

# Delivering high quality services for all mental health consumers

**VCOSS submission to the Joint Standing Committee on the NDIS**

February 2017



## About VCOSS

The Victorian Council of Social Service (VCOSS) is the peak body of the social and community sector in Victoria. VCOSS members reflect the diversity of the sector and include large charities, peak organisations, small community services, advocacy groups, and individuals interested in social policy. In addition to supporting the sector, VCOSS represents the interests of vulnerable and disadvantaged Victorians in policy debates and advocates for the development of a sustainable, fair and equitable society.

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VCOSS acknowledges the traditional owners of country and pays its respects to Elders past and present.

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# Acronyms

CALD	Culturally and Linguistically Diverse
ILC	Information, Linkages and Capacity building
LACs	Local Area Coordinators
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
PHaMs	Personal Helpers and Mentors
VCOSS	Victorian Council of Social Service
VICSERV	Psychiatric Disability Services of Victoria

# Executive Summary

The Victorian Council of Social Service (VCOSS) welcomes the opportunity to provide feedback to the Joint Standing Committee's inquiry into the provision of services under the National Disability Insurance Scheme (NDIS) for people with psychosocial disabilities related to a mental health condition.

We use the term psychosocial disability throughout this submission as it is used by the NDIS and is internationally recognised under the United Nations Convention on the Rights of Persons with Disabilities. For the purpose of this submission we adopt the definition of psychosocial disability as formulated by the National Mental Health Consumer and Carer Forum 2011<sup>1</sup>:

*“Psychosocial disability is a term applicable to mental health consumers and carers to describe the disability experience of people with impairments and participation restrictions related to mental health conditions. These impairments and restrictions include reduced ability to function, think clearly, experience full physical health and manage the social and emotional aspects of their lives. As with other disabilities, the best outcome for people experiencing psychosocial disability will be achieved through access to support that enhance their social and environmental opportunities to expand their capabilities”.*

As not everyone with a mental illness will have a level of impairment that will result in a psychosocial disability, we also use the terms “people with mental illness”, “mental health consumers” and “episodic mental illness” when referring to people who fall both in and outside the NDIS.

The inclusion of psychosocial disability in the NDIS represents an opportunity for people with mental illness and complex needs to receive improved support and greater choice and control over the services they receive. The advent of the NDIS will result in profound change, dramatically increasing the support available for people with disability who are eligible for the NDIS. However, there are risks it will create negative unintended consequences including gaps in services and support for some people.

Active lobbying by the disability sector precipitated the Australian Government to ask the Productivity Commission to undertake an inquiry in 2010 into the development of a universal disability insurance scheme. It was only after some deliberation that those with psychosocial disability were included in the scheme in 2012. As the NDIS has been essentially shaped by the

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<sup>1</sup> National Mental Health Consumer and Carer Forum, *Unravelling Psychosocial Disability: A Position Statement by the National Mental Health Consumer and Carer Forum on Psychosocial Disability Associated with Mental Health Conditions*, Canberra, 2011.

disability sector in its conception, with psychosocial disability included later, the mental health community<sup>2</sup> have raised concerns, including whether the scheme is adequately resourced to meet the needs of people with psychosocial disability.

This inquiry is an opportunity to ensure the NDIS is designed and resourced to meet the needs and aspirations of people with psychosocial disability. This includes embedding a recovery model in the NDIS and delivering high quality, suitable services and support. Pre-engagement planning and support is required to help some people with psychosocial navigate the new system and receive meaningful plans.

People who face multiple disadvantage, are marginalised or have complex needs are at greater risk of being underserved in the transition to the NDIS. Additional assistance is required to help engage and support these people to access services. This includes funding independent advocacy and assertive outreach, providing culturally responsive services and ensuring equitable coverage in rural and remote areas.

Many people living with mental illness will be ineligible for NDIS individual funding packages. VCOSS believes state and federal government have a joint responsibility to continue to fund community mental health services outside of the NDIS, so these people can access support for recovery. Community mental health services in Victoria have long provided psychosocial rehabilitation and support services, helping people with mental health difficulties stay well and able to work, study, care for their children and families, and participate in community life.

VCOSS supports the goals of the Information Linkages and Capacity Building (ILC), formerly known as tier two, to promote full inclusion in social and economic life. However, we are concerned the allocated funding is insufficient to fill the gap for people with mental illness and their carers who are ineligible for NDIS plans. The shift in state and federal responsibilities creates uncertainty about the continuity of current services and activities which provide essential support or people with mental illness and their carers. Effective initiatives operating in Victoria should not be lost.

It is also crucial all mental health carers can access respite and carer specific support that meet their needs, irrespective of whether the person they are caring for is eligible for NDIS individual funding packages. Actively engaging carers and family members in the NDIS planning process can help identify the support needed to assist people with psychosocial disability and their carers.

VCOSS consulted with our members and has drawn on their expertise supporting mental health consumers and carers, and their front line experience working in NDIS launch site in Barwon and the NDIS rollout in the North East Melbourne area (NEMA). Our submission raises some of the challenges and risks faced by Victorian mental health consumers and their carers in the transition to the NDIS. It also identifies opportunities to build effective systems of support for people with mental illness both inside and outside the NDIS.

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<sup>2</sup> T Williams and G Smith, 'Can the National Disability Insurance Scheme work for mental health?' *Australian and New Zealand Journal of Psychiatry*, 48, 391-394, 2014.

# Recommendations

## Help people access and participate in the NDIS

- Build the NDIS network's capacity, knowledge and understanding of psychosocial disability and recovery principles.
- Apply flexibility in demonstrating proof of eligibility for individual funding packages.
- Review the NDIS eligibility criteria and make support available to refugees and asylum seekers
- Provide pre-assessment support to help people understand the NDIS, check their eligibility and lodge an application.
- Provide pre-planning support to help people prepare for their planning session so the plan meets their needs.
- Ensure NDIS planners are adequately skilled in psychosocial disability and how to support people with complex needs.
- Ensure planning meetings take place face-to-face, and provide sufficient time for meaningful plans to be developed.
- Engage carers and family members, advocates and key workers in the planning process to better identify the support needed for individuals and their carers.
- Deliver high quality, suitable services to people with psychosocial disability under their NDIS package.

## Provide service continuity for mental health consumers and carers ineligible for the NDIS

- Adequately resource community mental health services outside the NDIS to support those ineligible for individual funding packages.
- Ensure all mental health carers can access carer specific support and services that meet their needs, irrespective of whether the person they are caring for is eligible or ineligible for an NDIS individual funding package.
- Government act as a systems steward and manager, to better coordinate the interface between the NDIS and mental health and mainstream services.

## Engage people who are marginalised and who have complex needs

- Fund assertive outreach to identify and engage people who are disengaged or hard to reach to link them into appropriate support.
- Fund independent advocacy to assist people to access and participate in the NDIS and to help people ineligible for NDIS packages to access appropriate services.
- Provide culturally safe, gender responsive planning and service delivery.
- Fund and work with existing services which have already established rapport with local communities.
- Provide equitable access to NDIS services in regional and remote areas.
- Undertake a comprehensive evaluation of the quality and suitability of psychosocial disability services and support for carers, including identifying and addressing systemic barriers preventing entry into the scheme.
- Meaningfully capture the voice of people with lived experience mental illness and psychosocial disability as well as their family and carers.

# Help people access and participate in the NDIS

## Improve the eligibility requirements and assessment

### Recommendations

- Build the NDIS network's capacity, knowledge and understanding of psychosocial disability and recovery principles.
- Apply flexibility in demonstrating proof of eligibility for individual funding packages.
- Review the NDIS eligibility criteria and make support available to refugees and asylum seekers.

## Build the NDIS network's understanding of psychosocial disability and recovery principles

Permanence of impairment and a mandate for life time support are terms embedded in NDIS legislation as preconditions for determining eligibility<sup>3</sup>. As a consequence, those who do not identify as having a disability or cannot reconcile compatibility between permanence and the recovery model, are less likely to attract funding under the NDIS.

*"Recovery is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness"*<sup>4</sup>

Mental health experts<sup>5</sup> and consumer and carer groups<sup>6</sup> report it is challenging to reconcile the language of permanent impairment with a recovery framework, because it limits opportunities of hope and optimism for people with mental health issues. A recovery framework is widely accepted

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<sup>3</sup> Federal Register of Legislation, *National Disability Insurance Scheme (Becoming a Participant) Amendment Rules 2016 (No. 2)*, Australian Government, 2016.

<sup>4</sup> M Slade and E Longden, 'Empirical evidence about recovery and mental health', *BMC Psychiatry*, 15:285, 2015, pg. 527.

<sup>5</sup> Mental Health Council of Australia, *Mental Health and the National Disability Insurance Scheme Position Paper*, 2013; B Bonyhady, 'Tides of change: the NDIS and its journey to transform disability support', *Newparadigm: the Australian Journal on Psychosocial Rehabilitation*, Summer 2014, 7-9; T M Williams, and G P Smith, 'Can the National Disability Insurance Scheme work for mental health?', *Australian and New Zealand Journal of Psychiatry*, 2014, 48(5): 391-394; M Slade and E Longden, 'The empirical evidence about mental health and recovery: how likely, how long, what helps', *Melbourne: MI Fellowship*, 2015.

<sup>6</sup> Victorian Mental Illness Awareness Council (VMIAC) and Tandem (Victorian peak body representing families and carers of people living with mental health challenges)

as mental health best practice,<sup>7</sup> and the National Disability Insurance Agency (NDIA) demonstrates a willingness to broaden the understanding of recovery framework in the NDIS. However, VCOSS members believe more could be done to embed a shared understanding of recovery in practice in the NDIS.

Formal, evidence based training for NDIS staff and partners designed in consultation with people with lived experience would aid in building an empathic understanding of the significance of language in recovery. It would also assist in demonstrating how NDIS tenets of choice and control and social inclusion facilitate recovery. As recommended by Mental Health Australia,<sup>8</sup> the NDIA could also consider developing a suite of operational tools and guidelines, which reflect the recovery framework to help implement the scheme effectively with participants with psychosocial disability. These could be developed to augment existing NDIS information offerings such as recovery fact sheets.<sup>9</sup>

Disability assessment for people with mental illness poses a more significant challenge than for other disability groups. This is due to the complexities associated with separating symptoms from impairment.<sup>10</sup> As episodes of disability or illness are not always immediately obvious, some people with episodic disability may appear 'well' to an outsider, invoking doubt and suspicion about the severity of their disability, and this may disadvantage them during eligibility assessments.

A deeper understanding of the impact of language and the 'hidden' nature of psychosocial disability across the NDIS network would assist in improving access for people with psychosocial disability. VCOSS members suggest developing a validated, standardised assessment instrument to quantify 'permanence' and the degree of functional impairment could assist the assessment process.<sup>11</sup> Furthermore, as outlined at the National Mental Health Consumer and Carer forum<sup>12</sup>, assessments undertaken for people with psychosocial disability could be better administered by people trained in the use of appropriate assessment instruments and by those who have knowledge of psychosocial disability issues including support requirements and available support resources.

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<sup>7</sup> A T Edgley, T Stickley, N Wright and J Repper, 'The politics of recovery in mental health: A left libertarian policy analysis', *Social Theory & Health*, 2012, 10(2): 121-140; A Nicholas and L Reifels, *Mental Health and the NDIS: A Literature Review*, 2014.

<sup>8</sup> Mental Health Australia, *The implementation and operation of the psychiatric disability elements of the National Disability Insurance Scheme: A recommended set of approaches*, Technical paper prepared by David McGrath Consulting on behalf of Mental Health Australia, p.33.

<sup>9</sup> NDIS, *Psychosocial disability, recovery*, <https://www.ndis.gov.au/medias/documents/heb/h21/8799160959006/Fact-Sheet-Psychosocial-disability-recovery-and-the-NDIS-PDF-774KB-.pdf>, accessed Feb 2017

<sup>10</sup> J C Wakefield, 'Disability and diagnosis: should role impairment be eliminated from DSM/ICD diagnostic criteria?', *World Psychiatry*, 2009, 8, 87-88

<sup>11</sup> Mind Australia, *Response to the Joint Standing Committee inquiry into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition*, 2017.

<sup>12</sup> National Mental Health Consumer and Carer Forum, 2011

## Apply flexibility in demonstrating proof of eligibility

The NDIS eligibility criteria draws upon a deficit based medical model; where application processes relies heavily on diagnostic evidence to confirm participation in ordinary life is substantially reduced. Such language processes further alienates it from a recovery model which includes a social process anchored in a strengths-based approach.

Additionally, the burden of proof is problematic for people who do not have a formal diagnosis, including younger people. It is challenging for people do not identify as having a disability or for those who cannot pay for or readily access medical reports and the necessary diagnostic evidence.

Enabling people to more easily meet the eligibility criteria by demonstrating their functional impairment, without a formal diagnosis, could help people successfully access the scheme. VCOSS members also suggest the scheme could permit third parties, such as service providers, to provide supporting evidence demonstrating a participant's eligibility.

## Review the NDIS eligibility criteria and make support available to refugees and asylum seekers

The NDIS is only available to people who are Australian citizens, permanent residents and people on protection special category visas.<sup>13</sup> This means some refugees and asylum seekers, including those on Temporary Protection Visas and people on Safe Haven Enterprise Visas will not be eligible.<sup>14</sup> This leaves them reliant on State-funded support services, but it is unclear if these systems can meet their needs in the transition to the NDIS. Many refugees and asylum seekers have experienced severe trauma, which can result in poor mental health and post-traumatic stress symptoms.<sup>15</sup> Extending eligibility criteria to include these groups, or developing other effective strategies to provide adequate support outside the NDIS would help refugees and asylum seekers with disability to help them manage their illness, develop life skills and build trust and engagement with the mainstream mental health system.

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<sup>13</sup> NDIS, Access requirements, <https://www.ndis.gov.au/people-disability/access-requirements>, accessed 21 February 2017.

<sup>14</sup> Refugee Council of Australia, [Victorian state disability plan 2017–2020](#), 2017.

<sup>15</sup> E van Ee, R J Kleber, M J Jongmans, T T M Mooren, and D Out, 'Parental PTSD, adverse parenting and child attachment in a refugee sample,' *Attachment & Human Development* Vol. 18 , Issue 3, 2016.

## Provide pre-assessment and pre-planning support

### Recommendations

- Provide pre-assessment support to help people understand the NDIS, check their eligibility and lodge an application.
- Provide pre-planning support to help people prepare for their planning session so the plan meets their needs.

People with psychosocial disability may face difficulties navigating and understanding the NDIS, be reluctant to engage with the NDIS or service system because of stigma surrounding mental illness, be unaware they are unwell or not identify with having a disability, or find the process intimidating or lack motivation to go through the application process.

Pre-planning workshops are being held for participants, their families and carers to prepare for their planning meetings, but VCOSS members report many people with psychosocial disability will require greater assistance to participate. Without adequate support to understand and access the scheme some people risk missing out on their support entitlement.

VCOSS members also raise concerns about the time lags between the application process, the planning process and being able to engage with services funded through the plan. For instance, VCOSS members in the Barwon launch site report delays of between four and six months between when a participant is assessed as eligible and their first plan being received. VCOSS members report people were unable to access funded mental health services during this transition period. It is crucial people with psychosocial disability and their carers can access services throughout this period and do not experience gaps in required services and support.

### Provide pre-assessment support

Providing mental health consumers and their carers with clear, accessible and non-stigmatising information about the NDIS process in a range of formats will help people prepare for the scheme.<sup>16</sup> However, some people will require additional assistance to understand and access the scheme.

To participate in the NDIS, consumers are required to complete an Access Request Form or can have a phone interview, if they are already receiving relevant disability services. Participants need to provide evidence they have, or are likely to have, a permanent psychosocial disability along with other relevant documents including proof of residency, address and age.

VCOSS members report the application form is lengthy and may be confusing for some consumers. The questions to determine functional assessment can also be invasive. Helping

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<sup>16</sup> Psychiatric Disability Services of Victoria (VICSERV), *Learn and Build in Barwon: The impact of the National Disability Insurance Scheme on the provision of Mental Health Services in the Barwon Launch site*, VICSERV, June 2015.

people prepare for the application process can help alleviate their stress and increase their chance of successfully entering the scheme. VICSERV's research in the Barwon launch site found services were filling this gap and providing substantial support to consumers to complete the forms, but this assistance was not billable to the NDIA.<sup>17</sup>

### Provide pre-planning support

Once a participant is eligible, they are invited to attend a planning interview. VCOSS members report some people will require assistance to prepare for this planning meeting so their plan includes the right mix of support. Feedback indicates people are attending meetings unprepared and unclear about the support they can request. Psychiatric Disability Services of Victoria (VICSERV) research in the Barwon launch site found mental health consumers experienced difficulties knowing and expressing their needs and goals and understanding what support they could receive through the NDIS.<sup>18</sup> They also experienced anxiety divulging personal issues to their planner, with whom they had no prior relationship.<sup>19</sup> Disability service providers surveyed through a recent NDIS evaluation also identified a need for pre-planning support.<sup>20</sup>

Funding pre-assessment support and pre-planning support for people who require greater assistance could help achieve better outcomes for participants and improve engagement. Lessons can be learnt from the Australian Capital Territory, where grants of up to \$1,000 were available to individuals to engage a planner to assist with pre-NDIS preparation and support<sup>21</sup> and the funded pre-engagement support in the Barwon launch site. Proactive outreach from planners along with access to independent advocates to help negotiate support would further help engage people with psychosocial disability.

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<sup>17</sup> Ibid.

<sup>18</sup> Ibid.

<sup>19</sup> Ibid.

<sup>20</sup> K Mavromaras, M Moskos, S Mahuteau, *Evaluation of the NDIS, Intermediate Report*, National Institute of Labour Studies, Flinders University, Adelaide, September 2016, p.36.

<sup>21</sup> ACT Community Services, Grants,

[http://www.communityservices.act.gov.au/disability\\_act/national\\_disability\\_insurance\\_scheme/grants](http://www.communityservices.act.gov.au/disability_act/national_disability_insurance_scheme/grants)

## Provide effective planning processes

### Recommendations

- Ensure NDIS planners are adequately skilled in psychosocial disability and how to support people with complex needs.
- Ensure planning meetings take place face-to-face, and provide sufficient time for meaningful plans to be developed.
- Engage carers and family members, advocates and key workers in the planning process to better identify the support needed for individuals and their carers.

### Ensure planners have adequate knowledge and skills in psychosocial disability

Ensuring NDIS planners have adequate knowledge and skills of psychosocial disability and the recovery approach is essential to developing meaningful plans. Being familiar with these concepts and using non-stigmatising language can help consumers feel more at ease when discussing their aspirations. It helps planners understand the impact of psychosocial disability on the participant's everyday functioning and the support required to meet their needs and achieve their goals.

VCOSS members working in the Barwon launch site report examples of planners lacking relevant knowledge, such as being unaware of the role of peer workers. They also cited numerous examples of plans which did not have appropriate support items to meet the needs of participants with psychosocial disability, such as allocating funding to personal care assistance and group activities, rather than capacity building support. In some of these cases group activities were not appropriate for the participant due to the nature of their mental health condition, and when participants indicated they did not wish to engage in group activities.

Providing all planners with comprehensive training could help build their capacity to work with people with psychosocial disability. Employing planners with expertise in psychosocial disability and having experts available to assist and support other planners within each region, could improve the planning process. Training in trauma informed practice could also help planners better assist people who have experienced trauma.

### Provide face-to-face meetings with adequate time to understand the plan

VCOSS members report a high number of planning meetings have occurred over the phone for people with psychosocial disability, including those with dual disability and complex needs. Conducting a planning session over the phone may prevent participants with a psychosocial disability from fully understanding or participating in the planning process, and makes assessment more difficult, potentially leading to poorly informed decision making. Members report instances where phone-based planning meetings have resulted in reduced support, and some cases where people were unaware the phone conversation constituted their planning meeting until they received their plan in the mail. The prevalence of phone planning appears to be driven by the NDIA striving to reach milestone targets for the number of people transitioning to the scheme.

The pace of the NDIS rollout should not come at the expense of quality. Providing people with face-to-face planning meetings is essential to providing a person-centered approach and ensuring people have the ability to identify their needs and goals and access the support they require.

Planning meetings require time for people to explore their aspirations and discuss how these can be achieved. In some cases, planning sessions may need several sessions. VCOSS members report cases where planning has been rushed, with people leaving planning meetings unclear about the support they will receive. In cases where people are not satisfied with their final plan, they can apply for a review, but VCOSS members report this process can be lengthy. Spending time to get the plan right can help avoid unnecessary reviews, and alleviate unnecessary stress.

### **Engage family, carers, advocates and key workers in the planning process**

Identifying and engaging family and carer involvement in NDIS planning meetings, as well as advocates or key workers, can also assist with the planning process. Carers and other key people often have valuable knowledge and understanding of the functional impact of the participant's psychosocial disability. Involving them in the planning process can help to effectively identify the participant's needs and support required. In some cases, outreach to identify and engage carers, particularly young carers, may be required to include them in the planning process. Some carers, such as older carers, carers who have a disability themselves, and carers from diverse cultural backgrounds, may require additional support to participate in the process.

Involving carers in planning can help identify their needs and support their wellbeing. This requires informing them of the options to submit a carer statement, arrange an individual planning meeting and understand the potential support available through NDIS packages to help them in their caring capacity.<sup>22</sup> Identifying the nature and extent of support can be particularly difficult where people with mental illness do not fully understand the support being provided by their families and carers.

VCOSS members report the planning process has not adequately engaged carers and considered their needs. Many carers in the trial sites report felt they received insufficient information about the NDIS and were unaware they could submit a carer statement, which describes the support they currently provide to the participant and the additional assistance that would help them sustain their caring role.<sup>23,24</sup> Some carers report experiencing reduced access to respite care and other support.<sup>25,26</sup>

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<sup>22</sup> Carers Australia and Mental Health Australia, *Mental Health Carers and the National Disability Insurance Scheme, Issues Paper*, January 2016.

<sup>23</sup> Ibid.

<sup>24</sup> B Kemp, S King, Z Paleologos, J Bellamy and J Mollenhauer, *Carers: Doing it Tough, Doing it Well*, Anglicare Diocese of Sydney, Social Policy and Research Unit, December 2016, p.40.

<sup>25</sup> Carers Australia and Mental Health Australia, *Mental Health Carers and the National Disability Insurance Scheme, Issues Paper*, January 2016.

<sup>26</sup> B Kemp, S King, Z Paleologos, J Bellamy and J Mollenhauer, *Carers: Doing it Tough, Doing it Well*, Anglicare Diocese of Sydney, Social Policy and Research Unit, December 2016, p.40.

## Deliver high quality, suitable services

### Recommendation

- Deliver high quality, suitable services to people with psychosocial disability under their NDIS package.

VCOSS members are concerned current NDIS prices will not sustain qualified mental health workers who can deliver effective support and rehabilitation services. This may affect the quality and effectiveness of services, compromising participants' wellbeing and recovery. Community Mental Health Australia's workforce research noted pricing was too low to employ skilled staff to undertake cognitive behavioral interventions.<sup>27</sup> Services operating in NDIS trial sites also identified mental health services and services for people with complex needs as under-priced.<sup>28</sup>

In particular, VCOSS members report current pricing structures do not reflect the skills required to support people with complex needs, including people who have experienced trauma. For instance, in some cases two workers are required for staff safety or to adequately manage the participant's behaviour. Funded 'support coordination' is available under NDIS plans to help participants connect and coordinate funded support but this support is 'time-limited'.<sup>29</sup> VCOSS members report some people with psychosocial disability will require ongoing assistance to help them manage their care and support, including the highest level of support: 'specialist support coordination'.

Mental health organisations are concerned 'a race to the bottom, where a less skilled workforce becomes a competitive advantage' will erode choice for those with psychosocial disability.<sup>30</sup> The viability of the NDIS is at risk if providers are unable to employ more highly trained workers due to pricing limits. VICSERV's submission further explores the impacts of the NDIS on the workforce.<sup>31</sup>

Reference packages provide a benchmark funding amount for people with similar support needs and characteristics and help determine what support is reasonable. The reference package for people with psychosocial disability is currently being developed, but is not yet complete.<sup>32</sup>

Developing an accurate reference package, with input from the community mental health sector, would help identify the suitable level and scope of support required to assist people with psychosocial disability, and better determine the appropriate pricing structure for this support. The funding package should be sufficiently flexible to meet the changing needs of clients with episodic and fluctuating mental health conditions.

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<sup>27</sup> Community Mental Health Australia (CMHA), *Developing the Workforce: Community Managed Mental Health Sector National Disability Insurance Scheme Workforce Development Scoping Paper*, Sydney Mental Health Coordinating Council, 2015.

<sup>28</sup> K Mavromaras, M Moskos, S Mahuteau, *Evaluation of the NDIS, Intermediate Report*, National Institute of Labour Studies, Flinders University, Adelaide, September 2016.

<sup>29</sup> NDIA, *NDIS Price Guide VIC/NSW/QLD/TAS, Valid from: 1 July, 11 July 2016*, p. 37.

<sup>30</sup> Mental Health Australia, *Letter to Disability Reform Council on 2017 Productivity Commission review on the NDIS*, 2016.

<sup>31</sup> VICSERV, *Submission to the joint standing committee on the NDIS, The provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition*, Melbourne, 2017.

<sup>32</sup> NDIS, *National Mental Health Sector Reference Group Sector Communiqué – October 2016*, <https://www.ndis.gov.au/NMHSRG-October-2016.html>, accessed 20 February, 2017.

# Provide service continuity for mental health consumers and carers ineligible for the NDIS

## Provide service continuity for mental health consumers ineligible for the NDIS

### Recommendation

- Adequately resource community mental health services outside the NDIS to support those ineligible for individual funding packages.

NDIS individual funding packages are targeted at people with severe and permanent psychosocial disability resulting from their mental health conditions, but there will be a large number of mental health consumers and their carers who do not meet the eligibility criteria. These people will continue to require support, but it is not yet clear what services will be available, or how this will be funded.

The Australian Government Actuary 2012 data estimates around 56,000 people with psychosocial disability will be eligible for individual funding packages, with an estimated 103,000 people with severe and persistent mental illness who are likely to need support but do not appear to be included in the NDIS. There is also an additional 321,000 people with episodic mental illness who may require some support.<sup>33</sup>

It is crucial a range of flexible services continue to be available to Victorians with mental illness and psychosocial disability who do not meet the eligibility for individual funding packages. This is a joint federal and state government responsibility. Without adequate support, people with mental health conditions' recovery and mental wellbeing is at risk, and it increases pressure on other health and social services, including the acute health, welfare and justice systems. Inadequate support is likely to increase reliance on family and carers.

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<sup>33</sup> Australian Government Actuary, *Review of National Disability Insurance Scheme Costings*, p. 13-14.

## Federal government programs

Under current arrangements, people with psychosocial disability deemed ineligible for the NDIS have access to federally funded support and services in the community through the Personal Helpers and Mentors (PHaMs) and Day to Day Living Programs. These services will gradually be replaced by the NDIS, conceivably leading to unintended gaps in service delivery.

For those who are eligible, diagnostic processes to access the NDIS are prohibitive for some people. PHaMs program practice principles outlined in the 2012 Resource Kit<sup>34</sup> acknowledge the benefit of enabling access without needing a diagnosis. This practice facilitates engagement for those who do not typically access traditional mental health services.

Under current access guidelines, VCOSS members report it is difficult to access the NDIS without a diagnosis. The withdrawal of programs such as PHaMs leaves those who are ineligible or unable to provide diagnostic evidence with limited options for ongoing community support, further excluding them.

There is also uncertainty about the ability of mainstream health services to fill this gap. Based on current guidelines, Primary Health Networks appear unable to commission psychosocial disability services. Continued access to flexible mental health services outside the NDIS are required to meet the support and recovery needs of this group.

## State-based community mental health

Victoria has a strong community mental health community sector, and has long provided treatment, support and rehabilitation services for people with serious mental illness, to help them manage their illness and build life skills. However, Victoria has allocated all its community-based mental health services funding toward the NDIS. Victoria is the only state to do this. In fact, other states such as NSW have recently increased their investment in community-based mental health<sup>35</sup>.

It remains unclear who will provide Victorians with mental health rehabilitation services, as rehabilitation is deemed outside the scope of the NDIS. State-funded clinical mental health services will continue to provide treatment services outside the NDIS. However they are not well-placed to provide rehabilitation services, because they are subject to legal frameworks for involuntary treatment. Community-based mental health services are best-placed to deliver rehabilitation services, because they respond to people coming to them voluntarily for these services.

Victoria's community-based mental health services need to be funded independently of the NDIS, alongside clinical and acute mental health treatment services. The community-based mental health sector estimates \$80-\$100 million is required to maintain the existing system in Victoria.

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<sup>34</sup> <https://www.google.com.au/webhp?sourceid=chrome-instant&ion=1&espv=2&ie=UTF-8#q=principles+of+PHaMS+program>, accessed 20.02.17

<sup>35</sup> NSW Government, *Strengthening mental health care in NSW*, 2015.

## ILC type activities

Many existing community-based mental health services align with the goals of the ILC framework. A number of Victorian mental health programs are in scope or under consideration to be rolled into the NDIS. The sector is still awaiting clarity on other programs, such as Mutual Support and Self Help, while the Victorian Government works with the NDIA to map program elements against funded ILC-related activity. VCOSS members are concerned some effective programs will be ineligible for ILC funding and it is unclear if they will continue to be funded through other mechanisms. Releasing a map of existing services and program elements against the ILC framework, and clarifying funding arrangements for those that do not meet the criteria, will help reduce uncertainty.

Even where current mental health services appear to meet the ILC framework, it is unclear if the same level of service will be available consistently across the state due to the nature and scope of ILC funding. ILC funding is grant-based which means coverage of programs across Victoria and Australia may be inconsistently offered and time-limited.

Due to the ambitious objectives and wide scope of the ILC, VCOSS members report allocated funding is likely to be insufficient to fill the gap for people with mental illness and their carers who are ineligible for NDIS plans. ILC funding will increase over the next four years, reaching \$132m nationally at full scheme in 2019-20.

The largest investment in the ILC is Local Area Coordinators (LACs). In theory, LACs in Victoria are meant to “work with non-participants as part of Information, Linkages and Capacity Building and work with community, providers and mainstream to build inclusion and awareness of the needs of people with disability”, as well as assisting people to develop and implement their plans.<sup>36</sup> However, VCOSS members report planning is the predominant feature of LACs’ roles due to the large workload, which means there is limited capacity to perform the other aspects of their role.

Providing ongoing funding for effective ILC-type activities and services would help ensure equitable access and consistent coverage of services. Effective Victorian-based initiatives should not be lost in the transition to the ILC.

VCOSS members want to ensure the value of the peer workforce is retained and strengthened. The peer workforce employs people with lived experience as mental health consumers or carers. They can be a trusted and credible source of information, and be more approachable than traditional mental health services, making people feel their experiences are valued and understood. This can reduce social isolation, combat stigma and improve service access.

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<sup>36</sup> NDIA, NDIS in Victoria, <https://www.ndis.gov.au/about-us/our-sites/VIC.html>, accessed 17 February 2017.

## Provide all mental health carers with respite and support

### Recommendation

- Ensure all mental health carers can access carer specific support and services that meet their needs, irrespective of whether the person they are caring for is eligible or ineligible for an NDIS individual funding package.

Carers provide invaluable support to people with mental health conditions and psychosocial disability. The annual replacement cost of care provided by informal mental health carers is estimated at \$13.2 billion.<sup>37</sup> Yet, this support is often provided at the expense of the carers' own health and wellbeing, and compromises their ability to participate in education, work or community activities.<sup>38</sup>

VCOSS members are concerned the transition to the NDIS may result in a reduction in respite and other carer specific support available to mental health carers of people who are eligible and ineligible for the NDIS individual funding packages. Funding for some carer support is in scope to transfer either in part or in full to the NDIS, including the Mental Health Respite: Carer Support programme and the Young Carer Respite and Information Service activities. It remains uncertain whether similar types and level of support will be available under NDIS individually funded support packages or through ILC services. It is also unclear which services will continue to be funded outside of the NDIS, including for carers of people with psychosocial disability aged 65 years and over.

To support mental health carers' wellbeing and allow them to continue in their caring role, all carers must have access to appropriate levels of carer specific support and services that meet their needs, irrespective of whether the person they are caring for is eligible or ineligible for an NDIS individual funding package. This includes access to general carer support, carer advocacy, counselling, and carer respite services. It is crucial the same level or type of support for carers is maintained both in the lead up to and following the full rollout of the NDIS.

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<sup>37</sup> University of Queensland, The economic value of informal mental health caring in Australia, Mind Australia, unpublished (expected release date March 2017).

<sup>38</sup> Australian Bureau of Statistics, Disability, Ageing and Carers, Australia: Summary of Findings, Cat. No. 4430.0, 2012.

## Improve system integration

### Recommendation

- Government act as a systems steward and manager, to better coordinate the interface between the NDIS and mental health and mainstream services.

Creating stronger referral mechanisms between the NDIS and other service sectors, including mental health services, mainstream health services, aged care and the broader disability sector can help support people to access the scheme. This relies on other services having a sound understanding of the NDIS and the support it can provide to people with psychosocial disability through both individual funding packages and ILC services.

VCOSS members also identified a role for government to act as systems steward and manager, to better coordinate the service elements for people with mental illness and psychosocial disability. Without effective coordination between NDIS packages, aged care, ILC activities, mainstream health services and state and federal funded programs for people with mental illness, it is likely people will 'fall through the cracks'.

# Engage people who are marginalised or have complex needs

VCOSS members report people who face multiple disadvantage or have complex needs are at greater risk of being underserved in the transition to the NDIS. Particular cohorts at greater risk of missing out on services include people with dual disability or dual diagnosis, Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse (CALD) backgrounds, lesbian, gay, bisexual, transgender, and intersex people, people experiencing homelessness, those involved in the justice or child protection systems, and people living in rural and regional Victoria. Moving to a market-based system for the NDIS increases the risk services will not adequately engage with hard-to-reach groups and people who are most vulnerable. Some people and communities may require additional and targeted assistance to understand and engage with the NDIS or other mental health services.

The independent evaluation of the NDIS supports these concerns, finding “people with mental health and psychosocial disability were more likely to report less choice and control over their support since becoming NDIS participants”.<sup>39</sup> Those most likely to experience reduced choice and control were ‘vulnerable NDIS participants’, people unable to effectively navigate the NDIS website and people less able to articulate their support needs.<sup>40</sup> The report also identified some people were experiencing poorer outcomes and reduced services since transitioning to the NDIS and those particularly at risk were “people with disability who were unable to effectively advocate for services on their own behalf, including some people with psychosocial disability or those people who struggled to manage the new and sometimes complex NDIS processes”.<sup>41</sup> People living in rural and remote areas also experienced more difficulties accessing disability support funded through their plans.<sup>42</sup>

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<sup>39</sup> K Mavromaras, M Moskos, S Mahuteau, Evaluation of the NDIS, Intermediate Report, National Institute of Labour Studies, Flinders University, Adelaide, September 2016, p.74.

<sup>40</sup> Ibid., p.74.

<sup>41</sup> Ibid., p.55.

<sup>42</sup> Ibid., p.55.

## Fund assertive outreach

### Recommendation

- Fund assertive outreach to identify and engage people who are disengaged or hard to reach to link them into appropriate support.

VCOSS members warn against the NDIA relying on internet and telephone contact as a means of communication and assuming people have the capacity and capability to apply for the scheme. For instance, VCOSS members report experiences of people with psychosocial disability not answering or returning phone calls or letters from the NDIA. People facing disadvantage may also have limited or no access to the internet or phone, or lack digital literacy required to find information or complete an Access Request Form. Up to a third of people experiencing severe mental health issues are also unlikely to engage in services.<sup>43</sup> Without proactive engagement and direct face-to-face contact, some people risk missing out on receiving services they are entitled to.

Undertaking assertive outreach can help identify and reach isolated people and communities who may otherwise not engage in the NDIS, especially those not currently accessing services. Adequate funding is required to perform this role, as it requires skilled and experienced workers, and can take substantial time to effectively identify and engage with people. While LACs can provide an outreach function, VCOSS members report they have limited ability to engage in outreach, as much of their time is consumed by developing individual plans. Similarly, ILC funding is limited, yet has a broad scope, and so it is unlikely the ILC could adequately perform the outreach function alone.

## Increase access to independent advocacy

### Recommendation

- Fund independent advocacy to assist people to access and participate in the NDIS and to help people ineligible for NDIS packages to access appropriate services.

Some people, such as young people leaving out-of-home care, may not have informal carers or family members available to assist them, or lack the skills or confidence to self-advocate. VCOSS members also report carers and family members experience difficulty navigating and understanding the system themselves, and may need help to advocate for their own rights.

Independent advocates can assist people with psychosocial disability and their carers to navigate the new system, understand their rights and entitlements under the NDIS, assist in preparing for

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<sup>43</sup> T Slade, A Johnston, M Teesson, H Whiteford, P Burgess, J Pirkis and S Saw, *The Mental Health of Australians 2: Report on the 2007 National Survey of Mental Health and Wellbeing*, May 2009, p.15

the NDIS planning process, and to access the internal and external review processes where required. Mental health consumers who received support and advocacy during the NDIS process were more likely to have a satisfactory plan.<sup>44</sup>

While some of the NDIS support funded through individual plans and the ILC may overlap with some support traditionally provided by advocacy services, people with disability will still require access to independent advocacy services. VCOSS members advise there is already substantial unmet demand for independent advocacy and this is likely to increase further as the NDIS rolls out. For instance, VCOSS members report disability advocacy services in the Barwon launch site have experienced substantial increase in demand that cannot be met.

Independent advocacy can also assist people who are ineligible or unable to access individual funding packages through the NDIS, to access appropriate services through other systems. Ongoing funding for systemic advocacy can also help identify and address systemic issues affecting the rights of people with psychosocial disability.

## Provide culturally safe and gender responsive services

### Recommendation

- Provide culturally safe, gender responsive planning and service delivery.
- Fund and work with existing services which have rapport with local communities.

People with mental illness from culturally and linguistically diverse backgrounds (CALD) and Aboriginal and Torres Strait Islander communities may face additional barriers accessing services. For instance, they may have low levels of English literacy, lack awareness or understanding about the NDIS and how to navigate the system, or may have a reluctance to access services due to cultural attitudes and stigma towards disability and mental health.<sup>45,46,47,48</sup>

Providing culturally safe service planning and service delivery, which uses appropriate concepts and language around mental health and disability inclusive practice, such as being open to working with carers or extended family, can help engage people from Aboriginal and CALD communities. Employing Aboriginal and CALD workers in NDIS roles and delivering comprehensive cultural competency training to LACs and other service staff could help improve the cultural safety of

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<sup>44</sup> Psychiatric Disability Services of Victoria (VICSERV), *Learn and Build in Barwon: The impact of the National Disability Insurance Scheme on the provision of Mental Health Services in the Barwon Launch site*, VICSERV, June 2015.

<sup>45</sup> Ethnic Communities Council of Victoria, *Talking Disability: under-representation of culturally diverse communities in disability support*, 2014.

<sup>46</sup> First Peoples Disability Network (Australia), *Ten-point plan for the implementation of the NDIS in Aboriginal and Torres Strait Islander Communities*, <http://fpdn.org.au/ten-point-plan-for-the-implementation-of-the-ndis-in-aboriginal-communities/>

<sup>47</sup> J Barney, "Listen Up" *Aboriginal & Torres Strait Islander people with disabilities living in Victorian yarns: Discussion on the Victorian State Disability Plans Discussion Paper 2017-20*, Victorian Council of Social Service, June 2016.

<sup>48</sup> Federation of Ethnic Communities' Councils of Australia, *Access and Equity in the Context of the National Disability Insurance Scheme*, <http://fecca.org.au/wp-content/uploads/2015/06/Access-and-Equity-in-the-Context-of-the-National-Disability-Insurance-Scheme-June-2015.pdf>

services. Providing gender responsive services will also help the NDIS and broader mental health system to be accessible to all members of the community.

Providing accessible and culturally appropriate information in different languages and through trusted sources can also help raise the community awareness of the NDIS and mental health support services. Aboriginal Community Controlled Organisations and CALD-specific and multicultural mental health organisations have strong existing relationships with local communities. Funding these organisations to deliver ILC activities, and encouraging LACs to work collaboratively with these organisations to perform outreach and help people access and participate in the scheme could help increase the reach into these communities. VCOSS members also suggest exploring the ability of LACs in commissioning these services to undertake outreach work. Providing access to interpreters would also assist people to access the NDIS.

## Provide equitable service coverage in rural and remote areas

### Recommendation

- Provide equitable access to NDIS services in regional and remote areas.

The market-driven nature of the NDIS may leave gaps in service delivery, particularly in rural and regional areas. VCOSS members advise some rural areas are already underserved, and shifting from the block funding model may make this worse. For instance, the cost of delivering NDIS services and ILC activities are likely to be higher in regional and remote parts of Australia as they lack economies of scale and may incur higher travel expenses. There is also a risk NDIS services and ILC activities will lack a physical presence in regional and remote areas, relying instead on fly-in-fly-out or drive-in-drive-out practices, or using remote service delivery, such as teleconferencing.

Providing adequate face-to-face service coverage in regional and remote locations will help people with psychosocial disability access the support they require. Providing equitable service coverage may require several strategies, including ensuring NDIS pricing reflects the true costs of service delivery in rural, regional and remote areas, along with 'developing the market' and building local expertise, where required.

## Meaningfully evaluate the outcomes of the NDIS

### Recommendation

- Undertake a comprehensive evaluation of the quality and suitability of psychosocial disability services and support for carers, including identifying and addressing systemic barriers preventing entry into the scheme.
- Meaningfully capture the voice of people with lived experience mental illness and psychosocial disability as well as their family and carers.

Undertaking a comprehensive evaluation of the quality and suitability of psychosocial disability services and support for carers will help determine gaps and systemic issues and inform improvements. This could include an ongoing review of which people are accessing the scheme and which are missing out, to help identify and address systemic barriers preventing entry. It could also help identify if services outside the scheme are accessible and adequately meeting the needs of people ineligible for individually funded packages, to ensure people do not fall through the gaps. This requires accurate and detailed data collection.

It is crucial the evaluation methodology includes meaningful ways of capturing the voice of people with lived experience of mental illness and psychosocial disability as well as their family and carers. Yet, VCOSS members report their voices have not been heard in the implementation of the NDIS in the Barwon launch site.<sup>49</sup>

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<sup>49</sup> Psychiatric Disability Services of Victoria (VICSERV), *Learn and Build in Barwon: The impact of the National Disability Insurance Scheme on the provision of Mental Health Services in the Barwon Launch site*, VICSERV, June 2015.



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