Inquiry into Planning Options and Services for People Ageing with a Disability

To: community.affairs.sen@aph.gov.au
Submission by ARAFEMI Victoria Inc.
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Background to Organisation:

ARAFEMI Victoria is a not for profit organisation which provides support to people with a mental illness and their families. ARAFEMI provides Statewide helpline support, education, advocacy and support groups to carers and families of people with a mental illness. In addition, we provide counselling support, peer work, housing support, respite and subacute services to people with a mental illness and their carers.

ARAFEMI currently delivers specialist services and supports to ageing carers and the people they care for. These supports include assertive telephone outreach to ageing carers, respite (in home and cottage style), education and counselling to assist future planning including wills and bequests. In addition, our work with people with a mental illness includes people with a chronic and severe mental health issue. Although adult mental health services primarily target ages 16 – 65, we have a large cohort of consumers who have long term support needs and who are now experiencing physical and social issues relating to ageing. We anticipate that the demands across our organisation to respond to the dual issues of mental illness and ageing will increase over the next 10 years.

In consultation with our staff, management, Board, carers and consumers we offer the following comments in relation to the Inquiry Terms of Reference.

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Access to options for and services to assist people with a disability and their cares to plan for the future, including:

(a) Inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers;

1. Lack of specialist planning services

There is currently a paucity of specialist planning options and services for carers and consumers affected by mental illness. In addition, there is little evidence or focus within policy or planning documents of the specific needs of consumers and carers affected by ageing and mental illness. Generic services and disability services often lack the specialist knowledge and linkage to mental health services that are necessary to navigate appropriate ongoing care and support. In addition, carers feel that there may be stigma and lack of awareness in how to respond where they are issues of mental illness as well as ageing.

2. Lack of appropriate accommodation options

One of the key factors with regard to accommodation for consumers is access to a range of accommodation options, for example, independent living, supported accommodation and the provision of support packages for consumers with a mental illness who are able to live with their families.

3. Need for carer and consumer input into planning

Services that assist families to have discussions around future accommodation and support needs must take into account consumer and carer views equally as well as the fluctuating nature of mental illness.

(b) Ways to ensure the continued quality of life for people with a disability as they and their carers age;

In making suggestions about how to improve the quality of life for people with a mental illness as their carers age, we draw on our expertise in:

- Developing and delivering shared Carer & Consumer support models including respite – which supports informed decision making in line with whole of family care, sustainable mental health and social inclusion. ARAFEMI has extensive expertise in carer and consumer involvement.
- Long history of providing accommodation and support
- Carer advocacy expertise

1. Housing

Maslow’s triangle of needs states that without security, affordability & suitability of accommodation any further possibility of improving health is significantly undermined, suitable accommodation is a basic human right. At present, consumers are priced out of the current market and mainstream accommodation options are more often than not, unsuitable for people with long term mental health needs – price, short term tenancies, unsupported, poor landlords, poor conditions in unsuitable areas, unsympathetic neighbours & social stigma and discrimination.

Sustainable supported suitable accommodation offers the stepping stone into mainstream life and future community contribution. Societal, health (both mental and physical) and justice costs are reduced.

We recommend that ongoing accommodation options include a range of independent, shared and group accommodation,to meet varied needs in both social and private housing. In addition, there needs to be opportunities for transition and flexibility as circumstances change given the episodic nature of mental illness.

2. Development of a skilled workforce (mental health and ageing)

Currently most services received by consumers and carers are provided via a specialist skilled mental health workforce. This includes families and carers who were the first wave of people post de-institutionalisation. This population is now ageing and requires more intensive support to navigate and utilise yet another and currently unlinked set of social services to meet the needs of ageing whilst maintaining primary care of mental health issues. This raises the need to develop the workforce in both sectors.

Currently the psycho-geriatric field is limited and whilst there are ad hoc moves to up-skill the mainstream mental health workforce to support the physical health needs and needs of ageing consumers and carers, such development at a systemic and sustainable level is unfunded.

3. Positive service framework (person centred care)

We work from a recovery, person centered, rehabilitation goal driven model to achieve sustainable change. Support coordination with all service and family are integral to success.

4. Development of specific mental health / ageing care packages with shared service support

Further aged care packages specific to mental illness, would allow families to utilize any existing accommodation that families may have and want to use for a person with longer term support needs. In addition, links between assessment processes within aged care and mental health services need to be developed and formalised.

Support would need to be tailored to suit the changing needs of consumers with a mental illness for example, active intense to moderate to low to inactive. Greater focus on social confidence and inclusion also requires consideration.

(c) The types of options and services that could be developed to help people with a disability and their carers to plan for the future;

1. Specialist services – mental health and ageing

As outlined above, we believe that specialist planning services that sit within a continuum of mental health services are necessary to best meet the needs of mental health carers and consumers. Services must have a sound understanding of the impact and consequence of mental illness from a consumer and carer perspective.

2. Housing

The single most important issue for carers and consumers with a mental illness is where will the person live and how will they be supported. Without options for accommodation and care, future planning is difficult. Recommendations include a range of models of accommodation which take into account the fluctuating nature of mental illness.

3. Support packages and service collaboration

Models of specialist support could be purchased via existing brokerage agencies from specialist mental health or carer services similar to the purchase of respite. It is essential that models partner and support cross collaboration between aged care services, carer services and mental health.

4. Further consultation and advocacy
   Carers and consumers with a mental illness who are ageing require further support to articulate and advocate for service models that would meet their needs.

(d) Any other matters which would assist carers to find an adequate and appropriate answer to the question: 'What happens when I / we can no longer care?'

1. Cross government approach and increased service links between mental health and aged care services.

A cross government approach is necessary to support the future needs of carers and consumers affected by mental illness as they age. A multi government approach that informs workers across family and community services, justice, housing, ageing would ensure that carers and consumers are informed regardless of their point of contact. Assisting consumers and carers at vital transition points within the mental health system ie. Intake or discharge from adult mental health services and creation of links with services often used for community based aged care (eg. District nursing, councils, respite brokers)

2. Community education and awareness

Clear and available access to services that can assist carers to navigate multiple systems of care is necessary. This may include awareness campaigns to assist carers to identify starting points. This would raise awareness of the supports available and reduce stigma. Player and Leggatt (1997) report that between 25 and 63 % of people with a mental illness live at home with family. The Australian Bureau of Statistics data indicates that 60% of carers provide ongoing care for periods of five years or more (ABS: 2004). Both the literature and our anecdotal evidence indicate that this group of carers and consumers feel highly marginalised and concerned about who will care in the future. Conversely, they report that physical health providers and aged care providers may feel unskilled in supporting the mental health needs of carers and consumers.

3. Further investigation of disability trusts in reference to mental health needs

Assistance for carers to set up ‘special disability trusts’ through Centrelink would be useful. For example, provision of funding for services to run specialist training to mental health carers on wills and bequests or coordinating pro bono work though legal firms to provide free legal advice to carers who wish to embark on this path would be beneficial.

4. Recognition of the ongoing nature of care, grief and loss and burden of care

Services that assist carers of people with a mental illness must also be in a position to support the broader wellbeing needs of carers. Carers have the lowest wellbeing of any population cohort in Austalia (Cummins, et al, 2007). To assist carers to plan for the future it is essential to recognise and support carers with a range of issues including compassion fatigue / burnout, social isolation, grief and loss and the ongoing nature of their carer burden. It is our experience that carers need to be supported to look at their own broader physical and emotional health needs prior to and during planning of care. In addition, carers indicate that knowledge of mental illness and its impacts is a significant factor for engagement with services (ARAFEMI, 2007). Therefore services must understand mental illness from a psychological, medical and social perspective to assist any discussions of support and care.

Further information in support of any comments and recommendations can be provided. We thank you for the opportunity to submit to this important inquiry on behalf of carers and consumers with a mental illness who are ageing.

Regards,

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ARAFEMI Promoting and improving the well being of people affected by mental illness

Background research:

Mental Illness – prevalence and social impact

More general data on disability and chronic illness reveals that there are increasing numbers of people with disability and chronic illness (Cummins, Hughes, Tomyn, Gibson, Woerner & Lai, 2007) and the prevalence of mental illness has risen to 1:4 in the last decade. Robinson, Rodgers and Butterworth (2008) report the sum prevalence for specific mental illness equates to 18.6% (if you add the prevalence of each major disorder together). This figure is significantly higher if including those people who may be counted twice due to dual diagnosis. Though statistical data captures those that meet the criteria for diagnosable mental illness, they do not reflect the true impact on the quality of life of those experiencing mental health problems (Robinson et. Al., 2008). Mental illness is the leading cause of non-fatal disease burden in Australia (Mathers, Vos & Stevenson, 1999), a significant cause of death (suicide 2%) and has major implications on economic and productivity burden, reflected in data on lost work days (Lim, Sanderson & Andrews, 2000).

The role of Carers

The role of carers has changed over the past three decades, with a dramatic escalation of community care roles in the past 10 years. These changes have been driven by three main forces; greater sophistication of psychotropic medication reducing length of hospital stays, increased awareness of the negative consequences of long hospitalisations and costs of providing care (Leggatt & Player, 1997, Robinson, Rogers and Butterworth, 2008). Deinstitutionalisation, social policy involving a shift away from long term institutionalised care; Government policy shifts, and shorter periods of hospitalisation, have led to an ever increasing demand for community care.

Most people with a mental illness live in the community with informal carers such as family, friends, neighbours and co-tenants. Player and Leggatt (1997) report that between 25 and 63 % of people with a mental illness live at home with family. The Australian Bureau of Statistics data indicates that 60% of carers provide ongoing care for periods of five years or more (ABS: 2004). The cost of caring and the economic, social and psychological consequences are major social health issues represented across major population surveys (ABS, 2004; AIHW 2006b). Lefley (1997) states that 'the movement towards deinstitutionalisation has in general imposed on families a caregiving role for which they are unprepared, untrained and from which they have been systematically excluded from in the past' (p.1).

Robinson et al, 2008, in discussion on family relationship services, identifies that the high population burden of mental disorders is significant in family relationships for the following reasons:

- "Mental disorders impact not just on the individuals affected but also on those around them - including immediate family and other relatives - and may be both a cause and a consequence of family/relationship difficulties.
- Although most common mental disorders are amenable to treatment, the majority go undiagnosed and untreated.

- Many disorders are chronic or recurrent and they often call for long-term management, not just acute care.
- Much of the care provided for people with mental disorders (even very serious disorders) is informal care provided by family members”. (Robinson et al, 2008; p.4).

The impact of caring for people with a mental illness

There is clear evidence that carers face ongoing difficulties beyond accessing support and care for their loved one. Carers must come to terms with a range of emotional and coping responses including shock and grief (“how can this have happened?”), guilt (“could I have prevented it?”) and the frustration at the lack of ability to cure or assist their loved one that can impact at a more personal level (Alexander, 1991; Carers NSW, 2006).

Living with a person with a severe mental illness impacts significantly upon the family and it can affect relationships, financial status, work, leisure and the mental and physical health of the carer (Baronet, 1999). Purves (2002) found that carers often feel a sense of distress and isolation as they strive on two fronts: first to understand their relative, who may have confused thoughts and show erratic behaviour, and second, to advocate on their behalf during intermittent contacts with the health service. This dual role is often difficult and stressful. Additionally, as key criterion for diagnosis of mental illness across almost all mental illness is fundamentally linked to distress or impairment across social functioning the impact across family relationships can be profound (Robinson et.al., 2008).

I’Anson (2004) found that carers and families of people with high prevalence mental health disorders experience significant and comprehensive impacts across all life and well being domains. The research showed that people with these disorders often become highly dependent upon carers (spouses, parents and children) and other family members, leading to a traumatised family system in which crises and tension in relationships are common.

Social isolation and low self-esteem, economic losses, decreased life opportunities, and difficulties accessing effective treatment and support services add to the pressures that carers and families experience. The lack of support and information about the illness, management and services was found to further compound feelings of powerlessness and frustration (beyondblue / Network fir Carers of People with a Mental Illness, 2004).

Carer Well-being: Depression and fatigue

In a 2007 study of over 4000 carers, factors concerning personal well-being, depression and stress were measured using standardised scales (Personal Well-being Index) and additional questions related to their carer situation to understand the subjective wellbeing of family carers in Australia (Cummins, et al. 2007). Carers were assessed in terms of their average level of satisfaction across seven aspects of personal life (health, personal relationships, safety, standard of living, achieving in life, community connectedness, and future security) and given two additional psychological measures of depression and anxiety. The results found that carers had the lowest collective wellbeing score of any group sampled utilizing the wellbeing scale. 56% of carers were also found to have an average rating on the depression scale that was consistent with moderate depression, with female carers showing the lowest wellbeing. Disadvantaged carers, such as sole parents, had much reduced wellbeing scores and experienced greater depression and anxiety.