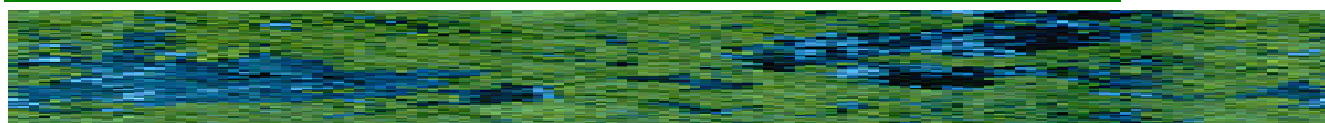


RESEARCH REPORT 1

ARAFEMI CARER CONSULTATION



Identifying carer needs for support and advocacy

Carers lived experience of supporting someone with a mental illness provides vital information on what help is needed to care more effectively and how we can raise the carer voice.

The de-hospitalisation and de-institutionalisation of mental health care to home based and community care has led to an increasing responsibility, reliance and demand on carers to have greater levels of knowledge and expertise in supporting their loved one with a mental illness.

In order to find services and seek care, carers often have to learn how to navigate services, deal with stigma, guilt and shame and also gain basic support to help them with the ongoing emotional demands of caring. It is essential to further explore and add to a knowledge base of understanding about the lived experience of carers, needs for support and ways in which carer voices can be better heard by decision makers and services.

This paper is part of a service evaluation and carer consultation conducted by ARAFEMI. Carers responded to information on current service and support needs, issues faced as carers, future service / support needs and the role of carers in advocacy.

Using social research methods to gather qualitative and quantitative information, the results are based on a sample size of 147 survey respondents, and 66 carers who attended 5 community focus groups and/or provided extended individual feedback. In addition, research literature into the needs of carers of people with mental illness was analysed and reviewed in the context of both a recovery model and the Carer Life Course Framework (Carers NSW, 2005).

Getting access to support

Carers identified a need for further exploration of how best to support families and carers at the first onset and early treatment stages. Carers identified that greater access to information would enhance their ability to find out about support at a time of great

confusion and distress. Carers identified that primary health providers (General Practitioners and hospitals) were often their first point of contact when things first go wrong and they strongly supported that these services be targeted to support early linkage to support and information services.

Recognition of the role that carers play

Carers identified barriers to care as a result of the negative perception of professionals or lack of inclusion in treatment or care planning. Inclusion was seen as particularly essential in periods of crisis and at discharge, when carers faced enormous stressors in providing and locating ongoing care. Supportive professionals made a huge impact in carers ability to access the right type of care, have the necessary information to assist them to care, to proactively work with treatment providers to prevent relapse and cope with the ongoing caring role. They highlighted the major impact of simply receiving recognition as a vital part of the treatment puzzle.

Carers felt that “**further information and education was required to effectively support professionals**” to have greater awareness of carer needs. Education aimed at professionals would also enhance linkage to further support and better utilize the important knowledge that carers can provide in planning ongoing support to mental health recovery.

The need for specialist carer supports

Stigma, guilt and shame were still seen as contributors to the isolation experienced by carers of people with a mental illness. Specialist supports allowed carers to talk about mental illness, explore the impact of mental illness on themselves and their families (and their wider living context); and gain access to other carers.

“Knowledge, moral and peer support to move from having ‘no idea’ how to get treatment to gradually ‘insisting’ that our son had treatment.” -Survey respondent

Understanding that there were people with similar needs with whom carers could share and learn from was described as a major breakthrough in reducing isolation and the trauma of discovering mental illness. The ARAFEMI Carer Help line, information / referral services and support groups provided a vital linkage to support information and validation that helped carers along a continuum of needs.

As these needs were strongly acknowledged as individual and changing, dependent on the wellbeing of the person with a mental illness and other life factors, carers called for a range of flexible supports along a continuum of care model. The need for more service support within rural and regional Victoria, was further identified as a key challenge in planning future services. Carers highlighted opportunities for innovative and sustainable support strategies that allowed rural communities to have a voice about their individual barriers and local needs through localized strategic responses, sharing of resources and usage of new technologies.

Advocacy - having a voice and having it heard

Carers, of people with a mental illness, identified that there was a strong need for advocacy at an individual level, supporting carers to make choices and navigate the mental health system. It was felt to be important that ARAFEMI position itself to act as an specialist carer information clearing-house and effectively advocate on the issues impacting on carers, families and the community in supporting people towards recovery.

The results indicate that carers ability to direct both self advocacy and systemic advocacy is very much based on ‘where the carer is at’ in the journey of caring. Though supporting information and training to empower carers to have a voice, strategies must be flexible and allow for the needs of those who need support from others to advocate effectively.

‘carers were interested in advocacy, but had little time for activity in their current journey of caring. ... though many (carers) expressed an interest in advocacy this was seen in the context of the struggles they faced and the real dilemma of how to manage care.’ - Evaluation report

Summary

Overall this evaluation highlights the importance of maintaining high quality carer specific support services, whilst developing the capacity of the mental health system to listen to and respond to the needs of carers and their families. Services like Arafemi provide a critical centre for information and knowledge as well as a voice advocating on behalf of carers at both an individual and systemic level.

Tools such as The Carer Life Framework provide a useful means of developing services in line with carers needs over the period or journey of caring and moves towards recovery-oriented services gave carers hope in ensuring that quality of life was a key outcome for consumers.

Carers clearly identified that the development of specific services would vary between carers along the continuum of supporting someone to recovery - taking into account other life factors such as access to support, other family members, financial support etc. As supports needs varied so to would carers ability to have a voice and therefore more support and flexible involvement would aid carers access to participate in advocacy.

FINDINGS / RECOMMENDATIONS

- Ensure early linkage to support & information for carers
- Improve training & leadership to professionals / mental health workers to support better carer practices
- Carer specific information & referral services including helplines are valued above more generalist services.
- Develop innovative ways of connecting to carers who may be isolated, or new to the mental health system.
- Support groups provide an important & unique avenue for peer support. Further group supports are needed in regional Victoria.
- The ‘wellness’ of the person with the mental illness & the ability to access relevant support, were the two greatest predictors of a carers ability to advocate.
- Carers identified differences in advocacy needs across the lifespan of caring. They identified that at times they needed someone to support them & ‘walk their walk’ & provide individual advocacy support.