**National Mental Health Consumer and Carer Forum
Position Statement on Psychosocial Disabilities
Associated with Mental Health Conditions.**

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Glossary

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Glossary

Activity Limitation
The difficulty an individual may have in executing activities.[1] For people with a psychosocial disability such activities could include planning and executing tasks to completion.

Disability
The umbrella term for any or all of: an impairment of body structure or function, a limitation in activities, or a restriction in participation. Disability is a multi-dimensional and complex concept and is conceived as a dynamic interaction between health conditions and environmental and personal factors.[2]

Disablement
The loss or limitation of opportunities to take part in the normal life of the community on an equal level with others, due to physical and social barriers.[3]

Functioning
Functioning is an umbrella term for body function, body structures, activities and participation.[4]

Impairment
The loss or limitation of physical, mental or sensory function on a long-term or permanent basis.[5] For people with mental health conditions this would also include a loss of function on an episodic basis which in many cases leads to long term or permanent impairment and subsequent disablement.

International Classification of Functioning Disability and Health (ICF) The World Health Organisation developed the International Classification of Functioning Disability and Health (ICF) in 2001.[6] The ICF puts the notions of 'health' and 'disability' in a new light. It acknowledges that every human being can experience poor health and thereby experience some degree of disability. Disability is not something that only happens to a minority of humanity. The ICF thus 'mainstreams' the experience of disability and recognises it as a universal human experience. By shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared. Furthermore ICF takes into account the social aspects of disability and does not see disability only as a 'medical' or 'biological' dysfunction. By including 'contextual factors', in which environmental factors are listed, the ICF records the impact of the environment on the person's functioning.[7]   It

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[1] World Health Organisation (WHO), 2002, *Towards a common language for Functioning Disability and Health ICF*, WHO, Geneva.
[2] Ibid.
[3] Disabled People's International, 1982, *Proceedings of the First World Congress on Disability*, quoted in Albrecht G, Seelman K and Bury M*, Handbook of Disability Studies*, 2001, Sage Publications Inc, London.
[4] World Health Organisation, 2002, op cit.
[5] Ibid.
[6] World Health Organisation (WHO), 2001, *International Classification of Functioning, Disability and Health* (ICF), WHO Geneva.
[7] World Health Organisation, 2002, op cit.

combines the medical and social models of disability to form a "biopsychosocial" model of disability and is of use in both the health and disability areas.

Mainstream services
Mainstream services accessed by people with disability include health services, public transport, education and training, employment assistance, and housing and accommodation assistance. However, people with disability may experience difficulty in accessing these services. For example, access to mainstream health services for people with disability is often restricted by issues such as insufficient training of the health workforce, communication difficulties and the misinterpretation of symptoms.[8]

Medical model of disability
The medical model views disability as a feature of the person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals. Disability, on this model, calls for medical or other treatment or intervention, to 'correct' the problem with the individual.[9]

Mental health condition
Mental health condition describes the broad range of features that characterise a mental illness whether it is diagnosed or not.

Mental illness
A mental illness is a diagnosable illness that significantly interferes with an individual's cognitive, emotional and/or social ability.[10] Some mental illnesses are not always diagnosed and people with these conditions may never come into contact with mental health services. Not all mental illnesses cause impairments.

Mental health carer
A person with a lived experience of caring for someone with a mental illness.

Mental health consumer
A person with a lived experience of mental illness.

Participation restriction
The problem that an individual may experience in involvement in life situations.[11] For people with psychosocial disability these life situations this could include restricted participation in social situations.

Psychiatric disability
- disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgement, or that results in disturbed behaviour.[12]

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[8] Australian Institute of Health and Welfare (AIHW), 2010, *Australia's Welfare 2009*, AIHW, Canberra.
[9] World Health Organisation, 2002, op cit, page 8.
[10] Commonwealth Department of Health and Aged Care. 2000, *National Action Plan for Promotion, Prevention and Early Intervention for Mental Health*, Mental Health and Special Programs Branch, Commonwealth Department of Health and Aged Care, Canberra.
[11] Ibid.

- the impact of a mental illness on a person's functioning in different aspects of a person's life such as the ability to live independently, maintain friendships, maintain employment and to participate meaningfully in the community.[13]
- is associated with clinically recognisable symptoms and behaviour patterns frequently associated with distress that may impair personal functioning in normal social activity. Impairments of global or specific mental functions may be experienced, with associated activity limitations and participation restrictions in a range of areas. Supports needed may vary in range, and may be required with intermittent intensity during the course of the condition. Change in level of supports tends to be related to changes in the extent of impairment and the environment. Psychiatric disability may be associated with schizophrenias, affective disorders, anxiety disorders, addictive behaviours, personality disorders, stress, psychosis, depression and adjustment disorders.[14]

Psychosocial
- 1. involving both psychological and social aspects …
  2. relating social conditions to mental health.[15]
- involving aspects of both social and psychological behaviour.[16]
- of or relating to processes or factors that are both social and psychological in origin.[17]
- refers to the interaction between psychological and social/cultural components of …disability. The psychological component refers to ways of thinking and processing …experiences and …perceptions of the world…The social/cultural component refers to societal and cultural limits for behaviour that interact with those psychological differences/madness as well as the stigma that society attaches to …[the]…label …of… disabled.[18]

Psychosocial disability
Disability associated a person's psychosocial experience.

Social inclusion
Social inclusion is about being able to participate in and contribute to all aspects of a society that genuinely includes people living with mental illness; that supports, intervenes and prevents crises; and that does not discriminate or stigmatise.[19]

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[12] Disability Discrimination Act, 1992, Commonwealth of Australia, Part1,4,1(g), http://www.comlaw.gov.au/Details/C2010C00023 accessed 4 May 2010.
[13] Australian Health Ministers, 2009, *Fourth National Mental Health Plan*, Department of Health and Ageing, Canberra.
[14] National Community Services Data Committee (NCSDC), 2008. *National Community Services Data Dictionary V5,* Australian Institute of Health and Welfare (AIHW). p118.
[15] Merriam-Webster's Medical Dictionary, 2007, Merriam-Webster, Inc.
[16] The American Heritage Stedman's Medical Dictionary, 2002, Houghton Mifflin Company.
[17] Collins English Dictionary – Complete and Unabridged, 2003, HarperCollins Publishers.
[18] World Network of Users and Survivors of Psychiatry (WNUSP), 2008, *Implementation Manual for the UN Convention on the Rights of Persons with Disabilities*, from the website of the WNUSP, http://wnusp.rafus.dk/
[19] Mental Health Coordinating Council (MHCC), 2011, information on social inclusion, accessed from the MHCC website, http://www.mhcc.org.au/resources/social-inclusion.aspx, on 29 March 2011.

The Australian Government's vision of a socially inclusive society is one in which all Australians feel valued and have the opportunity to participate fully in the life of our society. Achieving this vision means that all Australians will have the resources, opportunities and capability to learn, work, engage in the community and have a voice.[20]

Social model of disability
The social model of disability describes disability as a socially created problem and not at all an attribute of an individual. In the social model, disability demands a political response, since the problem is created by an unaccommodating physical environment brought about by attitudes and other features of the social environment.[21]

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[20] Australian Government Department of Human Services, from the Social Inclusion website http://www.socialinclusion.gov.au/, accessed on the 3 April 2011.
[21] World Health Organisation, 2002, op cit, p 9.

Executive Summary

The term 'psychosocial disability' is referenced in the National Disability Strategy 2010-2020,[22] but it has not been widely used in the Australian community. It is a term preferred by mental health consumers and carers to describe living with a disability that is associated with a severe mental health condition.

As with other disabilities, a psychosocial disability associated with a mental health condition is the result of the complex interactions between limitations in activity (related to impairments associated with usually severe mental health conditions) and the environment in which people live. As with other disabilities, not all people with a mental health condition will experience a psychosocial disability. Many will go on to lead fulfilling and productive lives with little support.

However, effects of psychosocial disability can be severe and the impact is frequently underestimated both for people with a psychosocial disability and for their carers. Psychosocial disability can exacerbate mental health conditions, cause social isolation and economic marginalisation that can spiral into crisis, homelessness, poverty and worse. This causes extreme hardship for mental health consumers and carers, placing an unfair burden on some of the most vulnerable members of Australian society. This also places an economic burden on society through demand for crisis intervention and health care supports that could be reduced with appropriate services.

The effect and impact of a psychosocial disability requires ongoing research to improve outcomes, skills enhancement, and the provision of support and resources to enable consumers and carers to attain a quality of life which is personally satisfying, rewarding and meaningful. Yet research into psychosocial disability, its effects and ways to reduce its impact, has lagged behind health policy and research when compared to other areas of disability.

Over the last three decades the Australian community has become more aware of psychosocial disability following the deinstitutionalisation of care for people with mental illness and a subsequent lack of support that has been made available to assist them to live in the community. However, despite nearly three decades of national documentation, beginning with the development of the first National Mental Strategy 1992,[23] there has been a failure to recognise and address the disabilities associated with severe mental illness.

Social inclusion is currently a national policy area in Australia, but it does not reflect an adequate understanding of the extent and role of mental illness and psychosocial disability in social exclusion. The NMHCCF calls on the Australian government to rectify this and ensure that measures to address the support needs of people with a psychosocial disability are made key elements of Australia's social inclusion policy.

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[22] Council of Australian Governments, 2011, *2010-2020 National Disability Strategy*, Department of Families, Housing, Community Services and Indigenous Affairs, Canberra.

[23] Australian Health Ministers Conference, 1992, *National Mental Health Strategy*, Department of Health and Ageing, Canberra.

There is still a significant lack of adequately specialised services to address the disability support needs of people who experience psychosocial disability and their carers. This is despite implementation of some significant funding for psychosocial disability support in 2006 under the Council of Australian Governments' (COAG) National Mental Health Action Plan.[24]

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 the skills and knowledge to understand and meet the support needs of people with psychosocial disability or their carers. 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 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.

Community ignorance, stigma and discrimination toward mental health conditions compounds the impact of psychosocial disabilities and contributes to poor self esteem, social isolation and individual and systemic discrimination for both people with a psychosocial disability and their carers.

The eight guiding principles underlying the *United Nations Convention on the Rights of Persons with Disabilities* are inclusive of all forms of disability. Having ratified the convention, Australia is yet to meet its obligations for people with a psychosocial disability associated with mental health conditions.

Mental health consumers with psychosocial disability and their carers urgently need systemic policy approaches to redress community stigma, social exclusion and to mandate the provision of appropriate services for people living with a psychosocial disability and their carers. These policies and services need to focus on recovery and use a personalised approach tailored to address specific disability support requirements and to maximise the capabilities of each consumer and carer. This includes the provision of access to appropriate mental and physical health interventions.

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[24] Council of Australian Governments (COAG), 2006, National Action Plan on Mental Health 2006-2011, Department of Health and Ageing, Canberra.

Recommendations
The NMHCCF makes the following urgent recommendations.

Psychosocial disability
1   Disability support arrangements in Australia must address the psychosocial disability support needs associated with mental health conditions.

Social Inclusion
2   The NMHCCF calls on the Australian Government to enhance its social inclusion agenda to appropriately reflect the identified needs of its citizens with a psychosocial disability, consistent with the *National Disability Strategy* and Australia's obligations under the *UN Convention on the Rights of Person's with a Disability*.

Who are people with a psychosocial disability?
3 1   Better data on prevalence of psychosocial disability needs to be developed and made available to provide indicators of need for this significantly disadvantaged group.

3.2   In the absence of current specific data on the prevalence of psychosocial disability in Australia, any consideration of long term disability care and support initiatives must:
   •   work with the sector to agree appropriate interim estimates make provision for people with severe and profound psychosocial disability. This will include budgeting for a minimum figure somewhere between 149,800 – 206,000 of people with mental illness who were estimated to have a severe or profound core activity limitation. These figures should be continually updated and inform ongoing support assessments.
   •   conduct ongoing work to ensure that people with a psychosocial disability who require significant supports, but who do not have a severe or profound core activity limitation, are able have their disability support needs addressed in the same way as others with that same level of disability.

Who are carers of people with a psychosocial disability?
4.1   Work needs to be undertaken in the psychosocial disability support sector to reduce the unreasonable burden faced by carers of people with a psychosocial disability. This should include a review of access to carer benefits, allowances and disability support trusts.

4.2   Any disability support initiatives must work with closely with mental health carers to ensure that their needs, and those of the consumers that they advocate, for are met.

Characteristics of common impairments related to mental health conditions
5.1   Disability support services need specialised training in psychosocial disability. This will be most effective when its development and implemented is directed by people with a lived experience of psychosocial disability.

Recovery and psychosocial disability

5 .2 Disability support services for people with a psychosocial disability need to acknowledge the unique role that recovery plays in the experience of mental health consumers and carers and work with them to achieve recovery focussed services.

Identification and assessment of psychosocial disability

6.1.1 Research needs to identify the impacts of psychosocial disability and evidence based approaches to mitigate these. This must be undertaken in consultation with people with a psychosocial disability and their carers.

6.1.2 Australian data collection, classification and assessment tools for disability need to include measures of psychosocial disability which focus on functioning and environmental impacts.

6.1.3 Specific tools to apply the conceptual framework of the *International Classification of Functioning, Disability and Health* to the assessment of psychosocial disability need to be developed.

6.1.4 Current data collection, classification and assessment tools as well as processes for determining psychosocial disability support needs across all sectors, must be reviewed in consultation with consumers and carers to ensure that they better reflect the support needs of people with a psychosocial disability.

6.1.5 Assessments undertaken for people with psychosocial disability, need to be administered by people trained in the use of appropriate assessment instruments and psychosocial disability issues including support requirements and available support resources..

Lack of housing options and homelessness

6.2.1 People with psychosocial disability urgently require development and implementation of a whole of government approach to the provision of a range of accommodation supports including:

- safe affordable and secure housing;
- appropriate support services that can assist them to maintain tenancy and work with them to achieve community participation goals that they have identified.

6.2.2 This accommodation strategy should be informed by current and former successful supported housing models.

Low income, interrupted education and poor labour force participation

6.3.1 Measures must be implemented to provide training to services in psychosocial disability support needs and to include consumers and carers in policy development and the delivery of generic and specialist psychosocial disability employment services.

6.3.2 Peer workers need to be employed in the disability, employment and income support sectors to:

- provide support to people with a psychosocial disability in navigating those service systems
- assist those services to improve their culture and eliminate stigma around mental illness and psychosocial disability.

Communication and social isolation

6.4.1   Options to support the social interactions of people with a psychosocial disability urgently need to be expanded. These need to include the expansion of social support networks for people with psychosocial disabilities and one to one advocacy and advice support options.

6.4.2   These options need to be implemented as part of a comprehensive targeted strategy to tackle community stigma around mental health conditions.

Lack of disability support services for psychosocial disability

6.5.1   The range of services for people with psychosocial disability needs to be urgently reviewed to ensure that appropriate services are available and accessible.

6.5.2   Agencies offering generic disability supports urgently need better information and training to be able to identify and address the support needs of people with psychosocial disability.

Poor physical health and co-occurrence with other health conditions

6.6   Disability supports for people with psychosocial disability must be integrated with health services to ensure that people with psychosocial disability have access to effective health care to support their physical and mental healthcare needs. Where possible, innovative models, including technological options should be used to assist in service delivery that meets people's needs and is provided in consultation with those people.

Stigma and discrimination

6.7   Tackling stigma and discrimination around mental health conditions and providing education on psychosocial disability urgently need to become a key element of national psychosocial disability initiatives including:
- on a community wide basis including service providers and the general population
- as part of ongoing long term national disability care and support
- as a key element of the *National Disability Strategy*
- as part of core training for disability support services.

Lack of community awareness about psychosocial disability

6.8   Initiatives to build the capacity of public institutions to meet the needs of people with a psychosocial disability need to be expanded. This would build on the momentum of community wide anti stigma campaigns and must include:
- implementation of consumer and carer informed education and training initiatives for staff and policy makers
- partnership arrangements with consumer and carer policy advisors

- employing specialist support officers designated to assist people with psychosocial disability to navigate organisational systems.

Barriers for carers

6.9 Carers of people with a psychosocial disability urgently need:
- better information services such as an expansion of Commonwealth Carelink services to provide information on mental health supports for both consumers and carers
- carer peer support for information, advice, mentoring and navigating systemic supports available to them and to consumers they support
- education and training in supporting someone with a psychosocial disability and caring for oneself
- accessible respite that meets the needs of mental health consumers and carers
- recognition of costs involved in caring and that this is reflected in income support and more appropriate assessment processes for carer allowance and carer payment
- improved service provision from Centrelink
- inclusion of carers in planning for psychosocial disability support.

Service requirements of people with a psychosocial disability and their carers

7.1.1 Mental health consumers and carers need disability support services that maximise their potential to manage everyday life and participate in the community by using personalised services that support their recovery.

7.1.2 Supports need to be flexible to meet the changing needs of mental health consumers and carers in recovery and meet the immediate needs of those most vulnerable to relapse.

7.1.3 Peer workers play a key role in developing better coordination pathways between disability services and mental health services. They should be part of the disability support services workforce to provide expertise in servicing people with a psychosocial disability.

7.1.4 Mechanisms to support the development of better relationships and the delivery of streamlined and integrated treatment between clinical services and disability support services need to be developed

Self directed funding arrangements for personalised services

7.2 Australian mental health consumers with psychosocial disabilities and their carers should to be able to use the power of their choice to develop the disability supports that they want. They must be included in any National Disability Insurance Scheme which proposes to use a self directed funding approach.

7.3 Self directed funding options need to include development and implementation of appropriate support mechanisms for people with a psychosocial disability to ensure that they are able to effectively control decision making about their lives.

1 Psychosocial disability

Mental health consumers and carers are amongst the most marginalised citizens in Australian society. Mental health services struggle to meet their needs for the whole of life supports that are required to ensure that people's well being is maximised. Loss of well being, homelessness, unemployment and underemployment, social isolation and community and self stigma are all consequences that can arise from mental health conditions. They are also circumstances that can exacerbate mental health and other health conditions, leading to a vicious cycle of social exclusion, poverty and co-occurring illness.

Carers provide the most disability support in Australia and the lack of services to support people with mental health conditions can make their role extremely burdensome and have a negative impact on their own health and ability to participate in the community.

Australia's social inclusion agenda acknowledges a relationship between social and economic marginalisation and disability, but has done little to focus on the significant role played by disabilities related to mental health conditions. Since the closure of mental health institutions there has been growing recognition of the need for community based support for people with mental health consumers and carers. Yet, despite nearly three decades of national mental health strategies and plans, Australian governments have failed to provide effective supports for people with mental health conditions to live in the community,.

The National Mental Health Consumer and Carer Forum (NMHCCF) proposes that part of the reason for this is the lack of recognition of the disabilities that are associated with mental health conditions. Policy and service development for the mental health sector has had a primarily health and treatment focus and has progressed with the unsubstantiated assurance that 'psychiatric disability' needs are picked up through 'disability supports' in Australia. Some disability support needs are met in this way. There has been little attempt to identify the specific disability support needs of mental health consumers and carers and systematically describe how these needs are best met.

The community managed mental health sector has developed some disability support services available to mental health consumers and carers. Significant funding was provided by the COAG National Mental Health Plan 2006-2011 for community based supports for people with mental health conditions. This included funding of the *Personal Helpers and Mentors Program*, through the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) and the Support with Day to Day Living program funded by the Department of Health and Ageing.[25] These initiatives provided some much needed psychosocial disability services, yet the Senate Standing Committee on Community Affairs in 2008 which reviewed the progress of the COAG National Action Plan, advised that mental health

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[25] Council of Australian Governments, 2006, *National Action Plan on Mental Health 2006-2011*, Department of Health and Ageing website http://www.health.gov.au/coagmentalhealth, accessed 24 April 2011.

community based support services have been so underfunded that substantial further investment was urgently required to meet the needs of people with a psychosocial disability.[26]

It will be through meeting these needs, that social inclusion for people with psychosocial disability will be enhanced, by providing support with accommodation, employment and living skills support. Until this happens in a comprehensive and strategic way, the whole of life support needs – or disability support needs – will not be effectively addressed.

The *National Disability Strategy*, which provides a framework for disability in Australia explicitly includes people with a psychosocial disability.[27] The National Mental Health Strategy also acknowledges that mental health consumers and carers need whole of life supports, but continues to try to address these through development of clinical services, for example allocating short term 'sub acute beds' when long term accommodation support options are needed.

Australia has recently ratified the *United Nations Convention on the Rights of Persons with Disabilities* and this should provide an impetus to closely examine the role that disability plays in disadvantaging mental health consumers and carers.[28]

The Productivity Commission's *Inquiry into Disability Care and Support* is a timely opportunity for mental health consumers and carers to work closely with policy makers to acknowledge and examine psychosocial disability in more detail. The NMHCCF calls on governments to acknowledge the often severe impacts of psychosocial disability and to take urgent action to quantify and address psychosocial disability support needs.

Recommendation

1   Disability support arrangements in Australia must address the psychosocial disability support needs associated with mental health conditions.

2 What is psychosocial disability related to a mental health condition?

2.1 Disability and mental health conditions

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. These impairments and participation restrictions include loss of or reduced abilities to function, think clearly, experience full physical health and manage the social and emotional aspects of their lives. The best outcome for people experiencing such disability will be achieved through supports that mitigate the effects of impairment or participation restriction and enhance the social and environmental opportunities to expand their capabilities.

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[26] Senate Standing Committee for Community Affairs, 2008, *Towards Recovery, Mental Health Services in Australia*, Senate Standing Committee for Community Affairs, Canberra.
[27] Council of Australian Governments, 2011, ibid, p23.
[28] United Nations, 2009, *Convention on the Rights of Persons with Disabilities and Optional Protocol to the Convention*, Landmine Survivors Network, Geneva.

Not all mental health consumers will experience psychosocial disability requiring support to participate in the community. Many will achieve a quality of life that enables their social inclusion. However, there are a significant number of mental health consumers who will require support if they are to achieve an integrated level of community participation. Some people require supports intensively and continuously and others will require supports only episodically.

The overwhelming experience of mental health consumers and carers is that there are insufficient supports available to assist them to maintain an acceptable quality of life.

> I came from the institution. I lived there from 7-21 [years of age]. I wasn't trained how to dress or how to wash. I am now 39 and I'm still trying to get over all my fears and anxieties. You need a lot of care and support and there is not a lot of that around.
> (Consumer, Victoria, Morwell Forum #9)[29]

Service availability for psychosocial disability support is problematic in programs that have distributed any available supports by geographic areas, rather than by assessed need. This results in a 'lucky dip' for services that are essential to minimise limitations, improve quality of life and promote social inclusion. The programs introduced under the Council of Australian Governments' *National Action Plan on Mental Health* are yet to be formally evaluated but reports from consumers and carers indicate that high levels of need remain unmet. This is supported by poor outcomes on social indicators that are characteristic of people with mental illness. Mental health consumers have poor labour force participation rates, make up significant proportions of those who are homeless, and have high rates of incarceration in criminal justice facilities.

2.2 Definitions of psychosocial disability

The preamble to the UN Convention on the Rights of Persons with Disabilities states that:

> *Disability is an evolving concept and that disability results from the interaction between persons with impairments and the attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis.*[30]

Psychosocial disability can significantly impair the achievement of life goals if support needs arising from impairments and limitations associated with a mental health condition are not addressed or fail to be identified. As a consequence, opportunities to enhance an individual's capabilities and improve health and quality of life are missed. Access to supports and opportunities are often compromised by social attitudes to impairments, as well as environmental factors that restrict participation such as lack of support services.

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[29] Mental Health Council of Australia (MHCA), 2005, *Not for Service, Experiences of Injustice and Despair in Mental Health Care in Australia*, MHCA, Canberra, p 213.
[30] United Nations, 2009, op cit.

The term psychosocial disability differs from the term psychiatric disability in that it places an emphasis on the social consequences of disability whereas psychiatric disability focuses on the medically defined illness or impairment. Using the social model of disability, which is described in Appendix 1, the term assists in identifying a person's functioning, what limits this and the supports that are required for their full and effective participation in the community.

The World Network of Users and Survivors of Psychiatry refers to psychosocial disability as:

> the interaction between psychological and social/cultural components of …disability. The psychological component refers to ways of thinking and processing …experiences and …perceptions of the world…The social/cultural component refers to societal and cultural limits for behaviour that interact with those psychological differences/madness as well as the stigma that society attaches to …[the]…label …of… disabled.[31]

2.3 Social Inclusion

Psychosocial disability can cause severe social isolation and marginalisation from mainstream community activities for both mental health consumers and their carers. The inter-relationship between social exclusion and psychosocial disability can cause a series of interconnected problems around poverty, discrimination, unemployment, low skills, poor housing and poor health.[32] As indicated by the social and bio-psychosocial models of disability outlined in Appendix 1, psychosocial disability is directly related to social inclusion.

Social inclusion is also a current key policy of the Australian Government:

> The Australian Government's vision of a socially inclusive society is one in which all Australians feel valued and have the opportunity to participate fully in the life of our society. Achieving this vision means that all Australians will have the resources, opportunities and capability to learn, work, engage in the community and have a voice.[33]

Despite this, the Government's social inclusion priorities only mention 'people with a disability or mental illness' in one of its five key priority areas, as follows:

> Assisting in the employment of people with disability or mental illness by creating employment opportunities and building community support.[34]

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[31] World Network of Users and Survivors of Psychiatry (WNUSP), 2008, *Implementation Manual for the UN Convention on the Rights of Persons with Disabilities*, from the website of the WNUSP, http://wnusp.rafus.dk/

[32] Rankin J, 2005 *Mental health and social inclusion, working paper two*, Institute for Public Policy Research , London.

[33] Australian Government, 2011, *Overview of the Social Inclusion Agenda*, accessed from the Australian Government's social inclusion website: www.socialinclusion.gov.au on 19 Jan 2011.

[34] Australian Government, 2011, ibid

In Australia, people with a psychosocial disability are likely to make up a signification proportion of Australia's population of most disadvantaged. People with a mental illness (21.7%) form the second largest group receiving the Disability Support Pension after those with musculoskeletal and connective tissue related disabilities (31.7%) and before 'other disability' (20.5%) and intellectual and other learning disabilities (10%).[35] The workforce participation rate for people with a mental illness in Australia in 2003 (29%) fell far short of the rate for those with physical disability (49%) and the general population (74%).[36] The NMHCCF continues to outline ways in which the current National Mental Health and Disability Employment Strategy falls short of meeting the needs of mental health consumers and carers.[37]

In the UK, examination of social inclusion has revealed that adults with a mental health condition are amongst the most excluded.[38] The subsequent development of action plans and policy around mental health service delivery in the UK recognises that mental health conditions can both lead to and reinforce social exclusion. Mental health policy in the UK is now focussing on a strategic, whole of government approach to improving social inclusion of mental health consumers in a range of life domains and is developing and using outcome measures that seek to reduce inequality. These not only include employment, physical, health, education and housing, but also social stigma and discrimination by the community and media.[39]

It is clear that governments providing support for people with psychosocial disability will require active pursuit of social inclusion agenda. On an individual level this will mean the provision of services guaranteed to reduce inequalities and provide opportunities for participation. On a community level this will include the reduction and ultimately the eradication of stigma and discrimination making sure that all social institutions actively seek out ways to meet the needs of people with psychosocial disabilities. This includes working in consultation with mental health consumers and carers to provide appropriate housing options and develop employment initiatives, more appropriate disability support services and better functioning health services for people with psychosocial disability.

All of these issues are specifically highlighted by articles of the *United Nations Convention on the Rights of Persons with Disabilities*, which Australia has ratified and which are outlined at Appendix 2.[40] Australia has some way to go to improve its performance in these areas for people with a psychosocial disability and meet its obligations under the convention.

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[35] Centrelink administrative data quoted by Australian Institute of Health and Welfare (AIHW) on their website in *Income support, trends in disability support*, http://www.abs.gov.au/AUSSTATS/abs@.nsf/2f762f95845417aeca25706c00834efa/48980d1138809db5ca2570ec000b7160!OpenDocument, accessed on 3 May 2011.

[36] Mental Health Council of Australia, 2007, *Let's get to work: a national mental health employment strategy for Australia*, MHCA, Canberra.

[37] National Mental Health Consumer and Carer Forum (NMHCCF), 2010, *NMHCCF submission to the National Advisory Council on Mental Health: Daily bread, income and living with mental illness*, July 2010, sourced from the NMHCCF website http://www.nmhccf.org.au/submissions.

[38] Office of the Deputy Prime Minister, 2004, *Mental Health and Social Exclusion, Social Exclusion Unit Report*, Office of the Deputy Prime Minister, London.

[39] Ibid.

[40] United Nations, 2009, op cit.

Recommendation

2   The NMHCCF calls on the Australian Government to enhance its social inclusion agenda to appropriately reflect the identified needs of its citizens with a psychosocial disability, consistent with the *National Disability Strategy* and Australia's obligations under the *United Nations Convention on the Rights of Person's with a Disability*.

3 Who are people with a psychosocial disability?

There is no data that accurately quantifies the number of people with a psychosocial disability in Australia. Most estimates, including those for psychiatric disability, are based on having a mental health condition although some data sources have attempted to define the degree of capacity limitation experienced by people with mental health conditions.[41]

The Australian Institute of Health and Welfare recommends that the Survey of Disability Ageing and Carers is the most accurate source of data on disability in Australia.[42] According to the Productivity Commission, of people with a disability that were captured by the 2003 Australian Bureau of Statistics (ABS) Survey of Ageing Disability and Carers (SDAC), an estimated 446,000 reported a mental health condition as their primary condition, and 214,000 of these people had associated disabilities. Of these around 70% (149,800) had what are defined as 'core activity limitations' and 30% (64,200) were restricted in 'non-core' areas such as schooling and employment.[43]

The Productivity Commission also found that the 2009 SDAC figures show that of the 263,000 people with profound core activity limitations, 40% or 105,200 people had mental health conditions.[44] The ABS have advised that 2009 estimates for people with a disability are being released incrementally. They will be of assistance in determining estimates of people with psychosocial disability and for ongoing data collection and results.

The 2010 report on the proposed National Disability Insurance Scheme (NDIS) estimated the 2009 prevalence of people with disabilities under 65 with a severe or profound core activity limitation at about 600,000 people, with condition groupings as follows:

- Congenital anomalies and intellectual disability (82,000)
- Nervous system disorders (41,000)
- Injury (15,000)
- Mental illness (206,000)
- Sensory conditions (12,000)
- Physical conditions (223,000).[45]

For people with mental health conditions, this comprises about 41,000 people in the age range 0-14 and 165,000 people in the age range 15-64. Mental illness is the

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[41] Australian Institute of Health and Welfare (AIHW) 2003, *Disability Prevalence and Trends*, AIHW Disability Series, AIHW, Canberra.
[42] Australian Bureau of Statistics, 2010*, Sources of Disability Information Australia 2003–2008*, ABS Catalogue No. 4431.0.55.002, ABS, Canberra.
[43] Australian Government Productivity Commission, 2011, *Disability Care and Support Draft Report*, Australian Government Productivity Commission, Canberra, Vol 1, p3.25.
[44] Ibid, p1.4-1.5.
[45] PricewaterhouseCoopers, 2009, *Disability Investment Group, National Disability Insurance Scheme - Final Report*, Department of Families, Housing, Community Services and Indigenous Affairs, Canberra.

second largest category. The range and level of supports required by this population will vary and will require the use of appropriate and comprehensive assessments to identify the extent of impairments and the resources needed to address them.

Using this data to identify psychosocial disability is problematic because it uses a narrow definition of activity limitation and does not identify the full range of factors which make up psychosocial disability. Core activity limitation only relates to specific core tasks involved in mobility, self care and communication. Psychosocial disabilities include cognitive impairments which can manifest in multiple ways, affecting memory, communication, organising skills, social interactions and visual interpretation deficits. People with psychosocial disability may be able to dress and feed themselves and walk from the house to the bus stop, but their disability can be such that they may wear very inappropriate clothing, not be able to maintain personal hygiene, be unable to plan the walk and carry out a walk to the bus stop or be unable to interact with other people. Such a person would face severe disability issues, but may miss being assessed as having a severe or profound core activity limitation.

The range of questions asked in the SDAC questionnaire do show some consideration of the range of participation restrictions encountered by people with psychosocial disability.[46] Therefore, given the number of people estimated to have a severe and profound core activity limitation under the survey, it is possible the interpretation of severe and profound core activity limitation for psychosocial disability may have been better at picking up psychosocial disability than the focus on core activity limitation would imply. However until it is clear how well the SDAC determines psychosocial disability, these numbers can only be very loose estimates.

The inadequacy of using core activity limitation as a proxy for disability is acknowledged by the Productivity Commission in the *Draft Report of the Inquiry into Disability Care and Support*. For people with intellectual disability, the Productivity Commission has used a broader definition than 'severe and profound core activity limitation' to include people with a significant disability:

> *This is because people with intellectual disability may not necessarily be restricted in core activities but may still require assistance with non-core activities, such as catching public transport.[47]*

Therefore, any long term disability care and support initiatives must make provision for people with a psychosocial disability who have significant support needs in the same way that they make provision for people with intellectual disability. In the absence of current data on psychosocial disability, this should include an initial provision for a minimum of the estimated 149,800 – 206,000 people with severe or profound core activity limitations, updated using the 2009 SDAC data. Ongoing work then needs to be undertaken to ensure that any other people with a severe

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[46] Australian Institute of Health and Welfare (AIHW), 2005, *Australia's Welfare 2005*, AIHW Canberra, p464 ; Australian Bureau of Statistics, 2003, *Survey of Disability Ageing and Carers Sample Questionnaire*, ABS, Unpublished.
[47] Australian Government Productivity Commission, 2011, *Disability Care and Support*, Draft Report Vol 2, p14.5, Australian Government Productivity Commission, Canberra.

psychosocial disability, but who do not have a severe or profound core activity limitation, have their needs addressed.

Recommendations

3.1   Better data on prevalence of psychosocial disability needs to be developed and made available to provide indicators of need for this significantly disadvantaged group.

3.2   In the absence of current specific data on the prevalence of psychosocial disability in Australia, any consideration of long term disability care and support initiatives must:

- work with the sector to agree appropriate interim estimates make provision for people with severe and profound psychosocial disability. This will include budgeting for a minimum figure somewhere between 149,800 – 206,000 of people with mental illness who were estimated to have a severe or profound core activity limitation. These figures should be continually updated and inform ongoing support assessments.
- conduct ongoing work to ensure that people with a psychosocial disability who require significant supports, but who do not have a severe or profound core activity limitation, are able have their disability support needs addressed in the same way as others with that same level of disability.

Sandy's Story

Sandy had her first psychotic experience when her twin children were about six months old and her other child was two years old. Prior to experiencing psychosis, Sandy was experiencing post-natal depression and she was already finding it difficult to take care of herself with bathing, cooking and washing, let alone taking care of three small children. Her husband, Phillip, was working full time and could not provide as much support as he would like and Sandy had no other family supports.

The pressure of trying to maintain a normal life and taking care of the children made Sandy's post-natal depression worse, until one day Sandy left her home and began wandering around the city. This was how her first psychotic episode manifested.

Mental Health Crisis services soon picked Sandy up and took her to the Psychiatric Services Unit (PSU). During her recovery in the PSU, Sandy's husband managed to take some time off from work and take care of the children.

Looking back at her experience, Sandy said if she had had access to some support to help her take care of her children and manage the day-to-day chores, her psychosis might have been avoided. Although she had received medication for her post-natal depression, her ability to perform daily chores and care for the children was so impeded that medication alone could not help her situation.

Sandy's story shows how crisis could have been avoided with the availability of some flexible support with the disabilities that resulted from her depression.[48]

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[48]Unpublished personal communication to NMHCCF in 2011, used with kind permission, names have been changed.

4 Who are carers of people with a psychosocial disability?

In 2003, Australians aged less than 65 years who needed help with self-care, mobility or communication received most of the assistance they needed from family and friends. Around 65% received informal assistance only; 26% received both formal and informal assistance; 3% received formal assistance only; and 6% had no provider of assistance.[49] While there is currently no data that identifies the total number of mental health carers in Australia, in 2007 for example, it is reasonable to assume that with 20 percent of Australians having experienced a mental health or substance abuse disorder during that year, the number of carers was significant.[50]

In 2009, the Mental Health Council of Australia (MHCA) undertook a national survey of mental health carers in Australia and documented their experience. [51] The carers surveyed by the MHCA consistently advised the significant need for improved and appropriate levels of support for mental health consumers as well as outlining their own urgent health and support needs. The needs of the most vulnerable carers, those who are ageing and unwell themselves, are perhaps the most urgent. The report found that it is not uncommon for carers in their 70s to be providing day to day living support in their own home or in the home of their sons or daughters who are mental health consumers with complex needs and requiring on call care that is not otherwise available. As a result, these vulnerable carers are often in the situation of being a main care coordinator and housekeeper for that family member. The report documents examples of aged carers moving or regularly travelling interstate to provide these sorts of services. At the same time these carers are often not entitled to Centrelink benefits or other financial support for their caring role.[52]

Jan and her parents' story

Jan is a 46 year old divorced mother of a 6 year old daughter. Her daughter lives with her father. Jan has been using mental health services for 4 ½ years. Over this time she has had a number of admissions to the local hospital. Each time, she was given medication, monitored for up to three weeks, then discharged back into the community. Sheltered accommodation was provided for a short time after discharge, and a mental health case worker allocated to supervise her medication use. A disability support pension is her only financial support.

Jan's parents, who are aged 71 and 70, recently re-mortgaged their home and purchased a unit for her, so that she would have somewhere to live, as she had no other accommodation options.

They describe her life with a psychosocial disability as follows:

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[49] From the website of the Australian Institute of Health and Welfare (AIHW) section *Introduction to disability and disability services in Australia*, http://www.aihw.gov.au/introduction-to-disability-and-disability-services-in-australia/ accessed on 3 May 2011.
[50] Mental Health Council of Australia (MHCA), 2009a, *Adversity to Advocacy – the lives and hopes of mental health carers*, MHCA, Canberra, p11.
[51] Ibid.
[52] Luck J, 2007, *How can we help carers to care? An update from the Australian Longitudinal Study on Womens' Health*, a presentation to *Partnerships for Better Health Outcomes conference: Carers and professionals working together*, 8-19 March 2007, Sydney.

- Over the period of her illness, Jan's ability to care for herself has deteriorated.
- Jan does not take prescribed medication at the correct times…if at all.
- When awake she will sit and smoke to excess and drink coffee to excess, day or night.
- She cannot manage her own household despite home help.
- She burns most of the food she attempts to cook. Food is regularly left uneaten in the pans or plates left out on the bench to dry up or go bad. She does not wash up. Does not take garbage scraps down to garbage bin or put bin out for collection.
- Rarely uses the washing machine, and when she does, the clothes are left to dry in the machine. Washing which, her mother does at home, is left in the baskets or bags until her mother next visits.
- Only changes the bedclothes when she has spilt coffee or milo on them, or burnt another hole. One bottom sheet and the doona had to be thrown out last week. They were too burned to be used, I was able to patch the under blanket.
- Does not clean the unit. Carpets were professionally cleaned twice last year. Coffee spills and cigarette ash.
- Smoking, eating and drinking in the bedroom is strictly forbidden by us but unfortunately this is ignored.
- We are forever in fear of her burning herself or the unit. There is a smoke alarm there and we have another to install.
- Her personal hygiene is at an all time low and on occasions she has worn the same clothing for days and nights on end.
- She does not flush the toilet during the night…blocks it up often. Has been known to pile up used paper in the corner.
- She appears to have lost the ability to use anything electrical properly, except the jug, toaster and radio. For example, she uses all the wrong settings on refrigerator, washing machine, ovens, clock, microwave, vacuum cleaner, telephone etc.
- She is constantly losing her cards, e.g. debit, Medicare, & Centrelink.
- She does not collect or open mail.
- She rarely answers the phone.
- She does phone at any time of the day or night and will phone to find out what day or time it is.
- She does not manage her own money well and leaves money in her pockets
- We are on call 24/7 and have often drive the 100 kms to let her in after she has lost her keys or clogged up the toilet – day or night. We have replaced many sets of keys.

Recently her parents were offered two weeks' respite while because Jan was not taking her medication correctly and it was proposed that accommodation elsewhere and a strict medication regimen may help.

They used the break to have their daughter's unit sprayed for cockroach infestation, undertaking cleaning and doing necessary repairs.

Until recently Jan had the support of a caring case worker, a home help worker and visitor volunteer program. However, it is proposed that she will be losing the visitor

volunteer and home help services because they feel there is nothing they can do to help her after six months of visiting.

The case worker is currently trying to find some permanent supervised accommodation for her but openings are scarce with one offer available in a different state.
Jan's parents describe their daughter is one of the lucky people with a mental health condition because she has accommodation and parents and older brothers who support her. However they are gravely concerned about who will support Jan when they are no longer alive. They were also recently rejected for a carers allowance, despite a supportive report from Jan's psychiatrist. [53]

Recommendations

4.1   Work needs to be undertaken in the psychosocial disability support sector to reduce the unreasonable burden faced by carers of people with a psychosocial disability. This should include a review of access to carer benefits, allowances and disability support trusts.

4.2   Any disability support initiatives must work with closely with mental health carers to ensure that their needs, and those of the consumers that they advocate, for are met.

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[53] Mental Health Council of Australia (MHCA), 2010, op cit, p 58.

5 Living with impairments related to mental health conditions

5.1 Characteristics of common impairments related to mental health conditions

Mental health conditions can give rise to a range of impairments. Impairments are generally understood to be the loss or limitation of physical, mental or sensory function on a long-term or permanent basis.[54]

Impairments in physical and cognitive functioning can occur because of the symptoms of a person's mental health condition, the side effects of medication and sometimes as a result of medical treatment which may include trauma. There is evidence that a significant proportion of young people who experience their first episode of psychosis have symptoms of post-traumatic stress condition one year after the event and it is possible that this is due to events occurring in treatment rather than from the illness itself.[55] There is also evidence to suggest that people with mental health conditions have a significant rate of exposure to past trauma.[56] Trauma can have devastating social and emotional effects resulting in cognitive impairments.[57]

Impairments can also occur on an episodic and/or a long term basis and these situations can lead to long term or permanent disablement. The disability experience of people with impairments resulting from mental health conditions can range from no restriction to severe restriction in activities and participation in the community.

Psychosis, anxiety mood disturbances, and cognitive impairments are among the most common and disabling manifestations of mental disorders. Others include physical symptoms and impairment of impulse control. However, it must be stressed that due to the individual nature of mental health conditions and imprecise diagnostic methods, no one set of impairments will necessarily characterise the experience of someone with a particular mental health condition.[58] Rather, people are likely to experience a range of impairments due to their mental health condition, and some of these are also commonly experienced by people with different diagnoses. Examples of this are shown in the table outlining some common mental health conditions and the potential resulting impairments at Appendix 3.

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[54] Disabled People's International 1982, *Proceedings of the First World Congress on Disability*, quoted in *Handbook of Disability Studies* , 2001, By Albrecht G, Seelman K and Bury M, Sage Publications Inc.

[55] McGorry P, Chanen A, McCarthy E, Van Riel R, McKenzie D, Singh BS, 1991, *Posttraumatic stress condition following recent-onset psychosis. An unrecognized post psychotic syndrome*. Journal of Nervous and Mental Disease Oct;179(10):640.

[56] Mueser K et al, 2004, *Interpersonal Trauma and Posttraumatic Stress Disorder in Patients With Severe Mental Illness: Demographic, Clinical, and Health Correlates*, Schizophrenia Bulletin 2004 30(1): 45-47.

[57] National Technical and Assistance Center, *Creating Violence Free and Coercion Free Mental Health Treatment Environments for the Reduction of Seclusion and Restraint*, National Technical Assistance Center, National Association of State Mental Health Program Directors accessed from the website of the Victorian Office of the Chief Psychiatrist on 29 Jan 2011 http://www.health.vic.gov.au/chiefpsychiatrist/creatingsafety/resources.htm.

[58] U.S. Department of Health and Human Services. *Mental Health: A Report of the Surgeon General*, 1999, Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health, 1999.

Functional impairments due to ongoing symptoms have not always been well understood by mental health workers, professionals, and consumers and carers. This has meant that they are not always acknowledged and addressed appropriately. These can include low mood, decreased motivation for physical activity and social withdrawal. They can cause people to talk slowly, sit or lie down for much of the time, or have no short-term goals or plans related to performing every day functions such as showering, socialising, answering the telephone. These behaviours are often misunderstood as laziness or uncooperativeness by health care workers, support workers, families and consumers themselves.[59]

Anosognosia is the medical condition that causes a lack of insight into ones own illness. It is often associated with severe mental health conditions and results in a reduced capacity to seek help or treatment.[60] It is thought that at least 15% of people with severe mental illnesses who refuse treatment have anosognosia.[61] This has implications for the delivery of services for people with psychosocial disabilities who do not wish to receive supports. Training needs to be available to services offering psychosocial disability supports to ensure that people receive the most appropriate support.

Paul and Sam and their family's story

Margaret and Ken are 63 and 66 years of age respectively and they have four adult children. They are a close family with two daughters and two sons. Cate, 42, and Jane, 34, are both married with two children each. Paul is 40 and Sam is 36, and both were diagnosed with schizophrenia, at the respective ages of 21 and 17.

Psychiatrists say that both Paul and Sam experience a particularly severe form of treatment-resistant schizophrenia and they take extremely high doses of antipsychotic and antidepressant medications. They also experience severe and enduring symptoms and cognitive impairments which impact significantly on their ability to function.

Paul and Sam they lead extremely isolated lives. They are both single, have no friends and their limited social interactions are with their family. Paul and Sam have been on disability support pensions and have not worked since the onset of their illness. Their daily lives revolve around consuming large quantities of cigarettes and caffeinated soft drink.

Several years ago, Margaret and Ken used their superannuation to purchase a home very close to their own for Paul and Sam to live in. When Paul and Sam first moved into their own home they received visits from the mental health service and four hours each per week of support from a non-government organisation.

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[59] Velligan D, 2000, *Cognitive Adaptation Training: The Use of Compensatory Strategies in the Psychosocial Rehabilitation of Patients with Schizophrenia*, University of Texas Health Science Centre San Antonio, Department of Psychiatry, San Antonio.

[60] McEvoy J, 1998, *The Relationship Between Insight in Psychosis and Compliance With Medications,* from Amador X & David A eds, 1998, *Insight and Psychosis*. Oxford University Press US.

[61] David A and Amador X, 2004, *Insight and Psychosis: awareness of illness in schizophrenia and related disorders,* Oxford University Press, Oxfordshire.

The support worker, named Grace, managed to develop a rapport with Paul and Sam by being non-judgmental about their impairments and by working with them and their parents to identify their needs and plan what would work most effectively. With Grace as a support worker, Paul and Sam went shopping and cooked with her and she introduced them to activities that they would never have undertaken on their own. When she went shopping with them, Grace always talked them into stopping for a coffee on the way home, as they were so isolated from the rest of the community.

Margaret and Ken saw these activities raise Paul and Sam's self esteem and certainly continued to help Grace gain their respect and trust. Eventually, Paul and Same even talked to Grace a little more.

After a year Grace moved to other employment. Although Paul and Sam had a support worker for another three years, these workers failed to engage with Paul and Sam and the service was eventually discontinued.

Margaret and continue to provide the daily support their sons require, such as shopping, cooking, making and transporting them to appointments, etc without assistance. Due to his inability to manage his financial affairs, Margaret is also the legal administrator of Paul's affairs.

Margaret and Ken are extremely worried about their sons' future and how they will survive, when they are no longer around to provide the very much needed support their sons require. Meanwhile, the major role they play in their sons' lives continues to have an impact on their own health and wellbeing

Several years ago, Ken gave up his paid employment in order to provide them with the daily support they require, and Margaret spends most of her time working in the mental health area and advocating, at local, state and national level, for better services and supports for people with severe mental illness and their families. They are unable to obtain respite from their caring role because, although they are eligible, Paul and Sam do not want a respite worker and usually refuse to participate.

Margaret advises that Paul and Sam are not really able to advocate for themselves as they are unaware that they even have an illness and would never sign a paper asking for support for independent living. She feels that this is partly the reason that they currently receive no community support even though this would assist Paul and Sam with independent living and improve their quality of life. This is despite regular appeals by their parents. Their experience is that service providers and support workers often seem quite unaware of the devastating affect that psychosocial disability can have.

Stories such as this are not isolated. They describe how services sometimes have not identified the extent of disability and at times abandon the person with the disability and their families. The story indicates the need for better training for workers to prepare them to undertake appropriate and proper assessment and follow

up with the service. Failure to do this results in recurring admission to the acute sector, or community disturbances and minor crime and incarceration.[62]

Medications for mental health conditions can also cause side effects that interfere with daily functioning. Some of the most common are:
- drowsiness or sedation
- dizziness
- dry mouth
- nervousness
- headaches
- tremors and shakiness
- confusion
- weight gain
- impotence
- incontinence
- diabetes.

These effects can work in concert with lifestyle changes that result from mental health conditions and lack of support with physical health monitoring and lead to other serious health conditions such as cardiovascular disease.

Cognitive impairments include thought disorders, memory problems and difficulty focussing attention on an activity for a long period of time when distractions are present. These effects can impair a person's capacity to organise thoughts and activities, typically resulting in an inability to manage a household and personal finances. They can also interfere with the ability to be flexible, the ability to monitor one's own behaviour and can cause people to become confused, resulting in disinhibited behaviour such as putting on many layers of clothes when dressing or dressing in clothing inappropriate for the weather.[63]

It is possible to provide assistance with these issues by, for example, making sure that people receive prompts from their environment or that triggers for inappropriate behaviour are removed. However, if such individualised support is not available, it is likely that these issues will limit the activities in which a person may effectively participate.

The result of impairments can lead to the following common challenges for people with mental health conditions.

Environmental stimuli

Many people who have mental health conditions are easily distracted by environmental stimuli and find it difficult to screen out background noises

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[62]Unpublished personal communication to NMHCCF in 2011, used with kind permission, names have been changed.
[63] Ibid, p13.

making it difficult to focus or concentrate.[64] People may not be able to concentrate in a noisy or high traffic area, for example in a Centrelink office.

Concentration

People with mental health conditions may have difficulty sustaining concentration, appearing restless and finding it difficult to focus on a single task for extended periods. Breaking down tasks into smaller achievable goals and scheduling breaks can assist to finish tasks.[65]

Stamina

People with mental health conditions may not have the stamina to work a full day while combating drowsiness from medications and sustaining concentration.[66]

Time pressures and multiple tasks

People with mental health conditions may need assistance with scheduling and prioritising tasks and meeting task goals.[67]

Interacting with others

Due to a mental health condition and associated cognitive and functional impairments, people may have a range of behaviours that make it difficult for them to function in social situations. Someone may not be able to make eye contact or speak to people or may not be able to keep a conversation going. At the same time they may stare inappropriately or focus on specific facial features, missing important verbal and body cues, resulting in poor interaction. They may also make plans and then not show up due to memory difficulties, distraction or difficulties with scheduling. This can be frustrating for services when a person fails to arrive for an appointment and failure to understand causes can result in blaming the individual.

Because of these impairments and particularly in combination with the other impairments listed, many people with mental health conditions find it difficult to fit in or get along with other people and find themselves isolated and lonely.[68] These impairments often result in poor service response from agencies such as Centrelink or home care services where staff may not have a good enough understanding of psychosocial disability to respond appropriately.

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[64] Boston University Centre for Psychiatric Rehabilitation, *What is psychiatric Disability and Mental Illness*, accessed from website on 27 Jan 2011, http://www.bu.edu/cpr/reasaccom/whatis-psych.html
[65] Ibid.
[66] Ibid
[67] Ibid
[68] Ibid

Understanding negative feedback

It is not uncommon for anyone to have difficulty responding well to negative feedback. However, cognitive impairments may make it difficult for people with psychosocial disability to interpret criticism and know what how to respond appropriately. This effect can be exacerbated by poor self esteem, which is often also an impairment and can be extremely disabling.[69]

Stress

People with a history of mental health conditions report that symptoms are often exacerbated by stress and many learn techniques for managing this response as part of their recovery.[70] For some people stress can also be triggered by change in routines or people in their lives.

Impairments resulting from mental health conditions can be difficult to recognise

The impairments of many people with mental health conditions can also be much less apparent than those of someone with a physical or intellectual disability. The experience of stigma means that people with mental health conditions may try to manage or ignore any impairments as much as possible to ensure that they can appear 'normal' to their peers. As a result the need for support for people with psychosocial disability can often be overlooked. This happens frequently in the disability employment sector where inexperienced Job Capacity Assessors or those lacking specific understanding of mental health issues can easily miss identifying specific support needs for someone with a psychosocial disability. Such situations are extremely disabling for people with psychosocial disabilities who may then be subject to potential inappropriate job placement, stress and exacerbation of their condition and possible loss of financial support.

Recommendation

5.1   Disability support services need specialised training in psychosocial disability. This will be most effective when its development and implemented is directed by people with a lived experience of psychosocial disability.

5.2 Recovery and psychosocial disability

The concept of recovery has grown out of the mental health consumer movement and describes the personal process by which mental health consumers and their carers work through the challenges of mental health conditions and their experiences with services to re-establish self esteem, identity and a meaningful role in society.[71]

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[69] Ibid

[70] Frese F, 1997, *Twelve aspects of coping for persons with serious and persistent mental illness*, from Spanil L, Gagne C and Kohler M editors, *Psychological and social aspects of psychiatric disability*, Centre for Psychiatric Rehabilitation, Boston University.

[71] Mental Health Coordinating Council (MHCC), 2007, *Social Inclusion, its importance to mental health*, MHCC, Sydney, p6.

When mental health consumers and carers talk about recovery, they do not necessarily mean achieving a state without mental illness or the impairments and disabilities that can result. Very often this is not possible. Even for people whose mental health condition is well managed, impairments and psychosocial disabilities can be long lasting or intermittent. Recovery is about achieving an optimal state of personal, social and emotional well being, as defined by each individual, whilst living with or recovering from a mental health condition.

In the context of the *National Disability Strategy*, recovery is about maximising the potential of individuals with a psychosocial disability to participate in the community.[72]

The principles of recovery include:
- The belief that recovery is achievable
- The facilitation of hope and optimism
- Provision of supports that:
    - are person centred and focus on individual choice – provide real choice
    - are strengths based and focus on developing individual capabilities – are empowering
    - address a person's whole of life needs – are holistic
    - are delivered in full consultation with consumers and carers – acknowledge rights and responsibilities of consumers and carers.[73]

Recovery approaches acknowledge the effects of illness and subsequent psychosocial disability may or may not diminish over time and often require trialling a range of treatments and regimens of service interventions and self monitoring to ensure that impairments are kept in check. This means that while some mental health consumers may recover to the point that they do not require any mental health or disability supports, others will always require supports to assist their recovery, ongoing community participation and social inclusion.

Recovery is about growth and empowerment and the provision of choice for community participation. It is a pathway to social inclusion and a foundation for the provision of disability supports for people with a psychosocial disability.

Recommendation
5 .2   Disability support services for people with a psychosocial disability need to acknowledge the unique role that recovery plays in the experience of mental health consumers and carers and work with them to achieve recovery focussed services.

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[72] Council of Australian Governments, 2011, National Disability *Strategy 2010-2020 Summary Document*, Council of Australian Governments, Canberra.
[73] From Psychiatric Rehabilitation Australia website http://www.pra.org.au/psychiatric/recovery.html, accessed 3 May 2011.

6 Barriers to social inclusion

Under the psychosocial model of disability highlighted in Appendix 1, disability results from the complex relationship between barriers to effective community participation, or social inclusion, and the lack of supports provided to mitigate these barriers. The interrelationship between the impairments related to mental health conditions described above and the following barriers to social inclusion highlight the key themes in psychosocial disability.

6.1 Identification and assessment of psychosocial disability

There is little documented research on the experience of people with psychosocial disability participating in the community and how personal and contextual factors work to inform this.[74] This is partly because there has been little systematic examination of the experience of people with a psychosocial disability. Available research has largely focussed on the experience of mental health conditions from the point of view of the treating mental health professional or mental health services. Psychiatry has identified mental illness and has designed interventions to treat it. The result of this is that much of the assistance that is available to mental health consumers and carers tends to revolve around medical interventions and treatment of illness. These are important but only address part of the consumer and carer experience. The psychosocial disability experience of mental health consumers and carers has not really been used to inform mental health or psychosocial disability related policy in Australia.

This is changing with respect to the mental health sector. The Fourth National Mental Health Plan acknowledges that the whole of life experience of consumers and carers needs to be addressed to support mental health.[75] Services are beginning to acknowledge that recovery is a broader process than treatment of mental health conditions. However, this acknowledgement is not appropriately backed up by effective service provision that is broadly available either within or outside the health sector.

Identification or assessment of disability has also been imprecise in Australia and this has led to missing information on the disability experience.[76] It has also resulted in a disability support system that has largely excluded the needs of mental health consumers and carers. For example, many assessment processes for mental health consumers and carers rely on clinically conducted medical assessments of illness to determine eligibility for supports. Yet clinicians are experts in illness and treatment and not necessarily experts in disability. There is clearly some scope for improved assessment of the support needs of people with a psychosocial disability in these

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[74] Cobigo V and Stuart H, 2010, *Social inclusion and mental health*, Current Opinion in Psychiatry 23, p464.
[75] Australian Health Ministers, 2009, op cit.
[76] Madden R, Glozier N, Mpofu E, Llewellyn G, 2011, *Eligibility, the ICF and the UN Convention: Australian perspectives,* in press.

instances and this would need to include a review of assessment instruments and the processes used to conduct them.

The World Health Organisation International Classification of Functioning, Disability and Health (ICF) is probably the best currently available tool for identifying disability. This is because it acknowledges that disability is multidimensional and universal and thus it defines and classifies the body functions, structures, impairments, activity, activity restrictions, participation, participation restrictions and environmental factors which make up the disability experience.[77] It attempts to define the complexity of the disability experience in a way that current medical diagnoses and many disability classification instruments do not. It also acknowledges the overlap between treatment and support services in the effective management of illness and prevention and management impairments[78] and this is of particular relevance to people with psychosocial disability.

The development of specific tools to apply the conceptual framework of the ICF to assessment of psychosocial disability is still ongoing in Australia and internationally. However the ICF does now underpin the Australian data standards for disability, agreed among health and community services administrators in the Australian Institute of Health and Welfare's National Community Services Data Dictionary.[79,80] This is yet to translate into effective data that identifies the prevalence of psychosocial disability in Australia and it remains to be seen how useful this information will be to inform the psychosocial disability support needs in the Australian population.

The ICF also now informs the process of Job Capacity Assessments for people with a disability.[81] Yet, consumers and carers continue to report difficulties with the use of Job Capacity Assessments for people with psychosocial disability. It is unclear if these difficulties are due to the inadequacy of the assessment instrument or inadequacy of its use and this needs urgent review.

It is essential that appropriate definitions and assessment instruments are developed in consultation with mental health consumers and carers to accurately reflect their disability experience. Mental health consumers and carers have been highlighting their needs for some time. An international 2009 analysis of 15 studies of the first person experience of people with psychosocial disability identified the following self described needs:
- Being accepted and recognised as an individual beyond the disability
- Having personal relationships with family, friends and acquaintances
- being involved in recreation, leisure and other social activities
- Having appropriate living accommodation
- Having employment

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[77] World Health Organisation (WHO), 2002, op cit.
[78] Ibid.
[79] Madden, R, Bundy A, Clemson L, Glozier N, Kayess R, Llewellyn G, Madden R, Manga R, Mpofu E, Stancliffe R, 2010, *Submission to the Productivity Commission on Disability Care and Support*, submission no 493, from the Productivity Commission website http://pc.gov.au/projects/inquiry/disability-support/submissions on 15 March 2011
[80] National Community Services Data Committee (NCSDC) 2008. op cit.
[81] Madden R et al, 2011, ibid.

- Having appropriate supports through formal service systems and informal support from family and other caregivers.[82]

These needs give some indication of the barriers that are commonly encountered by people with a psychosocial disability and their carers. We know that disability care and support is already an unmet need for mental health consumers and carers but a more comprehensive and systematic analysis of these barriers and their relationship to disability should be undertaken to provide more detail on these issues and to assist in quantifying the support needs of people with a psychosocial disability and their carers. The development of appropriate tools to do this will assist individuals to identify their own support needs and will inform effective research on the quality and quantity of current service provision.

Appropriate data collection, classification and assessment tools will:
- assist individuals to effectively determine their individual support needs in different life domains such as employment, housing support and physical health
- adequately quantify community wide psychosocial disability support needs
- identify service gaps.

Recommendations

6.1.1 Research needs to identify the impacts of psychosocial disability and evidence based approaches to mitigate these. This must be undertaken in consultation with people with a psychosocial disability and their carers.

6.1.2 Australian data collection, classification and assessment tools for disability need to include measures of psychosocial disability which focus on functioning and environmental impacts.

6.1.3 Specific tools to apply the conceptual framework of the ICF to assessment of psychosocial disability need to be developed.

6.1.4 Current data collection, classification and assessment tools as well as processes for determining psychosocial disability support needs across all sectors, must be reviewed in consultation with consumers and carers to ensure that they better reflect the support needs of people with a psychosocial disability.

6.1.5 Everyone, including mental health clinicians, undertaking any kind of assessment of people with psychosocial disabilities need to be appropriately trained in psychosocial disability issues and the use of appropriate assessment instruments.

6.2 Lack of housing options and homelessness

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[82] Hall S, 2009, *The social inclusion of people with disabilities, a qualitative meta analysis*, Journal of Ethnographic Qualitative Research, Vol 3.

> The problem of finding suitable accommodation is a constant source of frustration for all those working in this industry. I don't believe that the community or the government fully understand the impact that lack of care and accommodation has, not only on the chronically ill but also to the cost to society. (Social worker, Student, New South Wales, Submission #118) [83]

> We are still trying to find suitable accommodation for [X] after his release from hospital. It is very obvious to all that [X] needs to go into supported accommodation to help with his rehabilitation. He has shown that he can be very well, given the right set of circumstances, which include support of his family, psychiatrist and suitable supported accommodation. It is our greatest wish that [X] be well enough so that he may enjoy a useful and happy independent life.
> (Carers, Parents, New South Wales, Submission #198)[84]

> Undoubtedly, homelessness is a major issue for offenders with mental health issues… homeless mentally ill people are up to 40 times more likely to be arrested and 20 times more likely to be imprisoned than those with stable, suitable accommodation. While statistics are not available, there would appear to be no compelling reason why the situation would be different for mentally ill offenders in NSW. Incarceration appears to worsen post release accommodation issues… Further, offenders released with no stable accommodation were three times more likely to re-offend than those who had accommodation. (Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)[85]

Housing instability, homelessness and lack of appropriate housing options dominate the lives of many mental health consumers and carers. Support as part of flexible housing and accommodation options is a high priority for people with psychosocial disability. Australian and international studies indicate that there is significant overrepresentation of people with mental illness in the homeless population and who experience housing instability.[86] Mental health carers report that provision of stable housing can be a significant financial cost to families and the housing support needs of adult children of ageing carers can place a significant burden on this potentially vulnerable group.[87]

Yet a 2003 review of Australian and international studies found that providing stable housing for homeless people generated cost savings in a range of areas and in some cases exceeded the required housing budget. Access to stable housing also significantly increases the likelihood of employment, thus reducing costs through unemployment benefits.[88] Research from inner Sydney in 2007 found that the costs

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[83] Mental Health Council of Australia (MHCA), 2005, ibid, p 261.

[84] Ibid, p 216

[85] Ibid, p220.

[86] Mental Health Council of Australia (MHCA), 2009b, *Home Truths: Mental Health, Housing and Homelessness in Australia*, MHCA, Canberra.

[87] Mental Health Council of Australia, 2009a, op cit.

[88] Berry M, Chamberlain C, Dalton T, Horn M, and Berman G, 2003, *Counting the Cost of Homelessness: A Systematic Review of Cost Effectiveness and Cost Benefit Studies of Homelessness*, Australian Housing and Urban Research Institute, Melbourne, (Report prepared for the Commonwealth National Homelessness Strategy).

associated with reactive, crisis-based care are greater than those associated with engagement and early intervention with the homeless population.[89] Western Australian research from 2008 found that reductions in the use of health care and justice systems had the potential to save the annual cost of delivering effective homelessness programs.[90]

International research is consistent with the above findings and that higher quality housing in better neighbourhoods leads to better outcomes for people with mental health conditions, with the savings in mental health care costs outweighing those of the properties.[91]

The NMHCCF Advocacy Brief on supported housing and homelessness, summarises the issues that consumers and carers wish to see addressed. The NMHCCF seeks the:
- development and implementation of a whole of government approach to achieve the provision of safe, affordable and secure accommodation and the provision of access to appropriate support services that can assist people to maintain their lives and remain in their homes when support to do so is needed; and
- strategic funding and implementation of successful housing models in areas of need such as the Woolloomooloo Homelessness Project,[92] and programs like NSW Housing Accommodation and Support Initiative (HASI)[93] to provide appropriate accommodation options for people with mental illness. [94]

Recommendations
6.2.1 People with psychosocial disability urgently require development and implementation of a whole of government approach to the provision of a range of accommodation supports including:
- safe affordable and secure housing;
- appropriate support services that can assist them to maintain tenancy and work with them to achieve community participation goals that they have identified.

6.2.2 This accommodation strategy should be informed by current and former successful supported housing models.

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[89] L. Giles, F. Reynolds, J. O'Mahony and P. McGeorge, *Help the Homeless (Spend Less, Spend Wisely*), presentation to the *NSW NGO Mental Health Conference: 'Count-Me-In*', Sydney, 2007.
[90] Flatau P, Zaretzky,K, Brady M, Haigh Y and Martin R, 2008, *The cost-effectiveness of homelessness programs* (AHURI Research and Policy Bulletin No. 104), Australian Housing and Urban Research Institute, Melbourne.
[91] Harkness J, Newman S and Salkever D, 2004, *The Cost-Effectiveness of Independent Housing for the Chronically Mentally Ill: Do Housing and Neighbourhood Features Matter?,* Health Services Research 39(5), 2004, pp.1341-1360.
[92] NSW Audit Office, 2007, *Auditor General's Performance Report Responding to Homelessness*, NSW Audit Office, accessed from the Youth Accommodation Association website www.yaa.com.au on 3 May 2011.
[93] NSW Department of Health, 2007, *Housing Accommodation and support initiative*, NSW Department of Health website, www.health.nsw.gov.au/pubs/2007/pdf/hasi_initiative.pdf accessed on 3 May 2011.
[94] NMHCCF, 2010, S*upported Housing and Homelessness (shh!), Advocacy Brief*, sourced from the NMHCCF website www.nmhccf.org.au/advocacy-briefs on 3 May 2011.

Helen's story

Helen is a 30 year old Indigenous woman with a history of mental illness. She lives in a remote community with her parents, her brother and his partner and their three children and her sister and her partner and their two children. They share a small three bedroom house with limited facilities.

Due to over-crowding, noise and lack of privacy, Helen often chooses to go to Darwin and live in the 'longgrass' (on the street). This usually leads to an admission to the mental health inpatient unit.

Helen experiences chronic health problems and is often untreated for long periods of time due to her mental health condition. When she is in well she is able to maintain contact with the community through mental health services and the local clinic and she remains well.

Her parents have tried unsuccessfully to find alternative accommodation for her but this family is not considered to be a priority.

Her mother has applied to Centrelink for a carer's allowance, but was declined as they believe Helen is well enough to care for herself. This is true for a short amount of time until her mental health declines and her needs are greater.

There are limited support options in her community and her itinerant lifestyle makes it almost impossible to link into what is available in Darwin.

When unwell and living in the 'longgrass' Helen is very vulnerable and is often the victim of violence and has been sexually assaulted which resulted in an unwanted pregnancy.

Helen is aware that she has a mental illness but explains her lifestyle by saying she has no other options available. She also believes she is always going to be treated without respect due to having a mental illness and she has some concerns for herself when her parents are no longer able to support her.

Helen would benefit from appropriate accommodation assistance to support her to keep in touch with her community and services and remain well. This will be even more important when Helen's parents are no longer available to look after her. [95]

6.3 Low income, interrupted education and poor labour force participation

As well as the significant costs of health care and medications, mental health consumers and carers also face the financial burdens associated with episodic

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[95] Unpublished personal communication to NMHCCF in 2011, used with kind permission, names have been changed.

illness and the cost of medications. This financial burden can result in loss of stable housing, homelessness, interruptions to income and government income support and loss of opportunities for training, study and work experience.

As a result, living on a low income is a feature of the lives of most mental health consumers and carers. Options for healthy lifestyle choices such as fresh food, socialising and recreation are often not affordable for those on a low income.

Many people with psychosocial disability want to work and with the right individual support can do so. Yet they are significantly underrepresented in employment statistics in Australia. In a 2005, Australian survey of 134 disability employment service providers assisting 3,025 jobseekers, found that people with mental health conditions represented the largest category at 30 percent, and fared worse than any other category in both securing and retaining employment.[96] Ongoing support for this group is a requirement to achieve successful employment. Carers also find that the demands of their role directly reduce their capacity to participate in paid employment, with most primary carers working only part time.[97]

Barriers to employment include a lack of support to overcome impairments and systemic barriers resulting from community and workplace stigma and the way health and vocational services are organised in Australia. For example, without appropriate workplace training and education, employers and employment service providers may misinterpret the impairments caused by depression and anxiety as disinterest or poor motivation for work.[98] These barriers to employment can be overcome with appropriate specialised vocational assistance for people with psychosocial disabilities. The evidence for this is found in the controlled trials of supported employment in the US where 40-60% of people with severe mental illness in the trials obtained competitive employment.[99]

To assist the employment sector to use evidence based interventions for their clients with psychosocial disability, training in psychosocial disability needs to be undertaken by disability support services and policy makers. Mental health consumers and carers also need to play a central role in policy development and service implementation.

Recommendations
6.3.1 Measures must be implemented to provide training to services in psychosocial disability support needs and to include consumers and carers in policy development and the delivery of generic and specialist psychosocial disability employment services.

6.3.2 Peer workers need to be employed in the disability, employment and income support sectors to:

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[96] Waghorn 2005, *The employment of people with a mental illness*, Australian e-Journal for the Advancement of Mental Health, Vol 4, Issue 2 Supplement, Flinders University, p33.
[97] House of Representatives Standing Committee on Family, Housing, Community and Youth, 2009, *Who Cares: report into the inquiry into better support for carers*, Parliament of the Commonwealth of Australia, page 196.
[98] Waghorn 2005, op cit.
[99] Ibid.

- provide support to people with a psychosocial disability in navigating those service systems
- assist those services to improve their culture and eliminate stigma around mental illness and psychosocial disability.

Robert's story

Robert was diagnosed with bipolar disorder when he was in his thirties. He is now 62 years old and has been living in public housing for more than eight years following a major depressive period that led to him losing his job. During this time living in public housing, he became more isolated every day as his depressive periods could be very severe. He was developing paranoid thoughts and soon refused to go out at all. His social life was deteriorating; his friends did not visit him anymore as the environment at his home was unsuitable for guests.

The effects of living with bipolar disorder it made it difficult for Robert to secure any employment. He became dependent on the Disability Support Pension as his primary source of income. Occasionally he used illicit drugs and alcohol for self medication.

There were some occasions when Robert was interested in attending social functions but he found that it was difficult to navigate the public transport system.

His life and wellbeing improved when a relative offered him a loan to purchase a car, which helped him tremendously to get around. This has been a turning point for Robert. He was able to reconnect with the social activities that he used to do. The car enables him to attend social functions, go to community meetings, and to do volunteer work for several community organisations. When his connection with the community improved he was able to access more information about alternative public housing and is now living in housing that is more appropriate for his needs and enjoys his social life.

Robert's story shows how much benefit can result from and innovative intervention that is person centred, accessible and flexible enough to meet a diverse range of community participation needs. [100]

6.4 Communication and social isolation

Challenges with communication and social isolation are amongst the most pervasive of the psychosocial disabilities. Hearing voices and thought disorders, being distracted by environmental stimuli, being unable to concentrate and not being able to understand or respond appropriately in a conversation are all reasons that contribute to social isolation and difficulty in managing day to day living activities. One example of this would be a person with a psychosocial disability attending at a Centrelink office. These offices are often crowded and open plan and someone with a psychosocial disability could be severely disadvantaged in communicating in this environment.

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[100] Unpublished personal communication to NMHCCF in 2011, used with kind permission, names have been changed.

People with psychosocial disability can find it overwhelmingly difficult to maintain close relationships after being affected by mental illness and this can be caused by the stigma of mental illness, living on a low income limiting social activities, and social anxiety.[101] Because of this, people often find that there is little opportunity to pursue social relationships, despite a desire to do so.

The community managed mental health sector, including the Australian Government's *Support for Day to Day Living in the Community* program and the *Personal Helpers and Mentors Program* all provide much needed support to combat social isolation. However this support it is not targeted or available to all people with psychosocial disability who need it.

Community attitudes influenced by discrimination exacerbate social isolation. Many people grappling with disability or recovering from mental health conditions also suffer from extremely low self-esteem or feel self conscious about any impairments. This can make it difficult for people to feel motivated about pursuing community participation options.

People with psychosocial disability are often not in a position to access information about supports available to them. They will require assistance to help them identify what is available so that they can make choices about how to manage their lives.

For example, a 2010 report by the Women's Centre for Health Matters identified barriers to participation amongst women in the ACT with a mental health condition and psychosocial disability. The report revealed an overwhelming lack of awareness about their legal rights and the availability of legal services within the ACT amongst these women.[102]

Recommendations
6.4.2   These options need to be implemented as part of a comprehensive targeted strategy to tackle community stigma around mental health conditions.

6.5.1   The range of services for people with psychosocial disability needs to be urgently reviewed to ensure that appropriate services are available and accessible.

My son has paranoid schizophrenia, which at present is reasonably well controlled. He does require care in his daily life as he finds it difficult to motivate himself to do the usual daily chores such as cleaning, cooking and shopping. Things are fine when I am at home and he joins in (most of the time) and does his share. I wonder what would happen if I was not around? At the moment I am relying on friends to help out as I am only away for four months, but what would happen if I was no longer around? How do others in a similar situation actually cope? What assistance is available on a long-term basis?[103]

[101] SANE Australia, 2005, Mental Illness and isolation, SANE Australia Research Report 1.
[102] Judd K and Hale L, 2010, *Out of Reach: Women living with mental health issues in the ACT: What hinders their access to legal support?* Women's Centre for Health Matters Inc, Canberra.
[103] Mental Health Council of Australia, 2009a, op cit p 51.

Chris' story

Chris, aged 30, was diagnosed with paranoid schizophrenia at age 19. He was a heavy marijuana user at the time, and the psychosis was suspected to be drug induced. He was seen by mental health services for about six years and during the first few years was in receipt of a disability pension. About four years ago Chris decided to give up marijuana, and his psychiatrist weaned him off medication. Chris was determined that he'd never go back on medication and he was discharged from the mental health service soon after this.

Chris is an intelligent man and a year before being discharged from the mental health services he was employed to work from home by a family member who owned a software business interstate. He lives with his parents in a small three bedroom home and he set up his 'office' in his bedroom. A year later, the family member sold the business and Chris was retained by the new company.

At first glance it would seem that this story has a happy ending for Chris, who:

- is not on medication;
- has a job;
- has somewhere to live;
- does not require mental health services.

However, Chris' parents advise that over the two years after his discharge from mental health services he became more reclusive, stayed in his bedroom for most of the time and if he visited other parts of the house he needed to close the curtains.

Chris' parents did contact mental health services about two years after Chris ceased treatment, as they were extremely concerned about him. The mental health service agreed with Chris' parents about their concerns and referred Chris back to his previous case manager. This case manager contacted Chris by phone once and determined that he would not be engaged in the service as he did not believe he was unwell. The case worker advised that Chris needed to seek the service, and that they could not impose it on him.

The case worker also advised that he could apply for a community treatment order for Chris, but because he was not in any immediate danger this may not be upheld. This would also have involved having Chris taken into involuntary treatment, which Chris' parents did not want to do, believing it would have a detrimental effect on his mental health and their relationship with him, on which he relied for accommodation and living supports.

Chris has now been out of the house about five times in two years. He still displays paranoia but will not seek treatment. He also drinks alcohol consistently. He keeps his room clean but can't help out with housework in the rest of the house, as it requires him to be out of his room.

His parents feel Chris is only a few steps away from crisis. They are still only in their fifties and worry about what will happen to Chris when they are not around to look

after him. They also worry about the fact that at any time the new company owners may decide that the employment arrangement is not of benefit to the company and Chris would not be able to travel interstate to keep the job. In this situation they know that getting Chris back on any sort of benefit would be extremely difficult – and certainly don't think he could leave the house to seek employment.

Chris' parents advise that Chris needs someone to work with him to meet his needs and not deny him services because he does not fit into their criteria. They think that there are probably many clever young men such as Chris who miss out on services because they don't fit into a traditional approach. They feel he would benefit from some community support offered outside the traditional approach used by mental health services and that provided something that Chris could relate to. It may even be an avenue for getting him back into treatment, which his parents feel will not otherwise happen.

This is a good example of an opportunity for both the health and disability sectors to work together to ensure that further crises and ill health to do not occur and to significantly improve quality of life of this family.[104]

6.5 Lack of disability support services for psychosocial disability

People with a psychosocial disability receive care and assistance from a range of sources including:
- Unpaid care from family and friends
- Income support including payments and allowances and concession schemes
- Specialist mental health disability support services
- Generic disability support services
- Specialist mental health employment services
- Generic disability employment services
- Generic services such as Centrelink, state and territory housing departments and local councils whose clients include people with a disability.

People with mental illness are picked on in the community, but there is no community support from services until these people become very unwell. (Anonymous, New South Wales, Submission #156)[105]

Given the limited data available on psychosocial disability, it is unclear how many people with psychosocial disability are able to access disability services. Of the 245,746 people across Australia who made use of services funded under the Commonwealth State Territory Disability Agreement (CSTDA) in 2007/8, psychiatric disability rated as the second most commonly reported primary disability (16.3% or approximately 40,000 people) after intellectual disability (31.5% or approximately 77,400 people) and ahead of physical disability (14.8% or approximately 36,400 people).[106] This estimate should be compared to the 2003 Survey of Disability

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[104] Unpublished personal communication to NMHCCF in 2011, used with kind permission, names have been changed.
[105] MHCA, 2005, op cit, p 251.
[106] Australian Institute of Health and Welfare, 2011, *Mental Health Services in Australia 2007-08*, AIHW Canberra, p115.

Ageing and Carers estimate of 149,800 people with severe or profound core activity limitations who would require some form of disability support. Taking into account the fact that some of these people may be too unwell to access disability services, it is clear that there is likely to be a significant discrepancy between the number of people with psychosocial disability who could be eligible for disability services and those who are currently accessing them.

We know that, due to a lack of community support, people with mental health conditions are more likely to become unwell and require acute services from the hospital sector. This outcome exacerbates disability, limits recovery and threatens employment participation, income support, accommodation and social participation.

Specialist disability supports for people with psychosocial disabilities, such as housing, rehabilitation day programs, home based outreach, respite and employment services are generally provided by the community managed mental health sector. These are most likely to provide recovery focussed disability support for people with psychosocial disabilities (see section 5.2 *Recovery and disability*). They are funded through a complex range of state and territory and Australian Government health and community services funding streams and provide an innovative mix of service models for people with psychosocial disability.[107] However because there has been little strategic consideration of the extent of psychosocial disability support required in the community, the sector continues to fall short of community need.

Generic disability supports such as Home and Community Care (HACC) funded neighbour aid, community transport and home care services are not trained to identify and routinely fail to recognise the disabling psychosocial aspects of mental health conditions. Consumers and carers regularly report that these services do not have the skills to provide appropriate support or, with little knowledge of psychosocial disability, HACC services are not available to people with mental illness. This results in the needs of people with psychosocial disability being unmet and those people 'falling through the cracks'.

Further, many generic disability services explicitly exclude people with a psychosocial disability from their target group. This is possibly because they are so underfunded already that they do not have the resources to assist people with more complex needs. However, we already know that many clinicians in the mental health sector do not feel that they have the skills to deal with multiple disabilities. For example, Australian psychiatrists report that they do not have the training or confidence to assess and manage people with intellectual disability.[108] It is therefore extremely likely that people in the general disability sector feel they have the same lack of skill with respect to mental health conditions.

Recommendations

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[107] Psychiatric Disability Services of Victoria (VICSERV), 2010, *Community managed mental health in Victoria, the case for investment*, VICSERV Melbourne; Mental Health Coordinating Council (MHCC), 2010, The NSW Community Managed Mental Health Sector Mapping Report 2010, MHCC, Sydney.
[108] Torr J, Lennox N, Cooper SA, Rey-Conde T, Ware RS, Galea J, Taylor M, 2008, *Psychiatric care of adults with intellectual disabilities: changing perceptions over a decade*, Aust N Z J Psychiatry., Oct;42(10):890-7.

6.5.1 The range of services for people with psychosocial disability needs to be urgently reviewed to ensure that appropriate services are available and accessible.

6.5.2 Agencies offering generic disability supports urgently need better information and training to be able to identify and address the support needs of people with psychosocial disability.

Janet's story

Janet is a 35 year old Indigenous mother of one daughter who lives with her mother, severely disabled father, two sisters and their four children. They live in a remote Indigenous community.

She has a long history of mental illness with several long admissions to mental health inpatient units. She is now successfully treated with medication and has been able to resume her life, but is still very reliant on her mother for her daily care such as medication and assistance with her daughter when home from boarding school.

Janet's mother is the primary carer for both Janet and her father. She also works part-time which she sees as a break from her caring responsibilities. Janet's mother tries to access respite care for her husband from disability services on a regular basis, but this is very complicated and involves him moving to another community via air in the wet season and road during the dry.

Janet and her family have recently made the decision to move from their community and their extended family and relocate in Darwin where there are more support options for her mother and greater access to opportunities for Janet.

Janet's story shows how few supports are available to people in remote communities and how much these people would benefit from being able to access funding which could assist in developing appropriate locally based services.[109]

6.6 Poor physical health and co-occurrence with other health conditions

Mental health consumers are at higher risk of serious health conditions such as diabetes, heart disease, and obesity, and have considerably elevated mortality rates from all main causes compared to the general population.[110] This is not only due to the effects of illness and medication but also due to reduced access to appropriate healthcare including assessment and treatment.[111]

Poor physical health can hinder recovery from mental health conditions and contribute to disability. There has been a recent focus on the high incidence of metabolic disorders and increased incidence of diabetes among people taking psychotropic medication in particular. People with psychosocial disability and

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[109] Unpublished personal communication to NMHCCF in 2011, used with kind permission, names have been changed.
[110] Lawrence D, Holman CDJ, Jablensky AV, 2001, *Duty to Care – Preventable Physical Illness in People with Mental Illness*, The University of Western Australia.
[111] Muir-Cochrane E, 2006, *Medical co-morbidity risk factors & barriers to care for people with schizophrenia,* Journal of Psychiatric & Mental Health Nursing. vol no 13, pp. 447-452.

diabetes often have poor blood sugar control and poor dietary control, often compounded by a lack of motivation for exercise.[112]

Many people with mental health conditions also have drug and alcohol misuse problems. Mental illness may lead to increased vulnerability to drug and alcohol misuse in a number of ways, and vice versa, so that a high proportion of people with mental health conditions also have drug and alcohol problems. Such misuse of drugs, illicit and prescribed medication as well as alcohol, can amplify impairments and aggravate mental health conditions.

Many community managed disability support services already provide integrated approaches to support for people with psychosocial disability and have close links with mental health services. Further funding of disability supports for people with psychosocial disability will need to reflect this model.

Recommendation
6.6   Disability supports for people with psychosocial disability must be integrated with health services to ensure that people with psychosocial disability have access to effective health care to support their physical and mental healthcare needs. Where possible, innovative models, including technological options should be used to assist in service delivery that meets people's needs and is provided in consultation with those people.

Paul's story

One of my sons who has schizophrenia was diagnosed with diabetes 4 years ago. It is likely that his diabetes is a result of the high level of antipsychotic medication he needs to take. We struggled for 3 years, even with the occasional assistance of mental health service and a GP. He was hospitalised in general and psychiatric wards many, many times over three years. It is "his own choice" was an often repeated phrase we heard from mental health services.

Then one year ago, he was taken on by the Royal District Nursing Service (RDNS) after a hospital admission. They realised immediately he could not manage his illness himself and have been fabulous. After 6 months of daily contact, encouragement and teaching, they installed a special telephone with a screen in his home. They now call him every evening via visual phone link to observe him injecting his insulin and he can also see them. They talk briefly with him and check his blood sugar levels, which he now keeps and records in a booklet they have given him.

His key worker, who is a nurse from RDNS, visits him every Monday at the same time and talks to my son (and his father who is his main carer) about what has happened this week, adjusts his medication if necessary, and reminds him of the food he is supposed to eat.

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[112] Journal of Clinical Psychiatry Academic Highlights, *2005, Advancing the Treatment of People With Mental Illness: a call to action in the Management of Metabolic Issues*. Journal of Clinical Psychiatry, Vol 66 No 6, p 790-798.

This is a fabulous example of how people with cognitive impairment and severe mental illness and physical health issues should be cared for. RDNS are consistent, reliable and assertive, when it is necessary to be so. My son has never responded so well to workers. He is described by RDNS as 'motivated' and one of their 'star' clients, despite being described by previous mental health workers as 'difficult to engage'.

It is not that difficult to provide a good service and also not that expensive. It only takes 10 minutes a day for the phone call, plus one meeting once a week.
It is all about someone being accountable and having the right attitude, and actually caring about people. If people with schizophrenia were all receiving a service such as this, we could probably alter those appalling early mortality rates! [113]

6.7 Stigma and discrimination

Stigma is a big problem in this community – people fear what they don't understand. I've experienced a change in body language of a specialist when they ask you what medications you are on. I've been told by a solicitor not to tell anyone that – sometimes our integrity is questioned just because we have a mental illness – we might be unwell but that doesn't mean we're stupid.
(Consumer, New South Wales, Broken Hill Forum #24)[114]

Stigma is the negative effect of commonly held, mostly erroneous, beliefs about mental health conditions. Self stigma is the effect of an individual's internalisation of the stigma and discrimination found in the community. Stigma is complex and insidious, resulting in negative judgements, discrimination and victimisation. It influences not only community behaviours towards mental health consumers and carers but also the development of community institutions, processes and public policy.

Stigma is consistently identified as a major barrier to recovery by people with mental health conditions, their families and those working in the field of mental health. It is a key contributor to disability often causing equal, or even more, stress and isolation than the actual mental health problem.[115] It acts as one of the most pervasive barriers to mental health consumers and carers obtaining timely and effective services and supports and to developing community initiatives that will meet their needs.

Until the community experience of people with psychosocial disability excludes stigma and discrimination, opportunities for social inclusion will remain limited. Therefore, addressing stigma around mental health conditions will be a key step in combating discrimination and will be integral to supporting people with psychosocial disability to easily participate in the community.

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[113] Unpublished personal communication to NMHCCF in 2010, used with kind permission, names have been changed.
[114] Mental Health Council of Australia, 2005, ibid, p250.
[115] Rethink/Institute of Psychiatry, (2003) *Reducing Stigma and Discrimination: What works?*, Conference Report, Birmingham.

Recommendation

6.7   Tackling stigma and discrimination around mental health conditions and providing education on psychosocial disability urgently need to become a key element of national psychosocial disability initiatives including:

- on a community wide basis including service providers and the general population
- as part of ongoing long term national disability care and support
- as a key element of the *National Disability Strategy*
- as part of core training for disability support services.

Cliff's story

Cliff is a 30 year old Indigenous man living in a remote community. He lives with his brother and his partner plus their daughter and three daughters (one who is pregnant) from a previous relationship, his sister, and various other family members who need accommodation.

Cliff has a mental illness, an intellectual disability and an acquired brain injury, he has spent time in prison for violence and has had several admissions to mental health inpatient unit when unwell.

Cliff's mother was his primary carer but died recently leaving him without any real family support. Cliff's father chooses to live away from the community because he cannot cope with the responsibility of caring for Cliff. Cliff's brother also has a mental illness and is unable to take on the task of caring for his brother.

Cliff has his finances managed under public guardianship arrangements. For some time his meals were provided by Home and Community Care services but he was often not home when they went to deliver his meals, so this service was ceased. He has some basic cooking skills but mainly lives on fast food and soft drink.

Cliff is often the victim of abuse and ridicule by community members, adults as well as children, as he has very limited control over his responses and is good sport for bored people. Cliff has limited ability or opportunity to communicate with others in the community but likes to spent time with the mental health team, where he feels safe and is able to talk about his childhood. He generally responds well to any structured activities and routines but this is not readily available in his community.

Cliff's quality of life would improve with some community support that could provide structured activities and routines, information and support to make healthier food choices and link him with other essential services that may be of benefit to him. [116]

6.8 Lack of community awareness about psychosocial disability

Lack of awareness of the needs of people with a psychosocial disability, and lack of mechanisms to address this, has a huge impact on the lives of mental health consumers and carers. As already outlined above, many people with a disability are not in a position to easily access knowledge about the local or wider community.

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[116] Unpublished personal communication to NMHCCF in 2011, used with kind permission, names have been changed.

Further, most community institutions are not set up to meet the needs of people with a psychosocial disability. This can be seen as a form of systemic discrimination.[117] This lack of accommodation clearly evident in employment services such as Centrelink, disability employment services, accommodation services, legal services and other amenities that community members take for granted such as access to local government services or recreational options. These services are often unaware of the needs of people with psychosocial disability and unaware of how best to engage with them.

While government departments and other community institutions have made efforts to raise awareness about the support needs of people with psychosocial disability, it is clear that these have not been targeted effectively. For example, despite initiatives such as a Centrelink's Customer Service Charter[118] and a Disability Action Plan,[119] mental health consumers and carers regularly report dissatisfaction with Centrelink services and discriminatory policies of Department of Employment Education and Training and Department of Families, Housing, Community Services and Indigenous Affairs.

Mental health consumers and carers advise that to combat this systemic discrimination they need to be consulted about issues that affect them and work in partnership with agencies to develop policies that make services accessible to them. Currently there are few mechanisms to achieve this as these agencies generally do not involve them in service policy development and implementation.

Due to stigma and the other disadvantages of psychosocial disability outlined above, mental health consumers and carers advise that they are not always in a good position to be able to advocate for themselves. The National Mental Health Consumer and Carer Forum have called for the employment of specialist peer support officers need to be available to assist them with utilising services.[120] Employing peer support workers would also be of assistance to agencies seeking to implement systemic measures to break down barriers to access for people with psychosocial disability.

Recommendation.
6.8   Initiatives to build the capacity of public institutions to meet the needs of people with a psychosocial disability need to be expanded. This would build on the momentum of community wide anti stigma campaigns and must include:

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[117] Disability Council of NSW, 2003, *A Question of Justice: Access and participation for people with disabilities in contact with the justice system*, accessed from the Disability Council of NSW website www.disabilitycouncil.nsw.gov.au/archive/03/justice.pdf on 27 Feb 2011.

[118] Centrelink, 2010, *What you can expect from centrelink*, accessed from the Centrelink website www.centrelink.gov.au/internet/internet.nsf/about_us/customer_charter.htm on 25 Jan 2011.

[119] Centrelink, 2010, *Centrelink's disability action plan 2010-2013*, accessed from the Centrelink website www.centrelink.gov.au/internet/internet.nsf/filestores/id044_1007/$file/id044_1007en.pdf on 25 Jan 2011.

[120] National Mental Health Consumer and Carer Forum (NMHCCF), 2010, *Supporting and developing the mental health consumer and carer identified workforce – a strategic approach to recovery*, NMHCCF, Canberra.

- implementation of consumer and carer informed education and training initiatives for staff and policy makers
- partnership arrangements with consumer and carer policy advisors
- employing specialist support officers designated to assist people with psychosocial disability to navigate organisational systems.

6.9 Barriers for carers

Carers are a key support in the lives of many people with a psychosocial disability and require essential supports to carry out their role. Many such supports are lacking and the consequent burden of care experienced by many carers of people with severe psychosocial disability compromises the ability of carers to participate effectively in the community and meet their own social inclusion needs. We know that carers are socially isolated, are often unable to work or can only work part time, have little income support and often live with long term personal and emotional hardship that can take a heavy toll on their physical and mental health. Carers also carry a constant concern about what will happen to their family member once they have gone.

Further, the support provided by carers has significant and uncalculated cost benefits to the disability care and support sectors. Provision of supports to people with a disability must include a consideration of carers' needs.

Family carers generally don't take on this role by choice. They are catapulted into it by the onset of severe mental illness in a child, a spouse or other close relative and they are compelled to sustain it by the bond of love for their ill relative and by the lack of resources in the community for the care and support of mentally ill people. Most families have little choice when the only other options for their mentally ill relative are a grotty boarding house or hostel, wandering the streets homeless, or jail. [121]

The MHCA 2009 report on carer experiences identified urgent key priorities for carers including recognition of the significant role that carers play and the urgent need for practical and financial support with this role, including respite. The following is a summary of what carers need to continue to fulfil their role:
- to be respected and listened to
- integrated recovery-based care for mental health consumers
- more and better trained staff at all levels
- knowledge and information for carers
- carer and consumer education for all professional groups and agencies
- support systems, services and processes established for carers
- therapeutic and accessible acute care services
- addressing stigma, discrimination and isolation for carers and consumers
- accommodation options for consumers at all levels of care
- better financial support of carers

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[121] Mental Health Carers Arafmi Queensland Inc, 2009, *Submission to: Parliament of Australia House of Representatives House Standing Committee on Family, Community, Housing and Youth Inquiry into Better Support for Carers*, Submission number 574, http://www.aph.gov.au/house/committee/fchy/carers/subs.htm, accessed on 3 May 2011.

- better focus on addressing the physical and mental health of carers
- flexible respite options for carers
- privacy and confidentiality issues addressed in service provision
- early intervention at each episode of care
- employment options for carers.[122]

In addition, carers from culturally and linguistically diverse backgrounds, particularly those who are ageing, have an acute need for supports in their own language, sensitive to their cultural background. Those from rural and remote areas have a need for services of any description.

Recommendation

6.9   Carers of people with a psychosocial disability urgently need:
- better information services such as an expansion of Commonwealth Carelink services to provide information on mental health supports for both consumers and carers
- carer peer support for information, advice, mentoring and navigating systemic supports available to them and to consumers they support
- education and training in supporting someone with a psychosocial disability and caring for oneself
- accessible respite that meets the needs of mental health consumers and carers
- recognition of costs involved in caring and that this is reflected in income support and more appropriate assessment processes for carer allowance and carer payment
- improved service provision from Centrelink
- inclusion of carers in planning for psychosocial disability support.

A carer in her 80s has moved to a city 100 kilometres away from where she had lived previously and rents a bedsit to provide significant daily care for her son. He lives independently, but visits her daily at 4am for a cup of tea, and she then visits him later in the morning. He has difficulties keeping on top of household tasks such as laundry, and his mother assists him with this. She receives no carer benefit or pension.[123]

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[122] Mental Health Council of Australia, 2009a, op cit.
[123] Ibid p 50.

7 Services for people with psychosocial disability

7.1 Service requirements of people with a psychosocial disability and their carers

The World Health Organisation proposes that the optimal mix of services for mental health includes specialist and informal community supports.[124] This is supported by research evidence that shows that health outcomes for people with mental health conditions are significantly improved if comprehensive and holistic support to participate in the community is provided.[125] The NMHCCF welcomes the opportunity provided by the Productivity Commission's *Inquiry into Disability Care and Support* to advocate for improved support for people with psychosocial disability as a result of mental health conditions. Mental health consumers with a psychosocial disability and their carers look forward to the day when they can access supports of their choosing, when and where they want them, which will work with them to develop their capabilities and identify supports that will assist them to do this.

To achieve this, mental health consumers and carers support the use of a personalised approach to determining and providing disability supports. This approach does not seek to provide fixed services to people in need but works with individuals to place them at the centre of decision making about their lives. In the UK, personalisation of clinical and other services for people with mental health conditions is being undertaken in recognition of the need for people to increase autonomy and assist in their recovery. It is an empowering alternative to seeking information about a person's need from a third person with clinical expertise in mental health such as a psychiatrist.

The NMHCCF proposes that in implementing a personalised approach to delivering disability support services Australia would assist in generating more and improved services for people with a psychosocial disability. These services would not have a clinical or illness focus (although they may be integrated with such services) but a personal strengths based approach to develop their full potential in ways that would not otherwise be achievable. These services will be provided by staff who are trained in working with people with psychosocial disability. This model is currently demonstrated in the community managed mental health sector where the few best practice psychosocial disability supports are currently provided.

An acknowledgement of the difference between medical or clinical focussed services and disability support services is a likely reason that peer support workers are becoming an essential element of mental health service provision and a skill set of choice for community managed mental health services. Peer support workers are likely to be more familiar with the disability support needs of people with mental health conditions and are able to identify ways to meet these needs outside the mental health sector and in dealing with everyday life in the community. In these services they use their unique skills and experience to provide a conduit between mental health services and disability supports. They are also uniquely placed to

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[124] World Health Organisation (WHO) and WHO Family of Doctors, 2008, *Integrating Mental Health into Primary Care: a global perspective*, WHO, Geneva.
[125] Mental Health Coordinating Council (MHCC), 2007, *Social Inclusion, its importance to mental health*, MHCC, Rozelle.

provide pathways between generic disability services and people with a psychosocial disability.

The following principles have been adapted from the UK National Mental Health Development Units, *Paths to personalisation in mental health, a whole system, whole life framework*[126] to ensure that disability services are focussed on support for people with psychosocial disabilities. Services:

- are person centred and ensure that individual preferences are respected and people are supported to make their own decisions
- provide information, advice and skills to facilitate opportunities for self help, taking control and making choices
- provide opportunities for people to manage personal budgets for disability support and other resources that are available to them
- work with carers to identify and provide what they need to carry out their support roles effectively and maintain their health and live their own life
- are accessible, equitable and provides opportunities without stigma or discrimination
- are responsive to the episodic nature of mental illness, the changing nature of psychosocial disability and personal consumer and carer needs and provide quality and innovation
- work closely with clinical and other disability and community services to ensure that supports are streamlined and comprehensive. For example opportunities to address physical and dental health needs are provided
- use the skills of the mental health consumer and carer peer support workers in service design and delivery.

Recommendations

7.1.1   Mental health consumers and carers need disability support services that maximise their potential to manage everyday life and participate in the community by using personalised services that support their recovery.

7.1.2   Supports need to be flexible to meet the changing needs of mental health consumers and carers in recovery and meet the immediate needs of those most vulnerable to relapse.

7.1.3   Peer workers play a key role in developing better coordination pathways between disability services and mental health services. They should be part of the disability support services workforce to provide expertise in servicing people with a psychosocial disability.

7.1.4   Mechanisms to support the development of better relationships and the delivery of streamlined and integrated treatment between clinical services and disability support services need to be developed

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[126] National Mental Health Development Unit, 2010, *Paths to personalisation in mental health, a whole system, whole life framework*, National Mental Health Development Unit, Department of Health, London.

7.2 Self directed funding arrangements for personalised services

Self directed or self managed funding options or personal budgets for support are natural extensions of the idea of consumers and carers being in control of decision making about their lives. These sorts of arrangements include individuals receiving and directing a budget and purchasing services that they choose for disability support rather than having to rely solely on services that are already provided. Provision is also made to support people to decide how the budgets should be spent if this requirement identified by the person receiving support.

The principles behind using this approach is that consumers and their carers have more choice and autonomy about what sorts of services they purchase, leading to improved satisfaction with services. Exploring these sorts of funding arrangements can be a challenging concept for those who seek to protect people with disabilities from exploitation. However, early evidence on this type of support in the area of mental health conditions is promising and shows more satisfied consumers and carers and reduced need for crisis support.[127]

In the US preliminary findings are available from five different programs running for adults with serious mental health conditions providing self directed funding. They show significant consumer satisfaction with the programs. While some services are limited to outpatient mental health and rehabilitation services, they show a wide diversity of spending which included health club membership, bicycle related purchases, exercise equipment, tai chi classes. Where possible consumers also purchased assistance with accommodation and living expenses, indicating the high need for disability support in these areas.[128]

The programs generally indicate the following advantages for mental health consumers and carers:
- individual choice and autonomy and satisfaction with being able to choose services
- being able to choose tailored services to meet individual needs – many of which are disability focussed rather than specifically health related
- flexibility – obtaining services when and where you need them, eg. out of business hours or in your own home
- potential to utilise services outside those traditionally offered and the value of these services that see them as a whole person and not just a diagnosis
- being able to access disability services outside the mental health system at all times rather than relying on mental health services that are rationed due to limited resources or the belief that because you are now 'well' you do not need services
- improved service quality and being treated like a valued customer.[129]

For example, consumers involved in the US programs also expressed a preference for services provided by peer workers with whom they felt they could have an equal

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[127] Alakeson V, 2008, *Let patients control the purse strings*, British Medical Journal 336.
[128] Alakeson V, 2007, *The Contribution of Self-Direction to Improving the Quality of Mental Health Services*, U.S. Department of Health and Human Services Report from the Office of the Assistant Secretary for Planning and Evaluation.
[129]Ibid.

relationship.[130] Such services are more readily available in the US and the NMHCCF believes that a cohort of professional consumer and carer peer workers would be well placed to provide such services in Australia.

A key aspect of providing self directed funding options in the mental health sector is the provision of a funding system that provides a range of supports and options for management of funding, planning and purchasing of services.[131] Consumers in the US programs identified that this support was essential not only to help manage finances and buy services but also in assisting them to identify their individual needs, develop plans and goals and, with follow up support, carry these out.[132] It is likely that this sort of individualised disability support has not previously been a feature of support services offered to people with mental health conditions in the US and certainly in Australia this is the case. The US studies show the opportunity that individual person centred care can play in identifying the sorts of services that need to be available to people with psychosocial disabilities. It also highlights another service type that would be appropriate for peer workers.

In the US, counselling support for self directed care has been undertaken by peer workers. They are in fact the experts on recovery and how to utilise the available services and supports. This information is not generally held by professionals working in the mental health sector.[133]

Apart from the personal benefits to mental health consumers and carers, the other advantage of self directed funding systems shown in the US is the potential to increase the range and quality of service types available to consumers and carers, driven by consumer and carer demand. Under self directed funding arrangements, consumers and carers will choose the sorts of services that they require, that suits them and meets their needs. It is most likely that these are service types which will meet their needs with dignity, respect and a high degree of efficacy. However, a key risk is that service spending is capped by government agencies at a cost to the disability community generally. Such risk would need to be managed, which was an integral part of some of the US programs outlined above.[134]

International research has shown the benefits of a self directed budget approach to funding services for people with a psychosocial disability including improved service quality, increased satisfaction with services and service outcomes, and decreased reliance on crisis intervention. Australian mental health consumers and carers with psychosocial disabilities are keen to be able to use the power of their choices to assist in developing the sorts of disability supports that they want.

Recommendation
7.2   Australian mental health consumers with psychosocial disabilities and their carers should be able to use the power of their choice to develop the disability

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[130] Ibid.
[131] In-Control Australia, 2011, *About self directed funding*, accessed from the In-Control Australia website on 17 Feb 2011, www.in-control.org.au.
[132] Alakeson 2007, op cit.
[133] Ibid.
[134] Ibid.

supports that they want. They must be included in any National Disability Insurance Scheme which proposes to use a self directed funding approach.

7.3 Options for supported decision making for consumers

Support with decision making is an essential element of self managed support services. When identified as needed by an individual, it assists and empowers people who are making decisions, to direct their decision making process. This sort of support is are particularly important where legal and other life directing decision making is required and where the capacity of people to make appropriate decisions about their own lives is in question. Where individual decision making capacity is in question, assistance with decision making must include working with the consumer's own circle of intimate support.

Examples of such supports with decision making that could be provided under self directed funding programs include personal ombudsman services, peer support services, use of advance planning and systemic accessibility measures.

Characteristics of effective supports are those that:
- are based on a relationship of trust,
- demonstrate patience and respect for the person's own style and process of making decisions
- includes measures to prevent exploitation and abuse.

Where people are not able to manage their own decision making, appropriate safety nets need to be in place to ensure they continue to receive appropriate support and assistance for services that they need.

Recommendation
7.3   Self directed funding options need to include development and implementation of appropriate support mechanisms for people with a psychosocial disability to ensure that they are able to effectively control decision making about their lives.

Conclusion

People with psychosocial disabilities are amongst some of the most marginalised in the Australian community and many live with poverty, discrimination and social isolation as a normal part of their lives. Carers or people with psychosocial disability are often forced to step in to provide support that they feel they don't have the training or resources to deliver, compromising their own health and ability to maintain employment and their own community participation.

For too long the disability support needs of people with a psychosocial disability have been ignored and mental health consumers and carers and service providers are in despair. With Australia a recent signatory to the *United Nations Convention on the Rights of Persons on with a Disability* it is urgent that governments acknowledge the impact of psychosocial disability and consider their obligations to addressing psychosocial disability support needs.

Urgent research is needed on the identification of the numbers of people with psychosocial disability, their support needs. This needs to inform an urgent and ongoing review of how well the support needs of people with psychosocial disability are being met, including assessment processes and the effectiveness of current service provision.

The NMHCCF strongly endorses a National Disability Insurance Scheme for the delivery of long term disability support. The NDIS provides an opportunity for governments to consider how effectively the current and potential future disability support arrangements meet the needs of people with a psychosocial disability. . To ignore this opportunity to would be discriminatory and a human rights failure. As a part of this process people with mental health condition and a psychosocial disability and their carers must be consulted on the range of issues that effect their participation in the NDIS. This is to ensure that the current disadvantages that they experience in the delivery of disability support services are addressed fairly and sustainably.

While it is still difficult to determine exact numbers of people with a psychosocial disability, the NMHCCF proposes that the figures already outlined by the Productivity Commission provide an initial indication of the numbers of people with a psychosocial disability associated with a mental illness: 149,800 to 206,000 people. These figures will need to be refined through consultation with the sector, implementation and the development and implementation of assessment processes that effectively measure psychosocial. These figures will then need to be used to inform ongoing budgeting.

The current funding arrangements for services for people with a psychosocial disability are complex and fall far short of meeting the needs of the sector. This provides a compelling reason for the Productivity Commission to recommend the inclusion of psychosocial disability services in the proposed NDIS and better coordination between the mental health and disability sectors including the effective identification and provision of supports to people with a psychosocial disability.

What is disability?

The Preamble to the UN Convention on the Rights of Persons with Disabilities states that:

> *Disability is an evolving concept and that disability results from the interaction between persons with impairments and the attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis.* [135]

In this context, Article 1 of the UN Convention on the Rights of Persons with Disabilities, provides the following definition of disability:

> *Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.* [136]

This means that what is generally meant by the word disability actually describes the reduced participation or social exclusion experience of someone with a disability. This experience is shaped by a number of factors.

The First World Congress of Disabled People's International held in 1981 identified:

> *Impairment as the loss or limitation of physical, mental or sensory function on a long-term or permanent basis.*
>
> *Disablement as the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers.* [137]

These definitions help us to understand that a disability is not only related to impairment. It is also something that is triggered the limitations which are placed on all people who have impairments.

Many people also argue that disability is entirely due to limitations placed on people by society and that disablement is caused by the lack of accommodations that society makes for the needs of all of its citizens. In this way the determinants of disability can be seen as a cultural construction similar to the cultural beliefs that support racism and sexism. [138]

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[135] United Nations, 2009, op cit, Preamble.

[136] Ibid, Article 1.

[137] Disabled Peoples' International 1982, *proceedings of the First World Congress*, quoted in Gary L. Albrecht, Katherine D. Seelman, Michael Bury, 2001, *Handbook of Disability Studies* , Sage Publications Inc.

[138] McDermott R, Varenne H, 1995, *Culture as disability*, Anthropology and Education Quarterly 26:323-348.

Models of disability
While many people regard impairments as something that only happen to people with a disability, they are in fact a natural and normal part of the human experience. We all experience impairments to a greater or lesser degree and indeed they are an issue for the whole of society and not just an issue of a minority. For example, when we break a limb, or when we are feeling distressed about a life event, impairments in capacity to perform our daily work may occur. Having a cold is rarely considered to require more than self care and rest and such accommodations such as a short period off work may be acceptable. However, other disabling conditions can require much more complex support and accommodations may not be so easily made. The WHO definition of disability identifies that it is the interaction between the person with an impairment and the attitudinal and environmental responses that can entrench disability. Therefore disability is also a universal issue.

This idea of disability is called the social model of disability and it recognises people with a disability as valued citizens who have the right to participate in the community. It views impairments as valuable diversity in ability in all members of society. It uses a strengths-based approach to identifying the supports needed for people with a disability to participate equally. In summary, it focuses on people's capabilities, identifies obstacles to participation and seeks to overcome these.[139]

However, some people argue that this definition does not explain the full experience of someone with a disability and ignores the complex role that health conditions play in the lives of people with a disability.[140] Further, many people with mental health conditions who see themselves as survivors of the psychiatric system are not keen to associate themselves with the notion of disability.[141]

While definitions of disability continue to be debated, the WHO is currently using a bio-psychosocial model of disability which integrates the social and medical models. This model is demonstrated in the International Classification of Functioning, Disability and Health.

Assessment of disability and the International Classification of Functioning, Disability and Health
In 2001, the WHO launched the International Classification of Functioning, Disability and Health (ICF) which reflects the idea of disability as multidimensional and universal.

While still being based on a bio-psychosocial model of disability, it also seeks to define the disability experience by assessing a person's functioning rather than their health condition as well as acknowledging the crucial role of the environment in people's functioning.

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[139] Cobigo V, Stuart H, 2010, op cit, p454.
[140] Taylor R, 2005, *Can the social model explain all of disability experience? Perspectives of persons with chronic fatigue syndrome*, American Journal of Occupational Therapy, Vol.59(5).
[141] Beresford P et al, 2000, *What have madness and psychiatric system survivors got to do with disability and disability studies?* Disability and Society, Vol 15(1), p169.

The ICF describes disability:

> *Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.*
>
> *Thus disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives.*[142]

The complexity and multidimensional nature of disability are important underpinnings of the social model of disability. They are also consistent with the aspects of the social model of disability which underpin the *United Nations Convention on the Rights of Persons with Disabilities*.

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[142] World Health Organistaion (WHO), 2011, *Topics: Disabilities*, accessed from the WHO website http://www.who.int/topics/disabilities/en/ on the 10 Feb 2011.

Extracts from the *United Nations Convention on the Rights of Persons with Disabilities*[143]

From the United Nations Convention for Persons with a Disability, Article 1 – Purpose:

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others...

...The principles of the present Convention shall be:
   a. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
   b. Non-discrimination;
   c. Full and effective participation and inclusion in society;
   d. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
   e. Equality of opportunity;
   f. Accessibility;
   g. Equality between men and women;
   h. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities...

From the United Nations Convention for Persons with a Disability, Article 3 - General principles:

States Parties to undertake to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end States Parties undertake:
   a. To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognised in the present convention…

From the United Nations Convention on the Rights of Persons with Disabilities, Article 4 General Obligations:

States Parties undertake to adopt immediate, effective and appropriate measures:

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[143] United Nations, 2009, op cit.

b. To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;

c. To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;

d. To promote awareness of the capabilities and contributions of persons with disabilities…

From the United Nations Convention on the Rights of Persons with Disabilities, Article 8 - Awareness-raising

States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects…

…States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

United Nations Convention on the Rights of Persons with Disabilities, Article 16 - Freedom from exploitation, violence and abuse

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

United Nations Convention on the Rights of Persons with Disabilities, Article 19 - Living independently and being included in the community

States parties to this Convention recognise the equal righ of all persons with disabilities to live in the community, with choices equal to others, and shal take effective and appropriate measures to facilitate full employment by persons with disabilities of this right and their full inclusion and participation in the community, including ensuring that:

a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community and to prevent isolation or segregation from the community;
c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Article 26 - Habilitation and rehabilitation
1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:
a. Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;
b. Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.
2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.

3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

Table of some impairments related to common mental health conditions and treatment effects

<div align="right">**Appendix 3**</div>

This table shows that a range of mental health conditions can be associated with a diverse range of impairments and related disabilities.[144]

Type of impairments	Anorexia nervosa	Bipolar disorder	Depression	Panic Disorder	Schizophrenia
physical					
Weight loss	X	X	X		
Weight gain		X	X	X	X
Endocrine system changes (irregular menstruation, breast growth in men, impotence)		X	X	X	X
Unexplained fatigue or fainting	X		X		
Decrease or increase in appetite		X	X		X
Insomnia or excessive sleep, difficulty with sleeping patterns		X	X	X	X

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[144] It should be noted that as conditions are individual, not all people with these conditions will experience all of the impairments indicated. Individuals with these conditions may have impairments that are not listed or may share impairments that are not indicated as shared in this table. The table shows impairments that are commonly experienced by the people with the condition indicated.

Type of impairments	Anorexia nervosa	Bipolar disorder	Depression	Panic Disorder	Schizophrenia
Mental and physical slowing or restlessness		x	x		x
Fatigue or loss of energy		x	x		x
Overactivity or dramatically increased energy		x			
Drug and alcohol use		x	x	x	x
More sensitive to pain			x		
Palpitations, pounding heart, or accelerated heart rate		x	x	x	
Sweating				x	x
Rrembling or shaking		x	x	x	x
Agitation and movement of mouth and head					x
Restless motion, pacing					x
Dry mouth		x	x	x	x

Type of impairments	Anorexia nervosa	Bipolar disorder	Depression	Panic Disorder	Schizophrenia
Sensations of shortness of breath or being smothered				x	x
Feeling of choking				x	
Chest pain or discomfort				x	
Nausea or abdominal distress				x	
Feeling dizzy, unsteady, lightheaded, or faint				x	
Derealisation (feeling unreal) or depersonalisation (feeling detatched)		x		x	X
Numbness or tingling sensations	x	x		x	x
Chills or hot flushes.	x			x	
Unexplained physical sensations such as skin crawling		x			x
Sensitive to sunlight, smells, noise etc					x
A significant change in behaviour related to symptoms		x	x	x	x

Type of impairments	Anorexia nervosa	Bipolar disorder	Depression	Panic Disorder	Schizophrenia
cognitive					
Can't concentrate	x	x	x		x
An unrealistic perception about being fat	x				
Irrational thoughts about getting fat or dangers of eating	x	x			x
Difficulty in thinking logically, rationally or clearly	x	x	x	x	x
Indecisiveness, difficulty making decisions		x	x		x
Recurrent thoughts of death (not just fear of dying), recurrent		x	x		
Suicidal thoughts		x	x		x
Delusional thoughts		x	x		x
Worrying	x	x	x	x	x
Feeling worthless	x	x	x		x

Type of impairments	Anorexia nervosa	Bipolar disorder	Depression	Panic Disorder	Schizophrenia
Feeling hopeless		x	x		x
Guilt, self blame	x	x	x		x
Hallucinations		x			x
Difficulty planning	x	x	x		x
Difficulty interpreting others' emotions and motivations	x	x	x		x
Recurrent fears					**x**
Emotional/ mood					
Social withdrawal.	x	x	x	x	x
Disinhibition		x			
Depressed mood		x	x		x
Anxiety	x	x	x	x	x
Pervasive sadness		x	x		x

Type of impairments	Anorexia nervosa	Bipolar disorder	Depression	Panic Disorder	Schizophrenia
Irritable mood	x	x	x		x
Loss of enjoyment or pleasure	x	x	x	x	x
Derealisation (feeling unreal) or depersonalisation (feeling detatched)		x		x	X
Fear of losing control or going crazy		x	x	x	X
Feeling unmotivated		x	x		x
Not feeling any emotions		x	x		x
Feelings of worthlessness, or excessive or inappropriate guilt	x	x	x		x
Elevated mood		x			x
Constantly fearful					x
Changed perceptions					X
Insecure					X
Distrustful					X