



Submission

Disability Care and Support

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beyondblue: the national depression initiative
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beyondblue: opening our eyes to depression throughout Australia

Disability Care and Support

beyondblue: the national depression initiative

beyondblue is pleased to have the opportunity to present this submission to the Productivity Commission on the draft *Disability Care and Support* report. In making this submission, *beyondblue* has focussed on the **high prevalence mental disorders of depression and anxiety**, the impact on consumers and carers and we have responded on areas that are most relevant to our work and research findings. ***beyondblue* has consulted with members of blueVoices, our consumer and carer reference group, to inform this submission.**

beyondblue is a national, independent, not-for-profit organisation working to address issues associated with depression, anxiety and related disorders in Australia. Established in 2000, initially by the Commonwealth and Victorian Governments, *beyondblue* is a bipartisan initiative of the Australian, State and Territory Governments, with the key goals of raising community awareness about depression and reducing stigma associated with the illness. *beyondblue* works in partnership with health services, schools, workplaces, universities, media and community organisations, as well as people living with depression and anxiety, to bring together their expertise. Our **five priorities** are:

1. Increasing community awareness of depression, anxiety and related disorders and addressing associated stigma.
2. Providing people living with depression and anxiety and their carers with information on the illness and effective treatment options and promoting their needs and experiences with policy makers and healthcare service providers.
3. Developing depression prevention and early intervention programs.
4. Improving training and support for GPs and other healthcare professionals on depression.
5. Initiating and supporting depression and anxiety-related research.

Specific population groups that *beyondblue* targets include young people, Indigenous peoples, people from culturally and linguistically diverse backgrounds, people living in rural areas, and older people.

Prevalence and impact of depression and anxiety disorders

Depression, anxiety and substance use conditions are the most prevalent mental health disorders in Australia.¹ One in three Australians will experience depression and/or anxiety at some point in their lifetime and approximately 20 per cent of all Australians will have experienced depression, anxiety or a substance use disorder in the last year.² People experiencing depression and/or anxiety are also more likely to have a comorbid chronic physical illness.³

Mental illness is the leading cause of non-fatal disability in Australia, and it is important to note that depression and anxiety accounts for over half of this burden.⁴ Globally, the World Health Organization predicts depression to become the **leading cause of burden of disease by the year 2030**, surpassing ischaemic heart disease.⁵

Mental illness costs the community in many different ways. There are social and service costs in terms of time and productivity lost to disability or death, and the stresses that mental illnesses place upon the people experiencing mental illness, their carers and the community generally. There are financial costs to the economy which results from the loss of productivity brought on by the illness, 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 depression in the workforce costs the Australian society \$12.6 billion over one year, with the majority of these costs related to lost productivity and job turnover.⁶ The individual financial costs are of course not exclusively borne by those with mental illness. It is often their carers who experience financial hardship due to lost earnings, as well as increased living and medical expenses.⁷

beyondblue's response to the draft Disability Care and Support report

Who is the National Disability Insurance Scheme (NDIS) for? – Chapter 3

NDIS eligibility

The proposed NDIS eligibility includes people with a permanent mental illness who have significant limitations in communication, mobility or self-care. The focus on functioning, rather than just a diagnosis, is a key strength of the eligibility criteria. The nature, frequency, intensity and duration of mental illness vary considerably, and this may not be accurately represented through a diagnosis.

It is important, however, that the program considers the particular needs of people with a mental illness. The Australian Bureau of Statistics⁸ suggests that the types of limitations and restrictions of a disability include 'cognition or emotion'. The tasks associated with this limitation include:

- making friendships, interacting with others or maintaining relationships
- coping with feelings or emotions
- decision making or thinking through problems.

While this hasn't been identified as one of the 'core' limitations of a disability, it has a significant impact on the support needs and care of someone with a mental illness, and it is a barrier to workforce participation.⁹ Focusing exclusively on communication, mobility and self-care limitations will result in a program that targets *physical* needs, without considering *mental and emotional* needs.

"The clear lack of inclusion, as opposed to deliberate exclusion, for people with mental illness...is indicative of a society that continues to see disability in terms of physical causality, while mental illness as irresponsible madness not worthy of a community response." blueVoices member

The eligibility of the program should therefore be extended to include an assessment of cognitive and emotional limitations. Depression and anxiety result in significant levels of disability. People experiencing depression report having 11.7 'disability days' per month, in which they are

completely unable to carry out, or have to cut down, on their usual activities due to their health.¹⁰ People experiencing anxiety disorders also report having 9.2 ‘disability days’ per month.¹¹ Given the high prevalence and significant impact of depression and anxiety on functioning, it is essential that mental illness is included in the scope of the NDIS. As many people with a mental illness may not identify with the term ‘disability’, a comprehensive communication strategy will be needed to promote the scheme’s eligibility criteria.

The scheme’s eligibility will also include people with a disability and a co-morbid mental illness. It is important that the scheme recognises the impact of the co-morbid mental illness on functioning and wellbeing, including how this may impact the nature of required care and support. The NDIS needs to recognise the episodic nature of many mental illnesses, and provide regular needs assessments, and flexible care packages, to ensure people receive responsive care, tailored to their current circumstances.

“There is a need to ensure for those with mental illness that its episodic nature is encompassed into eligibility guidelines. That I am currently well and capable does not mean I no longer need the service and so am permanently disconnected. Nor that it takes a total relapse to re-enter. If this were to happen there would be no capacity for such services to take pressure off acute services...a continuous journey to recovery must be recognised.”
blueVoices member

Recommendations

1. Extend the eligibility criteria and assessment process to include cognitive and emotional limitations.
2. Ensure the assessment processes include mental health screening and a focus on the impact of mental disorders on functioning.

Boundaries between the mental health sector and the NDIS

To ensure best practice care is delivered to people with a mental illness who are receiving services through the NDIS, it is essential that the roles and responsibilities of the mental health sector and the NDIS are clearly established, and mechanisms are in place to facilitate integrated and collaborative care. The division of responsibilities across the mental health sector and the NDIS should recognise the expertise and strengths of each area. It should also adopt a flexible approach, to ensure that there are no gaps in service delivery.

“The issues for me, based on my experience are around service flexibility. That is issues such as cooperation and gaps between two departments running the system...There are invariably service gaps rather than overlaps where departmental boundaries mismatch and each feel their money is not meant for ‘that!’” blueVoices member

System-level initiatives could be introduced to help facilitate and incentivise a team-based approach to care across the disability and mental health sectors. The Team Care Arrangement system for the treatment of chronic disease in primary care, demonstrates a potential model that could be adapted to improve coordination by providers. Appointing central case managers/care

coordinators to work across the mental health sector and the NDIS will ensure that holistic care is provided, and the patient and their carer will not experience any gaps or perceptions of 'service silos' between the sectors.

"If the two services of 'support' and 'health' could be integrated through a liaison officer or case worker (a kind of 'one stop shop') that would be excellent." blueVoices member

Recommendations

3. Develop and implement system-level initiatives to promote collaborative team-based care between disability and mental health service providers.
4. Appoint case managers/care coordinators to work across the mental health sector and the NDIS, to ensure coordinated and holistic care is provided.

What individualised supports will the NDIS fund? – Chapter 4

The scheme's proposed flexible funding arrangements, which will allow the NDIS to support individual needs, will help to ensure the program is responsive by providing the right care at the right time. It is important that the type of specialist disability supports provided by the NDIS includes psychological support needs, as well as physical needs.

The support needs of a person with a mental illness vary, based on the stage of illness/recovery, and the impact on daily functioning. Psychological support needs that should be incorporated into the program include support groups, exercise programs, parenting assistance, recovery programs and strategies to prevent against social isolation and homelessness. The delivery of specialist employment support services, which understand the impact of mental illness on work, is also essential. Participating in meaningful work can help in the management of mental illness and participation in the community.

"It's about supporting the person to live the least restrictive life of their choice. So supporting them to be able to be a mother/father is valuable not only to the person with the disability but the whole family and community." blueVoices member

"...prevention and control supports such as access to CBT [Cognitive Behavioural Therapy] groups and various other recovery programs need to be incorporated as emotional and practical support within the public system...Whether through a peer support or Community Development framework these practical supports work well as preventative strategies against homelessness, crime and isolation within my community of people." blueVoices member

"Employment Support services need to develop an understanding of the capacities of we with mental ill health to access and retain employment." blueVoices member

“Practical support needs to be fit for purpose and promote dignity...”
blueVoices member

It is also important that support services are not restricted by geographic location. It is essential that people living in rural and remote regions have access to services which support their psychological and physical needs. Promoting care across geographic regions is also important to ensure consistency of service delivery.

“Geography must not be a limitation. Far too many services have magical lines where a client may cross but they may not. For any person receiving support which involves any caring or giving artificial boundaries must not be imposed. People with mental illness can be highly transient and mobile....If I simply move within South East Qld the same service provider agency should not be penalised for continuing to provide that service(s).” blueVoices member

The NDIS also provides the opportunity to support the carers of people with a disability. In 2007, the Australian Unity Wellbeing Index Survey Special Report¹² published results of a questionnaire undertaken by over 4,000 carers. Results showed the enormous impact caring has on the health and wellbeing of an individual. Key findings included:

- a majority of the participants (56%) had a rating consistent with either moderate (19%), severe (18%) or extremely severe (19%) depression
- female carers had lower wellbeing than male carers
- the wellbeing of carers is more vulnerable to physical pain than is normal
- carers are more likely than is normal to experience chronic pain.

The poorer mental health and wellbeing of carers warrants that the NDIS scope and services be extended to fully support and respond to their needs. It is important that this care is delivered in a non-stigmatising and inclusive manner.

“Carers also fall into multiple levels. Those that actively seek support through to those that deny they are even carers. Again whilst I acknowledge the desperate needs and insufficient response to those who care for the severely mentally ill, those with lesser burdens need ready quality accessibility to support without the stigma of my son, husband, brother etc is mentally ill and that’s why I am here.” blueVoices member

Recommendations

5. Extend the individualised supports available through the NDIS to include psychological support needs.
6. Increase the scope of the NDIS to provide individualised support to carers.

Workforce issues – Chapter 13

To improve the quality of care provided to people with a mental illness who are receiving services through the NDIS, it is important that staff in the disability sector understand the nature and impact of mental illness. NDIS staff should recognise the signs and symptoms of mental illness and understand the particular issues and challenges facing people living with mental illness and co-morbid conditions. Staff should also have the knowledge and skills to make

referrals to mental health services. Up-skilling the NDIS workforce could be achieved through working with the mental health sector to develop and implement mandatory training on mental illness for all staff within the disability sector; including the use of validated mental health screening tools.

The informal workforce also needs to be supported to care for people with a mental illness. This could be achieved by training and up-skilling carers to provide high quality and appropriate care for people with a mental illness, and to develop strategies to promote and protect their own mental health. This could be complemented by extending the support services available through the NDIS to fully meet the needs of carers.

Recommendations

7. Introduce mandatory training for staff working in the disability sector to understand and respond to mental illness.
8. Offer training programs to carers on strategies to care for someone with a mental illness and to look after one's own mental health.

A national injury insurance scheme (NIIS) – Chapters 15 & 16

The introduction of no-fault lifetime care and support for all people who have experienced a catastrophic injury will contribute to better health outcomes. The physical harm and suffering associated with a serious injury can often have an impact on mental health. For example:

- Between 10 and 20 per cent of people who experience a serious injury will develop Post Traumatic Stress Disorder (PTSD) within 12 months of the traumatic event occurring.¹³ Around half of all people with PTSD also have a co-existing disorder such as depression or Generalised Anxiety Disorder.¹⁴
- Three months after a traumatic injury, around one in three people will experience major depression.¹⁵
- For people who have suffered a traumatic brain injury (TBI), the risk of developing depression can be higher. Depression is the most commonly reported consequence of TBI, occurring in 23 to 45 per cent of people with a traumatic brain injury.^{16 17 18}
- People who have had a spinal cord injury (SCI) are also at greater risk of developing depression and anxiety disorders. Up to 40 per cent of people with SCI are at risk of developing PTSD¹⁹, while up to 30 per cent are at risk of experiencing depression.^{20 21}

The NIIS is an opportunity to promote the availability of mental health services to people who have experienced a catastrophic injury. Information resources, such as the *beyondblue Fact Sheet – Serious injury and depression, anxiety and post-Traumatic Stress Disorder*, provides information to people who have experienced an injury, and their carers, on the relationship between injuries and mental health, and best practice treatments and service pathways. The NIIS will provide a pathway to distribute important information and resources on mental health and wellbeing, and will also provide an opportunity to improve the coordination of care and services between health professionals. An important component of this coordinated care is the delivery of mental health services if needed.

Recommendation

9. Utilise the NIIS to promote awareness of the relationship between injury and mental health, and available support and treatment services.

Conclusion

beyondblue welcomes the community consultation on the draft Disability Care and Support report. The needs of people who experience disability due to mental illness are different from those who experience disability due to physical illness. It is important that the NDIS considers and incorporates these needs. This can be achieved by including cognitive and emotional limitations in the eligibility criteria, and conducting mental health screening in the assessment process. Providing coordinated and collaborative systems, that work across the mental health sector and the NDIS, together with psychological and carer support services, will also help to ensure that the needs of people with a mental illness are incorporated. This can be complemented by up skilling staff in the disability sector to understand and respond to mental illness. Including the needs of people with a mental illness are essential to providing an inclusive disability care and support scheme. *beyondblue* looks forward to continuing to work with the Australian Government to address mental health issues in the Australian community.

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