
Designing the new integrated carer support service

Response to the draft service concept for the delivery of interventions to improve outcomes for carers



About HelpingMinds

HelpingMinds (formerly Arafmi) is the pre-eminent mental health services and carer support organisation in Perth, Western Australia. It was established nearly 40 years ago as a not for profit charity by family members supporting loved ones who were living with mental distress.

We have a professional and compassionate team of staff and dedicated volunteers who provide quality, confidential support and services to children, youth, adults and families who are caring for someone living with mental distress and to individuals who are living with mental distress.

The majority of our services are free of charge and include individual advocacy, peer support, referrals, assistance with navigating the mental health system, education in schools, counselling and support, school holiday programs and respite. We are a registered NDIS provider, assisting individuals with psychosocial disability and their families with plan coordination and access to services.

HelpingMinds adopts a 'recovering families' approach, recognising that families or support networks may contain several carers and co-caring situations where people with mental ill health are also carers for other family members.

HelpingMinds works in partnership with government agencies and service providers throughout Western Australia including in regional, rural and remote areas with offices based throughout Perth and its suburbs, Mandurah, and the regional centres of Geraldton, Carnarvon, Port Hedland, Broome and Kununurra.

HelpingMinds appreciates this opportunity to respond to the consultation and would also strongly recommend a further process of engagement with a diverse population of carers and consumers, particularly in the sectors of mental health and child protection where issues for carers and consumers will reflect concerns that will differ somewhat from other sectors, such as aged care.

Assessment of carers – what does everyone in the family need?

HelpingMinds welcomes the broadening of research into the development of a carer assessment tool for use in intake, planning and referral. The following comments reflect our concern to adopt a person and family centred approach, and at times a community-centred approach, which encourages self-direction and capacity building, and which is consistent with a recovery approach but which is also cognisant of the varying abilities of individuals and families to self-direct in times of crisis and acute periods of being unwell. We also value the role of qualified peer workers who have lived experience of being in a caring role or have who have a lived experience of recovery.

It is important to keep in mind that there may be several carers, and co-caring relationships within a family or support network setting. There may also be carers who do not live in the same household, who are neighbours or members of the extended family, but who are nonetheless important providers of support and who may themselves require more support.

People with disability of any kind can be co-caring within family and friend networks, and may require carer supports alongside any supports required in relation to their disability. Co-caring can develop slowly within a family setting where, for example, a child with disability receiving care from a sibling or parent, may end up providing care to the other family member. Only a skilled assessor adopting a family centric approach will identify this relationship. An appropriate assessment tool will be helpful in supporting assessors to be family centric.

The setting for an assessment is important. Some carers would be reluctant to express a sense of burden if they are speaking in front of the person they support. Conversely, they may say things that are stressful to other family members. In some families, it will be worthwhile giving the carer and consumer time in a private space to complete the assessment. In other families, it may be worth having a counsellor/mediator/family support worker to assist the family to work together to complete the assessment process. The assessment process should be part of helping a family work well together, that is, part of the recovery journey as opposed to a divisive experience.

It will be important, and sometimes challenging, to identify young carers. In our experience, some parents experiencing mental distress will not always recognise the extent to which their child/ren have been providing assistance. Parental consent will also be required in order that the child/young person receives services. It is therefore necessary that the assessor is able to work respectfully and in a recovery oriented way with the parent/s in assessing the needs of a child or young person in a caring role. If the parent or other family member with mental ill health has an existing service provider and has undertaken an assessment for services, conferencing between the two assessors/service providers will be worthwhile as it may reduce the amount of information that needs to be repeated, and may uncover other needs not previously identified.

In the case where mental distress is experienced episodically, it could be that much of the time, the person does not require support and assistance from a family member. However, the unpredictable and episodic nature of some conditions can impose a load on both the consumer and those in a caring role. The assessment will need to properly capture this type of situation and support delivery mechanisms should be able to be planned in advance and be able to respond flexibly when need arises. Administrative/IT systems/staffing allocations need to be able to support this.

It is important that carers and other family members do not feel judged in the assessment process. Past experiences of assessment may have caused trauma, particularly in cases where parents are living with mental ill health, in Aboriginal families, and in other ethnic/cultural groups who have been subject to government authority in a traumatising manner. There will be many carers who have been assessed throughout their lives in terms of their capacity to provide care to their children, for example, or for eligibility for Carer Payment or Disability Support Pension, where their statements have been called into question by the assessment process. If the carer assessment is understood by the carer as an assessment of whether they are providing adequate care, this is likely to cause distress. The intention and possible outcomes of an assessment must be clearly explained.

Effective referral processes are necessary to ensure that all family members are made aware of and linked into the services they wish to take up. If the assessor is unaware of the existence of supports outside of their own organisation or outside of their expertise, this will be a major limitation. Evidence of this shortfall is emerging from the NDIS where staff who are inexperienced in supporting people with psychosocial disability are unaware of the full range of services needed and available. Self-direction, and possibly personal budgets, may assist here, depending on the choices made by family members as to how much they wish to coordinate their own services or whether they would prefer to have guided/warm referrals made.

In order to support the referral process and collaboration between service providers, informed consent to share details needs to be organised and the details captured. This can be challenging when an individual in the family setting does not agree but a recovery oriented approach to building trust and rapport usually results in agreement to sharing specific types of information that still protect the privacy and rights of individuals.

Avoiding inconsistency between service delivery models across the carer and mental health consumer sectors

Best practice recovery oriented approaches to assessment and service delivery in mental health settings should be consistent with family oriented carer assessment processes. The use of appropriately experienced and trained peer workers, both carer and consumer, is supported by evidence. In this, HelpingMinds concurs with the submission to this consultation by Mind Australia.

Supported decision making processes are adopted in settings where an individual is experiencing a diminished ability to make decisions. There needs to be an awareness of this approach which may be required in carer family settings given the high incidence of mental distress experienced by carers and where any other member of the family needs support to be an active participant in decision making including deciding to provide consent to participate in services.

Consistencies between state and national legislation regarding carers

Carer services should be delivered in a manner that is consistent with the National Mental Health Service Standards, as well as the Carer Recognition Act. Within WA, all carer, disability, health and mental health services are also required to report against the Carers Recognition Act. Many service providers across the carer and mental health sectors receive both Commonwealth and state funding to deliver carer services and any potential inconsistencies should be identified as part of the process of designing the integrated carer support system.

Flexibility and coordination of services in acute situations

Carers are at considerable risk of developing their own physical and mental ill health and may need to withdraw from their caring role at short notice, for example, if they are unwell, need to enter hospital or recover from medical procedures. When this occurs, other family or social network members are required to take on the caring role. This may be the other parent, or the children, or grandparents. It is at this point that a family member may come into contact with service providers through any number of channels including the school, GPs, child protection authorities, mental health visitors/advocates in hospital settings, youth support staff, prison chaplains and social workers, and mental health consumer and carer organisations.

Multiple services may be required including child care, transport, support with shopping and house cleaning and meal preparation. Counselling, respite and other family recovery strategies can be provided at the appropriate point in time. Some members of the family will be eligible for some services, on the basis of being a consumer, or a carer, or of a certain age, or cultural background or living in a particular geographic boundary. Navigating the eligibility criteria to provide a wraparound service is difficult for service providers. For families in acute crisis, it is almost impossible. The method of referral to services must reflect the needs of the person/family, at that point in time. When people are well, then it can be a capacity raising, recovery-oriented exercise for them to self-direct. When people are not well, or in crisis, support workers, with the individual's/family's permission, may need to contact service providers, make appointments, take people to appointments, organise alternative care so that the carer or consumer can attend appointments. The large numbers of 'did not attend' within mental health services is often the result of people not being well enough, or not being able to leave their caring role, to engage with a particular service provider.

Restrictive eligibility criteria restrict the ability of service providers to provide wrap around services. Instead, eligibility criteria should support service providers to identify

all the aspects of need, rather than putting individuals and family members into mutually exclusive boxes that limit or complicate access to services and funding streams.

As an example, in couples with children, where one partner is the carer for the other and the carer becomes unwell, suddenly or over time, the couple will often end up co-caring, that is, they are both carers and consumers. To restore their wellbeing, and their relationship, a break together, away from the children, or with supports in place for the children, may be exactly what they need. Eligibility criteria and service delivery models need to encourage the identification of people in the complexity of the roles they undertake and the supports they require.

For example, an assessment of such a family is likely to identify the need for respite for the couple and some of the younger children, with therapeutic interventions during their stay away such as with a family counsellor skilled in family and carer dynamics. The older children may have taken on a caring role for either or both parents, or for their younger siblings. They may benefit from young carer supports to assist with maintaining their links to education or employment, address any issues resulting from their parents' ill health, and help with the development of sustainable social and support networks. Counselling by staff skilled in working with young carers and children of parents with mental illness (COPMI) may be required in an ongoing way but the young person may require support to attend the counselling. Some parents will support this, while others may find it inappropriate or threatening. It takes time to work with the family in a recovery focused manner so that each family member feels more empowered as a result.

There is a strong evidence base for flexibility in the use of small amounts of individual budget, and for agencies to be able to allocate some funding for non-traditional services where assessment of a family/individual warrants this. As examples, the use of funding to support participation in creative arts or physical activities, the purchase of sporting equipment, payment for tuition, attendance at cultural events.

Familiarity with the Carer Life Course Framework will assist service delivery staff to be alert to the varying needs that carers and families may have. On this, HelpingMinds supports the work of Mind Australia.

Aboriginal families – what service delivery models work in regional, rural and remote communities?

HelpingMinds has extensive and ongoing experience working with Aboriginal families and with other community and government sector services in urban areas as well as in regional, rural and remote areas of Western Australia. Aboriginal carers are often involved in multiple caring relationships, and, due to high rates of disability, also in co-caring relationships where family members and other relatives across generations care for each other.

There are many grandparent carers who assume responsibility for their grandchildren and the younger children of other relatives. In some cases, the grandmothers are

recognised 'kincarers' as a result of child protection issues. The grandmothers range across ages with some in their mid 30s and many others under 65. While many of the grandchildren will not have diagnosed disability, the situation in which they have come under the care of grandparents is often traumatising for all of the family members, including the children. For example, the parent may have died by suicide after living with mental ill health for some time. The intergenerational impacts of this tragic set of circumstances are well documented.

A holistic family centred and community centred approach is necessary to determine, with the individual, the family and other people important to the community, the best way to provide supports of various types in a sustainable way. In some cases, it is necessary to provide basic necessities such as food, transport and clean clothes to a family or group of people before trust is established and it becomes possible to move forward with therapeutic services, mentoring or group activities.

Physical activities with groups of young people have provided the 'hook' to allow young people to engage with carer and mental health service providers. As well as there being a strong evidence base for physical activity to have a positive impact on mental wellbeing, it is also an activity that young people can participate in that avoids the stigma attached to participation in traditional therapeutic activities such as counselling. However, different physical activities may be acceptable for boys and girls. Consultation with grandmothers and other influential community members is important to determining what activities they will encourage the girls to participate in. Hence, flexibility and co-production is required.

Respite, in the form of short breaks away to 'country'; have provided the space for grandmothers to engage in activities and discussions about their caring role, and to identify solutions to issues relating to individual children. For example, a shortage of clean clothes due to a family having no power or washing machine may be the reason the child is refusing to attend school. Being back in country gives grandmothers the opportunity to connect with the young people and engage in conversations with individual children and young people about their responsibilities to their family, to their younger siblings, and about the impact of their behaviour on others in the community. These relationships are then utilised by health professionals and other service providers to encourage the younger people to link in to health checks or attend school. In this case, the 'respite' offered to the carers is providing them with an opportunity to strengthen their ability to care for the young people in their community.

The strong and consistent feedback is that the majority of people in outlying communities do not have access to the internet and do not consistently have access to a smart phone on which to complete online or telephone services. The lack of consistent internet access, lack of consistent telephone access, and lack of transport strongly influence which service delivery structures can be successful.

Collaboration with existing community organisations such as health centres, schools and Aboriginal corporations, to co-deliver group activities has proven successful as a

means of initial engagement. A mobile, face to face service with staff visiting people in their communities has proven most successful in delivering individual and family services. Formal and structured services requiring people to keep fixed appointments in service provider premises are less successful at engaging clients than flexible service provision models.

Family centred case conferencing across the carer/consumer/family support/child protection sector

In our work with the child protection sector, an effective approach to supporting a family with complex and multiple needs is multi-agency case conferencing. A lead agency provides the governance, administrative support and IT network to coordinate meetings to discuss complex cases. Service providers respond to the various identified needs and the list of identified available services is offered to the family by the lead agency. The parent/family decide which services they will access.

Partners in the network adopt a 'no wrong door' 'one stop shop' policy whereby when a person calls their particular agency to ask for supports which are not provided by that agency but are available from another provider in the network, they are advised of the other organisation and a warm referral undertaken. The referring organisation may not be funded to undertake this referral work, which takes skill and time and requires a holistic assessment. It is vital that the future integrated carer support service is able to maintain this networking, referrals and collegiality.

The interface between supports for people with disability and carer services

An effective interface is necessary to cross the divide between the NDIS and carer supports. Carers often engage initially with formal service providers when seeking help for the person they support. Their contact with service providers is often on behalf of the person they are supporting. Carers may only realise they are in a caring role, and be eligible to access support, when a service provider points this out. Some disability support providers have assessment processes that are family centric and will result in carer identification and referral, but many don't have an assessment process that will lead to carer identification. It is a critical loss not to identify the carer when they make contact with the disability sector, and it is a further loss when the needs of the carer are not taken into account.

Collating, sharing and learning from the knowledge gained by the integrated carer support sector

As part of the integrated carer support service, mechanisms should be in place to enhance opportunities to develop an evidence base of the most effective carer and family supports. While there is a considerable amount of research into what constitutes effective carer supports, little of it is comparable across particular carer populations and carer situations. Additionally, a clearing house of information relevant to carer service provision would be invaluable along with support to introduce outcomes based measurement and evaluations.

Assessments of outcomes from carer supports needs to be conducted by external agencies with service providers and carers encouraged and supported to be involved. Education and training across the sector and by the sector will increase the chances of shared understanding of service delivery models and terminology given that caring situations range across aged care, chronic health issues, palliative care, mental health, physical disability, intellectual disability, drug and alcohol use, acquired brain injury.

Questions to be explored

Under individualised budgets, will services be able to provide family centric services wherein parent and children carers might receive family interventions along with the person experiencing mental ill health?

How might family/group therapy services work in an environment of individualised funding?

Will families receive individual budgets, or a family budget?

How will young carers access individualised funding? In the UK, young people 16 and over received their own funding. But what about younger children in a caring role?

Experiences of carers using individualised budgets? What does the research tell us about when this works and when it doesn't?

Sources

carerstrust. 2014. *Assessing carer's needs: A short guide to taking account of everyone in the family who cares*. Skills for Care, Leeds.

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