The provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition

Joint Standing Committee on the NDIS

beyondblue Submission

27 February 2016

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Introduction

beyondblue welcomes the opportunity to make this submission to the Joint Standing Committee on NDIS's Inquiry into provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition.

beyondblue is committed to supporting all people in Australia to achieve their best possible mental health. As a national population mental health organisation, we have a range of integrated initiatives to prevent depression, anxiety and suicide and to support people who experience these conditions to get the right services and supports at the right time.

The National Disability Insurance Scheme (NDIS) is an admirable initiative – a national system of support focussed on the needs and choices of people with a disability. The scheme is intended to support people with any type of disability, including those with a mental health condition and associated psychosocial disability, subject to certain eligibility criteria around age, residency requirements and extent of disability. The system offers individuals, their family and carers, with choice about the kind of supports that assist with living a contributing life.

However, while the scheme is sound in theory, one of *beyondblue's* major concerns is that in reality it is likely that many of its intended beneficiaries, including people with a mental health condition, will miss out given the current restrictive eligibility criteria.

To make matters worse, some people with a mental health condition, may actually be worse off as a consequence of the current approach to NDIS implementation whereby existing Commonwealth Government funded services, such as Personal Helpers and Mentors Scheme (PHaMS), Day-to-Day Living (D2DL) and Partners in Recovery (PIR), will be rolled up into the NDIS. Given the more restrictive eligibility criteria connected with the NDIS compared to PHaMS or PIR, many people with a mental health condition currently benefiting from these programs will lose access as a result of this approach to NDIS implementation.

The erosion of people's access to these important services could potentially be compounded even further if State and Territory governments also move to amalgamate some or all of their existing psychosocial services, into implementing the NDIS in their jurisdictions.

From *beyondblue's* perspective it is crucial that no person with a mental health condition and psychosocial disability is worse off in the transition to the full roll out of the NDIS, and more importantly, it is essential that many should be considerably better off.

beyondblue is a national, independent, not-for-profit organisation working to promote good mental health. Our vision is that all people in Australia achieve the best possible mental health. We create change to protect everyone's mental health and improve the lives of individuals, families and communities affected by depression, anxiety and suicide.

Mental health conditions and disability

- Depression and anxiety conditions are common and associated with varying degrees of impairment in day to day functioning.
- For a significant minority of people, depression and anxiety conditions may lead to prolonged or enduring psychosocial disability, which can impact on their ability to lead a fulfilling and contributing life.
- The NDIS is an important new mechanism to enable people with a significant psychosocial disability to access the supports and services they need and want, to support their recovery.
- It is therefore essential that people with a significant psychosocial disability have appropriate access to the full range of benefits linked to the NDIS.

Depression and Anxiety

Depression and anxiety are significant public health problems. They are common, potentially disabling and associated with premature death. They cause considerable personal, social and economic impacts. The most recent National Survey of Mental Health and Wellbeing (NSMHWB) estimated that in any 12 month period, around 6 per cent of the population is likely to experience depression or related conditions, while around 14 per cent are likely to experience an anxiety condition. Females have higher rates of depression and anxiety than males.[1]

Depression and anxiety conditions costs the community in many different ways. Their impact on people affected by these conditions, and their families and carers are considerable. There are financial costs to the economy which results from the loss of productivity brought on by these conditions, as well as expenditure by governments, health funds, and individuals associated with mental health care. These costs are not just to the health sector but include direct and indirect costs on other portfolio areas, for example welfare and disability support costs. It is estimated that mental health conditions cost Australian employers $10.9 billion every year through absenteeism, reduced productivity and compensation claims.[2] The individual financial costs are of course not exclusively borne by those with mental health conditions. It is often their carers who experience financial hardship due to lost earnings, as well as increased living and medical expenses.[3]

Natural history

Depression and anxiety conditions occur early in life typically in childhood, adolescence or early adult life. Phobias, including social phobia often commence at quite a young age, while general anxiety disorder, panic disorder and PTSD have a median age of first onset between 20-40 years. The median age of onset of depression is also between 20-40 years.[4]

Depression and anxiety disorders are often chronic conditions. For example while around half of people with depression experience only a single episode, for others depression can be a chronic relapsing-

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[1] Slade, T., Johnston, A., Teesson, M., Whiteford, H., Burgess, P., Pirkis, J., Saw, S. (2009). The Mental Health of Australians 2. Report on the 2007 National Survey of Mental Health and Wellbeing. Department of Health and Ageing, Canberra.

[2] Pricewaterhouse Coopers (2014). Creating a mentally health workplace: return on investment analysis. http://www.headsup.org.au/docs/default-source/resources/bl1269-brochure---pwc-roi-analysis.pdf?sfvrsn=6

[3] Cummins, R.A., et al. (2007). Australian Unity Wellbeing Index, Survey 16.1, Special Report, in The Wellbeing of Australians - Carer Health and Wellbeing. Victoria: Deakin University

[4] Kessler, R. C., Angermeyer, M. C., Anthony, J. C., De Graaf, R., Demyttenaere, K., Gasquet, I., . . . Ustun, T. B. (2007). Lifetime prevalence and age-of-onset distributions of mental disorders in the World Health Organization's World Mental Health Survey Initiative. World Psychiatry, 6(3), 168-176

remitting or persistent condition. In a recent review of the natural trajectory of depression, Keller noted that: "The risk of recurrence after recovery is extremely high (36 per cent after one year following recovery, 40 per cent after two years, 60 per cent after five years, 65 per cent after 10 years, 85 per cent after 15 years, and greater than 90 per cent after 30 years)".[5]

Furthermore a significant minority will experience enduring problems that respond poorly to treatment. The pivotal Sequenced Treatment Alternatives to Relieve Depression (STAR*D) trial, found that even after several successive changes in pharmacological treatment for people who did not respond to first, second or third line treatment, the end remission rate was at best only 67 per cent.[6] Overall, the likelihood of remaining depressed for many years is high (30 per cent are still depressed after one year, 20 per cent after two years, 12 per cent after five years, 8 per cent after 10 years, 6 per cent after 15 years, and 4 per cent after 30 years.

Psychosocial disability and depression and anxiety

In 2003 it was estimated that depression and anxiety collectively accounted for about 8 per cent of the total fatal and non-fatal burden of injury and disease in Australia (4.8 per cent for men and 10 per cent for women.[7] Most of the burden of disease caused by these conditions results from their potential to cause disability (non-fatal burden).

People with depression or related conditions typically experience high levels of impairment as a result of their condition. Depression has the potential to impair functioning across a range of domains including home life, close relationships, work or study and social life. The 2007 NSMHWB found that 71 per cent of people with these conditions experienced severe or very severe interference in at least one of these life domains and that on average they experienced around 6 days in the previous 30 days where they were not able to carry out their normal activities.[8]

People with anxiety conditions may also experience impairment as a result of their condition. Impacts differ depending on the specific condition. People affected by generalised anxiety disorder (GAD) typically report higher levels of severe or very severe interference across a greater number of life domains compared to other anxiety conditions. Around 48 per cent of people with GAD reported experiencing this level of interference in at least one domain, while at the end other of the spectrum 20 per cent of people with social phobia or with post-traumatic stress disorder (PTSD) experienced severe or very severe impairment. The average number of days out of role for people with anxiety disorders was 4.4 days in the last 30 days. Days out of role were highest for agoraphobia (6.9 days) and lowest for social phobia (4.7 days).[9]

It is important to note, that depression and anxiety often co-occur. About 3 per cent of the males will experience both conditions in a given year while almost 5 per cent of females will experience both. These two conditions are often also co-morbid with a range of other mental health conditions, including alcohol and other substance use disorders. Furthermore, depression and anxiety also frequently co-occur with physical health conditions. The 2007 NSMHWB found that one third (34.0%) of people with 12-month mental disorders also identified that they had a chronic physical condition. The level of impairment

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[5] Keller, M. (2013). Major Depressive Disorder: Long-Term Course, Treatment, and Complications. Psychiatric news, 48(18), 1

[6] Rush, A. J., Trivedi, M. H., Wisniewski, S. R. et al. (2006). Acute and longer-term outcomes in depressed outpatients requiring one or several treatment steps: a STAR*D report. American Journal of Psychiatry, 163, 1905-1917

[7] Australian Institute of Health and Welfare 2015. Australian Burden of Disease Study: Fatal burden of disease 2010. Australian Burden of Disease Study series no. 1. Cat. no. BOD 1. Canberra: AIHW.

[8] Slade et al. Opcit

[9] Slade et al. Opcit

associated with mental health conditions is much higher among people with co-morbid mental and/or physical health conditions.[10]

A contributing life

The National Mental Health Commission developed the 'contributing life' framework through its extensive consultations with people who have experienced or been affected by depression, anxiety and suicide. A contributing life means people living "*a fulfilling life enriched with close connections to family and friends, and experiencing good health and wellbeing to allow those connections to be enjoyed. It means having something to do each day that provides meaning and purpose, whether this is a job, supporting others or volunteering. It means having a home and being free from financial stress and uncertainty.*"[11] This concept recognises that people with mental health conditions want the same things from life as everyone else – a safe home, something to do, something to look forward to, good relationships. The things that provide meaning and value in people's lives and are central to recovery are far beyond the health system.

In essence, this is also the ultimate purpose of the NDIS. It is a system designed to provide more than a safety net that helps people 'manage a disability'; instead it is a system that is intended to maximize the potential of all people with a disability to live a fulfilling and contributing life. It is explicitly designed for people who might otherwise miss out on these opportunities.

Given the potentially disabling impact of mental health conditions, it is clear that many people with a mental health condition should, and will, be eligible for the NDIS. And given the variability in the experience of this disability, it is important that the NDIS is flexible enough to take into account and respond to the varying and at times fluctuating levels of disability associated with mental health conditions. Unquestionably, it needs to be available to people with a significant enduring psychosocial disability. Just as crucially, it should also be available to people with a significant and persistent psychosocial disability, even if this is not permanent. Ideally it should even be available to people with more temporary but still significant psychosocial disability for certain periods of time. Otherwise, many people with a mental health condition and associated psychosocial disability, may miss out on the opportunity to lead a contributing life.

[10] Slade et al. Opcit

[11] National Mental Health Commission (n.d.) *National contributing life survey project.* Accessed online 20 January 2017: http://www.mentalhealthcommission.gov.au/our-work/national-contributing-life-survey-project.aspx

The NDIS and mental health

- Eligibility criteria should not be overly restrictive that it precludes people whose mental health condition is associated with a severe and prolonged disability, but not a permanent one. These consumers can gain equal benefit from temporary access to NDIS supports.
- Avoiding gaps during transition to the NDIS is critical for the wellbeing of people living with a mental health condition. Where existing services are being defunded with funding subsumed by the NDIS, transition plans should be in place and be communicated to all consumers. No consumer or carer should be worse off.
- There are a number of major reforms being implemented concurrently in Australia – including regionalised health service commissioning by PHNs and the transition to NDIS. It is crucial that these reforms do not occur in isolation and there is integration at the community level between PHNs and NDIS service provision.
- Acknowledging the complexities of the NDIS implementation in rural areas of Australia is important; planning in partnership with these communities is vital for success.
- Building understanding of disability through the ILC Program is a strength of the NDIS. Consideration should be given to the funding provided under these grants to ensure this program doesn't duplicate existing services, in particular the soon-to-be-launched Digital Mental Health Gateway.

There is no doubt that the NDIS is a wonderful initiative for Australia. The scheme will provide hundreds of thousands of people with a disability, with access to funding that will enable them to exercise choice and control over the services they receive to allow them to lead a fulfilling and contributing life. The scheme is a partnership between the Commonwealth Government and State and Territory Governments and as such involves a change from previous State and Territory funded approaches to contracting disability services towards a more consumer driven system where people with a disability can choose their supports through individualised commissioning.

At the same time that the NDIS is being implemented, a number of other significant health care reforms are also being implemented, particularly in mental health care. In late 2015, the Commonwealth Government released its response to the National Mental Health Commission's Review of Mental Health Services and Programmes and outlined a bold reform agenda that centred on a dual track approach: a core set of national initiatives coupled with regional level planning and commissioning of mental health services, through the Primary Health Networks (PHNs). Simultaneously, States and Territory have also introduced a number of their own reforms.

While these parallel reforms in disability and mental health are likely to produce significant benefits for the community, the relative lack of integration between the two agendas has the potential to create complexities for people who fit within both camps – those with a mental health condition and associated psychosocial disability. On the positive side, some of these individuals will derive benefit from both reforms – improvements in mental health services for people with severe mental health conditions that will occur through PHN commissioning, coupled with tailored access to other necessary supports and services through the NDIS. However, most people with a mental health condition and associated psychosocial disability are likely to derive benefit only from the mental health reforms, and some may actually be disadvantaged by the disability reforms.

It is clear that this complexity needs to be addressed so that no-one with a mental health condition and an associated psychosocial disability is worse off, and indeed that more such individuals are better off.

Eligibility criteria for people with a mental health condition

The NDIS eligibility requires a person to prove permanency of both their psychosocial disability and their need for support, in order to be eligible for services. While this will be relatively easy to establish for many people with a severe mental health condition, it may be harder for others, despite their equal level of need. Unlike many types of disability which are relatively stable over long periods of time, the disability associated with mental health conditions can have a more variable quality or be generally less predictable. This creates a 'grey zone' for those assessing eligibility, which can lead to potentially incorrect decisions. Furthermore it may mean that some people with prolonged, though not permanent disability, miss out on what would otherwise be a very beneficial scheme for them.

Ultimately is it likely that far more people with a mental health condition and associated psychosocial disability will be eligible for the NDIS than has been anticipated and this needs to be understood and appropriately resourced, rather than controlled through tightening eligibility. Indeed, overly restrictive eligibility can create perverse incentives. Anecdotal evidence from the communities where the initial trials of NDIS were carried out, indicate consumers were encouraged to present 'on their worst day' in order to improve their chances of being deemed eligible for supports. This practice undermines the work of the mental health sector in driving system reform towards delivery of recovery-focussed care. The eligibility criteria should also be consistent with the nature of mental health conditions and provide for a degree of flexibility in defining 'permanent' disability.

The criteria should also be specific to mental health and consistent with the UN Convention on the Rights of Persons with Disabilities. Namely, respectful of individual autonomy, non-discriminatory, supportive of full and effective participation and inclusion in society, accessible, and equal between genders.[12] Eligibility should be under regular review as the roll out of the NDIS progresses. It is important to ensure that the system is reaching its intended audience and is supporting people to live a more contributing life.

1. *beyondblue* recommends the NDIS eligibility criteria for people with a mental health condition is clarified and communicated clearly and broadly to consumers. The criteria should be aligned with the underlying nature of psychosocial disability, including the fact that many people may have quite significant and prolonged, though not necessarily permanent disability. It should also be consistent with the UN Charter of the Rights of People with a Disability.
2. *beyondblue* recommends the eligibility criteria form part of the ongoing review of the NDIS implementation.

Avoiding gaps during service transition

Recognising the government's intention to provide continuity of existing services and supports for people with mental health conditions and associated psychosocial disability who will not be eligible for NDIS must also be considered.

A number of existing community-based programs funded by Commonwealth government, including Partners in Recovery (PIR), Day-to-Day Living, and Personal Helpers and Mentors (PHaM), are being defunded with funding subsumed by the NDIS. However, all indications suggest numerous people who have previously been able to access these and other services, will not fulfil the eligibility requirements for the NDIS. Importantly, for those consumers, this loss of service access will not necessarily be offset by

[12] https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/guiding-principles-of-the-convention.html

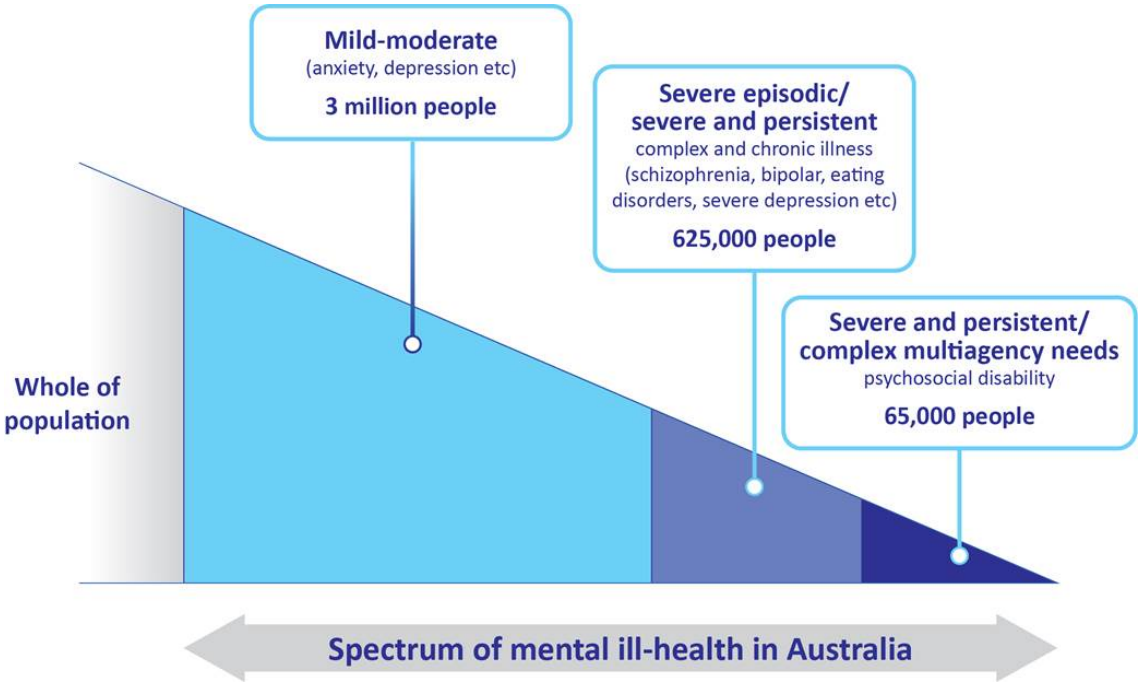
commissioning undertaken by Primary Health Networks (PHNs) since they are not allowed to fund psychosocial services.

Furthermore, there is some concern that States and Territories may also bundle up some services for people with a psychosocial disability into the NDIS, further eroding service availability for those not deemed eligible for the NDIS.

As such, there will be a gap in service provision for a significant number of people affected by mental health conditions. As Figure 1 below illustrates, the group with significant, yet potentially sub-NDIS threshold levels of disability, represents a significant number of people in the Australian population. Consequently, the greatest burden of disease may align with the service gaps left by the NDIS transition, leaving many people without comparable community-based supports that are currently being delivered.

It is vital that all levels of government work together to ensure the needs of these consumers, their families and carers are met. Where appropriate, consideration should be given to reinstating or re-enacting support services that have been withdrawn from the market to support people who are not eligible for NDIS supports.

Figure 1: Annual distribution of mental ill health in Australia (ref NMHC review)



3. *beyondblue* recommends that greater focus is placed on service delivery where there is the largest burden of mental ill health – among people with mild-moderate and severe episodic illness.
4. *beyondblue* recommends that community-based services who have had their funding withdrawn for transition to NDIS be reinstated or replaced to support people with a mental health condition who are not eligible for the NDIS.

The role of Primary Health Networks

PHNs differ from NDIS in that they are excluded from commissioning broader social support services. Where PHNs are in a position to commission services for consumers not able to access NDIS, there is a risk that service quality will differ. There is concern that NDIS will deliver 'gold standard' services, whereas PHN-commissioned services will be less integrated and of varying quality. This situation would create further inequity among people living with a mental health condition, depending on their access to these services.

Recognising the overlap of NDIS and PHNs in local communities, opportunities to partner should be supported. This would allow for better understanding of the needs of people with psychosocial disability in their area, and ensure consistent service options and approaches are available, regardless of the funding source.

At present, community consultation being undertaken by PHNs is highly variable and there is a need for improvement across the board. This inquiry is an opportunity to reinforce the importance of strong engagement and co-design processes, across the spectrum of mental health needs.

5. *beyondblue* recommends opportunities for NDIS and PHNs to partner should be supported, to reduce inconsistency and improve integration of services at the regional level.
6. *beyondblue* recommends the importance of strong engagement and co-design processes are reinforced during the implementation of NDIS.

Outreach services for rural and regional Australians

Access to NDIS in rural and regional areas of Australia must be considered.

Some people may not self-identify that they are eligible for the scheme. It's important that for people in rural areas, the NDIS is well communicated through publicity channels and support is provided to assist people to identify that they are eligible to apply.

Outreach services for coordinators to support assessment and entry into the NDIS will not be sufficient; consideration must also be given to how consumers will access services once they are deemed eligible. Mental health service gaps and fragmentation exist in these areas at present.

NDIS implementation in these areas must occur in partnership with the local community who will not only understand the needs of the people living in the area, but the services that can be leveraged.

The establishment of an NDIS Community of Practice for rural areas may support and encourage information sharing and assist communities to learn from one another about successes in delivering NDIS in their community.

7. *beyondblue* recommends that consideration is given to delivery of services through NDIS for people living with a mental health condition in rural and regional areas.
8. *beyondblue* recommends that a Community of Practice be established to support the roll out of NDIS to rural areas, with a specific focus on supporting consumers with a mental health condition.

Adequate funding is critical

Estimates suggest that current funding models will fail to provide care to all who need it. In their submission to this Inquiry, Mental Health Australia notes that the accepted prevalence figure on which funding for NDIS psychosocial disability cover is based is insufficient, and the proportion of consumers and carers who will be outside the scope of NDIS is extraordinarily high.

It is critical that resources for people experiencing a mental health condition are not diminished through the implementation of the NDIS. Actual spending over time, particularly during this transition phase, should be monitored and publicly reported at regularly intervals to hold the government and the service system to account.

The additional funding delivered through the Information, Linkages and Capacity Building (ILC) program provides new opportunities and its focus on community inclusion is well placed. However, the "grant round" approach to funding programs through the ILC can lead to instability for program delivery in the community. There is also concern that eligibility for ILC funding is not sufficiently broad enough to support people with a mental health condition. In practice, ILC needs to:

- Be comprehensive
- Be public health focussed
- Focus on improving awareness
- Focus on improving community capacity
- Deliver accessible models of care
- Have a single point of accountability for its implementation.

The inclusion of the ILC program is a strength of the NDIS. It is crucial that in working to build the understanding of disability, the ILC doesn't unnecessarily duplicate work that is already underway. In particular, the Commonwealth-funded Digital Mental Health Gateway that will be launched later this year.

9. *beyondblue* recommends actual spending over time, particularly during the NDIS transition phase, be monitored and publicly reported at regular intervals.

Summary

One of the positive aspects of the NDIS is the role it can play in helping an individual to lead a 'contributing life'. Support to complete daily living tasks, find employment or to access education – these things are not only useful for someone whose mental health condition is chronic and debilitating, but all people who experience a mental health condition. To achieve this, the NDIS cannot sit in isolation. There must be integration between and across systems that consumers use to enable participants the best possible chance of living such a fulfilling life.

Like many others in the sector, *beyondblue* is concerned that many people living with a mental health condition will 'fall through the cracks' of the NDIS due to issues of ineligibility. For those eligible for NDIS supports, the ability to exercise choice and control should be balanced with an overwhelming choice of providers or services to suit an individual's needs.

It has been acknowledged that the implementation of the NDIS is unlike any other program or system implementation before. As such, it is important that there is ongoing, transparent monitoring and review until the NDIS is more fully developed and more broadly implemented. As this occurs, we will be better informed as to the scale of unmet need and what will best suit these people. Governments need to be able

to respond to these needs, particularly given the strong commitments that have been made to improve the lives of all people living with a mental health condition.

We support the NDIS, its roll out and the support it promises for people living with a severe and disabling mental health condition. However, we also want to ensure that in implementing the NDIS, any potential negative impacts on other budgets are taken into account and there is no net reduction in mental health funding to cover these costs.

Recommendations

1. *beyondblue* recommends the NDIS eligibility criteria for people with a mental health condition is clarified and communicated clearly and broadly to consumers. The criteria should be aligned with the underlying nature of psychosocial disability, including the fact that many people may have quite significant and prolonged, though not necessarily permanent disability. It should also be consistent with the UN Charter of the Rights of People with a Disability.
2. The eligibility criteria form part of the ongoing review of the NDIS implementation.
3. Greater focus should be placed on service delivery where there is the largest burden of mental ill health – among people with mild-moderate and severe episodic illness.
4. Community-based services who have had their funding withdrawn for transition to NDIS be reinstated or replaced to support people with a mental health condition who are not eligible for the NDIS.
5. Opportunities for NDIS and PHNs to partner should be supported, to reduce inconsistency and improve integration of services at the regional level.
6. The importance of strong engagement and co-design processes are reinforced during the implementation of NDIS.
7. Consideration should be given to delivery of services through NDIS for people living with a mental health condition in rural and regional areas.
8. A Community of Practice should be established to support the roll out of NDIS to rural areas, with a specific focus on supporting consumers with a mental health condition.
9. Actual spending over time, particularly during the NDIS transition phase, be monitored and publicly reported at regular intervals.