



# Understanding psychosocial disability

THE NATIONAL MENTAL HEALTH CONSUMER AND CARER FORUM

**The National Mental Health Consumer and Carer Forum (NMHCCF) is the combined national voice for mental health consumers and carers in Australia. In this article, the NMHCCF discusses the support needs of the thousands of Australians who experience psychosocial disabilities. Understanding psychosocial disability and its social consequences is critical when discussing the roll out of the National Disability Insurance Scheme and ensuring it is able to meet its ultimate goal of providing individualised support for people with a disability, their families and carers.**

## National Mental Health Consumer and Carer Forum

The National Mental Health Consumer and Carer Forum (NMHCCF) was established in 2002 by the Australian Health Ministers' Advisory Council. It is funded through contributions from each state and territory government and the Department of Health. It is currently auspiced by the Mental Health Council of Australia.

NMHCCF members use their lived experience, understanding of the mental health system and communications skills in systemic advocacy to promote the issues and concerns of Australian mental health consumers and carers. NMHCCF members represent consumers and carers on national and state committees including working groups, expert reference groups, forums and summits, providing a tangible opportunity for mental health consumers and carers to play a positive role in reforming the mental health sector to improve the lives of millions of Australians.

We produce submissions, advocacy briefs and position statements on issues that are important to consumers and carers, including seclusion and restraint, peer workforce, stigma, confidentiality and psychosocial disability. Focusing on the latter, the NMHCCF Position Statement, Unravelling Psychosocial Disability, outlines our position on this controversial issue that is rarely discussed openly (NMHCCF, 2011).

## What is psychosocial disability?

Psychosocial disability is the term that mental health consumers and carers use to describe the disability experience of people with impairments and participation restrictions related to mental health conditions. While not everyone with a mental illness will experience psychosocial disability, those that do can experience severe psychological effects and social disadvantage (NMHCCF, 2011).

One of the main examples of psychosocial disability relates to the capacity to use working memory. Most people with psychosocial disabilities that are associated with severe mental

illness have a deficit of the working memory. Working memory is that part of the memory which holds in conscious thought our everyday activities or thinking.

The social consequences of psychosocial disabilities make functioning in society and negotiating everyday life incredibly difficult for a person with this disorder. Lack of organisational skills affects their functioning and their ability to negotiate housing needs, establish income through Centrelink, make and socialise with friends, shop, cook, organise their household and keep appointments. The consequence of such significant incapacity is inadequately addressed by services and can have enormous impacts on families.

There is no data that accurately quantifies the number of people with a psychological disability in Australia. There is little documented research on the experience of people with psychosocial disability and few ways of measuring their support needs. Until there is a better understanding in the community around the need for psychosocial disability support, data will continue to be inadequate. (NMHCCF, 2011)

## Remaining unmet needs of people with psychosocial disability

Despite years of national and state mental health reform across Australia, many individuals who experience psychosocial disabilities as a consequence of severe and enduring mental illness still do not receive the supports they so desperately need. These supports can include a range of assistance from providing motivation to get up in the morning through to assistance with personal care, food preparation, managing a household or communicating with people (even those they are close to). While people with psychosocial disability may well be able to undertake these activities they often require support such as prompting to undertake them or assistance with completing complex tasks in sequence. Lack of support often results in an inability to maintain housing and personal care, leading to tragic consequences such as becoming homeless, living in seedy, rundown boarding houses or incarcerated for minor crimes, and worse. A high proportion of those with a severe mental illness are regularly at risk of exploitation and manipulation.

An effective support system for people with mental illness would take these needs into account. Government urgently needs to redirect its attention to whole-of-life needs and not just medication and crisis-driven service delivery. People affected by a psychosocial disability are sometimes forced into hospital, often transported by police, and compelled to take large amounts of antipsychotic medications against their will. Their physical health is often ignored and control of their own finances is taken away. These inhumane and discriminatory actions cannot be allowed to continue. There needs to be a national focus on providing support aimed at helping people with a psychosocial disability to live a decent life and become contributing members of society – something everyone wants and deserves, whether they have a mental illness or not.

According to the World Health Organisation (2002), on average, people with schizophrenia have a life expectancy which is 25 years below the general population; this is likely a sign that their physical health needs are not being adequately addressed. Another great area of need is for long-term supported housing; there are currently varying levels of provision from state to state but nowhere near the level required anywhere in Australia.

In order to make a positive difference to their lives and that of their carers, it is essential that governments take the lead in providing direction, through appropriate policies and adequate funding, for the wide range of supported accommodation options that are needed by people with psychosocial disabilities. People with psychosocial disabilities, like anyone else in our community, are entitled to the full rights of citizenship and this means that they have a right to safe and adequate housing, and a right to be adequately supported to achieve the highest level of function they possibly can.

Anyone unable to live independently requires appropriately supported accommodation where they can be properly cared for, where their physical and mental health is properly monitored, and they receive decent meals and assistance with their physical and mental health needs and everyday activities. Worldwide research indicates very strongly that there are huge economic gains for the community when its members are adequately supported in this way.

## **Lack of data on the number of people with psychosocial disability in Australia**

One of the main barriers to providing adequate services to this cohort is the lack of data. Data in mental health is often collected based on diagnostic categories and psychosocial disability is the consequence of a diagnostic group, not a diagnosis in its own right. It is unclear how many people there are in this cohort; the Australian Government Productivity Commission in 2011 estimated the number of people affected by disabilities with a severe or profound core activity limitation to be anywhere between 60,000 and 200,000 between the ages of 15-64, nationally. The NMHCCF's Position Statement recommended budgeting in the National Disability Insurance Scheme (NDIS) for 149,800 – 206,000 people. This figure was based on a report in 2009 conducted by PricewaterhouseCoopers estimating the

prevalence of people with disabilities with a severe or profound core activity limitation.

Although there is no doubt that people within this cohort have a significant degree of disability, they have largely been overlooked by contemporary mental health services. Today, government planning for the NDIS has meant that approximately 55,000 people with psychosocial disability will be eligible for support under the scheme. Getting the data right is critical in providing support to those we know are among the most socially and medically marginalised members of the Australian community.

In 2011, the NMHCCF in collaboration with mental health consumers and carers, called for the development of functional assessment and data collection tools for psychosocial disability that reflect the World Health Organisation's International Classification of Functioning (ICF), Disability and Health. However, the development of tools to apply the conceptual framework of the ICF to the assessment of psychosocial disability is still a work in progress in Australia and internationally.

## **Considerable burden being carried by carers**

Approximately 75% of persons living with a severe mental illness are still living with their families because appropriate supported housing is so limited (MHCA, 2012). Lack of secure and stable housing is a major barrier to recovery and places additional pressures on carers and the care relationship (MHCA, 2012, p. xi). Across Australia, there are very few good examples of supported accommodation. Often, the only alternative is living in privately-owned, substandard facilities. Family carers have serious concerns about the lack of appropriately supported accommodation and what will happen to their loved ones when they are no longer around to support them, and this is impacting significantly on the health and wellbeing of family and friends.

Family mental health carers across Australia are reporting that recovery-based care in the community for people affected by a psychosocial disability is not readily available or appropriate. The absence of individualised and coordinated support adds a great deal of pressure on carers which leads to physical, psychological and financial stress (MHCA, 2012).

## **Psychosocial disability is not widely understood**

To identify individual needs and clearly look at how a person with severe and enduring mental illness and psychosocial disability can make their way in the world, it is critical that there is a comprehensive assessment of the individual's functional capacity performed by people who understand mental illness and psychosocial disabilities. Families and carers must be included in this assessment, where appropriate to do so, particularly when the individual experiences anosognosia. Anosognosia is a lack of insight or lack of awareness and leads to the belief of the individual affected that they are not sick or disabled. It is believed to be the single largest reason why

individuals with schizophrenia and bipolar disorder do not take their medications and this significantly impacts on the capacity of the individual to lead their own recovery.

As outlined in the NMHCCF Position Statement (2011), mental health assessments of people with a psychosocial disability often fail to identify disability support needs and mental health services are not funded to provide the range of community-based supports needed by people with a psychosocial disability. Generic disability support services do not always have access to the skills and knowledge to understand and meet the support needs of people with psychosocial disability or their carers and many are not aware that people with a psychosocial disability even need their support services.

Many government departments providing support services to people with psychosocial disability often do not have sufficient skills, knowledge, and understanding to identify and meet their needs or those of their carers. Traditional or mainstream assessments of people with a disability can often fail to identify the most disabling aspects of psychosocial disability and thus lack relevance and accuracy for identifying support levels and needs.

## **Psychosocial disability and the National Disability Insurance Scheme (NDIS)**

The issues addressed in the NMHCCF's Position Statement, *Unravelling Psychosocial Disability*, are of course critical when it comes to rolling out a national disability insurance scheme that is fair, targeted and appropriate for those people living with psychosocial disability in this country. In a submission provided to the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs in March 2013 on the draft Rules to support the NDIS Bill 2012, the Mental Health Council of Australia noted that disability is not a medical issue but an artefact of the diversity of community experience and the capacity of communities to embrace and support the needs of each member. This is also outlined in the preamble to the 2006 United Nations Convention on the Rights of Persons with Disabilities (2006).

Undoubtedly, the interface between the health and disability sectors in the area of mental health is complex, as it can be with other conditions. It is clear that much more thought needs to be undertaken in relation to the challenges posed in designing a funding system for people with psychosocial disability resulting from mental illness. The needs of people with psychosocial disability have been poorly addressed to date.

In their submission, the Mental Health Council of Australia quotes the Australian Government Productivity Commission's report (2011) which acknowledged that people with mental illness, intellectual disability, and acquired brain injury are over-represented among the homeless, imprisoned and among drug and alcohol service users. There is significant scope to reduce the numbers in this position through the community support funded by the NDIS.

Australia is working on ways to restore varying degrees of health, wellbeing and dignity to the lives of its citizens, including those who have physical disabilities. The NMHCCF recommends that the same level of focus and commitment be paid to support the hundreds of thousands of individuals who have a psychosocial disability and their families and carers.

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