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Submission No. 574

(Inq into better support for carers)



Mental Health Carers

Arafmi Queensland Inc.

Submission to:

Parliament of Australia

House of Representatives

House Standing Committee on Family,

Community, Housing and Youth

'Inquiry into better support for carers'

*'What part do family carers play in the care
of people with mental illness in Australia?*

*To put it simply, they are the 'glue' that
holds the whole mental health
system together'.*

(Skelton 1997)

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1. Background:

Arafmi Queensland was first established in 1977 as a self-help group for family carers of people with mental illness.

Since that time Arafmi has grown into a state-wide organisation providing support services to families and carers and is currently the only organisation in Queensland providing a full range of support services specifically for mental health carers.

Since its inception, Arafmi has seen many changes introduced to the mental health system including de-institutionalisation, the introduction of community based mental health services (both clinical and non-clinical), improved access to information and resources, improvements in medication and the adoption of several frameworks of practice that guide the delivery of both clinical and non-clinical services. However, whilst these initiatives have, to varying degrees, improved treatment and support for people who experience mental health issues, they have not always achieved substantial changes that ameliorate the position of those who care for them.

As a non-clinical support service for carers and families, the stark reality of the pressures (and pleasures) of day to day caring and the lived experience of families coping with mental illness forms the frame of reference for Arafmi's work.

'It is impossible to distance myself from the deeply felt emotions aroused by the traumatic experiences of the last 22 years. It is a tale dictated by the harsh reality of schizophrenia – an endless world of day-to-day tensions and worry and total disruption to normal life' ('Meg' 2002. 25 Years ~ 25 Stories. 44).

Whilst it is acknowledged that the purpose of this enquiry is to obtain an improved understanding of the position of carers, including their role and barriers to participation in employment, it is Arafmi's experience that the position of carers of people with mental illness, including a carer's own wellbeing, is inexorably linked to the wellbeing of the person for whom they care.

2. The role and contribution of carers

'Individual carers on average contribute 104 hours per week caring for a person with mental illness' (MHCA & Carers Australia, 2000. 4).

Caring for a family member with mental illness is not a role that families choose to take on. *'Family carers generally don't take on this role by choice. They are catapulted into it by the onset of severe mental illness in a child, a spouse or other close relative and they are compelled to sustain it by the bond of love for their ill relative and by the lack of resources in the community for the care and support of mentally ill people. Most families have little choice when the only other options for their mentally ill relative are a grotty boarding house or hostel, wandering the streets homeless, or jail'* (Skelton, 1997).

Out of necessity, carers need to assume multiple roles. In addition to their caring role they are also wives, mothers, husbands, fathers, brothers, sisters, sons and daughters. Each role carries expectations and responsibilities that can sometimes come into conflict with the responsibilities of caring. Due to the nature and impact of mental illness mental health carers also experience, stigma, guilt and quite often - isolation (Victorian Government Department of Human Services. 2004. 1).

'The care provided by family members, friends and other people to a person with mental illness often exceeds the usual expectations of close family or personal relationship. This informal care can enable people with mental illness to function more effectively than may otherwise be possible' (Victorian Government Department of Human Services. 2004. 1).

Due to the later onset of mental illness, many carers and families have already embarked on creating a future with their family - establishing a home and building a future that carries corresponding personal expectations and financial obligations. A diagnosis of mental illness can create doubt and uncertainty about this future, particularly for the future security and wellbeing of their family member with mental illness.

Skelton (1997) addressed the role and contribution of the family following deinstitutionalisation when he said that out of necessity, the family have had to assume roles once undertaken by paid staff *'but it is a ward staff without training, without shifts, without backup, without days off or holidays, without the ability to enforce daily routines or compliance with medication, without techniques of rehabilitation'* (Skelton, 1997).

Carers of people with mental illness wear many hats. They often assume the responsibilities of:

- Financial advisor, budget planner and money lender
- Housing and accommodation provider
- Personal and domestic support

- Counsellor and/or life skills coach
- Case manager, OT and/or social worker
- Advocate
- Friend, companion and confidante
- Medication manager/monitor of symptoms
- Appointments manager and taxi driver

However, unlike paid workers in the mental health system, family carers who take up these roles receive inadequate or no financial support. Despite this, carers are often the one constant in the life of their family member; they remain there for the long haul. They do not get promotions to higher paid positions nor can they leave to take up another position elsewhere. Carers are as concerned about 'outcomes' as mental health services but the crucial difference is that their concern is based on love for the person for whom they care and their emotional and often financial investment comes at great personal cost.

Whilst caring can be rewarding and personally fulfilling the personal cost to individual carers, family and friends can be significant. Recent research into caring indicates that one of the key issues to emerge from the study is that carers and their families experience high rates of mental health problems (Australian Institute of Family Studies, 2008. xiii). When the carer and the person for whom they care both experience mental health issues the family's capacity to cope is greatly diminished. Carers also report poorer levels of physical health compared to the general population (Australian Institute of Family Studies, 2008. xiv). The combined impact of the mental and physical wellbeing of carers plays a substantial part in their capacity to continue in their caring role.

For carers of people with mental illness their role and contribution to society is difficult to quantify in financial terms. What is apparent is that their caring responsibilities often take a heavy toll on their own emotional, psychological and physical health – and also other family members.

3. Barriers to social and economic participation for carers

The episodic nature of mental illness can make it difficult for many carers and families to sustain regular employment due to the changing needs of the person for whom they care. Due to the unpredictable nature of their caring role, carers may not be able to pre-determine their availability for work making it difficult to commit to an established work routine.

Consequently, primary carers of people with mental illness can experience unemployment and under-employment.

Unemployment of carers can result from the specific mental health needs of the person for whom they care and their caring responsibilities. As indicated above, the role of caring also influences a carer's own mental health and when good mental health is not sustained difficulties in maintaining continuous employment can ensue.

'Many Carers of workforce age wish to combine their caring responsibilities with employment and education, but are excluded by significant barriers. Most people who are primary Carers report that they provide care either because alternative care is unavailable or too costly, or because they consider there is no choice. Caring can reduce a Carer's income because they are likely to be working less than they would otherwise. To balance their lives, Carers need resolution to the conflicting demands of work and caring'. (Carers SA. 2007. 10)

In the longer term, unemployment and under-employment reduces a carer's capacity to accumulate savings, build superannuation reserves, and maintain an adequate level of skill for workforce participation and as a result may have reduced access to opportunities for promotion. The end result of reduced income can mean that carers may have less opportunity for home ownership. Carers, who out of necessity have to enter the rental market, have to contend with increasing rental costs. It is also difficult to develop community links and establish social networks if families have to keep moving house.

The very nature of mental illness can be difficult for some people to understand. Behaviour related to the symptoms of mental illness can be perceived by some people as 'bad behaviour'. Despite education and awareness campaigns this lack of understanding prevails within the community and as a result, many people with mental illness and their carers can become isolated from friends and their community and/or become estranged from other family members. This in turn reduces a carer's social support network and reduces their capacity to maintain supportive relationships. Time spent in the caring role also reduces time available to spend with friends.

Workforce participation may be assisted through flexible workplace arrangements and appropriate support for the care recipient. In addition, limits on carers' earnings imposed through Centrelink can be a barrier to workforce participation especially as caring involves hidden costs such as medication, counselling and support service fees.

4. Practical measures required to better support carers

For many carers the practical measures that will most assist them in their caring role are support services and flexible respite options for the person for whom they care.

Many carers attending Arafmi support groups indicate that the following would assist them in their caring role:

- Safe, secure and affordable housing for their family member with mental health issues is a 'must' for many families. This includes housing models that include support and/or independent living.
- Equitable access to carer payments and allowances. Many carers report tension between the 'recovery paradigm' that predominates within the mental health sector. Carers report that there is a perceived need for them to 'paint the bleakest picture' of the support needs of the person for whom they care to be considered or qualify for carer payment.
- Whilst Centrelink, as a 'one stop shop', may have some advantages it takes time and commitment on the part of the carer and care recipient to negotiate access to services and support with bureaucracy. Some people who experience mental illness also experience reduced motivation, which in turn impacts on carers and families access to support.
- Eligibility for services can sometimes be restrictive for families who experience mental health issues and can result in arbitrary decisions being made by service providers that do not meet the individual needs of families.

Carers and families also need access to effective and responsive clinical and non-clinical services. Many carers report an imbalance of power between themselves and mental health services. Whilst many community Mental Health Services have introduced policies on consumer and carer participation the reality for many families indicate that this is the exception rather than the norm. For example, an Arafmi staff member recently contacted a Mental Health Service with a request for them to distribute information to carers on an upcoming event only to be met with the response "we don't have carers, we have patients". When the Arafmi staff member asked did they not think that patients may have carers, the response was, 'possibly – but we don't have anything to do with them'. Unfortunately this is probably not an isolated example with many carers feeling that they have to resort to making an official complaint before they get an adequate response.

Carers need to be listened to and heard by clinical service providers and have available to them the same level of confidentiality as the person for whom they care. Carers report that when they request information from clinical services they are often met with workers using privacy and confidentiality as the reason for not providing information. Yet at the same time, carers are the primary means of support for their family member and to expect them to do this without information and support is to at the very least - unreasonable.

5. Strategies to assist carers to access the same range of opportunities and choices as the wider community

For many carers the foremost strategies that will assist them to access the same range of opportunities and choices as the wider community are – a range of flexible and appropriate support options for their family member with mental illness. Effective and responsive clinical and non-clinical support services for their family member with mental illness are a priority and can be directly linked to carer well being and their own mental health.

Knowing that their family member is safe, secure and has meaningful engagement will provide peace of mind for many carers and provide space and time for them to consider the opportunities and choices available to them.

Arafmi Queensland provides emotional support for carers through facilitating a network of carer support groups around the State. Overwhelmingly, carers report the benefit of these groups. They provide an opportunity to share experiences and feelings with others who really understand what they are going through in a safe and non-judgemental environment. Groups also allow time for carers to come to terms with what is happening to them and their family member and to gain understanding of mental illness and work through the emotional aspect of their caring role.

During a recent survey of support group participants, respondents provided the following comments about the benefit of support groups:

- *'It is important to me to keep the support for carers. Sometimes we feel we are the only ones going through the ups and downs. Just to know the support from the Arafmi group is these is a big help'.*
- *'Knowing you are not alone. People who understand and don't judge'.*
- *'It is good to get away from my responsibilities of caring'.*
- *'At first I did not think it was my kind of group meeting, discussing topics that were not discussed at home and swept under the carpet and to discuss them in front of people you don't know was even more foreign to me. I persevered and kept attending, finally realising I was not alone and there were other people out there going through similar experiences. I find it extremely helpful to attend as I get so much support now from others and I am able to offer support in return now'.*
- *'I can cry in the group'.*

On the whole, it would be Arafmi's experience that carers do not have unreasonable requests or expectations. They want a good life for their family member/friend. They want information and support - both for their family member and themselves.

They want **HOPE** for the future.

'While there are these personal benefits flowing to a caregiver, it nevertheless comes at significant emotional, social and economic cost to the family. The challenge for a community is to seek out ways in which the impact of these costs can be reduced so that families have the opportunity to experience a positive outcome from the caring role both for themselves and for the person with the disability' (Australian Institute of Family Studies 2008. 110).

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