



# Lead by Example!

## Response to the NSW Disability Inclusion Plan: Discussion Paper and Draft Outline

**This submission was compiled on behalf of Being | Mental Health & Wellbeing Consumer Advisory Group by:**

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### **Acknowledgements**

Being would like to thank the individual participants who generously shared with us their experiences and insights.

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# Being | Mental Health & Wellbeing Consumer Advisory Group

**Being | Mental Health & Wellbeing Consumer Advisory Group (Being) is the independent, state-wide peak organisation for people with a lived experience of mental illness (consumers). We work with consumers to achieve and support systemic change.**

Being's vision is for all people with a lived experience of mental illness to participate as valued citizens in the communities they choose. Participation is a fundamental human right as enshrined in Article 25 of the International Covenant on Civil and Political Rights (ICCPR). We work from the premise that the participation of consumers results in more effective public policy and facilitates individual recovery.

Our work is guided by six principles:

- Being person centred and empowering consumers in the interests of consumers;
- Adopting a recovery approach to building positive futures;
- Promoting positive images and reducing stigma and discrimination;
- Enhancing best practice and building understanding of effective approaches to consumer participation;
- Capacity building of our organisation, consumers and services; and
- Promoting professionalism and continuous improvement in our ways of working.

Being is an independent non-government organisation that receives core and project funding from the Mental Health Commission of NSW.

# Introduction

Being | Mental Health and Wellbeing Consumer Advisory Group (Being) is pleased to comment on the *NSW Disability Inclusion Plan: discussion paper and draft outline* (discussion paper).

Being is the independent state-wide peak organisation for people with a lived experience of mental illness (mental health consumers). We work with mental health consumers to achieve and support systemic change. Ongoing engagement and consultative work with mental health consumers across NSW informed our views in this submission.

We agree with many of the actions proposed in the discussion paper, however, we feel that there are some considerable gaps. Our response will start by discussing why it is important to understand and address the disability needs of mental health consumers. It will then focus on some of the key areas that the NSW Disability Inclusion Plan (NSW DIP) needs to address in order to meet the disability needs of mental health consumers. These are:

- The need to align the NSW DIP with the National Disability Strategy 2010-2020
- The need to align the NSW DIP with key mental health policies
- The need to make the clearing house of learning and development resources as accessible as possible
- The need to build the capacity of the Disability Council NSW to engage with and represent people with mental illness
- The need to make the NSW DIP and related materials as accessible as possible
- The need for a comprehensive approach to involving people with disability in the ongoing development and implementation of disability inclusion in NSW

# Background

For a long time, policies and services in NSW have overlooked the disability needs of mental health consumers. This is due to a number of reasons. Firstly, mental health and disability sector often worked in “silos”, which meant that mental health consumers were often unaware of the disability support and services available, or did not consider their impairments as disabilities, and therefore did not access disability support or services. Secondly, funding for services were typically allocated either for disability or mental health, with very little being available to people who have both a mental illness and a disability. This

segregation of funding led to a long-held practice by disability services to assess (often on an arbitrary basis) whether a mental health consumer had a disability or a mental illness, and therefore, whether they were eligible for disability services or not.

Even for mental health consumers who were able to access disability services, many found that those services could not fully meet their needs. Often, it was because services were not skilled to work with people with mental illness. Sometimes, it was also because of misunderstanding, stigma and discrimination towards people with mental illness.

While there are now increasing efforts to break the silos between the mental health and disability sectors<sup>1</sup>, there is still a lot of confusion around mental illness and disability.<sup>2</sup> Therefore, as a starting point, it is important to understand the link between the two issues.

The World Health Organizations (WHO) defines disability as:

*"...an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations."<sup>3</sup>*

The WHO adds that disability is not just a health issue. It is a complex phenomenon reflecting the interaction between features of a person's body and that of the society.

In relation to mental health consumers, WHO's definition of disability highlights that while mental illness is a health problem, the impairments, activity limitations and participation restrictions linked to having a mental illness are in fact disabilities. The paper, *Unravelling Psychosocial Disability* by the National Mental Health Consumer and Carer Forum provides a list of examples of physical, cognitive and emotional impairments that are directly related to particular types of mental illness.<sup>4</sup>

Not every mental health consumer has a disability, but a significant number do. Due to limited research, we only get glimpses of the scale of the issue. For example, we know that a 2012 survey by the Australian Bureau of Statistics (ABS) has found that 813,900 people with disability across Australia reported a mental or behavioural disorder as the long-term health condition causing them the most problems when completing everyday activities. At least

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<sup>1</sup> Efforts such as the *National Disability Insurance Scheme*. The Scheme limitedly includes mental health consumers with impairments that are likely to be permanent, and substantially reduce the person's functional capacity to perform everyday activities (Section 24 of the *National Disability Insurance Act 2013*).

<sup>2</sup> For example, whether mental illness itself is a form of disability.

<sup>3</sup> 'Health Topics: Disabilities', *World Health Organization*. Available online: <http://www.who.int/topics/disabilities/en/> [5 January 2015]

<sup>4</sup> National Mental Health Consumer & Carer Forum (2011). *Unravelling Psychosocial Disability, A Position Statement by the National Mental Health Consumer & Carer Forum on Psychosocial Disability Associated with Mental Health Conditions*.

Canberra: NMHCCF, p59-62.

3.8% of these individuals reported having depression or mood affective disorders.<sup>5</sup> Quoting ABS statistics and reports by the Productivity Commission, the paper, *Unravelling Psychosocial Disability* by the National Mental Health Consumer and Carer Forum also highlighted the high prevalence of mental illness amongst people with disability, and vice versa.<sup>6</sup>

For all of the above reasons, Being welcomes the inclusion of mental health consumers with disability in the NSW *Disability Inclusion Act 2014* and the proposed NSW Disability Inclusion Plan (NSW DIP). This is consistent with the international approach towards mental illness and disability. It is also consistent with what mental health consumers, and their carers and support persons have said is required to ensure the disability needs of mental health consumers are identified and addressed.

## Comments on the draft NSW Disability Inclusion Plan

### Alignment with the National Disability Strategy 2010 - 2012

It is uncertain how the NSW DIP will be aligned with the *National Disability Strategy 2010 - 2020* (NDS). The four focus areas proposed in the Discussion Paper do not reflect the six priority areas in the NDS. In particular, NDS priority areas such as rights protection; justice and legislation; economic security; learning and skills; and health and wellbeing are missing in the NSW DIP discussion paper.

It is important that the NSW DIP properly addresses all areas of the NDS, because the NDS is informed by broad national consultations, and its priority areas have been identified as crucial to improving the lives of people with disability, their families and carers. The NSW Government also has a responsibility to meet its obligations under the NDS, which has been endorsed by the Council of Australian Governments (COAG).

Being recommends aligning the focus areas in the NSW DIP with those in the NDS. This would make it easier to cross-reference the two frameworks. It would ensure government agencies are able to develop plans and reporting that would align with both frameworks. It would also make it easier for the NSW Government to monitor and demonstrate the implementation of both frameworks. This in turn would enhance the accountability and transparency of the NSW Government's actions on improving the lives and inclusion of people with disability.

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<sup>5</sup> 'Disability – Long-term Health Condition', 4430.0 - *Disability, Ageing and Carers, Australia: Summary of Findings* (2012). Available online: <http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/E569E99F36BB63E6CA257C210011ACDE?opendocument> [5 January 2015]

<sup>6</sup> National Mental Health Consumer & Carer Forum, p19.

## **Recommendation:**

1. The NSW DIP to align its focus areas with the NDS.

## **Alignment with key mental health policies**

Being is pleased to see in the NSW DIP the inclusion of mental health consumers with disability. This approach represents a shift from the long-time silos between the disability and mental health sector, and from the long-held arbitrary distinction between 'primary' and 'secondary' diagnosis as an eligibility criteria for services. To clearly signal this fresh approach, the NSW DIP should state, as early in the NSW DIP as possible, that all people with disability, including disability relating to mental illness are included in the plan.

To ensure relevance to and coordination with the mental health sector, the NSW DIP should also be guided by key mental health policies, including the *Roadmap for National Mental Health Reform 2012 – 2022* (Roadmap)<sup>7</sup>, and the newly released *Living Well: A Strategic Plan for Mental Health in NSW 2014 – 2024* (Strategic Plan)<sup>8</sup>.

Both documents contain cross-government priorities and actions that are relevant to people with disability. For example, the Roadmap identifies improving the social and economic participation, and promoting person-centred approaches in both specialist and mainstream services as priorities. Similarly, many of the priorities and actions in the Strategic Plan, such as building the capacity of individuals and communities to develop and carry out solutions to local issues, are highly relevant to disability inclusion.

The NSW DIP should include these mental health policies as guiding documents, and incorporate relevant aspects of these documents into its own strategies. Particularly, incorporating the relevant actions from the Strategic Plan would enhance the comprehensiveness of the NSW DIP, as well as its relevance to people with mental illness and other disability.

## **Recommendations:**

2. The NSW DIP to state, as early in the NSW DIP as possible, that all people with disability, including disability relating to mental illness are included in the plan.

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<sup>7</sup> Council of Australian Governments (2012), *Roadmap for National Mental Health Reform 2012 – 2022*. Available online: <http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-roadmap> [3 December 2014]

<sup>8</sup> Mental Health Commission of NSW (2014), *Living Well: A Strategic Plan for Mental Health in NSW*, Sydney, Mental Health Commission of NSW.

3. The NSW DIP to be guided by and incorporate relevant elements from key mental health policies, including the *Roadmap for National Mental Health Reform 2012 – 2022*, and *Living Well: A Strategic Plan for Mental Health in NSW 2014 – 2024*.

### Making the clearing house of learning and development resources as accessible as possible

The Discussion Paper proposed the development of a clearing house of learning and development resources relating to disability access and inclusion, and to make the resources available to government agencies and broader community. Being welcome this proposal, and we recommend the clearing house to include resources that are relevant to people with mental illness.

To ensure the broader community is able to access these resources, the clearing house needs to be widely promoted at the community level, and the resources need to be freely available and easy to locate. There also needs to be more proactive strategies for promoting and making available the resources to rural and remote communities, and to other disadvantaged groups. For example, the NSW DIP could require all local councils to actively promote the clearing house and its resources to their local communities, with a specific focus on reaching out to disadvantaged groups. It is important that disadvantaged communities and groups are not excluded from accessing the clearing house and its resources.

#### Recommendations:

4. The clearing house of learning and development resources to include resources that are relevant to people with mental illness.
5. The NSW DIP to include, as an action, that the clearing house be widely promoted to communities and its resources to be freely available.
6. The NSW DIP to include strategies to ensure that the clearing house and its resources are available and accessible to disadvantaged communities and groups, and to people living in rural and remote areas.

### Building the capacity of the Disability Council NSW to engage with and represent people with mental illness

Being supports the proposal to increase the capacity of the Disability Council NSW (the Council) and its Secretariat to better capture and report on public feedback. We recommend that specific attention and resources be allocated to significantly improve the Council's

understanding of issues affecting people with mental illness, and also the Council's ability to engage with and report on feedback from people with mental illness.

Due to the silos between the mental health and disability sector in NSW, we are concerned that the Council is currently unable to represent the issues and views of mental health consumers. Since the Council will be playing a significant role in providing advice on and monitoring the implementation of disability inclusion policies in NSW, it is critical that the Council improves considerably its ability to work with and represent issues affecting people with mental illness.

To do this, we recommend that the Council includes at least one person with a lived experience of mental illness in its membership. We also recommend that the Council establishes strong links with key mental health organisations and peak bodies in NSW, including the Mental Health Commission of NSW, Being, ARAFMI NSW and the Mental Health Coordinating Council. Being and ARAFMI NSW in particular have strong experience and expertise in working with mental health consumers and carers, and representing their issues. Having strong links with these organisations would be invaluable to the Council. Collaboration between the Council and these organisations would also help mend the divide between the two sectors.

#### **Recommendation:**

7. The NSW DIP to require and support the Disability Council NSW and its Secretariat to improve their ability to engage with mental health consumers and to represent their issues. This to include:
  - a. having at least one person with a lived experience of mental illness in its membership.
  - b. establishing strong links with key mental health organisations and peak bodies in NSW, including the Mental Health Commission of NSW, Being, ARAFMI NSW and the Mental Health Coordinating Council.

#### **Making the NSW DIP and related materials as accessible as possible**

Being agrees that the NSW DIP should be available in electronic format with links to other relevant documents and websites. This should include a website, as well as DVD discs or USBs that can be distributed. For people with computer access, having all relevant information electronically and clearly linked would make it easier to locate and use the information.

It is also important that the NSW DIP, and key information relating to it, is available in printed form and in other accessible forms. This is because many people with disability, including

those in disadvantaged communities, those living in rural or remote areas, and those in institutional settings (including hospitals and prisons), do not have computer access. It is crucial that the NSW DIP leads by example and ensures its access is as inclusive as possible to all people in NSW. A suggested action would be to require government agencies and local governments to work with their communities, and to implement ways to make the information accessible to their specific settings.

**Recommendation:**

8. The NSW DIP and its related information to be made as accessible and available to all people in NSW as possible.

**Having a comprehensive approach for involvement and feedback**

Being welcomes the decision for the NSW DIP to be a dynamic document which allows for public feedback at any time during its four-year lifespan. To maximise opportunities for people with disability across NSW to give input, it is important that the NSW DIP has a range of feedback mechanisms. These should include web-based mechanisms as well as face to face engagements that are conducted at locations and settings suitable for people with different disability experiences.

An example of a highly effective and meaningful engagement approach is the one used by the Mental Health Commission of NSW to inform its development of the Strategic Plan. The Commission held a number of face to face consultations in different communities to gather input. People could also call the Commission, or write to the Commission by email or post. The Commission also partnered with many different mental health and community managed organisations to maximise the Commission's reach into diverse communities across NSW. For example, the Commission funded Being to carry out a Community Mobilisation Project specifically to gather input from people with a lived experience of mental health issues. The project involved building the capacity of mental health consumers in different communities to consult with other mental health consumers in their community, and to synthesise the feedback into a report. The Commission also took part in many of Being's community engagement activities, and used those opportunities to gather information and consumer views for the Strategic Plan.

Being strongly suggests the government agency responsible for the NSW DIP to develop comprehensive feedback mechanisms and engagement strategies similar to that used by the Mental Health Commission of NSW. We particularly recommend that government agency to have strong collaborative working relationships with all of the disability peak and

representative organisations in NSW, and also with the NSW Disability Network Forum, which is made up of many of those disability peak and representative organisations.<sup>9</sup> Disability peak and representative organisations have significant expertise working and engaging with people with different disability experiences. They are trusted by people with disability and the broader community. They have a long history as effective intermediaries between people with disability, mainstream community and services, and government agencies. They are ideal partners to support the ongoing development and implementation of disability inclusion in NSW.

### **Recommendations:**

9. The NSW DIP to require the establishment of a comprehensive engagement strategy, which maximises opportunities for people with disability across NSW to have input into the NSW DIP, and to other matters relating to disability inclusion.
10. The government agency responsible for the NSW DIP to have strong collaborative working relationships with all of the disability peak and representative organisations in NSW, and also with the NSW Disability Network Forum.

## **Summary of recommendations**

Being makes the following recommendations in relation to the NSW Disability Inclusion Plan:

1. The NSW DIP to align its focus areas with the National Disability Strategy 2010-2020.
2. The NSW DIP to state, as early in the NSW DIP as possible, that all people with disability, including disability relating to mental illness are included in the plan.
3. The NSW DIP to be guided by and incorporate relevant elements from key mental health policies, including the *Roadmap for National Mental Health Reform 2012 – 2022*, and *Living Well: A Strategic Plan for Mental Health in NSW 2014 – 2024*.
4. The clearing house of learning and development resources to include resources that are relevant to people with mental illness.
5. The NSW DIP to include, as an action, that the clearing house be widely promoted to communities and its resources to be freely available.
6. The NSW DIP to include strategies to ensure that the clearing house and its resources are available and accessible to disadvantaged communities and groups, and to people living in rural and remote areas.

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<sup>9</sup> Refer to NCOSS website for more information about the NSW Disability Network Forum and a list of its members. Link: [http://www.ncoss.org.au/component?option=com\\_docman/task,cat\\_view/gid,367/Itemid,78/](http://www.ncoss.org.au/component?option=com_docman/task,cat_view/gid,367/Itemid,78/)

7. The NSW DIP to require and support the Disability Council NSW and its Secretariat to improve their ability to engage with mental health consumers and to represent their issues. This to include:
  - a. having at least one person with a lived experience of mental illness in its membership.
  - b. establishing strong links with key mental health organisations and peak bodies in NSW, including the Mental Health Commission of NSW, Being, ARAFMI NSW and the Mental Health Coordinating Council.
8. The NSW DIP and its related information to be made as accessible and available to all people in NSW as possible.
9. The NSW DIP to require the establishment of a comprehensive engagement strategy, which maximises opportunities for people with disability across NSW to have input into the NSW DIP, and to other matters relating to disability inclusion.
10. The government agency responsible for the NSW DIP to have strong collaborative working relationships with all of the disability peak and representative organisations in NSW, and also with the NSW Disability Network Forum.

## Conclusion

People with disability, including mental health consumers with disability, have a right to inclusion. The full and meaningful inclusion of people with disability also adds significant diversity and value to community and society as a whole. It is positive to see the NSW Government taking an active role in facilitating and supporting the inclusion of people with disability in NSW. It is particularly heartening to see the inclusion of mental health consumers with disability in the *Disability Inclusion Act* and the proposed State Disability Inclusion Plan.

Being is pleased to provide comments on the Discussion Paper, and has focused our feedback on ways to enhance the usability of the plan and its relevance to people with disability and mental illness. We welcome opportunities to provide further input to assist the development and implementation of the NSW DIP.