National Disability Insurance Scheme: Information, Linkages and Capacity Building consultation

*beyondblue* Submission

March 2015

*beyondblue*
PO Box 6100
HAWTHORN WEST VIC 3122

Tel: (03) 9810 6100
Fax: (03) 9810 6111

[www.beyondblue.org.au](http://www.beyondblue.org.au)
Information, Linkages and Capacity Building consultation

Introduction

beyondblue is pleased to have the opportunity to present this submission to the Department of Social Services consultation process for the Information, Linkages and Capacity Building (ILC) policy under the National Disability Insurance Scheme (NDIS). In making this submission beyondblue has focussed on the high prevalence mental health conditions of depression and anxiety, and suicide prevention. Background information on the relationship between depression and anxiety and disability, which should inform the development and delivery of ILC services, is at Attachment A.

beyondblue believes that the NDIS will be an important resource for people affected by depression and anxiety and their families and carers, and the requirements of this group of people must be considered in framing any policy or service response. Given the NDIS eligibility criteria, it is likely that many people with depression and anxiety would be eligible for NDIS assistance to varying degrees depending on the severity of their condition. While many would not be eligible for Individual Funded Packages, the majority are likely to benefit from the activities to be provided through the ILC program, at some point over their lifetime. It is therefore essential that the proposed ILC has the capacity to respond to the needs and choices of people with depression and anxiety and the often cyclical and potentially chronic and disabling nature of these illnesses.

beyondblue is a national, independent, not-for-profit organisation working to reduce the impact of depression and anxiety in the Australian community. Established in 2000, beyondblue is a bipartisan initiative of the Australian, State and Territory Governments, supported by the generosity of individuals, corporate Australia and Movember. beyondblue takes a population health approach, which focuses on improving the health of the whole population with programs and initiatives for people of every age, at every stage of life.

beyondblue submission
March 2015
1. What are the most important elements of ILC?

The goal of the ILC program is to influence the social environments within which people with disability live, work and play to ensure that these environments contribute to maximising an individual’s physical and mental health and their social and economic inclusion, as well as supporting each person’s family and carers.

The policy Framework would indicate that the objectives of the ILC are to:

- raise awareness about disability;
- assist individuals to access relevant disability specific and mainstream supports and services;
- enhance the acceptability, inclusiveness and quality of these supports and services;
- contribute to their coordination at the local level;
- assist in the creation of local informal support networks;
- equip individuals to make choices and take control of how they wish to address their needs; and
- contribute to creating a more inclusive society for people with disability.

The ILC can be considered the ‘meta-activity’ that ensures the principles and expectations outlined in the international conventions and national legislative, regulatory and policy frameworks are translated into reality on the ground and drive positive changes in people’s lives. The ILC is intended to complement the assistance available through Individual Funded Packages that are part of the NDIS.

The focus of the ILC is therefore similar in many ways to the focus of population health organisations such as beyondblue. Our remit is to improve the lives of people affected by depression and anxiety by facilitating change at the individual, community and systems level.

In our experience, changing the way the community thinks about and responds to an issue requires an integrated suite of interventions that are sustained over time. To be successful, all of the proposed elements of the ILC are therefore equally important and need to be implemented together.

However, it is likely that one of the biggest challenges for the ILC will be to influence what occurs in the general community and in mainstream services. While not all people with disability require access to disability-specific supports and services, they all live in the one community and often interact with mainstream services. From this perspective, the Capacity Building for Mainstream Services, the Community Awareness and Capacity Building and the Local Area Coordination stream of activities will be particularly important, as these are targeted to community and systems changes, rather than directly working with people with disability, and their families and carers, as the two other streams are.

beyondblue believes that it would be useful for the NDIA to draw upon lessons from other organisations that have implemented similar population health frameworks – such as beyondblue. beyondblue has led community-wide improvements in responses to depression and anxiety. Recent national data suggests that the number of people getting help for depression and anxiety is
increasing at a rapid rate.\(^1\) beyondblue’s Depression Monitor data\(^2\) also shows that the Australian community is now better educated about depression, more likely to talk to family and friends when experiencing difficulties, and more accepting of others experiencing depression and anxiety.

beyondblue has contributed to these successful changes through our comprehensive population health model, which includes:

- increasing the community’s awareness and understanding of these conditions – for example, through campaigns and information resources
- improving the community’s capacity to recognise and effectively respond to depression and anxiety – for example, through skill-based training programs in schools and workplaces
- delivering accessible and alternative models of care, which ensure that people get appropriate and timely help – for example, through the beyondblue Support Service, the NewAccess program, and a suite of online programs.

beyondblue would be pleased to provide the NDIA with a more comprehensive briefing of our approach relating to the types of activities that will be included in the ILC, such as Community Awareness, Information, Linkages and Referrals, and Individual and Community Capacity Building.

**Recommendations:**

- Adopt a strong focus on the elements of the ILC that influence the general community and mainstream services.
- Ensure all elements of the ILC are well integrated, across planning, implementation and evaluation.
- Consider the implementation of other successful population health frameworks, such as beyondblue, to ensure that the right elements of the ILC are prioritised.

2. What is missing?

The ILC component of the NDIS is an ambitious undertaking since it is seeking to influence the environments around a person with disability, not just the services that they may need. Given the importance of the ILC program, beyondblue believes that the ILC Framework needs a clearer description of the proposed governance, operational and resourcing arrangements for the ILC. The current description is quite general and confined to listing a number of broad principles rather than the specifics of the roll out of this program.

Given the breadth of the activities and their relevance for people with disability, and their families and carers regardless of where they live in Australia, the successful introduction of the ILC program is likely to be enhanced by creating a single point of accountability for its implementation. There is

---


beyondblue submission
March 2015
a very strong case for centralising most elements of the Information, Linkages and Referrals stream (apart from perhaps the face-to-face and group information sessions), as well as for the Capacity Building for Mainstream Services and Community Awareness and Capacity Building activity streams, while decentralising certain activities, for example Individual Capacity Building and Local Area Coordination to the local level. This will create economies of scale, build a critical mass of expertise, help to avoid duplication of effort and minimise variability from jurisdiction to jurisdiction while taking into account local nuances as well as how each State and Territory intends to implement the NDIS.

Another element that is missing from the current Framework is the linkage between the ILC program and the vital work of consumer and carer advocates and groups. Such groups have a long history of working towards and achieving many of the improvements that the ILC is hoping to accomplish. While the Individual Capacity Building and Local Area Coordination include some attention to consumer and carer participation and empowerment, a greater focus on peer-to-peer support and self-advocacy is required in the policy Framework.

blueVoices is beyondblue’s reference group and online community for people who have personal experience of depression and anxiety, or support someone who does. Through our online community, members can connect with each other, participate in discussions, share stories and take part in beyondblue activities. beyondblue has also established a Speaker’s Bureau and the Ambassadors program whereby people share with others their personal experiences and provide messages of hope, recovery and encouragement to others. A similar model could be useful for the ILC to ensure that people with disability, and their families and carers can influence the design and implementation of the ILC program.

Another element that is missing from the ILC Framework is research and development. Success will depend on how well each stream of ILC activity is designed and implemented. It is important that the approach taken for each stream of activity is evidence-based and subject to monitoring and evaluation. The ILC Framework should therefore include some reference to how evidence will be used to inform program activities and generated to enable continuous improvement. It also needs to indicate how performance of the ILC program will be monitored. This is covered in more detail in the following section.

**Recommendations:**

Update the Framework to incorporate:

- Clearer governance, operational and resourcing arrangements, including a single point of accountability for implementation
- Essential linkages with consumer and carer groups
- A research and development focus, which ensures the design, implementation and monitoring of the ILC is informed by evidence
3. How will we know the ILC streams are meeting their objectives/vision?

The NDIA’s approach to monitoring and evaluation of ILC activities should be articulated within the ILC Policy Framework. The NDIS ‘Outcomes Framework’³ that is currently in development should also incorporate the ILC activities and objectives. The National Disability Insurance Scheme Act 2013, the National Disability Insurance Agency 2013–2016 Strategic Plan, the National Disability Strategy 2010-2020 and the National Standards for Disability Services provide a strong backdrop for the development of a set of Key Performance Indicators specific for the ILC activities.

Drawing on these existing documents the NDIA, working in partnership with people with disability, their families and carers and other stakeholders, should develop a program logic that specifies the goals, objectives and strategies for the ILC as a whole and for each stream of activity. This will enable the NDIA to establish a set of KPIs associated with each activity stream, determine the data that will need to be collected to measure progress and success, and the processes and infrastructure that are required to support monitoring and evaluation. It is essential that this performance framework is in place from the start.

Drawing on the aims and objectives outlined in the ILC Framework potential KPIs may include:
- Increased accessibility and ease of navigation for people with disability, or their families and carers, seeking supports and services
- Enhanced responsiveness and quality of mainstream supports and services
- Improved community awareness, reduced stigma and discrimination and more inclusive communities and institutions
- Increased confidence and ability to exercise choice among people with disability, their families and carers
- Better coordination between formal and informal, disability specific and mainstream services and supports at the local level

Monitoring and evaluation will require a combination of ongoing administrative data collection and regular cross-sectional surveys coupled with case studies, or even longitudinal follow-up of people accessing ILC activity streams to determine their impact over time. Quantitative and qualitative data must capture the perspectives of people with disability, their families and carers, the general community, and mainstream and disability specific service providers. The ILC-specific outcome data should be incorporated into the broader NDIS Outcomes Framework.

The NDIA’s approach to monitoring and evaluation of the ILC could potentially include the following elements:
- Collecting output, impact and financial data for each of stream of activity
- Collecting outcome measures for direct service delivery programs
- Conducting regular independent, external evaluations of each stream of activity and the ILC as a whole

---

• Conducting regular community surveys that measure changes in key parameters such as community awareness, stigma and discrimination and inclusiveness. The beyondblue Depression and Anxiety Monitor provides an example of how community knowledge and attitudes can be assessed over time.

Recommendations
• Integrate the assessment and monitoring of ILC activities into the NDIS Outcomes Framework.
• Develop Key Performance Indicators and a program logic for each stream of the ILC. The KPIs should focus on client and family outcomes.

4. What would be the implementation challenges?

The national roll out of the ILC Framework is a major undertaking that will be resource and time intensive. One of the most significant implementation challenges relates to the internal capacity of the NDIA, which is only a few years old and still evolving – as noted in A review of the capabilities of the National Disability Insurance Agency (2014).

As a first step the NDIA will need to:
• Clarify how the implementation of the ILC activity streams will be financed
• Establish the organisational and technological infrastructure to support the implementation of the ILC Framework, over and above the arrangements that are in place for the trial sites
• Engage and train the workforce required to design and deliver each of the activity streams. It is essential that this workforce is trained to understand the needs and experiences of people with psychosocial disability, to ensure that services are delivered in an inclusive and non-discriminatory manner.

Avoiding duplication will be a major implementation challenge. As part of this process, it is important that the NDIA undertake a ‘situation analysis’ to determine what existing organisations may already be doing within each of the five ILC activity streams. This ‘situation analysis’ will enable the NDIA to:
• Collate existing print resources, tools and templates relevant to the five activity streams
• Create the services database that will be required for the Information, Linkages and Referrals and Local Area Coordination streams of the ILC
• Determine which elements of the ILC need to be created and which can be leveraged from initiatives currently in place through existing organisations.

The National Mental Health Commission’s recent Review of Mental Health Programmes and Services, delivered to Government on 30 November 2014 but not yet publicly released, could serve as a key source of information on activities in the mental health sector that overlap with some of the planned ILC activities.

beyondblue submission
March 2015
The next implementation challenge will be for the NDIA to forge relationships with existing organisations doing similar or complementary activities that are planned for the ILC. For example, beyondblue and other mental health organisations are already very active in supporting people with depression and anxiety conditions who may experience impairment or disability as a result of their condition. beyondblue undertakes many of the activities outlined in the ILC program – for example, the beyondblue Support Service provides information on depression and anxiety, referrals to existing services, and short-term solutions focused counselling. The scope of this service overlaps with the intended support available through the Information, Linkages and Referrals stream of the ILC.

It will be critical for the NDIA and beyondblue to cross promote and support each other’s work, rather than duplicating information and services. beyondblue is particularly keen to ensure that the NDIA is able to meet the needs of people affected by depression or anxiety conditions. The already-established NDIA Mental Health Sector Reference Group provides an important advisory channel to better understand the potential for duplication across the ILC and the mental health sector.

**Recommendations**
- Ensure the NDIA has the capacity to plan, deliver and evaluate the ILC, in accordance with its intended scope and objectives.
- Train staff who are planning and delivering ILC services to understand the needs and experiences of people with psychosocial disability, including that arising from depression and anxiety.
- Undertake a situation analysis to minimise the risk of duplication with existing services, and enable appropriate cross-referrals.

5. Which aspects of a person’s life do you think ILC could have the greatest impact on?

The aim of the NDIS is to enable people to choose and obtain services and supports tailored to their unique circumstances that can be adjusted over time, as their requirements evolve. While each stream of ILC activity is important, some streams may be more relevant to individuals at certain life stages. For example, the Information, Linkages and Referrals stream is likely to have a major impact on the family and carers of a child with disability that has just been identified. By contrast, the Individual Capacity Building stream of activity may be more useful to people with disability at a later stage in life.

beyondblue is focused on fostering hope, promoting recovery, and building resilience. People with depression and anxiety who experience impairment or disability, including psychosocial disability, must be able to participate in social and economic life to the fullest extent that they can and wish to participate. One of the key foci of the NDIS overall and the ILC program specifically is to reduce the risk of social exclusion that is associated with these conditions.

There is still a large level of untreated depression and anxiety, and high numbers of people who still do not receive evidence-based services and treatment even when they do seek help. The ILC is not necessarily the mechanism for improving the effectiveness of clinical service provision but it could
over time play a role in positively influencing culture, practice and behaviours of traditional mental health service delivery, especially around the value of non-clinical supports and the principles of self-determination, choice and control. The **ILC needs to complement the mental health system and focus on the psychosocial aspects of recovery** – building resilience, helping people to build and maintain supportive interpersonal relationships, supporting their social and economic participation, protecting their human rights, and helping to create strong, connected and inclusive communities. In undertaking these activities the NDIA should work very closely with others already active in the field of mental health promotion, since these organisations share the same aspirations.

**Beyondblue**’s work in education, through the KidsMatter and MindMatters programs, along with our action on workplace mental health, through the National Workplace Program and Heads Up, underscores our commitment to ensuring that children, young people and adults affected by depression and anxiety are able to experience the benefits of education and employment regardless of current or life time mental health issues. Addressing stigma and discrimination is a major element of this activity. These two domains should be similarly central to the ILC activities.

**Recommendations**

- The ILC should aim to improve all aspects of a person’s life, however addressing stigma and discrimination in education and the workplace to enable full participation and inclusion, should be given particular emphasis.
- Partner with mental health promotion and support organisations to deliver psychosocial care, as part of the ILC.

### 6. What are some of the principles that should guide investment across ILC streams?

Since all activity streams are useful it is important that an appropriate level of investment occurs across each stream of activity. However, it is likely that each stream will require different levels of resourcing since the costs associated with implementing the initiatives are not uniform. For example:

- The Information, Linkages and Referrals stream will probably have high ICT associated costs for databases along with high staffing costs
- The Capacity Building for Mainstream Services stream will probably have high training and resource development costs along with moderate staffing costs
- The Community Awareness and Capacity Building stream will probably have high marketing and communications costs and costs associated with community engagement and advocacy activities along with moderate staffing costs
- The Individual Capacity Building stream will probably have high operational and discretionary costs along with moderate staffing costs
- The Local Area Coordination stream will probably have high staffing costs
Another potential determinant of resource allocation relates to the likely level of demand for the particular stream of activity. From this perspective, it could be argued that the Information, Linkages and Referrals stream should have the highest level of resourcing since this stream is likely to have the highest level of demand – and this demand may not be able to be capped. By contrast, activity across the others streams is less demand driven and the NDIA has greater control over outputs.

However while this demand driven approach is reasonable, it fails to take into account the relative contribution of each stream of activity towards improving the lives of people with disability, and their families and carers. From this perspective, it could be argued that the Capacity Building for Mainstream Services and Community Awareness and Capacity Building streams have greater relative value, since they can support greater social inclusion and not just access to services and supports. Given their contribution to social change it could be argued that these streams should be better financed.

While in the first instance, resources should be allocated across activity streams on the basis of demand and likely operating costs, ultimately, further research is required to enable resources to be allocated across activity streams based on the economic and social return on investment that can be achieved by each stream.

Recommendations:
- Initially invest in the ILC streams based on expected demand and operating costs.
- Undertake research to understand the economic and social return on investment for each ILC stream. Utilise these research outcomes to inform ongoing investment in the ILC.

7. How do you see the interface between ILC functions and activities and the interaction with the mainstream service systems?

Disability-specific supports and services will never be able to fully address the needs of people with disability, and their carers and families. One of the chief aims of the ILC is therefore to exert influence over the way mainstream services respond to people with disability, and their carers and families.

It is important that there are strong and clearly understood partnerships between those implementing ILC activity streams and disability-specific and mainstream services, to ensure that people accessing services receive integrated and coordinated care. These strong partnerships should include:

- referral pathways between disability and mainstream services, which includes ‘step up’ and ‘step down’ services
- national and local level initiatives to facilitate effective service delivery across both mainstream and disability-specific services (for example, system-level initiatives that provide
incentives to delivering integrated and coordinated care, together with local-level partnerships between service providers)
• support for service delivery agencies to better engage with either disability or mainstream services (for example, ensuring organisations and staff have a good understanding of the scope and appropriateness of available services).

It is essential that there is strong coordination and integration of existing and new services, to ensure that clients do not continue to ‘fall between the cracks’ of the system – whether it be direct service or the systems initiatives included in the ILC framework.

Developing strong networks and relationships across sectors can be difficult, however, partnership models and frameworks developed in other sectors could be used to inform ILC practice. beyondblue has effectively influenced how different services and sectors respond to depression and anxiety. This has resulted in improvements in the mental health care system, as well as changes in sectors such as education and employment (for example, there has been widespread adoption of the KidsMatter mental health initiative in primary schools, and depression and anxiety education and training programs in workplaces).

In beyondblue’s experience, leading and implementing cross-sector changes requires a high-level and ongoing commitment and investment from each sector, and a strong evidence base to demonstrate the benefits of engagement. It is also important that there are strong accountability and reporting mechanisms in place, to ensure that the intended changes are achieved.

Important lessons can be learned from the work of other population mental health organisations, as well as mental health peak bodies and advocacy groups that have achieved similar success. The linkages that exist between mental health services and alcohol and other drug services, psychosocial rehabilitation services, housing services, and employment services to name a few, demonstrate both the need and the importance of cross-sector activity.

Similarly Aboriginal and Torres Strait Islander and ethno-specific peak bodies and advocacy groups also have significant experience in achieving changes in the quality, accessibility and inclusiveness of services and systems with respect to the specific needs of their population groups in the community.

The experiences from the mental health sector and these population specific representative organisations could be used to inform the NDIA’s approach to managing the interface between the ILC activities and mainstream services.

Recommendations:
• In genuine partnership with people with a disability and their families and carers, and key advocacy groups, develop, implement and evaluate a service delivery framework that stipulates how disability and mainstream services can effectively provide integrated and coordinated care.
Attachment A - Background

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. ⁴

Depression and anxiety conditions cost the community in many different ways. The impact on people affected by these conditions, and their families and carers, is considerable. 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 untreated mental health conditions cost Australian employers $10.9 billion every year through absenteeism, reduced productivity and compensation claims. ⁵ 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. ⁶

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. ⁷

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 relapsing–remitting or persistent condition. In a recent review of the natural trajectory of depression, Keller (2013, 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)”. ⁸

---

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.9 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).

**Depression and anxiety and disability**

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).10 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 National Survey of Mental Health and Wellbeing (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.11

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).12

It is important to note, that depression and anxiety often co-occur. About 3 per cent of 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 per cent) of people with 12-month mental disorders also identified that they had a chronic physical

---

11 Slade et al. Op cit
12 Slade et al. Op cit

*Beyond Blue* submission
March 2015
condition. The level of impairment associated with mental health conditions is much higher among people with co-morbid mental and/or physical health conditions.\textsuperscript{13}

It is clear that while the impairment associated with these conditions may fluctuate, for large numbers of people these conditions can lead to more chronic disability. Disability support for people with depression and anxiety conditions needs to be flexible enough to take into account and respond to this diversity of experience and need.

\textsuperscript{13} Slade et al. Opcit