psychosis(100), suicide prevention(101, 102) and non-suicidal self-injury behaviours(103). There is a need for further research into how families may be involved in treatment interventions to achieve improved outcomes for their young person.

POLICY SOLUTION	EVIDENCE AND RATIONALE	OUTCOME	MECHANISM
DEVELOP THE EVIDENCE BASE FOR INTERVENTIONS THAT INCLUDE FAMILIES			
<p>The potential for family involvement in treatment interventions for young people is informed by the nature and severity of a disorder.</p> <p>Research into family inclusion needs to be included as part of intervention studies for specific disorders.</p> <p>Incorporate family involvement in future grant programs for mental health disorders and intervention research.</p>	<p>Families can play an important support role for young people experiencing mental ill-health and receiving treatment.</p> <p>How family can be involved in treatment interventions is an area needing further research.</p> <p>There are a number of avenues available for incorporating this research focus. This includes, but is not limited to:</p> <ul style="list-style-type: none"> • The Special Initiative in Mental Health • Million Minds Mental Health Research Mission. 	<p>Increased evidence for how family can be involved in treatment interventions.</p>	<p>National Health and Medical Research Council.</p>

TRANSITION TO ADULT SERVICES

The establishment of youth mental health services bridges the gap between child and adolescent mental health services and adult services. This transition can mean a change in approach to family involvement. It can also be a point where young people disengage from treatment. Youth mental health services recognise the changing needs and preferences of the young person as they enter emergent adulthood.

The Royal Commission into Victoria's Mental Health System heard concerns about the transition between services.(7) Studies have noted that this transition results in an almost immediate decline in family support services and a restriction on the role that parents are allowed to play.(104, 105) An integrated and collaborative approach that includes a young person's family can support continuity of care and facilitate a young person's transition.(106) Factors that can enable a positive transition include: a gradual transition, maintaining good communication with young people and their families and information sharing between services.(76) The transition process needs to consider how family inclusive practice is included in the transition between service systems.

Transitions from a youth mental health service to an adult mental health service can be challenging for young people and their families, with shifts in culture, roles and responsibilities. Many young people have difficult transitions to adult services that can result in disengagement. Young people have identified that preparation and continuity are key factors to transitioning between systems.(107) This is reiterated by parents who have expressed difficulties in the cultural transition between a family orientated youth system to an adult system with limited family involvement. Parents also described difficulties adjusting to being uninformed about a young person's care and expressed a desire for greater involvement

during the transition to adult services.(108-111) Families have also noted a lack of information and coordination in transitions to adult care.(108) There is some evidence to suggest that parental attendance at youth mental health services facilitates the transition to adult services, with one study finding a link between no parent involvement and a failure to transition to adult mental health services.(109)

Guidelines highlight the importance of including family in transition support. Guidelines from the National Institute for Health and Care Excellence (UK) identify the need to ensure available supports that families are included in and supported through the process. All families should receive information about what to expect from services and the support available to them.(112) The NSW Ministry of Health have developed guidelines for supporting young people during transition to adult mental health services, highlighting the need to produce individualised transition plans that include family support, and that services should consider the needs of both young people and their families.(113)

The inclusion of families, however, must be balanced with the changing needs and preferences of the young person as they enter adulthood. Some young people may not want to continue involving family when transitioning to adult mental health services, but others have expressed that continued involvement is preferred, with the abrupt change in their involvement producing feelings of being overwhelmed and alone.(107, 109) Increased confidentiality, independence, autonomy and self-management responsibilities require that the involvement of families is negotiated sensitively.(114) This may require additional supports for families to remain engaged in the care of the young person, or it may involve family-specific supports that assist them to adjust to a lower level of involvement and role as the young person enters the adult mental health system.

POLICY SOLUTION

EVIDENCE AND RATIONALE

OUTCOME

MECHANISM

INVOLVING FAMILIES IN MAKING SUCCESSFUL TRANSITION TO ADULT SERVICES

A coordinated review of transition policies and practices is required to incorporate improved family support and involvement.

The review focus should incorporate the perspectives of young people, families and health professionals.

Despite the evidence supporting a youth category for mental health services from 12 to 25 years of age many young people are confronted with a transition to adult services when they turn 18.

This transition can result in disengagement from treatment and services and a decline in family involvement.

Improved support for young people and families in the transition to adult services.

State and territory health departments.

SUMMARY

Including families in a young person's care can support engagement, treatment adherence and contribute to improved outcomes.

Young people need to be consulted on how their families are included to ensure it will be beneficial.

Shared decision-making in treatment choice is an opportunity for family inclusion.

“Engaging with family members can be helpful in understanding a young person's home and social situation.”





IMPLEMENTING FAMILY PEER SUPPORT WORKER ROLES

Family peer support can also be important for families who experience isolation from friends and support networks when their young person is experiencing mental ill-health. Implementing FPSW roles requires defining the role; organisational preparedness, developing training and support and promoting the role to families. Existing experience and documented evidence provides direction for developing a FPSW service model.

ROLE DEFINITION

Implementation requires defining what the parameters and expectations of role will be. Having clear role definition(115) and practice parameters(116) have been identified as foundations for successful implementation. The role can include informational, instructional, emotional, instrumental and advocacy support to empower family members and reduce family isolation.(28, 52) A Canadian youth mental health service implementing a FPSW role focused on three areas; (i) assistance with system navigation, (ii) advocacy for the family voice with service providers, and (iii) support and understanding of the experience that youth and their families are going through.(117) The NMHC is currently developing peer workforce guidelines.

ORGANISATIONAL PREPAREDNESS

Organisational culture has been identified as a key factor in the successful implementation of a FPSW role in mental health services.(118) A workplace culture resistant to the change is a barrier to implementation,(119) success has been achieved by focusing on organisational change rather than the individual behaviour. (54) An organisational focus is achieved through leadership, management approaches and endorsement for the role,(115) support from senior clinicians for FPSWs,(120) and professional development for staff.

PROFESSIONAL SUPPORT

The primacy given to lived experience as qualification for a FPSW can mean people lack formal training for the role.(121, 122) While lived experience is an important factor, it alone is not sufficient training to undertake the role. Training and professional supports should be part of induction into the role. The types of skills that FPSWs need includes self-efficacy, the capacity to collaborate(123) and working with expressions of anger.(28) Development of mental health education and support programs for FPSWs can be adapted from manuals, supervision and administration assistance already provided to clinicians.(53)

PROMOTING THE ROLE TO FAMILIES

It is important that the provision of FPSW services does not increase the burden on families. Anecdotal evidence for why families decline FPSW services include a lack of understanding of the services the role provides and families being overwhelmed by the number of people they are already engaging.(121) To overcome these barriers implementation of a FPSW role needs to include promotion of the role to families and an explanation of the support they can provide.

SERVICE MODEL

Implementation of family peer support in youth mental health services can help orient a service to a more family inclusive model of care. A service model for implementing FPSW in youth mental health services needs to include:

- organisational planning and staff preparation;
- recruitment and training; and
- service provision and supervision.
- Evaluation.

PROGRAM LOGIC

Implementation program logic has been developed to support the expansion of FPSW roles in youth mental health services. Program logic outlines activities at each implementation phase and identifies associated outputs, measurable service outcomes and projected longer-term impact. The forthcoming NMHC peer workforce guidelines and implementation strategies (e.g. Strategy for the Family Mental Health Carer Workforce in Victoria) provide inputs for the program logic for implementation of FPSW roles in youth mental health services together with evidence and experience from existing examples.

POLICY SOLUTION	EVIDENCE AND RATIONALE	OUTCOME	MECHANISM
IMPLEMENTING FAMILY PEER SUPPORT WORKER ROLES IN YOUTH MENTAL HEALTH SERVICES			
<p>Program logic provides a guide to enable implementation of FPSW roles (see Appendix A).</p> <p>The Commonwealth Department of Health enable implementation of FPSW roles through setting service commissioning requirements of youth mental health services through Primary Health Networks.</p>	<p>The lived experience of people employed as FPSWs gives the role credibility with families. There is a strong evidence base for the role. Families engaged for this project identified the support role they can play.</p>	<p>Expanded access to family peer support services.</p>	<p>Commonwealth Department of Health, PHNs, youth mental health services.</p>

APPENDIX A PROGRAM LOGIC FOR IMPLEMENTING FAMILY PEER SUPPORT WORKER ROLES IN YOUTH MENTAL HEALTH SERVICES.

GOAL IMPLEMENTATION OF FAMILY PEER SUPPORT IN YOUTH MENTAL HEALTH SERVICES

OBJECTIVES

1. National model for program implementation.
2. Support services to integrate a FPSW role.

PHASE	INPUT	ACTIVITIES	OUTCOMES	OUTCOME MEASURES	IMPACT
Planning and preparation	National guidelines developed by NMHC provided to services to guide implementation.	<ul style="list-style-type: none"> Establish an implementation team (leadership, senior clinicians): Define principles of role and place within service. Fit role within existing service model or modify model to incorporate role. Identify potential issues or risk factors. 	<ul style="list-style-type: none"> Develop program expectations: Principles of role. Timelines and goals. Anticipated level of service need. Identify key relationships. Appoint champion role(s). Identify potential risks and responses. 	<ul style="list-style-type: none"> Engagement in implementation process: Staff aware of how they will interact with new role. Promotion of coming service option. Develop: <ul style="list-style-type: none"> - evaluation framework; and - risk and response document. 	<ul style="list-style-type: none"> Greater team engagement. Increased awareness of benefits of family involvement. Refine FPSW role to service context.
Recruitment and training	<ul style="list-style-type: none"> Example position descriptions provided to services. Guidelines on integrating FPSW role into a service. 	<ul style="list-style-type: none"> Recruit to role: Advertise position. Shortlist for interview. Provide initial training. 	<ul style="list-style-type: none"> Suitable candidates apply: Minimum four interviewees. Preferred candidate identified. Position filled. Training and orientation. 	<ul style="list-style-type: none"> Appoint FPSW: Receive applications. Strong candidates. Position filled. Evaluate training. 	<ul style="list-style-type: none"> FPSW role is filled and service model becomes operational.
Service provision	FPSW active in engaging with young people, families and staff.	<ul style="list-style-type: none"> Promote FPSW role across service: Awareness raising. Service provision. Attend team meetings. Professional supervision. 	<ul style="list-style-type: none"> Engagement with colleagues and families: Program take-up. User surveys completed. Workforce: <ul style="list-style-type: none"> - Collaboration with clinicians. - Supervision. 	<ul style="list-style-type: none"> Engagement with colleagues and families: Number of families engaged. Positive experience of service. Clinician review: <ul style="list-style-type: none"> - Family inclusive practice. - Family engagement in care. 	<ul style="list-style-type: none"> Move to or improved family inclusive practices. Greater family engagement. Workforce development.
Evaluation	Evaluate service implementation.	<ul style="list-style-type: none"> Evaluate service experience: User surveys. FPSW role review. Staff appraisal of program impact. Program fidelity. 	<ul style="list-style-type: none"> Evaluation process: Completion of surveys and interviews. Independent program audit. 	<ul style="list-style-type: none"> Evaluate: FPSW service. FPSW role. Secondary effects (sibling support, treatment retention). National collection of evaluation data. 	<ul style="list-style-type: none"> Service model and role improvements Increased evidence base: <ul style="list-style-type: none"> • FPSW role. • National program funding.

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