Submission by the ACT Mental Health Consumer Network on Disability Care and Support

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Background

This submission has been prepared by the ACT Mental Health Consumer Network in response to a draft report - *Disability Care and Support* - released by the Productivity Commission in February 2011.

The ACT Mental Health Consumer Network (the Network) is the peak body for mental health consumers in the ACT. Run by consumers for consumers, our aim is to advocate for services and support for mental health consumers to assist them to live fuller, healthier and more valued lives in the community. We do this through advocacy, representation, lobbying and active involvement in new developments in the mental health sector, as well as in the wider health and community sectors.

SUMMARY OF RECOMMENDATIONS

Recommendation 1: NDIS should provide support for people living with mental illness, especially those who experience psycho-social disability.

Recommendation 2: Eligibility criteria for access to the NDIS should be based on functionality rather than medical diagnosis.

Recommendation 3: Eligibility criteria should support early intervention and prevention strategies to avoid rising levels of needs and costs at later stages.

Introduction

The Network welcomes the draft report – *Disability Care and Support* – written by the Productivity Commission to propose a National Disability Insurance Scheme (NDIS) to provide cover for all Australians in the event of significant disability.

The Network supports a personalisation approach to mental health care that would allow consumers to have access to the care when they need it, and in a way that suits their needs. This would allow people to access the services that best target their needs and that do this at suitable times and places. This approach promotes prevention and early intervention and supports consumers to have greater control of their lives.

The Network sees the potential of personalised budgets within NDIS to change the way public services are delivered to suit mental health consumer needs and circumstances. This would mark a positive move away from the current situation where the onus is on mental health consumers to adapt to the way services are delivered.

However, the Network is concerned that the proposed NDIS may exclude people living with mental illness. The Network advocates that it is important for the NDIS to avoid using *types* of disability as criteria for eligibility and instead focus on the *impact* of disability on people's ability to learn, work and participate in the community. To do otherwise would be inconsistent with international norms and best practice. The *United Nations Convention on the Rights of People with Disability*, for example, includes mental illness as a disability.

RECOMMENDATION 1: NDIS SHOULD PROVIDE SUPPORT FOR PEOPLE LIVING WITH MENTAL ILLNESS, ESPECIALLY THOSE WHO EXPERIENCE PSYCHO-SOCIAL DISABILITY.

The NDIS should play a role as a safety net that empowers people to choose how they access their support. On one hand, some individuals with significant and ongoing functional limitations resulting from a mental health condition do not see themselves as having a 'disability', so would rather approach the mental health sector than the NDIS. Similarly, some people with functional limitations from physical conditions may prefer to access services other than the NDIS. However, this should not preclude other people with mental health conditions from accessing the NDIS should they prefer this option.[1] People should be able to choose how and from where they can access their support.

Mental illness is more than a clinical condition. While clinical care is an important part of recovery, a social model of mental health that looks at the whole person, including their family situation, employment, living conditions and wellbeing has been recognised to play a more significant role in the recovery journey. David Braniff from SANE Australia discusses the "80:20 rule"; he argues that 20% of the recovery

[1] Productivity Commission. (2010). Disability Care and Support: Productivity Commission Draft Report Volume 1. Page 3.27

journey for most people with a mental illness concerns recovery from the symptoms of the mental illness(es), while the other 80% involves dealing with everyday life.[2]

The Network proposes that the NDIS adopt the term 'psycho-social disability' to provide support for people living with mental illness to live meaningful lives in their homes and communities. The psycho-social category of disability is mentioned in the *National Disability Strategy 2010-2020*[3] and should be used to differentiate the types of support that people can access under the NDIS and other systems. Four consumer stories have been included in Appendix 1 of this submission to illustrate how psycho-social disability impacts people's lives and how the NDIS can play an important role in supporting them.

RECOMMENDATION 2: ELIGIBILITY CRITERIA FOR ACCESS TO THE NDIS SHOULD BE BASED ON FUNCTIONALITY RATHER THAN MEDICAL DIAGNOSIS.

The Network is against the use of medical diagnosis as the criterion to access personalised budgets offered by NDIS. Instead, the Network supports the position of the PwC Report on NDIS initiated by FaCHSIA which recommends that the assessment tool to gain access personalised budget within NDIS be based on functionality rather than impairment or medical diagnosis.

Medical diagnosis may inform and clarify functionality and could therefore be one of several ways of assessing fulfilment of the criteria for accessing the NDIS.[4] To use medical diagnosis as an actual criterion would be to confuse the *means* and *ends* of assessment.

A good example of how to formulate criteria based on functionality rather than medical diagnosis, as cited in the PwC Report, is the German Long Term Care (LTC) Scheme. The LTC is a long-term care insurance scheme that was introduced by the German Parliament in 1994. In order to claim benefits from the compulsory LTC insurance scheme an insured person must be defined as 'frail'. A frail person is defined as

> *a person who requires for a minimum period of approximately six months, permanent, frequent or extensive help in performing a special number of Activities of Daily Life (ADL) and Instrumental Activities of Daily Life (IADL) due to physical, mental or psychological illness or disability"*

[2] SANE Australia. (2010). SANE News 55. Spring 2010

[3] The Council of Australian Governments. (2011). National Disability Strategy 2010-2020. Pg. 23

> *For the purposes of this Strategy, the term 'people with disability' refers to people with all kinds of impairment from birth or acquired through illness, accident or the ageing process.* ***It includes cognitive impairment as well as physical, sensory and psycho-social disability.***

[4] Price Waterhouse Coopers. (2009). National Disability Insurance Scheme: Final Report. Pg. 149

The PwC Report explores in detail the different types of ADL and IADL and the level of support that people can access.[5]

The NDIS should consider the development of similar access criteria based on functionality and within the framework of the *International Classification of Functioning, Disability and Health* (ICF).[6]

RECOMMENDATION 3: ELIGIBILITY CRITERIA SHOULD SUPPORT EARLY INTERVENTION AND PREVENTION STRATEGIES TO AVOID RISING LEVELS OF NEEDS AND COSTS AT LATER STAGES.
The Network supports a focus on early intervention as part of the eligibility criteria. The UK Government's policy in this area, for example, recognises that eligibility thresholds without adequate preventative strategies often lead to short-term gains which are soon followed by a longer term loss. As such, the eligibility criteria should not be used to limit the number of people able to access the personalised budget within NDIS but rather, the eligibility criteria should be considered as part of preventative strategies to avoid rising levels of need and costs at later stages.[7]

Thank you for the opportunity to provide feedback. We appreciate the time and effort that has been put into producing this important document. The Network is looking forward to being part of this important and significant initiative that can improve quality of life for people living with mental illness.

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[5] Price Waterhouse Coopers. (2009). National Disability Insurance Scheme: Final Report. Pg. 135
[6] World Health Organisation. (2001). International Classification of Functioning, Disability and Health
[7] Department of Health. (2010). Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care. London.

Appendix 1. Consumer Stories

Sandy – A mother of three children

Sandy had her first psychotic experience when her twin children were about six months old. She also had another child under two years old. Prior to experiencing psychosis, she was experiencing post-natal depression. Her husband, Phillip, was working full time and could not provide as much support as he would like.

Sandy found it difficult to take care of herself with bathing, cooking and washing, let alone taking care of three small children. Her mother had passed away when she was a teenager. Her father was living interstate and having health issue himself. She has no brothers or sisters. Her in-laws are not in position to assist with day-to-day chores.

The pressure of getting organised and being left alone to take care the children made her 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. CATT soon picked Sandy up and took her to the Psychiatric Services Unit (PSU). During her recovery in the PSU her 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.

James – An ex-public servant experiencing severe depression

James was working as a public servant for several years when he decided to resign after he experienced bullying in the workplace. Soon after this, he was diagnosed with severe depression. Due to his medication, he could not maintain usually his high level of functioning as he did before. His social life became disconnected as he was not able to keep track of days or organise his activities.

Even simple tasks, such as cleaning, writing a shopping list, putting away groceries after shopping, or putting away washing became very challenging. Often these tasks were not completed for months until one of his friends was able to help him out. He soon developed a hoarding problem in his home because his decision-making was deteriorated so significantly.

James' physical health declined as he was not able to prepare his own meals. His diet consisted mostly of fast food meals. Going out to buy groceries was difficult as he quite easily became irritated when overwhelmed. He also started to incur debts from unpaid bills, due to his growing inability to manage his personal finances.

Several attempts were made by friends and family members to help with his hoarding problem without any success because James was not able to cope with the changes. As he said, '*I don't even know where to begin*.' He became estranged from his friends and family as he felt that they had walked away and betrayed him.

Having access to the National Disability Insurance Scheme would help James tremendously. He would be able to pay for professional help for his hoarding problem and arrange for professional domestic assistance services, as well as helping him keep track of his social activities. With his personal and social life up and running, he could concentrate on his recovery from severe depression.

Robert – A mature age person living in isolation

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 the 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.

His bipolar disorder it made it difficult for him 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 he was interested in attending social functions but he found that it was difficult to navigate the public transport system.

His life and wellbeing was improved when a relative offered him a soft 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. Now, his connection with the community has improved he can access more information about alternative public housing that he can apply for. He is now living in housing that is more appropriate for his needs and enjoys his social life.

Judith – An adolescent looking to build her future in Australia

Judith came to Australia with her parents when she was 17 years old. Her parents sought refugee settlement and were soon accommodated in public housing. Judith has two younger brothers and her family come from a non-English background. Her father was having difficulty finding work due to his limited English language skills. Her mother was feeling depressed due to the fact that she needed to live a long distance from her family.

Judith was an active young girl who liked to play sports and meet with her friends however after her move to Australia she was diagnosed with depression. She is worried about her future in Australia and feeling lonely because of her mental illness. She finds it difficult to get up in the morning or feel excited about anything. She does not want to further her education and has lost hope for the future.

Judith often becomes aggressive towards people because she feels no one can understand her. Her father contacted Mental Health ACT and was able to find medical treatment for her depression. Her father also contacted a community worker that helps her to get around and be more involved in sporting activities and social gatherings. Unfortunately the community worker is only able to see Judith once each week due to high workload. Judith needs help to improve her social life and medication is no magic cure.

The National Disability Insurance Scheme would help Judith to improve her social connections, improve her English, and look at future work options, as well as pick up social skills to adapt in Australia. Judith is also keen to look at work and further study, as a possibility.