SUBMISSION

to the Productivity Commission

in relation to the National Disability Insurance Scheme

from

Mental Illness Fellowship Victoria

June 2011

Submitted by:
Laura Collister
CEO (Acting), Mental Illness Fellowship Victoria

Prepared by:
Margaret Burdeu
Policy and Advocacy Manager

Recommendations regarding the development and design of the NDIS

1. The name of the national disability insurance agency should reflect the goal of enhancing the quality of life for people entitled to benefits under the insurance, rather than a focus on deficits being addressed.

2. That equity should be the key issue driving the distribution of resources under the NDIS and so people with mental illness should able to access the benefits that accrue to others with similar levels of disabling symptoms, injuries and conditions under Tier 3 of the insurance scheme.

3. That there be four critical design features of the NDIS, the two identified by the Commission: 1) an entitlements based approach and 2) choice and control, and a further two additional elements:

   Social inclusion and community connection*:* the NDIS would be based on the fundamental principal that all recipients of NDIS benefits be supported to be independent, develop social relationships and connect with the broader community

   Facilitating coordination across systems: that the NDIS is designed to interface effectively with, and assists those receiving benefits under the scheme to navigate through the health, income support, employment and housing sectors.

4. That the assessment of Tier 3 eligibility entitlements be based on a broader range of restrictions and limitations than are anticipated by the Commission's report. It should include three domains proposed by the Commission that relate to personal limitations in:
   - *Understanding and communicating*
   - *Getting around*
   - *Self care*

   It should also include impairments and restrictions in the following areas:
   - *Getting along with others*
   - *Life activities: household, school and work*
   - *Participation in society.*

5. That benefits available under the NDIS, include respite services for carers and families of people with mental illness.

1. Introduction

1.1. Mental Illness Fellowship of Victoria

The Mental Illness Fellowship Victoria (MI Fellowship) is a member based not-for-profit organisation focussed on creating a better life for people with mental illness and their families. We are one of Australia's leading psychiatric disability rehabilitation and support agencies striving to reduce stigma and discrimination and deliver programs and services that help people find homes and jobs, undertake education and develop meaningful relationships.

MI Fellowship is a leader in the field in the delivery of recovery focussed non clinical support services to people with severe mental illness. These include home based support, community based day programs, long term rehabilitation, housing and support, employment services, vocational education and training, peer-based consumer education, respite and family education. We currently deliver services across Victoria and deliver step-up step down services in the ACT and employment services in North Queensland.

1.2. Current context for mental illness in Australia

People with severe mental illness in Australia:

- Experience stigma and social isolation
- Have very poor physical health and as a consequence can expect to die 20-25 years earlier than the general population with a higher rate of death from all causes than the overall community[1]
- Tend to be economically disadvantaged with 72% of people with a psychotic disorder not in regular occupation or employment [2]
- Generally have a low educational attainment with 50% not completing secondary education[3]
- Are likely to be homeless or at risk of homelessness with 42% living in tenuous forms of housing [4]
- Are disproportionately represented in the prison population with the prevalence of bipolar and schizophrenia among prisoners almost 10 times the general population.[5]

[1] Lawrence, D., C. D. J. Holman, et al. (2001). Duty to Care- Preventable physical illness in people with mental illness (with Consumer Summary), University of Western Australia.
[2] Jablensky, A. V. e. a. (1999). National Survey of Mental Health and Well Being: Bulletin . People Living with Psychotic Ilnesses, An Australian Study 1997-98: an Overview. Canberrra.
[3] Ibid.
[4] Mental Illness Fellowship Victoria, Mind Australia, et al. (2010). "Housing experience of people experiencing mental illness (unpublished)."
[5] Victorian Department of Justice (2010). Justice Mental Health Strategy. Victorian Department of Justice. Melbourne Government of Victoria

1.3. Recovery model

MI Fellowship's model of recovery seeks to support people on their personal journey of health, growth, learning and change. In the context of mental illness, recovery does not imply cure. It focuses on working with people to manage the symptoms of their illness, build confidence and self identity and connect with the community through relationships, education, housing and jobs.

2. Support for national disability insurance scheme

MI Fellowship Victoria supports the establishment of a national disability insurance scheme with the goal of enhancing the quality of life and increased economic participation for people with disabling symptoms, injuries and conditions. Further, we believe that people experiencing the disabling symptoms of mental illness who have support needs consistent with the NDIS should be entitled to benefits under the NDIS.

Given that the NDIS has this objective, the name of the agency should reflect that aspiration, rather than a focus on deficits seen to being addressed. Some people in our community need targeted support and intervention for them to have equitable opportunity to share in the good life we all expect. The scheme supporting that intervention should remind us of the goal not the just the gap.

Recommendation 1
The name of the national disability insurance agency should reflect the goal of enhancing the quality of life for people entitled to benefits under the insurance, rather than a focus on deficits being addressed

2.1. Equity for people with mental illness

MI Fellowship is of the view that the most fundamental issue driving the inclusion of people experiencing mental illness within the NDIS is equity. That is, people with mental illness should receive similar access to public resources and support, including those accruing from public insurance. Therefore, they should be able to access the benefits that accrue to others with similar levels of disabling symptoms, injuries and conditions.

Recommendation 2
That equity should be the key issues driving the distribution of resources under the NDIS and so people with mental illness should able to access the benefits that accrue to others with similar levels of disabling symptoms, injuries and conditions under Tier 3 of the insurance scheme.

3. Nature of our submission

This submission addresses Mi Fellowship's concern that the equitable distribution of resources is facilitated through the design of the NDIS, including the key criteria for assessment for entitlements under the insurance scheme, and also responds to the Commission's request for advice on where the boundaries between the mental health sector and the NDIS might lie. In particular:

> *feedback on which system would be best placed to meet the daily support needs (not clinical needs) of individuals with a disability arising from long lasting mental health conditions (such as schizophrenia, bi-polar and severe depression and borderline personality disorder), including:*
>
> - *which services would be provided by the NDIS and not the mental health sector and how these could be clearly identified*
> - *the magnitude of the budget that would be required*
> - *how to guard against cost shifting*
> - *how the NDIS would practically integrate any role in ongoing non-acute services with the wider mental health sector.*

4. Ensuring equitable access to Tier 3 of the NDIS

For equity for access to the NDIS to be achieved the design and assessment features of the insurance scheme must take account of the disabling affects experienced by people with mental illness and enable them access to appropriate intervention and care.

We agree with Mind Australia that the NDIS, as proposed in the draft report, includes two critical design features that are neither widely advocated nor anticipated in mental health services but would be of great value to people experiencing mental health disorders. They are:

1. ***An entitlement based approach***. *Entitlements are subject to assessment and other processes but for those who meet the criteria, the insurance approach ensures appropriately resourced support.*

2. ***Choice and control***. *The NDIS is predicated on a system by which the beneficiary either directly or through trusted advisers has substantial control over the arrangements, processes and structures through which support is delivered.*

We also propose a further two features:

3. ***Social inclusion and community connection****:* the NDIS would be based on the fundamental principal that all recipients of NDIS benefits be supported to be independent, develop social relationships and connect with the broader community

4. ***Facilitating coordination across systems***: that the NDIS is designed to interface effectively with, and assists those receiving benefits under the scheme to navigate through the health, income support, employment and housing sectors.

In relation to the four criteria we make the following comments:

Entitlements based approach: This approach would result in provision of resources to people who have to date been denied essential support and care. A 2006 study of the service needs of people with mental illness in Victoria found that of the cohort of people with severe mental illness, nearly half (44%) were not receiving services from either the public or private system at the State or Commonwealth level (p.20-21).[6] It can be expected that many more were not receiving all the support services that they need.

MI Fellowship notes that, even with the recent State and Federal government commitments to future funding injections into the mental health system, resources will not meet the need. Given the gap that exists, there is no reason to believe that these needs will be addressed in future through current resourcing arrangements.

Choice and control: MI Fellowship strongly supports these being key features of the NDIS. More individualised service approaches are already at the forefront of emerging service models. By way of example, choice is a key feature of in the development of a new MI Fellowship housing and support demonstration that will draw on housing stock in the private sector. The project seeks to offer participants the opportunity to choose their own home environment, and participate in the co-design of wrap-around services that best support their needs and recovery goals. A range of programs in Victoria already include features of this approach, such as multiple and complex care packages. New Commonwealth flexible care packages and proposed coordinated care arrangements are another example.
The application of personalised models of service will result in restructured resourcing arrangements across the sector. The NDIS however will be only one of many factors hastening this process.

In relation to the funding mechanisms to be used, the voucher system proposed by the Commission is not supported as the only resourcing option used by the NDIS. People often need to be supported to develop skills and confidence to take on more choice and control. What is needed is a step-wise process with the NDIS offering a range of resourcing models that progressively enable people to take greater responsibility for their own care and support.

Social inclusion and community connection: As human beings we all need a sense of belonging and connection with others. Stigma and social isolation are major barriers to people with severe mental illness being able to participate as members of the community. Creating a community in which mental illness is understood and accepted is crucial to breaking down these barriers.

The NDIS should play an important role in promoting public policy and community education that leads to change in community awareness of mental health. At the individual level, it is essential that development of individualised support packages under the NDIS promote the development of independence and connection into education, jobs and relationships.

Facilitating coordination across systems: Another key issue for people with a mental illness or disability and their families is system navigation. A Boston Consulting group report into the service needs of people with mental illness in Victoria identified that a lack of coordination across systems impede people's capacity to access services. They advised that what is needed is as follows:

- Access to consumer focussed services
- Connectedness across systems

[6] Boston Consulting Group (2006). Improving Mental Health Outcomes: the Next Wave of Reform. B. C. Group. Melbourne

- Prevention and early intervention to reduce the incidence and severity of the mental health problems over the longer term
- Local partnerships and accountability to enhance the coordination of service delivery at the local level and provide a more consumer centric approach (p.26).[7]

The NDIS will have the capacity to influence the development of integrated care and coordination systems and support seamless care pathways for consumers. In Victoria, this could be built on the work already in train in the areas of coordinated planning, consistent approaches to assessment and referral and other system integration responses

Individual care planning under the NDIS should also support integrated treatment and care by including the full range of services and supports individuals are receiving in individual support plans, not just the services funded through the NDIS. This would include working with families and carers to engage them in the development of care options.

> **Recommendation 3**
> That there be four critical design features of the NDIS, the two identified by the Commission: 1) an entitlements based approach and 2) choice and control, and a further two additional elements:
>
> > ***Social inclusion and community connection****:* the NDIS would be based on the fundamental principal that all recipients of NDIS benefits be supported to be independent, develop social relationships and connect with the broader community
> >
> > ***Facilitating coordination across systems:*** that the NDIS is designed to interface effectively with, and assists those receiving benefits under the scheme to navigate through, the health, income support, employment and housing sectors.

5. Relationship of the mental health system to the NDIS

Our view is that assessment of Tier 3 eligibility entitlements would be based on a broader range of restrictions and limitations than are anticipated in the Commission's report.

This would include three domains proposed by the Commission that relate to personal limitations in:

- *Understanding and communicating*
- *Getting around*
- *Self care*

We agree with Mind that assessment should also include impairments and restrictions in the following areas that pose major impediments:

- *Getting along with others*
- *Life activities: household, school and work*
- *Participation in society.*

Stigma together with the disabling affects of symptoms of mental illness can severely impede people's capacity to plan and act on plans, manage self care, build social relationships and participate in the community, or even leave home. The positive symptoms

[7] Op cit

of mental illness can include disorganised thinking, delusions, and hallucinations and disorganised behaviour, while negative symptoms result in poor concentration, low mood, loss of interest or pleasure, low energy, lack of motivation and so on. Specific strategies are needed to overcome the barriers that result from these symptoms.

Recommendation 4
That the assessment of Tier 3 eligibility entitlements be based on a broader range of restrictions and limitations than are anticipated by the Commission's report. It should include three domains proposed by the Commission that relate personal limitations in:

- *Understanding and communicating*
- *Getting around*
- *Self care*

It should also include impairments and restrictions in the following areas:

- *Getting along with others*
- *Life activities: household, school and work*
- *Participation in society*

Case study

By way of example, a man with schizophrenia thought that the traffic lights were talking to him, so he was afraid to go near them. Unable to leave his home, he could not have friends, social contact or a job. To address this issue required someone to walk alongside him as he crossed and recrossed traffic lights until he was able to overlay his experience against his fears and gain the confidence and knowledge to travel alone. From there he was able to start the journey that led to him taking up the job he has today. In the absence of this support he may well still be unable to venture far from his home.

5.1. NDIS must acknowledge the episodic nature of mental illness

This case study also demonstrates why access to the NDIS cannot be restricted to recipients with a 'permanent disability'. Mental illness is by nature episodic. This means the disabling impact of the illness varies over time. Targeted support can enable people increase their capacity to manage the symptoms of their illness, build social relationships and potentially engage in education, work and other activities. Denying people support when intervention is called for risks locking them into a lifetime cycle of illness and distress with consequent social costs.

Recommendation 4
That access to the NDIS be related to the severity of disabling symptoms, injuries and conditions experienced rather than restricted to those with a 'permanent disability'. Assessment and planning under Tier 3 should take account of the episodic nature of mental illness and the benefits achieved through intervention and support in enhancing recovery.

MI Fellowship's view is that the services that would sit within the NDIS are readily identifiable. As with other people receiving entitlements under the NDIS, services provided would include rehabilitation and recovery focussed support and care. Clinical care would be provided through the health system, pharmaceuticals through the MBS and social and public housing by state and territory governments. Medicare would fund clinical services provided

by private psychiatrists and general practitioners. Allied health professionals would also be clearly a health system responsibility.

Though there are variations in the provision of services across jurisdictions, there is a fairly clear dividing line between service sectors. Psychiatric disability and support services are in general delivered by readily identified specialist providers and non government not for profit providers.

There will be some planning and negotiation needed between the NDIS and other parties to resolve small variations that may exist across jurisdictions. Mind Australia's submission provides some further more detailed discussion regarding the issues likely to impact on the interface of the clinical mental health sector with psychiatric disability and other services.

The NDIS should also include benefits for the provision of respite services. The challenge for the NDIS is that much of the day to day care of people with mental illness is through informal effort by families and friends. Family support is an important aspect of the recovery support for people with mental illness. However, the current level of support and care provided by families, mainly by women - is not likely to be sustained. The trend towards and expectation for higher levels of workforce engagement by women, together with the older age of retirement, will increasingly lead to shifting of that effort to funded support, either through the NDIS or other public funding model.

Recommendation 5

6. That benefits available under the NDIS, include respite services for carers and families of people with mental illness.

7. Costs of the system

7.1. Numbers of people with mental illness to benefit from the NDIS

Detailed modelling will be required to estimate the number of people with a mental illness that would be included in NDIS. However, a 2006 report prepared for the Victorian Government estimates that around 19% of Victorians per year experience some degree of mental illness and that 3% of people with a mental illness experience severe mental illness (Boston Consulting Group 2006), p.11. The 3% included people with severe and disabling psychotic disorders or people with highly disabling symptoms of depression and anxiety.

Applying this methodology to Australia's total population of around 22,624,000 (ABS 2011), there would be around109,000 people experiencing severe mental illness in Australia that could be expected to receive entitlements under Tier 3 of the NDIS.

Further, in relation to the capacity for offsets under the NDIS the Boston Consulting study suggests that the need for services for people with severe mental illness outstrips those provided. The study found that of the cohort of people with severe mental illness, nearly half (44%) were not receiving any service from either the public or private system at the State or Commonwealth level (p.20-21). Many more would not be receiving the support services that they need.

Government investment in ongoing non acute rehabilitation services and recovery focussed care and support for people with severe mental illness has shifted considerably over the last few years. However, even with the recent $1.5 billion Commonwealth commitment to mental health funding, the offsets from the transfer of funds from existing services to the NDIS would fall far short of what would be needed with the entitlements based approach that is core to the development of the NDIS.

This does not mean that there would not be cost offsets to the community through the provision of appropriate support and care for people with mental illness under the NDIS. People with severe mental illness are over represented among users of high cost social infrastructure including prisons, crisis accommodation and hospitals. Recent advice to the House of Representatives Standing Committee on Education and Employment suggests that people with mental illness make up around 30% of people in Australian receiving the disability support pension (around 240,000).[8] The provision of appropriate rehabilitation and support to people with severe mental illness together with support to gain and sustain employment can bring significant potential benefits to the community and to the individuals concerned. The issue is how to reflect these offsets within funding of the NDIS.

7.2. Risks of cost shifting

Given the fairly clear line between different elements of the mental health service system, there seems very limited risk of cost shifting into the NDIS.

The issues that face the NDIS are:

- how to transfer the current state government investment in non clinical mental health services into the NDIS. However, this challenge is similar to the issues faced in the broader disability sector; and
- meeting the resource gap given the current under resourcing of rehabilitation and support for people with severe mental illness.

References

Boston Consulting Group (2006). Improving Mental Health Outcomes: the Next Wave of Reform. B. C. Group. Melbourne

Housing of Representatives Standing Committee on Education and Employment (2011). Hansard, Mental Health and Workforce Participation Inquiry; Wednesday 13 April 2011. Melbourne House of Representatives, Commonwealth of Australia. **Wednesday 13 April 2011**.

Jablensky, A. V. e. a. (1999). National Survey of Mental Health and Well Being: Bulletin . People Living with Psychotic Ilnesses, An Australian Study 1997-98: an Overview. Canberrra.

Lawrence, D., C. D. J. Holman, et al. (2001). Duty to Care- Preventable physical illness in people with mental illness (with Consumer Summary), University of Western Australia.

Mental Illness Fellowship Victoria, Mind Australia, et al. (2010). "Housing experience of people experiencing mental illness (unpublished)."

Victorian Department of Justice (2010). Justice Mental Health Strategy. Victorian Department of Justice. Melbourne Government of Victoria

[8] Housing of Representatives Standing Committee on Education and Employment (2011). Hansard, Mental Health and Workforce Participation Inquiry; Wednesday 13 April 2011. Melbourne House of Representatives, Commonwealth of Australia. **Wednesday 13 April 2011**., p.8