Families and carers - - SANDAS Position Paper No.4

Background:

Carers play an immensely valuable role in society, with unpaid care work central to our social and civic responsibilities.

Families and carers of those with co-existing substance misuse and mental health problems often experience heightened levels of stress, anxiety and depression and a higher care-giving burden. They often report feeling helpless and isolated from social support and connection.

The diversity of relationships and social support networks that exist now mean a carer may be defined as; immediate and extended family, partners, grandparents, friends, carers, and anyone who plays a significant part in a consumer's life.

According to research in 1999, the definition of family has been expanded to include "people related by marriage or biology, or adoption, as well as people related through affection, obligation, dependence or cooperation."[1] The South Australian Network of Drug and Alcohol Services (SANDAS) use this definition of 'family' throughout this position paper.

Carers and caring roles within families are significant growth areas in the Alcohol and Other Drug (AOD) sector due to the high cognitive and physical health impact of AOD and the frequency with which its misuse leads to long term and disabling chronic disease, including many cancers. Households with such circumstances frequently start a caring role well before one or more diagnoses is made and well before any primary health care support system is put in place. Frequently AOD misuse starts creating these family burdens while one of more members are still misusing.

A case in point is the growing number of grandparents caring for their grandchildren as a result of AOD misuse. It is important to acknowledge that there is also an evidence base that shows that these roles can create very high stress, shame and guilt and in some instances, can lead to various forms of self-medication which can go unreported for long periods.

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[1] Rothausen, T.J. (1999). '*Family in organizational research: A review and comparison of definitions and measures.'* Journal of Organizational Behavior

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Family support is one of the most influential factors in successfully dealing with the effects of AOD use. Much of the literature suggests that unless the whole of a family's situation is addressed, AOD abuse treatment is unlikely to be successful.

Given the impact and effect on family members can vary depending on their relationship with the user, governments across the board must develop and support initiatives that are tailored to encompass prevention, support and treatment. In particular, early intervention is critical to assess impact on the family and provide appropriate support services as part of the recognised and funded AOD service mix.

Who are carers?

While the role of caring has traditionally been seen within a gender context, with the majority being female,[2] carers are not a homogenous group; rather they come from all walks of life, cultures and religions. They may be spouses, parents, grandparents, sons or daughters, siblings, friends, nieces or nephews, neighbours or volunteers.

More than five million Australians provide help and support to a family member or friend[3], with the Australian Bureau of Statistics (ABS) estimating that 213,700 South Australians provide ongoing assistance to someone with a disability or an age-related frailty.[4]

Rates of unpaid care are highest amongst people aged 35 to 44 years. In this age group 73 per cent of women and 64 per cent of men had some form of unpaid care responsibility.[5]

The rates of unpaid care are also higher amongst Aboriginal and Torres Strait Islander peoples with 13.2 per cent of people indicating they provide care compared with 11.2 per cent of the non-indigenous population.[6]

When we look at paid caring work, according to the latest census there is a staggering 1,167,636 in healthcare and social assistance.

Put simply, 12 per cent of the workforce is employed in caring for other Australians, which equates to more than one in 10 employed people in the health and community sector.

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[2] In 2009, there were 2.6 million carers who provided assistance to those who needed help because of disability or old age. Just under one third of these (29%) were primary carers; that is, people who provided the majority of the informal help needed by a person with a disability or aged 60 years and over. Over two-thirds of primary carers (68%) were women. (Table 5) (http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features22009?opendocument&tabname=Summary&prodno=4430.0&issue=2009&num=&view=)

[3] Carers SA 'who are carers?' http://carers-sa.asn.au/facts/who-are-carers

[4] 2009 Australian Bureau of Statistics Survey of Disability, Ageing and Carers http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0

[5] Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers, Australia 2009,* Basic CURF, Version 3, CD-Rom (2009). Findings based on SPRC's analysis of ABS CURF data.

[6] Australian Bureau of Statistics, *A profile of carers in Australia,2008,* Catalogue no.4448.0 (2008), p 27. At http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4448.02008?OpenDocument (viewed 14 September 2012).

Caring, at what cost?

According to an economic analysis conducted by The Australia Institute (TAI), for every million dollars invested in community services, an average of 21.2 jobs is created, while the same amount invested in mining or agriculture would create 4.7 or 11.1 jobs, respectively.[7]

TAI Executive Director, Dr Richard Denniss, argues that "while the immediate beneficiaries of better public support for carers is likely to be the (largely female) army of family members now doing most of the work, the long-term beneficiaries will be the industries that need the skills those voluntary carers possess."[8]

According to a recent report conducted by the Australian Human Rights Commission, acknowledging unpaid caring work as an important component of our economy is essential, in understanding the true cost of caring in our society. For instance, an estimated 1.32 billion hours are spent providing unpaid care for people with disabilities each year. If these unpaid carers were replaced by paid care providers the cost would be approximately $40.9 billion per annum.[9]

It is important to note, that caring can be incredibly demanding and mentally exhausting work, often restricting the lives of individual carers and their families. Many carers miss out on important life opportunities, particularly for paid work, a career and education.

Indirect health and wellbeing impacts often associated with caring responsibilities have been summarised by Carers Australia, to include the following:

- Caring can be emotionally taxing and physically draining. Carers have the lowest wellbeing of any large group measured by the Australian Unity Wellbeing index.
- Carers often ignore their own health and are 40 per cent more likely to suffer from a chronic health condition. Some health problems, like back problems, anxiety and depression, can be directly linked to caring.
- Many carers are chronically tired and desperately need to refresh with just one night of unbroken sleep, a day off or an extended period with no caring responsibilities.[10]

What services and support mechanisms are needed?

The impact of problem AOD use on the family members and carers of consumers is profound, and can take many forms.

Families, in particular, often suffer the consequences of AOD use by a family member. The consequences can stem from lack of involvement in treatment processes, lack of coordination between appropriate services, and the stigma associated with substance use. Because of this stigma, the AOD problem is often hidden, which not only exacerbates the

[7] Denniss, R. "Why investing in carers will pay' Australian Financial Review http://www.afr.com/p/opinion/why_investing_run_carers_will_pay_AOl7ruJ3U7MKX4esh62j7N

[8] Ibid

[9] Access Economics, *The economic value of informal care in 2010* (2010).

[10] Carers Australia 'Impact of caring' http://www.carersaustralia.com.au/about-carers/carer-issues/

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family's stressful experience but may also prevent the potentially useful contribution that family members and carers can make to the recovery of the consumer.

What works for families with a single discrete problem may not be appropriate for families with multiple problems.

Given caring can be undertaken by more than one individual or a community, support and information needs are consequently diverse. Consumers and carers, alike, need information on pathways to support, especially where support can be incorporated into treatment and care plans for consumers with co-existing substance misuse and mental health issues.

In addition to the hidden nature of family harm associated with AOD use, services for substance abuse problems on the whole tend to focus on the consumers, with the needs of family members often seen as peripheral and not central to the treatment process.

Prioritised recognition, intervention, treatment and respite services for families and carers should be assessed, particularly in relation to capacity building within carer networks, to deal with the complexities associated with co-existing substance misuse and mental health issues.

DisabilityCare – interaction with the AOD sector

DisabilityCare (formally NDIS), brings to Australian families a new era and recognition of the nature and needs of a caring relationship where disabilities exist. The role of the AOD sector in the DisabilityCare support mix may be further expanded and acknowledged. The penetration of AOD misuse into families with one or more disabilities is not likely to be vastly different to families without disabilities. Future funding programs must more closely consider the need for support with AOD issues and establish clearer service pathways and efficient access to those services.

It is now very clear in our society that AOD misuse causes a large number of various physical and psychological disabilities and the brunt and burden of these are borne by families. A strong, responsive and cost effective AOD sector can play a vital role in preventing and reducing this burden. All governments are strongly encouraged not to lose sight of this.

While efforts have been made to incorporate and represent the views of our member organisations, the position presented in this paper are those solely of SANDAS

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