



**Supplementary Submission from the Mental Health Council of Australia (MHCA), with input from the National Mental Health Consumer and Carer Forum (NMHCCF), to the Productivity Commission's *Inquiry into Disability Care and Support*.
July 2011**

Productivity Commission question

We think it is useful to look at all dimensions. In the draft report we contend that the care and support needs of individuals (no matter the source of their disability) who have relatively short lived, low intensity and/or infrequent support needs should receive services under Tier 2 (not Tier 3). (See for example page 3.10 of the Draft Report¹). We would be keen to hear your views on this matter.

MHCA response

It is reasonable for some compromises to be made in the allocation of precious disability support resources. This might include the difficult decision that some people with short term, low intensity or infrequent support needs might not have access to high intensity support.

However, any long term disability support scheme needs to focus on relative functional impairment and disability to determine service eligibility. Functional impairments and support needs differ with disability type and may not be easily comparable. An alternative is to assess levels of severity by comparing likely outcomes of withdrawing support.

For example, it is likely that people with psychosocial disability

- who are functionally impaired and without support for periods of say, two weeks or more are likely to breach their Centrelink Newstart Allowance requirements and
- who are functionally impaired and without support for say one month would considerably increase the risk of compromising their employment, losing their accommodation, and encountering long term stressors that could seriously impede their recovery and threaten their physical and mental health.

These scenarios are comparable to those which would be experienced by someone with an intellectual disability and a similar level of functional impairment, whose support needs were withdrawn for periods of two weeks or a month, and would be therefore likely to risk severe hardship, crisis, homelessness and ill health.

It is therefore proposed that people with a psychosocial disability associated with mental health conditions should have access under the scheme to the same level of support that their functional impairment requires as any other eligible person with an equivalent level of disability.

¹ Australian Government Productivity Commission, 2011, Disability Care and Support Draft Inquiry Report, Canberra.

A 2006 project undertaken by the Boston Consulting Group for the Victorian Department of Premier and Cabinet estimated that 19% of Victorians had a mental illness. Of these, the following breakdown by level of disability was identified:

- Three per cent had a severe disability, often associated with psychotic disorder, bipolar disorder, severe depression, severe anxiety or severe eating disorder. A typical example is a 37 yr old male who episodically hears voices, has severe depression and has attempted suicide several times. He is unemployed, lives in public housing and is alienated from friends and family.
- Four per cent had a moderate disability, often associated with moderate depression, moderate anxiety disorder, personality disorder, substance-related disorder, eating disorder or adjustment disorder. A typical example is a 21 yr old male with chaotic behaviour and complex problems. He is suicidal, uses drugs heavily, experiences panic attacks, gets into fights and was arrested for assault 4 weeks ago. He cannot hold onto a job and is currently unemployed.
- Twelve per cent had a mild disability, often associated with mild depressive disorder or mild anxiety disorder. A typical example is a 42 yr old female who feels down, tearful, irritable and has withdrawn from friends over the past 4-6 months. She takes many sick days because she feels down.²

Such categories would appear to fit with the Productivity Commission's proposed tiers of disability support and may provide a proxy for estimating numbers of people with specific disability needs. However, due to the complex and episodic nature of psychosocial disability, it may be the case that some people who have moderate psychosocial disabilities, intermittently develop severe long term disabilities during the course of their illness. Such circumstances would trigger an elevated need for support services. It is common for this to occur as a result of a person with a psychosocial disability not receiving the right kind of support, which in turn exacerbates stress and triggers further episodes of mental illness. Therefore any support scheme should consider the use of early intervention to mitigate this effect, which will necessarily involve provision of monitoring and assistance for people with a moderate psychosocial disability.

These figures should also be compared with those identified by the *Low Prevalence Disorder Study*, which was undertaken over 1997-98 as part of the 1997 National Survey of Mental Health and Wellbeing.³ Although the ABS notes that the Survey of Mental Health and Wellbeing does not provide a good indication of disability prevalence,⁴ the Low Prevalence Disorder Study provides the best current estimates of people with a severe mental illness. These people are most likely to comprise the group that have a severe ongoing psychosocial disability. These figures could be used by the Productivity Commission as an initial proxy for the numbers of people with a psychosocial disability who would require Tier 3 support. These figures are also likely to include people whose disability has increased from moderate to severe, due to lack of appropriate service provision.

² Boston Consulting Group, 2006, *Improving mental health outcomes in Victoria: The Next Wave of Reform*, Boston Consulting Group, accessed from the Victorian Government Department of Premier and Cabinet website www.dpc.vic.gov.au on 20 June 2011, p11.

³ Jablensky A, McGrath J, Herrman H, Castle D, Gureje O, Morgan V, Korten A, 1999, *People Living with Psychotic Illness: An Australian Study 1997-98*, Australian Government Department of Health and Ageing, Canberra.

⁴ Australian Bureau of Statistics, 2003, *Disability Prevalence and Trends*, Australian Bureau of Statistics, Australian Institute of Health and Welfare, Canberra.

More up to date estimates of this population will be available through the Survey of High Impact Psychosis (SHIP) which is a national survey examining the prevalence and profile of psychosis, and identifying factors associated with good outcomes for people with a psychotic illness. It is being conducted through the University of Western Australia School of Psychiatry and Clinical Neurosciences.⁵ This study used a methodology that is comparable to that outlined in the Low Prevalence Disorders Study.

Project contacts at the University of WA have advised that in the absence of data from SHIP, estimates from the Low Prevalence Disorders Study could be used by a statistician to develop an estimate of the national numbers in this group. They propose that this statistical exercise be undertaken using the core sampling weights published in the National Survey of Mental Health and Wellbeing Bulletin 2, *Costs of Psychosis in Urban Australia*.⁶

Further data are presented for the Low Prevalence Disorders Study in the publication by Harvey et al, *Disability, homelessness and social relationships among people living with psychosis in Australia*.⁷

The MHCA proposes that in the absence of better data on psychosocial disability, the Productivity Commission use the data provided by the Low Prevalence Disorders Study to develop estimates of the number of people with psychosocial disability who should be made eligible for Tier 2 and Tier 3 support under the proposed disability support scheme. This recommendation also includes the proviso that more robust estimates of the prevalence and level of psychosocial disability in the Australian population are developed as soon as possible, including appropriate assessment tools and training of assessors. The final report of the SHIP project, due for publication later this year, should be a useful guide in this endeavour.

Productivity Commission question

The nature of the need – what does the individual require assistance with - say organisational planning, personal hygiene, communication.

MHCA response

These are exactly the aspects of everyday living for which individuals with psychosocial disability would require support. In the case of serious psychosocial disability, this support is likely to include assistance with identifying and planning appropriate activities, together with prompting to carry out and complete tasks.

The need for help with organisational planning arises from problems with concentration. For instance, an individual may have difficulty grasping and following instructions. The analogy frequently used to explain this difficulty is of a telephone exchange which becomes jammed with multiple callers. The impact on concentration is often demonstrated at conferences by providing headphones through which the person hears loud music whilst being asked to complete a puzzle. A similar difficulty can occur for someone experiencing auditory hallucinations (hearing voices) and simultaneously being required to respond to a spoken

⁵Information on this survey is available at the University of Western Australia, School of Psychiatry and Clinical Neurosciences website <http://www.psychiatry.uwa.edu.au/research/neru/survey>.

⁶ Carr V, Neil A, Halpin S and Holmes S, 2002, *Costs of Psychosis in Australia*, Commonwealth Department of Health and Ageing, Canberra, p47.

⁷ Harvey C, Evert H, Herrman H, Pinzone T, Gureje O, 2002, *Disability, homelessness and social relationships among people living with psychosis in Australia A Bulletin of the Low Prevalence Disorder Study*, Department of Health and Ageing, Canberra.

request. The person may have trouble interpreting what is being said, or following instructions because of the distracting nature and messages of the voices.

Problems with memory are also common amongst people with serious psychosocial disability, which can markedly affect a person's ability to function. Memory problems can be an obstacle to completing activities scheduled at particular times of the day, such as taking medication and attending appointments. Centrelink are currently exploring reasons for non-attended appointments and it is likely that these will include memory problems amongst people with mental health conditions.

Personal hygiene issues are mostly shown through difficulty in maintaining a reasonably clean and tidy living environment, and remembering to bathe and change clothes regularly. Unless there are other disabilities, most are able to undertake these tasks by themselves, but require some form of prompting. Assistance may also be required with selection of clothing to match weather conditions.

Maintaining a domestic environment to an acceptable standard can be a major challenge for people with a serious psychosocial disability. It is not uncommon to see a person's living environment in disarray with clothes strewn everywhere, mail unopened and rubbish accumulating, often resulting in vermin infestation unless assistance is provided. The person may lack the motivation and focus to undertake regular cleaning. Once people are assisted to carry out these tasks, ongoing support may also be required to avoid recurrence of problems. Failure to maintain a household to a reasonable standard often results in loss of tenancy and homelessness.

Communication can be problematic. Many people with a serious psychosocial disability will have difficulty initiating or maintaining everyday social interaction. They may find direct or complex questions hard to answer. The capacity to understand non-verbal communication cues may also be severely impaired. This can result in social behaviour considered odd by the general public. Social skills for many may have been impaired through isolation, discrimination and rejection.

From the Activities listed in the Survey of Disability Ageing and Carers, support with the following is likely to be required

- cognition or emotion including the following tasks
 - making friendships, maintaining relationships or interacting with others
 - coping with feelings or emotions
 - decision making or thinking through problems.
- communication including the following tasks
 - understanding family or friends
 - being understood by family or friends
 - understanding strangers
 - being understood by strangers.
- health care including the following tasks
 - foot care
 - other tasks, such as:
 - taking medication, or administering injections
 - dressing wounds
 - using medical machinery

- manipulating muscles or limbs.
- housework or household chores including the following tasks
 - washing
 - vacuuming
 - dusting
- meal preparation including the following tasks
 - buying appropriate food (weight gain is a major side-effect of some psychotropic medication)
 - preparing ingredients
 - cooking food.
- mobility (Mobility is less of an issue for people with psychosocial disabilities but may be affected by co-morbidities, some of which are high for this group – eg diabetes as a result of poor diet and long term medication use. In this case, such individuals would have difficulties with the standard range of tasks under this heading).
- paperwork including reading or writing tasks such as:
 - checking bills or bank statements
 - writing letters
 - filling in forms.
- property maintenance including maintenance and gardening tasks such as
 - changing light bulbs, tap washers, car registration stickers
 - making minor home repairs
 - mowing lawns, watering, pruning shrubs, light weeding, planting
 - removing rubbish.
- self care including the following tasks
 - showering or bathing
 - dressing
 - However, it would be rare that assistance would be required with eating, toileting or bladder or bowel control, unless other disabilities were present.
- transport such as going to places away from the usual place of residence, or any other travel without support for such as assistance with planning or travelling.

To these activities requiring assistance the MHCA would also add

- Managing finances and budgeting. This would include all activities around financial management including budgeting and monitoring of spending.
- Carer and family educational support to assist families and friends understand the nature of the mental health condition and psychosocial disability, the importance of medications and how to recognise the first signs of relapse so that help can be sought early.
- Communication – assistance with dealing with government agencies such as Centrelink.

Productivity Commission question

The frequency with which it occurs – eg more than once a day, daily, weekly, once a month

MHCA response

It is difficult to generalise here – once order is established and an individual is assisted into a routine – a weekly visit may be appropriate. However, many will need a daily visit if assistance with everyday tasks such as shopping/cooking etc is needed. Twenty-four hour accommodation options are sometimes required.

Productivity Commission question

The duration of the need – ie permanent, lasting several years, lasting 12 months, 6 months

MHCA response

The duration of need is commonly for many years – although with early intervention, the level of disability may well be reduced and its duration possibly minimised. The duration of untreated psychosis (DUP) has been shown as an indicator of prognosis, with a longer DUP associated with more long-term disability.⁸ Effective psychosocial disability supports together with appropriate housing are significantly linked to reduction in relapse and hospitalisation.⁹ And the protective factors for relapse prevention include quality of life, effective social networks, housing and employment (or other meaningful activity).¹⁰

For this reason, it may be counterproductive for the scheme to consider providing benefits only to those who have had a severe psychosocial disability for say, six months or more. It may be more effective for the scheme to ultimately provide support for people with psychosocial disability when they indicate that they need it.

Productivity Commission question

The intensity of the support required – for example some people require supervision or prompting whereas some individuals with complex needs require two people to support them in an activity (2 on 1 support)

MHCA response

Generally a ratio of 1:1 support or less is required. Services do occasionally send two staff where they believe there is a risk to occupational health and safety.

⁸ Marshall M; Lewis S; Lockwood A; Drake R; Jones P; Croudace T (2005), *Association between duration of untreated psychosis and outcome in cohorts of first-episode patients: a systematic review*, Arch Gen Psychiatry **62** (9): 975–983

⁹ Anthony W and Blanch A (1989), *Research on Community Support Services, What we have learned*, Psychosocial Rehabilitation Journal, Vo12, no3, January.

¹⁰ Rickwood D (2005), *Pathways of Recovery, Preventing further episodes of mental illness*, Australian Government Department of Health and Ageing, Canberra.

Productivity Commission request

Number of the people who would require specialist, but not acute, accommodation options (eg group homes).

MHCA response

It has not been possible within current timeframes for the MHCA to locate any meaningful estimates of accommodation requirements amongst people with psychosocial disability who would be eligible for Tier 2 and 3 supports under a proposed NDIS. For instance, Victoria's Mental Health Reform Strategy 2009-2019 states that "it is estimated that over 40 per cent of people with severe mental illness are homeless or housed in tenuous forms of accommodation, often interspersed with period of hospitalisation and sometimes incarceration".¹¹ However, no source is given for this estimate and it is difficult to gauge whether this estimate could be generalised across Australia.

However, there are potentially useful data to inform both accommodation and cost estimates for support services in the above mentioned Low Prevalence Disorder Survey. For example, one analysis of the survey showed that hostels and crisis centres were the primary source of accommodation for 18.1% of the survey population.¹² Using this estimate, a minimal figure of numbers of people requiring accommodation could be estimated. However, this estimate would not include those being housed inappropriately in hospitals and those housed in unsustainable accommodation arrangements with ageing parents.

Finally, some useful estimates of costs associated with accommodation and support services for people with psychosocial disability in NSW have also been made. These are outlined in the Social Policy Research Centre evaluation of the *Housing Accommodation and Support Initiative*.¹³

¹¹ Mental Health and Drugs Division, Department of Human Services, 2009, *Because mental health matters, Victorian Mental Health Reform Strategy 2009-2019*, Mental Health and Drugs Division, Department of Human Services, p.106.

¹² Carr V et al, *ibid*, p40.

¹³ McDermott S, Bruce J, Oprea I, Fisher K and Muir K, 2011, *Evaluation of the Whole of Mental Health, Housing and Accommodation Support Initiative (HASI), Second Report*, SPRC Report 5/11, prepared for NSW Health and Housing NSW, December 2010.