



Mental Health Council OF TASMANIA

**The Mental Health Council of Tasmania asks
'Who Cares?'**

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Executive Summary

The Mental Health Council Tasmania (MHCT) seeks to understand the definition of 'carer' from the various stakeholders' perspectives. Based on the 2006 Census it is estimated that more than 1 in 8 Australians (or 2.87 million people) are providing informal, unpaid care. This represents 13% of Australia's population. Of these, approximately 10% were identified as carers of people with mental health issues. These statistics include an estimated 69,500 carers in Tasmania. The majority of carers (54%) were female, with women much more likely to be primary carers (71%)¹. However, these figures are a conservative estimate because they only reflect those people who have recognised and identified their role as that of carer. Therefore, it is reasonable to expect that there are potentially far more carers in Australia than indicated by these statistics. In addition, this piece of research suggests that while every carer's experience is unique, the definition of carer consistently includes people who provide personal care, support and assistance to care recipients. Therefore, carers are usually defined by what they do, regardless of the amount or quality of care and support they provide. As a result of this research the following recommendations became evident:

- ✓ The care recipient is usually best placed to identify their own carer.
- ✓ A carer's role needs to be defined by what they do, regardless of their relationship to the care recipient.
- ✓ Unidentified carers need to be identified so services can find the best way to support them in their carer role and include them in service planning and policy development.
- ✓ The role of carer can change so services supporting carers need to be consultative, flexible and responsive to carers' needs.
- ✓ Carers are a valuable resource and need to be consulted by services seeking to identify and eliminate barriers that hinder care recipients in their recovery process.
- ✓ Greater visibility of the carer's voice at every level of service delivery can further inform cultural and structural change in workplace culture and professional development.
- ✓ Considerable work needs to be done to encourage disenfranchised and disengaged carers to make use of services and available resources because adopting a caring role is not without significant personal cost.
- ✓ The more carers who are identified will mean an increased number of carers able to contribute to the development of mental health strategies and support solutions that will feed into policy and research processes to improve outcomes for care recipients.
- ✓ Carers need increased financial support. All carers need to be financially compensated to redress the costs of caring.

¹ ABS 2006, Cat.no.2901.0 Q49

Introduction

The MHCT is the peak body representing the interests of consumer, carer and community mental health sector organisations, providing a public voice for people affected by mental illness and the organisations in the community sector that work with them. The MHCT advocates for effective public policy on mental health for the benefit of the Tasmanian community as a whole and has a strong commitment to participating in processes that contribute to the effective provision of mental health services in Tasmania.

This position paper has been developed by Jacqueline Murray, student social worker on placement at the MHCT in consultation with some of its members. The MHCT seeks to understand the definition of 'carer' from the various stakeholders' perspectives. This position paper assumes that carer expertise can only be provided by people with a lived experience, who can provide extensive knowledge of what life is like for carers, and who offer a unique understanding of what they need from services. Carers have the potential to provide valuable policy input through their intimate knowledge of the needs of the people they care for. Carers have the ability to actively contribute to mental health service teams as peers, thus placing them in a position to use their influence to contribute creatively to service improvement. Unidentified carers need to be identified so they can better be supported as part of a strategic approach to improving the culture of the mental health sector and the lives of those they care for.

An opportunity to address the needs of the identified mental health carer workforce exists with the implementation of the **Fourth National Mental Health Plan**.² The Plan promotes the implementation of a recovery oriented culture within mental health services. To support this, the Plan proposes the establishment of a peer specialist workforce in the mental health sector and an expansion of opportunities for meaningful involvement of carers.

Policy Context

In 2011, Parliamentary Secretary for Disabilities and Carers- Senator Jan McLucas, and Minister for Health and Ageing - MP Nicola Roxon, made a joint media release at the National Mental Health Consumer and Carer Forum (NMHCCF) as follows:

Australia's 2.6 million carers will receive improved recognition and support following the launch of the Gillard Government's National Carer Strategy in Victoria in August 2011. The Minister for Families, Housing, Community Services and Indigenous Affairs, Jenny Macklin, the Minister for Health and Ageing, Nicola Roxon, and the Parliamentary Secretary for Disabilities and Carers, Senator Jan McLucas visited Carers Victoria in Footscray to launch the Strategy, which includes \$60 million in new funding over the next four years. The Strategy delivers on the Australian Government's commitment to better respond to the needs of carers, and helps to ensure carers have the opportunity to take part in all aspects of society, including the chance to participate fully in work, community and family life. New funding delivered under the National Carer Strategy includes:

- \$42.6 million to extend automatic eligibility for the Carer Allowance (child) for around 2,200 carers of children with Type 1 Diabetes who are aged between 10 and 16 years.

² Fourth National Mental Health Plan, An agenda for collaborative government action in mental health, 2009-2014, Australian Government, Canberra.

- \$10.3 million to continue the Carer Adjustment Payment, a one-off payment for families who, following a catastrophic event involving a child aged 0-6 years, need additional support to cater to the needs of their child.
- \$2.9 million to improve access to the Carer Supplement for carers who are working when the Supplement is paid in July each year, which will help carers to maintain paid employment.
- \$2.1 million to ensure fairer access to Bereavement Payment, which will provide some assistance to carers receiving Carer Allowance and an income support payment at the difficult time following the death of the person they are caring for.
- \$1.6 million for a national and targeted campaign to raise awareness of the role of carers.

*The National Carer Strategy*³ has been developed in consultation with carers, state and territory governments, service providers and peak organisations. The National Carer Strategy will help to ensure carers have the same rights, choices and opportunities as other Australians. It also aims to help build a society which genuinely values and respects carers.

The Strategy sets out how governments, business, health and community professionals and the wider community will work cooperatively together to achieve this vision. It is supported by the Australian Government and all State and Territory Governments. Through their hard work and sacrifice, carers greatly improve the quality of life of millions of people across the nation. However, too often this work goes unnoticed. The National Carer Strategy recognises the invaluable contribution of carers to the Australian community. In August, the Australian Government received the Productivity Commission's final report into a long-term disability care and support scheme and will now carefully consider the report.

The National Carer Strategy builds on the work the Government has already done to improve the lives of carers and the people they care for. This includes:

- The National Disability Strategy, a ten year reform plan to address the barriers faced by Australians with disability, which was endorsed earlier this year by the Council of Australian Governments (COAG).
- Australia's first national Carer Recognition legislation.
- Historic increases to the Carer Payment delivered in 2009, now worth \$128 extra per fortnight for singles on the maximum rate and \$116 extra for couples combined on the maximum rate.
- A permanent \$600 annual Carer Supplement.
- Simpler and fairer assessment process for Carer Payment (child) and Carer Allowance (child).
- A \$54.3 million boost to mental health respite services in this year's Budget.

The development and implementation of the **National Carer Strategy** is the Australian Government's recognition of the valuable contribution of carers to the Australian community. It outlines how this contribution can be valued, supported and shared. The National Carer Strategy builds on what the Australian Government already provides for carers and complements reforms to improve supports provided through the aged care, disability, mental health, primary health care, hospital, and community care systems.

³ *The National Carer Strategy* 2011 www.fahcsia.gov.au

The National Carer Strategy gives effect to the principles of the **Carer Recognition Act 2010**. It sits alongside and complements the **National Disability Strategy**, a ten year plan for improving the lives of Australians with disability, their families and carers⁴.

The Hon. Jenny Macklin MP Minister for Families, Housing, Community Services and Indigenous Affairs, and The Hon. Nicola Roxon MP Minister for Health and Ageing, Senator the Hon. Jan McLucas Parliamentary Secretary for Disabilities and Carers, The Hon. Mark Butler MP Minister for Mental Health and Ageing released the following statement:

“Each morning in this country more than 2.6 million people wake up and their first thought is for the needs of someone else. These people are Australia's carers. They are family members, friends, partners, parents, children, or neighbours who care for a loved one with disability, medical condition, mental illness or who is frail aged. Some carers shoulder their responsibilities alone; some share their responsibilities with others. Some do it full time, all day, everyday, while others only occasionally. What they do not only makes a profound difference to the lives of those they care for, but makes an important contribution to the economic and social life of the nation. Carers deserve the same opportunities as other Australians to participate in work and the community, and live a meaningful life. The Australian Government is determined to ensure Australia's carers get the support they deserve from the Government and the community. The Government has developed the National Carer Strategy to ensure that our community values and respects carers. The National Carer Strategy represents the Australian Government's long term commitment to carers. It will guide future reforms, and it builds on reforms the Government is already delivering to better support carers. These include providing increased financial security through record increases to the Carer Payment; delivering carer recognition legislation; and establishing a National Disability Strategy.”⁵

One in five people are affected by mental illness at some stage in their lives⁶. In Australia policy makers and funding bodies acknowledge the importance of carers in supporting collaborative partnerships between service providers and consumers and carers in delivering services and in improving service quality. The National Mental Health Strategy, which includes the **Fourth National Mental Health Plan**, the COAG **National Action Plan on Mental Health 2006-2011**, state and territory mental health plans, and policies have aimed to develop a mental health sector where carer participation is a key element of best practice policy development and delivery in mental health. The Plan recognises that carers will need to be supported in these roles. To date there has been no national audit of mental health carers, paid or unpaid, in Australia⁷.

The NMHCCF Consumer and Carer Participation Policy states:

“Consumers and carers have distinct and separate needs. All public, private and non-government mental health organisations will recognize the distinction between consumer and carer issues and needs, and acknowledge that it is generally inappropriate for consumers to represent the interests of carers and for carers to represent the interests of consumers”.⁸

⁴ *ibid*

⁵ National Mental Health Consumer and Carer Forum (2004) *Consumer and Carer Participation Policy: a framework for the mental health sector*, NMHCCF, Canberra.

⁶ www.sane.org

⁷ National Mental Health Consumer and Carer Forum (2004) *Consumer and Carer Participation Policy: a framework for the mental health sector*, NMHCCF, Canberra.

⁸ *Ibid*

- **Key steps to identifying and supporting mental health carers:**

- address remuneration and unpaid carer's associated out of pocket expenses
- provide carers access to information and resources
- offer carers training opportunities e.g. managing personal stress, understanding mental health issues, understanding legal rights and responsibilities as a carer, guardianship,
- address a carer's dual relationship and potential conflict of interest
- provide scheduled respite options
- address privacy, confidentiality, and the disclosure of information
- provide counseling and support for carers
- coordinate support services for carers

- **Effects of significant others not identifying themselves as carers:**

- carer burn out and stress related illness
- lack of trust and respect between carers, consumers, and support workers
- lack of support and resources

Literature Review

The main focus in reviewing the literature in this project is on the various definitions of term 'carer', rather than care recipients, although the two are practically inter-twined. There is a diversity of goals of the Australian community care sector. Carer quality of life, the quality and sustainability of the care-giving relationship, participation in care planning and service delivery, relationships between formal and informal carers all become part of the effectiveness and outcomes.

The task for this project is to identify the various definitions of 'carer' relevant in the Australian context. The literature search has focused on the definition of carer as defined by Government and non-government services within the mental health sector. The search was not restricted to the academic literature. Instead, the review has accessed a wide range of data sources including the practice literature, surveys and policy documents.

In 2008, a New South Wales health services survey found that over one third of respondents indicated that they were not paid for their consumer-related work⁹. This highlights the potentially significant number of consumer and carer workers who are working in a voluntary capacity. Issues affecting paid carers would also be relevant to these often, unidentified workers.

Social care as a multi-dimensional concept focuses on three aspects of care:

- *Care as labour*—care involves work, either unpaid or paid and the conditions under which it is conducted and government's role in the provision of formal care services should be considered.
- *Care is located within a normative framework of obligation and responsibility*—care is provided within interconnected relationships, obligations and reciprocity.
- *Care is an activity with financial and emotional costs*—these costs, indirect and direct, are incurred by individuals, families and society.¹⁰

⁹Stewart, S., Watson, S. Montague R., Stevenson, C., (2008) Set up to fail? Consumer participation in the mental health service system, *Australasian Psychiatry*, Vol. 16, Issue 5:348-353

¹⁰ Ibid

The Social Policy Research Centre for the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) recently published *'The Costs of Caring and the living standards of carers'*¹¹. The report provides the following definition:

Informal carers are people who provide unpaid help, support or assistance to family members or friends with disability, chronic illness, mental illness, other illness, or alcohol or other drug problems.

Approximately 16 per cent of the adult population in Australia provide informal care¹². The majority of people who require help or assistance receive support from family or friends. The need for informal carers is likely to increase with an ageing population. Women, who are the main providers of informal care, are entering the labour force in increasing numbers. Carers often need to negotiate the competing demands of caring and paid employment. The evidence suggests that, given limited alternative care arrangements, many carers adapt to their caring role by reducing or leaving employment.¹³

Definition of Carers

According to the Commonwealth of Australia's Fourth National Mental Health Plan - An agenda for collaborative government action in mental health 2009–2014 a carer is a person who has a caring role for a person with a mental health problem or mental illness. They could be family, friends or staff and be paid or unpaid. The role of the carer is not necessarily static or permanent, and may vary over time according to the needs of the consumer and carer. A carer is someone whose life is affected by virtue of his or her close relationship with a consumer, or who has a chosen caring role with a consumer. A carer may also refer to the consumer's identified family, including children and parents, as well as other legal guardians and people significant to the consumer¹⁴

Young Carers – Adult mental health also impacts on the mental health of Tasmania's children and young people. Young carers for those with mental illness are one of the most vulnerable groups of carers and are often unidentified. Unless they are directly accessed by a knowledgeable worker they can remain hidden until possibly high school or later. The reality is that 16 percent of new adult clients receiving care from Mental Health Services have a child living with them at home. There are numerous barriers to young carers receiving assistance, including stigma and discrimination relating to mental illness. Young carers have expressed that requests for assistance could result in families being split up with children taken into care. This is a very real concern and creates difficulties in identifying our most vulnerable group of carers. Young carers regularly report that they were not included in discussions about the care and treatment of those they care for. Young carer's views are rarely sought, and they are seldom kept informed of diagnoses. Young carers also experience difficulties in obtaining recognition from other service providers, including Centrelink¹⁵ Young carers needs should also be recognised, so they can be supported in their crucial role as carers and be included in the discussions about treatment, diagnosis and care. Young carers indicated that they wanted respite, and assistance with housework and transportation¹⁶.

¹¹The Social Policy Research Centre for the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) *'The Costs of Caring and the living standards of carers'*.

¹² Australian Bureau of Statistics, 2006 Census

¹³ The Social Policy Research Centre for the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), *'The Costs of Caring and the living standards of carers'*.

¹⁴ *Mental Health Discrimination & Insurance – A survey of consumer experiences* Beyond Blue, Mental Health Council of Australia, 2011.

¹⁵ Centrelink Carers Australia, 2009.

¹⁶ Adversity to Advocacy, The Lives and Hopes of Mental Health Carers, 2009.

Who are Australia's 'Hidden' Carers?

These carers are people who are often unaware they are carers and struggle on alone without support or services. They are family members and friends who help out a consumer when they are unwell and cannot be identified as a member of a specific group. Other hidden carers are not easily identifiable as carers because of the nature of their care. Most carers are not aware that there is help available for them and their family or how to access it. Carers may not realise that there are many other people experiencing the same problems and emotions. Caring can be so demanding that little energy is left to search for assistance and obtain more support. Carers of people with a co-morbidity of mental illness and drug and alcohol use often hide away, fearing stigma and discrimination from the community and other mental health carers. Same sex partner carers of someone with a mental illness often find it difficult to access mainstream services and thus remain hidden with little or no support from either the carer community or within their own gay/lesbian/transgender community¹⁷.

Challenges in identifying hidden carers!

Carers doing tasks seen as upholding normal family responsibilities: There exists a large group of people who undertake some or all of the above listed activities and other "caring" activities but who do not recognise or identify themselves as carers. They are "hidden carers" because they do most of the work of a carer without interpreting these activities as acts of caring and support.

Carers –Caring as an act of unconditional love: Hidden carers provide care and support without recognising it as such because in many instances they are caring for a parent, child, sibling, or a family member where such care is seen as a normal responsibility a family member would undertake for another family member as an act of unconditional love and support, or as part of their role as a family member.

Carers overlooked because the 'caring' does not occur as society would expect: It is common among hidden carers to not identify as carers because of the nature of the relationship between consumer and carer and the expectations of society surrounding care-giving in these circumstances. For instance, it is common for adults to be associated with providing care to other adults and children. In comparison, it is not seen as normal for young people to be care-givers, but rather only care recipients. However, children of people living with a mental illness may in fact provide significant levels of support to their parents and siblings while never identifying themselves as performing a carer's role, due to a lack of understanding of their parent's condition. Another example is when care or support is provided outside of the family context, for example, between friends or work colleagues, particularly between men, who are often not expected to fill a 'caring' role¹⁸.

Carers providing different forms and levels of support beyond expectations of society: The experience of caring varies according to the form or type of care and the extent of care (that is, the amount of support or care given to the person who requires care) which can make some forms of caring difficult to recognise. For instance, some individuals may only provide emotional rather than physical assistance to a consumer.¹⁹

¹⁷ *ibid*

¹⁸ Smyth, C., Blaxland, M., and Cass, B., (2011) 'So that's how I found out I was a young carer and that I actually had been a carer most of my life'. Identifying and supporting hidden young carers. *Journal of Youth Studies*, 14(2), 145-160.

¹⁹ Aldridge and Becker, 1993, 1999; Robson, 2004

Carers concealed due to consumer illness being unrecognised especially when dealing with someone living with an undiagnosed and perhaps unrecognised mental health issue, a person may gradually find themselves needing to devote an increasing amount of time to providing emotional or physical assistance to a relative, partner or friend, without recognising fully that this is happening, or why. In cases when the consumer's illness remains unrecognised, for example, the person is often supported and assisted by family and friends to help them in their daily lives. In such circumstances naturally these "hidden consumers", will tend to be supported by hidden carers. Naturally, if carers are not aware of the true nature of their loved one's condition this can also mean that providing support may be more difficult and/or less effective than it could be. Such carers can continue to remain unrecognised and unrealized even after the formal diagnosis of the consumer if they do not associate the support they provide with the condition of the consumer²⁰.

According to the National Respite for Carers Program (NRCP), a carer is defined as "a person who, through family relationship or friendship, looks after a frail older person or someone with a disability or chronic illness. Carers look after these people in the community or in their own homes"²¹.

The definition of a carer refers to someone who has assumed the primary caring role for at least six months, and is not paid for their services. Carers can include friends and neighbours as well as relatives of the care recipient. Older couples living together are often 'co-dependent' carers; that is, each plays the role of both carer and care recipient, depending on their needs and circumstances at the time²².

- Carers for people with mental illness – present some difficulties in drawing a borderline between particular disabilities (e.g., ADHD, autism) and mental illness. This group is included where it is clear there is a disability associated with the mental illness
- Young carers (under 18 years) are included if they are the primary carer²³.

Department of Health and Human Services Statewide and Mental Health Services (SMHS)

The Consumer and Carer Participation Policy defines a carer as a family member, friend or other significant person who provides ongoing care and assistance to a consumer of SMHS and who the consumer identifies as a "carer" or "family member" or a "significant person"; this may include people who are not related to the consumer by biology or marriage but who are nevertheless actively involved in the consumers care such as intimate friends, housemates and professional carers²⁴.

²⁰ Aldridge, J., & Becker, S. (1999) *Children as carers: The impact of parental illness and disability on children's caring roles*. Oxford: Blackwell Publishers.

²¹ Department of Health and Ageing, 2006.

²² *ibid*

²³ *ibid*

²⁴ *Mental Health Services Consumer and Carer Participation Framework*, 2006

²⁴ *Children of Parents with a Mental Illness Australian national initiative*, 2006

SMHS recognise that consumers and carers/families have distinct and separate needs and generally a single person should not be appointed to represent the views of both consumers and carers/families, unless that person is both a consumer and a carer.

- *The role of the carer is not necessarily static or permanent and may vary over time according to the needs of the consumer and the carer.*
- *Families and carers are recognised, respected and supported as partners in providing care. The role of families and carers in the treatment relationship must be explored with the consumer as early as possible and the extent to which families and carers are involved will depend on the wishes of the consumer.*
- *The consumer is best placed to identify their carer/family member. Specific identification of a carers/family members that the consumer would like involved in their care is particularly crucial in circumstances where their role, in caring for the consumer, is likely to be ongoing and over an extended period of time.*
- *Children of parents who are SMHS consumers and who have a caring role must be recognised as having special needs and must be appropriately supported.²⁵*

Victorian Government Department of Health, Mental Health Services

A carer is a person whose life is affected by virtue of his or her close relationship with a consumer and who has a caring role with the consumer.²⁶

National Practice Standards for the Mental Health Workforce, Australia Government Department of Health and Ageing

A carer is a person whose life is affected by virtue of a close relationship and a caring role with a consumer.²⁷

Central and North Weston London, NHS Foundation Trust

A carer is someone who gives you regular support, but is not paid or employed by the statutory services. They can be a neighbour, friend, family or partner. Carers are often involved in planning your care, and the care co-ordinator will therefore need to know if you have a carer, and if you want them to be involved. We also need to look at the needs of carers, so we can find the best way to help them care for you.²⁸

North East London NHS, Mental Health Trust Carer

A carer is someone who looks after their relatives or friends on an unpaid, voluntary basis often in place of paid care workers.²⁹

²⁵ ibid

²⁶ Victorian Government Department of Health, Mental Health Services

<http://www.health.vic.gov.au/mentalhealth/archive/casemgt/glossary.htm>

²⁷ National Practice Standards for the Mental Health Workforce, Australia Government Department of Health and Ageing

[http://www.health.gov.au/internet/main/publishing.nsf/content/EE630ADE7F40F80FCA2572220002D081/\\$File/pla7.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/EE630ADE7F40F80FCA2572220002D081/$File/pla7.pdf)

²⁸ Central and North Weston London, NHS Foundation Trust

<http://www.health.gov.au/internet/publications/publishing.nsf/Content/mental-pubs-n-workstds-toc~mental-pubs-n-workstds-att~mental-pubs-n-workstds-att-glo>

²⁹ North East London NHS, Mental Health Trust Carer

<http://www.cnwl.nhs.uk/glossary.html>

National Consumer and Carer Forum of Australia, *Consumer and carer participation policy: A framework for the mental health sector*, NCCF, Canberra.

In the mental health field, consumer, family and carer participation is generally accepted as the involvement of consumers, families and carers in decision making about their own care (or that of the person they are caring for), service planning, policy development, setting priorities, training and evaluation, and addressing quality issues in the delivery of mental.³⁰ health services. All participation must be meaningful, supporting consumers, families and carers to provide input that influences and improves mental health services.³¹

Avon and Wiltshire Mental Health Partnership NHS Trust

A carer is a person who gives up their own time often without payment, recognition or thanks to help another person who is disadvantaged due to physical or mental illness or disability.³²

National Health Service of the United Kingdom

'Carers look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid.' –

- a carer's contribution is important to maintaining the health and welfare of the cared for person.
- Carers take on this role without training and are expected to take on a variety of tasks as well as managing to sustain their own lives and this can be very stressful and affect their own health without them realising.
- Carers may live with the cared for person or they may live at a distance but still find themselves having to be available 24 hours a day, 365 days a year.
- Often carers are the people who have to support the cared for person for long periods of time between contacts with professionals. In some situations that can be supporting the person through a traumatic time before services become involved.
- A carer needs information, support and guidance and sometimes empathy and a listening ear, so they can carry out their role as a carer. Carers must be informed so they have the choice to step away from the caring role if they choose to.³³

Methodology

This study was an exploratory qualitative research project. The emphasis in qualitative research is concerned with how the social world is interpreted, perceived, and organised, and with the often multifaceted meaning of that construction for the people concerned³⁴

³⁰ National Consumer and Carer Forum of Australia, *Consumer and carer participation policy: A framework for the mental health sector*, NCCF, Canberra. <http://www.malg.org.uk/glossary.pdf>

³¹ *ibid*

³² Avon and Wiltshire Mental Health Partnership NHS Trust
<http://www.mhcc.org.au/documents/Terms%20of%20Reference%20-%20Families%20and%20Carers%20Sub-Committee%20-%20Mental%20Health%20Program%20Council.pdf>

³³ National Health Service of the United Kingdom
<http://www.sabp.nhs.uk/serviceusers-carers/carers/Carersinfomationpack/whoisacarer>
<http://www.awp.nhs.uk/templates/Page732.aspx>

³⁴ Mason, J. (1996) *Qualitative researching*. London: Sage Publications.

As a consequence, results are based on the words participants used to describe their understanding of the term 'carer'. Participants interviewed were all experienced, senior staff of the Mental Health Council of Tasmania member organisations. Interviews lasted approximately one hour and were undertaken by the researcher, a student social worker, while on placement at the MHCT. Interview participants were asked to reflect on and define the term 'carer' from their professional perspective. All the MHCT members were given the opportunity to submit their definition of 'Carer' via email as advertised in the MHCT e-newsletter.

Consultations with MHCT Members

ADVOCACY TASMANIA – Working to protect your rights

Advocacy Tasmania Inc. is an independent, non-profit organisation offering a free, confidential, state wide service to assist older people, people with disabilities or a mental health disorder, as well as their relatives and carers, to protect and promote their rights and interests. The Mental Health Advocacy program is funded by Mental Health Services, Tasmania Department of Health and Human Services. Mental health advocates can assist people to exercise their rights and responsibilities when they are in hospital, correctional facilities, rural and remote areas, and in the community. It also offers free representation for people on involuntary orders for hearings before the Mental Health Tribunal.

With reference to the *National Carer Strategy* definition of carer as contained in the *Carer Recognition Act 2010* carers are defined as people who provide personal care, support and assistance to people with disability, medical condition (including terminal or chronic illness), mental illness, or frailty due to age. Carers include family members, friends, relatives, siblings or neighbours. Grandparents or foster carers providing care to a child with disability, medical condition (including terminal or chronic illness) or mental illness are included as carers³⁵. All these people are defined as carers regardless of the amount of care, support and assistance they provide.

Carers not covered by the *National Carer Strategy* include people who are paid to undertake a caring role, such as formal care workers engaged under the contract of service. Other carers not included are those who provide voluntary care work for a charity or community organisation and those who provide care as a requirement of a course for their education and training.

A distinction was made between carers from four sectors: Aged Care, Disability, Alcohol, Tobacco and Other Drugs (ATOD), and the mental health sector. The episodic nature of care required with regards to those people living with ATOD and mental health issues are recognised as distinctly different from those carers working within Aged Care and Disability sectors. From an advocacy perspective, unpaid carers who do not identify as carers may not have access to the resources and funds available to them to maintain quality care e.g. Carers Allowance, and respite services. On the flip side, unidentified carers may be left unchecked when they disrespect the rights of those they care for. The notion of multiple carers or a team of carers, supporting an individual was also discussed. The term 'primary carer' was used to identify the immediate contact at the point of intervention. Abusive carers and 'enablers' sometimes undermined treatment and recovery by their conflicting views with clinicians and support workers, criticism of treatment, or clash of values. A spectrum of care was described from self-sacrificing 'angels' through to fraudulent and dangerous individuals assuming the role of carer.

³⁵ *The National Carer Strategy* 2011 www.fahcsia.gov.au

The distinction between paid, unpaid, and volunteer carers was evident and the ramifications of each of these roles were significant. The importance of training, supervision, and on-going support for carers was a distinct advantage for those who identified as carers. Those not identifying as carers were perceived as more vulnerable to the stresses of caring, as was the individuals they cared for.

RICHMOND FELLOWSHIP TASMANIA

Richmond Fellowship Tasmania (RFT) is a not-for-profit, non-government agency that supports members of the community suffering mental illness. RFT provides psychosocial rehabilitation, recreation and support services to encourage mental health and emotional wellbeing. The focus is on preventative after care in a non-institutionalised environment that fosters psychosocial rehabilitation programs in a communal environment for people living with mental illness. RFT was primarily established in Tasmania to provide residential recovery-focused rehabilitation programmes for people experiencing major mental illness.

RFT prefer that individuals identify their own carers. However, with reference to the *Carer Recognition Act 2010* carers are defined as people who provide personal care, support and assistance to people with disability, medical condition, including mental illness. Carers include family members, friends, relatives, siblings or neighbours. All these people are defined as carers regardless of the amount of care, support and assistance they provide. It is preferred that individuals identify their own carers. Carers include people who are paid to undertake a caring role, such as formal care workers engaged under a contract of service and those who provide voluntary care work for a charity or community organisation.

CARERS TASMANIA – Supporting family carers

Carers Tasmania is an organisation completely dedicated to supporting the needs and representing the views of carers throughout Tasmania. Carers Tasmania is a non-profit, community based, incorporated association and registered charity dedicated to improving the quality of life of the estimated 69,500 carers living in Tasmania. Carers Tasmania exists to support the thousands of Tasmanians who provide informal care to family members or friends requiring assistance because they have a disability, mental illness, chronic condition, terminal illness or who are frail.

Carers Tasmania has a vision 'to achieve recognition of the value and contribution of Carers and endorse caring as a shared whole-of-community responsibility'. Its Mission Statement is 'to enhance the health, wellbeing and resilience of carers in Tasmania, and promote their rights and needs'.³⁶

Who cares?

Carers Tasmania define carers as people who provide unpaid care and support to family members, neighbours or friends who have a disability, mental illness, chronic condition, terminal illness or who are frail and aged. There is no such thing as a 'typical' carer, as they come from every background, culture and socio-economic group. Carers are often family members: parents, partners, sisters, brothers, friends, grandparents or children. Many people struggle to identify as a carer: they see themselves firstly as a family member or friend. Often they see their contribution as 'just doing what is needed' because they love the person they care for. Most Carers Tasmania clients are primary carers and provide very intensive care of more than 40 hours per week.

³⁶ Carers TAS Australia Report on the Profile of Carers in Tasmania IMC-LINK 2009

Carers and their situations may vary considerably. Some carers are eligible for government benefits, while others are employed or have a private income. Caring for someone may be a 24 hour job that can become emotionally, physically and financially stressful. They may care for a few hours a week, or just occasionally as required. Carers feed and prepare meals; bath and attend to personal care needs; offer emotional support; provide constant supervision and give medication.

Tasmania faces a planning dilemma when trying to prepare for the ageing population, as current models of care depend upon the continued, substantial, social and economic contribution of carers³⁷. However, many unidentified carers are quietly contributing to the carer workforce who provides invaluable support to keep others living in their own homes and communities.

ARAFMI Tas. Inc. – Association of Relatives and Friends of the Mentally Ill (TAS) Inc.

ARAFMI's is the peak carer organisation specifically set up by carers of people living with mental illness to support other carers facing challenges in their role. The MHCAA (Mental Health Carers ARAFMI Australia) is the national voice of mental health carers. ARAFMI advocates for better treatment and support for family members with a serious mental illness. ARAFMI Tasmania exists to improve the quality of life for families, friends, carers and people living with mental illness across Tasmania.

Defining the act of Caring

The 2011 Census represented only the second time when questions regarding Carers were included in an effort to capture statistics on how many people look after someone with a disability or illness on an unpaid basis in Australia. Everyday tasks or actions considered “assistance” or support given by a carer were listed in the Census as a means to help classify a carer. Accordingly, a carer role involves:

- bathing, toileting, feeding
- helping in moving around
- helping to understand or be understood
- emotional support
- supervising medication or dressing wounds
- cleaning duties, performing housework
- managing finances
- driving or accompanying someone to appointments

Access Economics (based on the 2006 Census) estimated that over 1 in 8 Australians (or 2.87 million people) were providing informal care of the above type. This represents 13.1% of Australia's population. Of these, around 10% were classed as carers of people with mental health issues. These statistics, whilst noteworthy, only reflect those who have recognised and identified their role as that of a carer. Accordingly, it is reasonable to expect that there are potentially far more carers in Australia than suggested by statistics³⁸.

³⁷ Ibid

³⁸ Article by [Chris Beards](#), [Kuhu Barua](#) September 2, 2011

Definition of a Carer

A carer may be a family member, friend, neighbour, or other community member who provides care and assistance to another person, often in regular and ongoing manner without receiving any recognised benefit or payments beyond a pension or something nominal in some cases. In fact a carer can be anyone providing regular ongoing care or support to others, where these “other” person(s) is someone disabled, a frail older person, suffering dementia, terminal illness, living with HIV/AIDS, or has a chronic illness, or experiences a mental illness. Everyone has a different experience of caring. Caring can last for a few weeks or for several years. It can occupy a few hours each week or 24 hours a day. Caring may be through the provision of assistance with everyday type of activities such as, shopping, paying the bills, house work, personal care or meals³⁹.

The NSW Carers Recognition Act 2005 defines a carer as an individual who provides ongoing care or assistance to a person in the target group, referred to in the Disability Services Act 1993 defining a person with a mental illness, or chronic illness, or a frail person, requiring assistance to carry out everyday tasks. A person providing care or assistance under a contract of service or as a volunteer is not considered a carer by the Acts definition. Notably, it is not the relationship of a person to another e.g. spouse, defacto that defines or classifies a carer role. It is the act of providing ongoing frequent support and care that is what essentially defines a carer⁴⁰.

The Unique Characteristics of a Mental Health Carer

In simple terms, a mental health carer provides care and support to someone living with mental illness. The NSW Mental Health Act 2007 defines a primary carer (which is a special recognition afforded to mental health carers who have been ‘nominated’ with regard to a particular mental health services consumer). This also gives some insight into who the government expects will be providing care and support to mental health services consumers and should be recognised in this role. Although mental health carers share commonalities with other carer groups, they are recognised as unique because of the additional stressors they have to face in their caring role. The nature of mental illness itself, with predominantly behavioral symptoms as opposed to clear physical ones, societal perception of the illness and the structure and delivery of mental health services, make mental health carers position different and unique to others carer groups. Carers of people who experience mental illness require ongoing support themselves, in the form of relevant information on coping strategies and general support, which often remain unmet. The need for psychotherapeutic support and counseling also exists among many carers⁴¹.

Discussion

This paper has attempted to capture the various definitions of ‘carer’ as defined by Government and non-government services within the mental health sector and some of the member organisations of the MHCT. The findings of the literature survey for this research show there are an estimated 69,500 carers in Tasmania. The ABS Survey of Disability, Ageing and Carers (SDAC) estimated that in 2003, 2.6 million Australians were providing some assistance to people requiring support from a carer. The majority of carers (54%) were female. Women were much more likely to be primary carers (71%). 474,000 people or 2.4% of the population were identified as primary carers.

³⁹ Kennedy, S., (2011) *What or who are 'carers' of people living with mental illness according to official definitions?* July 28, [Kuhu Barua](#)

⁴⁰ ibid

⁴¹ ibid

A primary carer was defined as a person who provides the most informal assistance, in terms of help or supervision. Most primary carers care for someone living in the same household⁴². A primary carer is used to identify the immediate contact person at the point of service intervention. The term 'primary carer' is useful when there are multiple carers or a team of carers involved. It is clear from this research that there is no such thing as a 'typical carer'. Often carers see their supporting role as 'just doing what is needed'. Therefore, many people struggle to identify as a carer because they see themselves primarily as a family member or friend. Census statistics only reflect those who have recognised and identified their role as that of a carer.

The Australian Government and non-government policy makers recognise that mental health consumers and their carers have distinct and separate needs. It is widely acknowledged that many carers are not receiving all the support and resources available. Support for carers includes remuneration to offset care related expenses, education and training opportunities designed for carers, scheduled respite options, counselling and advice, participation in care planning and coordination of support services for those they care for. Over one third of carers are voluntary and are also known as informal carers. Voluntary carers may also provide care as an education and training requirement or as an act of community service. However, most informal carers are within interconnected relationships of obligations and reciprocity and are caring for someone they have a personal relationship with. Women, being the main providers of informal care, often have to manage the demands of caring with their other family commitments and financial responsibilities at significant personal cost.

Young carers and hidden carers are some of the most vulnerable groups of carers and are often unidentified because they do not identify with the definition of carer. This may be a conscious choice due to the fear of stigmatisation and discrimination related to mental illness; or it may be due to the risk of families being split up and children being taken into care. However, it may also be because people do not define themselves as carers due to their narrow understanding of the definition of the term. Sometimes people seek anonymity for fear of scrutiny by others. There are advantages and disadvantages to identifying as a carer. The 'carer' label is seen as restrictive or inappropriate by many carers. A positive aspect of identifying as a carer is that it can provide recognition, validation, peer support and, most importantly, the basis for accessing support and a broad range of social services. In particular, the act of caring can affect the mental condition of carers, due to the ponderous responsibility associated with supporting those that need care⁴³. Hidden carers, however, may be unaware of the support services provided by a wide range of organisations which may help ease some of their burden.

This piece of research suggests that while there is a diversity of carer experiences, the definition of carer consistently includes people who provide personal care, support and assistance to people with a medical condition, mental illness, disability, or people who are aged and frail. Therefore, carers are often defined by what they do, regardless of the amount of care, support or assistance they provide. It is important to understand that the role of the carer is not necessarily permanent. The extent to which families and carers are involved will depend on the wishes of the care recipient and their circumstances. Regardless, the consumer is usually best placed to identify their own carer, particularly if a carer is needed over an extended period or due to the episodic nature of their illness. However, services need to be able to identify the carer so they can find the best way to help them support their loved one, and be included in service planning and policy development.

⁴² Australian Bureau of Statistics, 2006 Census

⁴³ Aldridge, J., & Becker, S., (1993) *Children who care*. Leicestershire: Nottinghamshire Association of Voluntary Organisations.

Enhanced visibility of the carer's voice at both the individual treatment and service delivery level can further inform cultural and structural change in service delivery, workplace culture and workforce development. Carers are a powerful resource for services seeking to identify and eliminate those barriers that stop care recipients achieving their full potential. Carers also improve the quality of life of the person they care for and enable them to remain in the community. The economic value of caring as well as the enormous social contribution of carers is increasingly being recognised.

As Tasmania's population ages, demand for informal care is projected to increase rapidly, outstripping the supply of informal carers. By 2028, the number of people in Tasmania requiring a carer's support is projected to increase by approximately fifty percent.⁴⁴ Adopting a caring role is not without personal cost. Carers are significantly worse off than the general population and are disadvantaged in their ability to participate in society. Therefore, considerable work may need to be done to encourage disenfranchised and disengaged carers to make use of services and available resources. It is important that all carers have the same rights and opportunities as other Australians. By using the broadest definition of the term 'carer' an increasing number of carers may be identified.

With a view to looking forward in a developmental strategy both for services and for a research agenda, the focus taken on understanding the full mix of useful definitions of the term 'carer' assists in understanding the issues of the effectiveness of interventions within a broader frame of reference. That means taking into account the diversity and variability of community care for people living with mental illness. Once carers are identified, services can appropriately respond to support those who seek assistance. More carers will also be able to contribute to the development of mental health strategies and support solutions that will feed into policy and research processes to improve service delivery.

This study involved only four face-to-face interviews with the MHCT member organisations. Therefore, the scope of this study has been limited and different results might have been seen if more of the MHCT member organisations had accepted the invitation to contribute to the research via email. Further examination of this issue would help to confirm whether the findings from this study are representative, and if so, provide some ideas about how the definition of carer may be further explored in future research projects.

Recommendations

1. The care recipient is usually best placed to identify their own carer, particularly if a carer is needed over an extended period or due to the episodic nature of their illness. The extent to which families and carers are involved may depend on the wishes of the care recipient and their circumstances.
2. Carers need to be defined by what they do regardless of their relationship, or the amount or quality of care, support or assistance they provide.
3. Unidentified carers need to be identified so services can find the best way to support them in their carer role and include them in service planning and policy development.

⁴⁴ Carers Australia TAS *Report on the Profile of Carers in Tasmania* IMC-LINK 2009

4. The role of the carer can change so services supporting carers need to be consultative, flexible, and responsive to carer's need.
5. Carers are a valuable resource and need to be consulted by services seeking to identify and eliminate barriers that hinder care recipients in their recovery process.
6. Enhanced visibility of the carer's voice at the individual treatment, service development, and service delivery level can further inform cultural and structural change in service delivery, workplace culture and workforce development.
7. Considerable work needs to be done to encourage disenfranchised and disengaged carers to make use of services and available resources because adopting a caring role is not without personal cost.
8. The more carers who are identified will mean an increased number of carers able to contribute to the development of mental health strategies and support solutions that will feed into policy and research processes to improve service delivery.
9. Carers need increased financial support. All carers need to be financially compensated to redress the costs of caring.

The economic value of carers, as well as their enormous social contribution needs to be valued. It is in everyone's best interest to support as many informal carers as can be identified. The more carers who are identified, the more Government and agencies can respond to their needs through a multitude of service types, strategies and interventions. Supports can be delivered in a range of settings, for groups of carers whose needs and care goals are diverse, but whose main common role is that they are caring for someone in the community. The MHCT values and encourages collaboration between mental health policy makers, services, consumers and carer groups to implement effective approaches to mental health recovery within the mental health sector and in the broader community. It is hoped that after considering the various definitions of the term 'carer' and by better understanding what carers do, more people will recognise themselves as carers and will gain greater access to the support and resources available.

References

Adversity to Advocacy, The Lives and Hopes of Mental Health Carers, 2009.

Advocacy Tasmania www.advocacytasmania.com.au

Aldridge, J., & Becker, S. (1993) *Children who care*. Leicestershire: Nottinghamshire Association of Voluntary Organisations.

Aldridge, J., & Becker, S. (1993) Punishing children for caring: The hidden cost of young carers. *Children & Society*, 7(4), 376-387.

Aldridge, J., & Becker, S. (1999) *Children as carers: The impact of parental illness and disability on children's caring roles*. Oxford: Blackwell Publishers.

ARAFMI Association of Relatives & Friends of the Mentally Ill (TAS) www.arafmitas.org.au

Australian Bureau of Statistics, 2006 Census, Cat.no.2901.0 Q49

Avon and Wiltshire Mental Health Partnership NHS Trust

Banks, P., Cogan, N., Riddell, S., Deeley, S., Hill, M., & Tisdall, K. (2002) Does the covert nature of caring prohibit the development of effective services for young carers? *British Journal of Guidance and Counseling*, 30(3), 229-246.

Carers TAS Australia Report on the Profile of Carers in Tasmania IMC-LINK, 2009

Cass, B., Smyth, C., Hill, T., Blaxland, M., & Hamilton, M., (2009) Young carers in Australia: Understanding the advantages and disadvantages of their care giving *Social Policy Research*, 38, 1-117.

Central and North West London, NHS Foundation Trust
 Centrelink Carers Australia, 2009
 Children of Parents with a Mental Illness Australian national initiative, 2006
 Consumer and Carer Participation Policy: a framework for the mental health sector
 Department of Health and Ageing

Fourth National Mental Health Plan, Promotion, Prevention, and Intervention Strategy
 2009-2014, Australian Government, Canberra.

Gaffney, M.,(2007) *A research study of young carers: The development of a recording tool for agencies to identify young carers*. Wellington: Ministry of Health

Jarvis, A., and Worth, A., (2005) *The development of a screening tool to identify carers in a general practice by a large-scale mailed survey: The experience in one Scottish general practice*. Edinburgh: Blackwell Publishers.

Mason, J., (1996) *Qualitative researching*. London: Sage Publications.

Mental Health Discrimination and Insurance – A survey of consumer experiences,(2011) Beyond Blue, Mental Health Council of Australia

Mental Health Services, *Consumer and Carer Participation Framework*, 2006

National Mental Health Consumer and Carer Forum, 2004, Consumer and Carer Participation Policy: a framework for the mental health sector, NMHCCF, Canberra

National Health Service of the United Kingdom

National Mental Health Consumer and Carer Forum (NMHCCF), 2011

National Practice Standards for the Mental Health Workforce, Australia Government: Department of Health and Ageing

North East London NHS, Mental Health Trust Carer

Richmond Fellowship

Robson, S., (2004) *Hidden child workers: Young carers in Zimbabwe*. Oxford: Blackwell Publishing

Services and Indigenous Affairs (FaHCSIA) '*The Costs of Caring and the living standards of carers*'.

Smyth, C., Blaxland, M., and Cass, B. (2011). 'So that's how I found out I was a young carer and that I actually had been a carer most of my life'. Identifying and supporting hidden young carers. *Journal of Youth Studies*, 14(2), 145-160.

Stewart, S., Watson, S. Montague R., Stevenson C.(2008) Set up to fail? Consumer participation in the mental health service system, *Australasian Psychiatry*, Vol. 16, Issue 5:348-353

The National Carer Strategy 2011 www.fahcsia.gov.au

The Social Policy Research Centre for the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) '*The Costs of Caring and the living standards of carers*'.

Victorian Government Department of Health, Mental Health Services

www.sane.org