

# Funding the NDIS in full

VCOSS submission to the Productivity Commision's review of NDIS costs April 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.

## **Contents**

Executive Summary	2
Recommendations	4
Guarantee access for eligible people	5
Provide pre-assessment and pre-planning support	6
Fund assertive outreach	7
Increase access to independent advocacy	8
Provide culturally safe services	9
Provide gender responsive services	10
Provide equitable service coverage in rural and remote areas	10
Refine eligibility requirements and assessment	11
Develop tailored plans meeting people's needs and aspirations	12
Build skills and knowledge of diverse disability in the NDIS	12
Engage family, carers, and advocates in planning	16
Make plans adaptable	17
Provide service continuity during planning	17
Reflect service quality in pricing	18
Support a qualified and experienced workforce	18
Reflect quality services in prices	19
Resource the NDIS to support participants with complex needs	20
Adequately fund travel to deliver services	21
Improve the interface between the NDIS and mainstream services	22
Provide service continuity for ineligible people with disability and their carers	23
Provide coordinated supports across the NDIS and mainstream services	25

## **Executive Summary**

The Victorian Council of Social Service (VCOSS) welcomes the opportunity to comment on the Productivity Commission's review of NDIS costs. The NDIS is a major social reform promising to increase support available for eligible people with disability to gain greater control over their lives. However, NDIS design and resources affect whether it will achieve improved social and economic inclusion for people with disability.

VCOSS believes this review should genuinely estimate the resources required for the scheme to achieve its goals, regardless of previous estimates. It should not be an exercise in cutting back the scheme to fit a pre-determined funding envelope. There is no point in replacing the existing underresourced service system with another underfunded scheme, which will similarly fail people with disability. Instead, this review should genuinely consider the system elements and resources required for the NDIS to be implemented effectively.

The Commonwealth, state and territory governments agreed to a review of NDIS costs in 2012 and 2013 to inform the final scheme's design. However, this review is producing great trepidation from people with disability and service providers, given recent Federal Government and media attention on NDIS cost pressures, such as higher than expected numbers of participants entering the scheme and increasing package costs. People fear the review could reinforce a perceived shift away from viewing the scheme as an investment in people with disability, to become a cost to be controlled.

This submission draws on evidence and VCOSS members' first hard experience from the NDIS launch and early rollout sites. It makes recommendations to help the NDIS deliver its promise, and ensure no person with disability or their carers are worse off after the transition, regardless of their NDIS eligibility.

The submission focuses on four key areas:

## Guarantee access for eligible people

Some people risk missing out on their support entitlement because they don't know they are eligible, or have difficulty navigating entry or planning processes. People with disability need targeted assistance to access and participate in the NDIS, particularly people who face multiple disadvantage or have complex needs. Providing assertive outreach, access to independent advocacy and pre-planning support for some people can mitigate this risk, alongside equitable provision of culturally safe, gender responsive planning and services across Australia.

<sup>&</sup>lt;sup>1</sup> National Disability Insurance Scheme, COAG Disability Reform Council Quarterly Report, December 2016, Version 1, National Disability Insurance Scheme Launch Transition Agency, January 2017, pp.4 and 84.

## Develop tailored plans meeting people's needs and aspirations

It requires time to holistically assess participant's needs, goals and aspirations and determine which supports are most suitable. Planners require adequate knowledge and skills of different types of disability to determine what is reasonable and necessary, including accommodating the episodic nature of some participants. Enabling participants to bring key supports with them to planning meetings and actively engaging carers can help provide a more comprehensive and accurate assessment.

## Reflect service quality in pricing

NDIS participants' service quality and diversity may be compromised if prices do not reflect the true costs of delivering services, including adequate supervision, administration, travel and professional development. Having an accurate and flexible NDIS pricing structure helps sustain a qualified and experienced disability workforce. People with complex needs may require greater support, such as outreach, workers with specialist skills, or two workers attending support sessions. Underpriced supports risk creating service gaps for clients with the highest support needs.

## Improve the interface between the NDIS and mainstream services

Providing mainstream service continuity outside the NDIS helps ensure ineligible people with disability and their carers do not miss out on services. The NDIS needs better integration with mainstream systems such as education, health, justice, travel, family violence, child and family services, and housing. In particular, services deemed outside the scope of the NDIS require guaranteed funding so people with disability receive all necessary and reasonable supports. It is of little use to a person with disability for their support to be declared out of scope of the NDIS, when the mainstream service system does not provide it. Current arrangements risk neither system will fund particular supports.

Getting the design of the NDIS right may require increased upfront investment, but will deliver better outcomes for people with disability, their families and carers. Further medium and long-term savings may be achieved in mainstream service systems such as education, employment, justice and health.

## Recommendations

## Guarantee access for eligible people

- 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.
- Fund assertive outreach to identify and directly engage hard to reach people and link them with 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, planning and service delivery.
- Fund and work with existing services which have rapport with local communities.
- Provide gender responsive planning and service delivery, including the capacity to identity and respond to the risk of violence and abuse in all its forms in the NDIS
- Provide equitable access to NDIS services in regional and remote areas.
- Build the capacity, knowledge and understanding of psychosocial disability and recovery principles in the NDIS.
- 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.

## Develop tailored plans meeting people's needs and aspirations

- Build the capacity, knowledge and understanding of all types of disability in the NDIS, including the early childhood early intervention approach and psychosocial disability.
- Adequately resource the planning process to enable face-to-face meetings and sufficient time to develop plans.
- Include support people in planning meetings.
- Assess and support carers' needs during planning.
- Ensure plans can respond to the episodic nature of some disabilities and respond to changing circumstances of participants.
- Provide participants with service continuity while plans are developed or renewed.

#### Reflect service quality in pricing

- Review the pricing structure to ensure it is funded at a rate commensurate with the skills and expertise required to deliver effective support.
- Review prices to reflect quality service delivery, including adequate supervision, administration and professional development.
- Cover the costs of providing support to participants with complex needs.
- Adequately fund travel costs to enable high quality, equitable service delivery.

## Improve the interface between the NDIS and mainstream services

- Adequately fund mainstream services outside the NDIS, to ensure ineligible people with disability and their carers do not miss out on services.
- Better coordinate the interface between the NDIS and all mainstream service and guarantee funding for services deemed outside the NDIS so NDIS participants can receive all necessary and reasonable supports.
- Fund collaboration meetings to enable NDIS workers and mainstream services to coordinate participant's supports.

## Guarantee access for eligible people

The NDIS is meant to cover all eligible Australians. It is unfair and unjust if the most vulnerable and marginalised people with a disability are excluded or under-serviced by the NDIS due to its administrative procedures.

For the majority of participants, the NDIS has improved choice and control, and increased access to services. However, around one third report their service quality has not changed and "15 per cent felt that it has become worse." "Vulnerable NDIS participants" were most likely to experience reduced choice and control. They are people unable to effectively navigate the NDIS website and are less able to articulate their needs.<sup>3</sup>

"People with disability who were unable to effectively advocate for services on their own behalf" were at greater risk of experiencing poorer outcomes and reduced services since transitioning to the NDIS. This includes "some people with psychosocial disability or those people who struggled to manage the new and sometimes complex NDIS processes". People living in rural and remote areas also experienced more difficulties accessing disability support funded through their plans. Substantially fewer women with disability (36.4 per cent) entered the NDIS compared with men (63.3 per cent).

This may be partly due to transitional problems in the rollout, but the final NDIS design should ensure people are not worse off after the NDIS transition, and the scheme is equally available to eligible people. Some people and communities require additional, targeted assistance to understand and engage with the NDIS, particularly those facing multiple disadvantage or have complex needs. Particular cohorts at greater risk of being underserviced 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
- · people experiencing family violence
- those involved in the justice or child protection systems
- people living in rural and regional Australia.

<sup>&</sup>lt;sup>2</sup> K Mavromaras, M Moskos, S Mahuteau, *Evaluation of the NDIS, Intermediate Report*, National Institute of Labour Studies, Flinders University, Adelaide, September 2016, p.28.

<sup>3</sup> Ibid., p.74. 4 Ibid., p.55.

<sup>5</sup> Ibid., p.55.

<sup>6</sup> Ibid., p.55.

<sup>&</sup>lt;sup>7</sup> National Disability Insurance Scheme, COAG Disability Reform Council Quarterly Report, December 2016, Version 1, National Disability Insurance Scheme Launch Transition Agency, January 2017, p.48.

## 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.

Despite preparatory work, there remains widespread confusion about who is eligible for the NDIS and how to access and participate in the scheme. This includes among people with disability and their families and carers, mainstream services and disability organisations. People with disability, particularly those with complex needs, are facing difficulties navigating and understanding the NDIS, be reluctant to engage with the NDIS because of stigma surrounding disability or mental illness, or find the process intimidating and overwhelming.

VCOSS members report the application process is bureaucratic and confusing for some people. The functional assessment questions can be invasive. NDIS administrative processes take longer than previous disability service arrangements. Without adequate support, this can be a barrier and stressor for some participants, their families or carers. In the Barwon launch site, services provided substantial support to mental health consumers to complete forms, but this assistance was not billable. Funding to help people prepare their applications can help alleviate stress and increase successful entry.

Once a participant is deemed eligible, they are invited to attend a planning interview. VCOSS members report many people attend meetings unprepared, and unclear about the types of support available. For instance, in the Barwon launch site, mental health consumers experienced difficulties knowing and expressing their needs and goals and understanding what support they could receive. Disability service providers also identify a need for pre-planning support. Assisting people with adequate planning meeting preparation can help them better articulate their goals and aspirations and get the right mix of support. For example, in the Australian Capital Territory, grants of up to \$1,000 were available to individuals to engage a planner to assist with pre-NDIS preparation and support, and the pre-engagement support was funded in the Barwon launch site. Educating mainstream and disability services about the NDIS can help them provide supported referrals.

This is not just a transition to scheme rollout issue. There will be an ongoing need for preassessment and pre-planning support for people with disability who have complex needs.

<sup>&</sup>lt;sup>8</sup> K Mavromaras, M Moskos, S Mahuteau, *Evaluation of the NDIS, Intermediate Report*, National Institute of Labour Studies, Flinders University, Adelaide, September 2016, p.xi. *Evaluation of the NDIS, Intermediate Report* 

<sup>&</sup>lt;sup>9</sup> Ibid. <sup>10</sup> Ibid.

<sup>&</sup>lt;sup>11</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>&</sup>lt;sup>12</sup> ACT Community Services, Grants,

 $http://www.communityservices.act.gov.au/disability\_act/national\_disability\_insurance\_scheme/grants$ 

## **Fund assertive outreach**

#### Recommendation

 Fund assertive outreach to identify and directly engage hard to reach people and link them with support.

The NDIA largely relies on the internet for conveying information about the NDIS, particularly for people who are not already accessing disability services. VCOSS members warn against overreliance on this avenue, and assuming people have the capacity and capability to apply. Online communication does not reach everyone, particularly those most marginalised. People with disability and those facing disadvantage are more likely to have limited or no access to the internet, accessibility issues, are lack the digital literary required to find information or apply for the scheme.

Phone calls and letters from the NDIA may also be problematic for people with complex needs and mental health conditions. For instance, VCOSS members report experiences of people with psychosocial disability being confused and concerned when contacted by the NDIS, and not answering or returning phone calls or letters. 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. For instance, up to a third of people experiencing severe mental health issues are unlikely to engage in services. <sup>15</sup> 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 people. VCOSS members report that while current block-funded services are undertaking some of this work, there is no identified funding source for this outreach role once funding is individualised.

While Local Area Coordinators (LACs) can provide an outreach function, VCOSS members report they have limited ability to engage in outreach, as they are required to prioritise developing individual plans.

<sup>&</sup>lt;sup>13</sup> Women with Disabilities Victoria and Self Advocacy Resource Unit, Your Say, Your Rights: A Project about Information and Communication Technology and Women with Disabilities, Melbourne, Australia, 2012.

<sup>&</sup>lt;sup>14</sup> G Goggin, S Hollier, and W Hawkins, *Internet accessibility and disability policy: lessons for digital inclusion and equality from Australia*, Internet Policy Review, 6(1), 2017.

<sup>&</sup>lt;sup>15</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

## 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.

Access to free, independent advocates can assist people with disability and their carers to navigate the new system, understand their NDIS rights and entitlements, assist in NDIS planning preparation, and access internal and external review processes when required. For instance, mental health consumers who received support and advocacy during the NDIS process were more likely to have a satisfactory plan. Retaining specialist advocacy services with expertise in different diagnostic and specific population groups can help people get tailored assistance.

Independent advocacy is particularly beneficial for participants who cannot self-advocate, such as people with complex needs, those experiencing disadvantage, or those with trouble articulating their needs due to their nature of their disability, such as people with complex communication needs or cognitive disabilities. It also assists people without informal carers or family members able to assist them, such as young people leaving out-of-home care. 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.

VCOSS members advise there is substantial unmet demand for independent advocacy, and this is likely to increase 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 assist people with disability and their carers access appropriate services through other systems, where they are ineligible or unable to access individual funding packages through the NDIS. Permanent funding for systemic advocacy can also help identify and address systemic issues affecting the rights of people with disability and their carers.

<sup>&</sup>lt;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.

## Provide culturally safe services

#### Recommendations

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

People with disability from culturally and linguistically diverse backgrounds (CALD) and Aboriginal and Torres Strait Islander communities face additional barriers to service. They may mistrust government services, be unaware or misunderstand the NDIS navigating it, have low levels of English proficiency, feel uncomfortable sharing personal information, or have a reluctance to access services due to cultural attitudes and stigma towards disability and mental health. 17,18,19,20,21

Culturally safe service planning and delivery uses culturally appropriate concepts and language around disability, such as focusing on 'health and wellbeing'22 and demonstrates inclusive practice, such as working with carers or extended kinship networks. This can better assist people from Aboriginal and CALD communities participate in the NDIS. Employing Aboriginal and CALD workers, including bilingual staff in NDIS roles, and delivering comprehensive cultural competency training to planners and other service staff, can help improve the culturally safety of services.

Aboriginal people and people from CALD backgrounds are more likely to engage with trusted people and existing community networks with whom they already have rapport, such as Aboriginal Community Controlled Organisations and CALD-specific health and disability organisations. Resourcing and working with local CALD and Aboriginal communities to develop engagement strategies, perform outreach and deliver services could help increase their NDIS access and participation. This is not currently funded through the LAC program and it is unclear if the Information Linkages and Capacity Building (ILC) will address this.

Providing accessible and culturally appropriate information in different languages can also help reach more people. Existing information about the NDIS was identified as too generic and not easily accessible to Aboriginal and CALD people.<sup>23</sup> Providing access to qualitied interpreters, who have a good understanding of the NDIS, would also assist people access and participate in the scheme. VCOSS members report people can access interpreters and translating services through the initial planning process but experience difficulties and inconsistencies getting interpreters included in their plans to help them access services.

23 Ibid.

<sup>&</sup>lt;sup>17</sup> Ethnic Communities Council of Victoria, Talking Disability; under-representation of culturally diverse communities in disability support,

<sup>18</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>19</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>&</sup>lt;sup>20</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/Acc -and-Fauity-in-the-Context-of-the-National-Disability-Insuranceheme-June-2015 pdf

<sup>&</sup>lt;sup>21</sup> NCOSS, Plan first don't 'retrofit': Delivering on the promise of the National Disability Insurance Scheme (NDIS) for Aboriginal and CALD people in NSW, 2016. <sup>22</sup> Ibid.

## Provide gender responsive services

#### Recommendation

• Provide gender responsive planning and service delivery, including the capacity to identity and respond to the risk of violence and abuse in all its forms in the NDIS.

Providing gender responsive services, and ensuring practices are sensitive to the needs of lesbian, gay, bisexual, transgender and intersex people can help the NDIS be accessible and safe for everyone. This includes allowing participants to select the gender of their support worker, especially for personal care or other high risk services.

Women with disabilities experience higher levels of all forms of violence than other women and are subjected to violence by a greater number of perpetrators. Over one third of women with disabilities experience some form of intimate partner violence and more than 70 per cent have been victims of sexual violence at some point in their lives.<sup>24</sup> Building the skills of NDIS planners, other agency staff, and disability services to identify and appropriately respond to family violence and risk of abuse, neglect and violence in all its forms, including emotional, physical, sexual and financial, can provide early intervention and help prevent violence or abuse from occurring.

## Provide equitable service coverage in rural and remote areas

#### Recommendation

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

To date, NDIS participants living in rural or remote areas are 15 per cent more likely to experience unmet demand for supports, compared with participants living in metropolitan areas. <sup>25</sup> VCOSS members advise some rural areas are already underserviced, and introducing individualised funding may lead to unintentional service gaps. 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. This is particularly the case for specialist services, which may lack the scale to operate outside metropolitan areas. Organisations report difficulties and additional costs involved with recruiting staff with specialist experience and qualifications. Rural and regional NDIS services and ILC activities risk losing 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 disability access the support they require. VCOSS members suggest the NDIA resource and support local organisations who have existing relationships in communities to provide adequate service coverage. This may require several strategies, including ensuring NDIS pricing reflects the

<sup>&</sup>lt;sup>24</sup> Women with Disabilities Australia, University NSW and People with Disabilities, *Stop the Violence: Improving Service Delivery for Women and Girls with Disabilities*, 2013.

<sup>&</sup>lt;sup>25</sup> K Mavromaras, M Moskos, S Mahuteau, *Evaluation of the NDIS, Intermediate Report*, National Institute of Labour Studies, Flinders University, Adelaide, September 2016, p.31.

true costs of service delivery in rural, regional and remove areas, along with 'developing the market' and building local expertise, where required. For instance, VCOSS members suggest the NDIA incorporates a rural/regional loading which enables organisations to build their staff capacity.

## Refine eligibility requirements and assessment

#### Recommendations

- Build the capacity, knowledge and understanding of psychosocial disability and recovery principles in the NDIS.
- 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.

To access the NDIS people require proof of an impairment or condition likely to be permanent and severely affecting daily life.<sup>26</sup> This poses a barrier for mental health consumers, who must characterise their illness as permanent from which they are unlikely to recover. A recovery framework<sup>27</sup> is widely accepted as mental health best practice.<sup>28</sup> Requiring people to identify as having a 'permanent' psychosocial disability can create stigma, distress and limit people's hope and optimism. Building capacity, knowledge and understanding of psychosocial disability and recovery principles could help embed shared understanding of recovery in practice.<sup>29</sup>

The application process relies heavily on diagnostic evidence, making applications difficult for people with psychosocial disability who do not have a formal diagnosis, particularly 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 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. For instance permitting third parties, such as service providers, to provide supporting evidence demonstrating a participant's eligibility.

The NDIS is only available to people who are Australian citizens, permanent residents and people on protection special category visas.<sup>30</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>31</sup> Extending eligibility criteria to include these groups, or developing other means of supporting them outside the NDIS would help refugees and asylum seekers with disability get the assistance they require.

Funding the NDIS in full

<sup>&</sup>lt;sup>26</sup> Federal Register of Legislation, *National Disability Insurance Scheme (Becoming a Participant) Amendment Rules 2016 (No. 2)*, Australian Government, 2016.

<sup>&</sup>lt;sup>27</sup> 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

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.
 VCOSS, Delivering high quality services for all mental health consumers: VCOSS Submission to the Joint Standing Committee on the NDIS, February 2017.

<sup>&</sup>lt;sup>30</sup> NDIS, Access requirements, <a href="https://www.ndis.gov.au/people-disability/access-requirements">https://www.ndis.gov.au/people-disability/access-requirements</a>, accessed 21 February 2017.

<sup>&</sup>lt;sup>31</sup> Refugee Council of Australia, Victorian state disability plan 2017–2020, 2017.

# Develop tailored plans meeting people's needs and aspirations

VCOSS is concerned the planning process is being compromised, including lacking proper consultation, planning taking place primarily by telephone, inadequate skills of planners to determine suitable support, and poor engagement with families, carers and advocates. Poor planning processes compromises the quality and suitability of support, and contributes to plan underutilisation. Qualitative data from the NDIS evaluation identified some NDIS participants were receiving less support than prior to entering the NDIS.<sup>32</sup>

If people are not satisfied with their plan, they can apply for an internal review of a decision, and if necessary escalate this to the Administrative Appeals Tribunal. However, VCOSS members report this process can be confusing and time-consuming, taking months to resolve. Over 70 per cent of complaints brought to the Administrative Appeals Tribunal relate to participant's plans,<sup>33</sup> with most decisions resolved by plan amendments in favour of the participant.<sup>34</sup> Upfront investment to develop suitable plans can help avoid unnecessary and costly review processes, alleviate stress and improve outcomes.

## Build skills and knowledge of diverse disability in the NDIS

### Recommendations

• Build the capacity, knowledge and understanding of all types of disability in the NDIS, including the early childhood early intervention approach and psychosocial disability.

VCOSS members report there are varied skill levels among planners, with inadequate training and experience from some planners contributing to poor plans being developed. VCOSS members report numerous examples where limited understanding of particular types of disability led to inappropriate plans being developed. For instance:

 A deaf participant with cochlear implants was allocated two hearing aids in their package, despite hearing aids being ineffective for people with cochlear implants. Fortunately, this error was picked up by the senior LAC manager, who is deaf herself, but would otherwise have required onerous processes to amend the plan.

<sup>&</sup>lt;sup>32</sup> K Mavromaras, M Moskos, S Mahuteau, *Evaluation of the NDIS, Intermediate Report*, National Institute of Labour Studies, Flinders University, Adelaide, September 2016, p.37.

<sup>&</sup>lt;sup>33</sup> National Disability Insurance Scheme, COAG Disability Reform Council Quarterly Report, December 2016, Version 1, National Disability Insurance Scheme Launch Transition Agency, January 2017, p.40.

<sup>&</sup>lt;sup>34</sup> National Disability Insurance Scheme, COAG Disability Reform Council Quarterly Report, December 2016, Version 1, National Disability Insurance Scheme Launch Transition Agency, January 2017, p.40.

- Some people with psychosocial disability are being allocating funding for personal care
  assistance and group activities, rather than capacity building support. In some of these
  cases group activities were inappropriate due to the participant's mental health condition,
  and participants did not wish to engage in group activities.
- Some plans for children aged 0-6 focus lower cost centre-based therapies rather than services in children's familiar settings, such as in the home, community or early childhood settings. Best practice for early childhood intervention involves engaging children in daily routines in familiar learning environments.<sup>35</sup>

VCOSS is concerned the NDIS is over-reliant on reference packages to decide support, without sufficient attention to participants' goals and aspirations. VCOSS members also report plans are skewed to providing for daily support needs over improving people's independence. For example, an advocacy organisation reported five people with similar disabilities recently went through the planning process in the North East Metropolitan Area. Their plans were almost identical and did not reflect the participants' highly divergent individual goals and aspirations.

Local Area Coordination (LAC) organisations report the NDIA has provided limited training. Almost 550 LACs were to be trained by June 2016, but less than a third had completed an online training-program and only 10 per cent had completed face-to-face training.<sup>36</sup>

Planners with adequate knowledge and skills of all types of disability, and asking appropriate questions, will help participants create suitable plans. This means training planners in the early childhood intervention approach best practice guidelines<sup>37</sup> for plans for children with disability or developmental delay. Building planners' skills in the recovery approach for psychosocial disability helps them determine the correct support required. Using non-stigmatising language also helps people feel more at ease when discussing their aspirations. Training in trauma informed practice could also help planners better assist people who have experienced trauma.

Employing planners with expertise in different disability types and having experts available to assist and support other planners within each region could complement training and further improve the planning process. Providing a base level of training would support workers share an understanding of different disability types.

<sup>&</sup>lt;sup>35</sup> Early childhood Intervention Australia, National Guidelines: Best Practice in Early Childhood Intervention, 2016.

<sup>&</sup>lt;sup>36</sup> D Conifer, National Disability Insurance Scheme rollout plagued with problems, FOI documents reveal, ABC News, March 2017.

<sup>&</sup>lt;sup>37</sup> Early childhood Intervention Australia, National Guidelines: Best Practice in Early Childhood Intervention, 2016.

## Provide face-to-face meetings with time to develop plans

#### Recommendation

 Adequately resource the planning process to enable face-to-face meetings and sufficient time to develop plans.

VCOSS understands most planning meetings now occur by telephone phone and some participants' plans are approved without consultation. Telephone planning sessions impede good communication and discussion, potentially leading to poor decision making. A single telephone conversation is a poor foundation to determine a person's needs. It is especially inappropriate for people with complex needs, people with low-English language skills, people with psychosocial disability and people who require assistance to articulate their needs and aspirations due to the nature of their disability, such as participants with complex communication needs, or with an intellectual disability.

For example, VCOSS has been alerted to phone-based planning sessions causing people's support to be cut, and cases where people were unaware the phone conversation constituted their planning meeting until received the plan by post.<sup>38</sup> VCOSS is concerned that phone-planning is being used as a 'short-cut' to reach targets with limited resources. A better approach can be employing more skilled planners, rather than compromising the quality of plans.

Face-to-face planning meetings allow time for people to explore their aspirations. In some cases, planning may need several sessions. Discussing the planning meeting in advance assists people prepare and allows them to organise relevant support people to be present. Participants should be given an opportunity to review and discuss plans before finalisation. For example, the following case study provides an example of best practice.

<sup>&</sup>lt;sup>38</sup> M Perkins, "It's like a five-year-old wrote it": disability advocates slam NDIS care plans, the Age, October 2016.

## Case Study: Tailoring to participant's aspirations

Laura\* is a new NDIS participant with Huntington's disease and a mental health condition. She lives in the family home in remote Tasmanian with her mother Sandra,\* her guardian and carer. Laura wants to live at home, but has trouble leaving the house and a limited social life. Laura's father died of Huntington's disease, and Laura has difficulty accepting her situation and requirement for "disability supports".

Her LAC contacted Laura and Sandra to arrange a face-to-face planning meeting at home to guide them on planning preparation, including thinking about Laura's goals and aspirations. They identified Laura is a passionate artist, and requires some home modifications to improve her mobility. Sandra requires respite from her caring role. Together a decision was made to employ an art mentor to regularly assist and motivate Laura with her art. They also agreed to include respite care, home modifications, and low-risk equipment in Laura's plan.

The LAC contacted other mainstream services, including the nurse assisting Laura to manage the Huntington's disease, and the service provider working on home modification, to coordinate their work. The LAC continued to liaise with Laura and Sandra to discuss and amend plan details as required.

Laura and Sandra elected to self-manage the plan, but engaged a third party 'plan manager' to manage financial transactions. This reduced the administrative burden while allowing Laura to employ and negotiate with known workers.

Sandra recently contacted the LAC to advise how happy they were with the supports they are receiving, including the art program, qualified respite carer and home modifications. Sandra stated the NDIS has been a positive experience with the capacity to enrich Laura's life.

The LAC is an experienced worker, being involved in the NDIS trial site and previously working as a state-based Local Area Coordinator before the NDIS. The LAC provider was also well established in the community having existing relationships with mainstream service. Taking the time to engage the family, including face-to-face visits despite lengthy travel, allowed the LAC to understand and tailor support suited to the needs and aspirations of both Laura and Sandra.

\*names changed to protect identify

## Engage family, carers, and advocates in planning

## Recommendations

- · Include support people in planning meetings.
- Assess and support carers' needs during planning.

Families, carers, advocates, and support workers often have valuable expertise, knowledge and understanding of the participant and the functional impact of their disability. Involving them in the planning process can help to effectively identify the participant's needs and support required.

Actively engaging carers in the planning process can help identify their needs and support their wellbeing. This requires informing carers 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>39</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.

Advocates and support workers are often excluded from planning, even when participants have explicitly requested their presence. VCOSS members also 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. One NDIS evaluation identified carer needs and were not addressed in the planning process. Some carers report cuts to respite care and other carer support. Anecdotal feedback suggests the level of informal care can affect support provided, meaning participants with high levels of informal care receive less formal support.

Planners often do not tell participants they can bring support people to NDIS planning meetings, including advocates, key workers, family members and carers. 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.

<sup>&</sup>lt;sup>39</sup> Carers Australia and Mental Health Australia, *Mental Health Carers and the National Disability Insurance Scheme, Issues Paper*, January 2016.

<sup>40</sup> Ibid.

<sup>&</sup>lt;sup>41</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>&</sup>lt;sup>42</sup> K Mavromaras, M Moskos, S Mahuteau, *Evaluation of the NDIS, Intermediate Report*, National Institute of Labour Studies, Flinders University, Adelaide, September 2016, p.xiv.

<sup>&</sup>lt;sup>43</sup> Carers Australia and Mental Health Australia, *Mental Health Carers and the National Disability Insurance Scheme, Issues Paper*, January 2016.

<sup>&</sup>lt;sup>44</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.

## Make plans adaptable

#### Recommendation

 Ensure plans can respond to the episodic nature of some disabilities and respond to changing circumstances of participants.

Plan flexibility can accommodate the changing needs of people with episodic disability, including mental health conditions. VCOSS members, and the mental health advocates, <sup>45</sup> believe the NDIS is not meeting people's fluctuating needs. VCOSS members report plans are rigid and it is difficult to adjust supports once in place. As a result, people with episodic conditions have to prepare for the worst case scenario, so they have adequate levels of support if required. This may also contribute to the rates of plans being underutilised.

Other NDIS participants experience changing circumstances and require flexible plans, or timely reviews, to match support with need. For instance, NDIS participants escaping family violence may require rapid crisis packages, or children involved in child protection moving between home and out-of-home care placements may require different supports for themselves and their families or carers.

## Provide service continuity during planning

#### Recommendation

• Provide participants with service continuity while plans are developed or renewed

There can be substantial time lags between the application and planning process and services actually being delivery. Periods without services can be harmful and cause people's conditions to deteriorate. For instance, during the last quarter around 30 per cent of participants did not receive the first plan until over 90 days from the time they are assessed as eligible. 46 VCOSS members report people could not access funded services during this transition period.

There can be delays of up to three months from when a participants' plan expires and their new plan is signed off. This leaves participants in a difficult situation where they require supports but there is no guarantee they will be able to purchase particular types of services until their new plan is agreed. VCOSS members report providers have continued to deliver services out of goodwill, but are unsure whether they will be able to recoup these costs. This issue could be resolved by timelier plan updates or extending existing plans where delays in renewing plans occur.

<sup>&</sup>lt;sup>45</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.

<sup>&</sup>lt;sup>46</sup> National Disability Insurance Scheme, COAG Disability Reform Council Quarterly Report, December 2016, Version 1, National Disability Insurance Scheme Launch Transition Agency, January 2017, p.48.

## Reflect service quality in pricing

VCOSS members report NDIA pricing is inadequate to cover overhead costs and sustain a qualified workforce. Community sector organisations report providing large quantities of unfunded support to participants, such as follow up and outreach work. VCOSS members report a low priced fee-for-service model is threatening service providers' financial viability, potentially compromising NDIS participants service quality and diversity. Services providers are currently absorbing financial losses, however, over time anticipate "their organisation would need to cease particular services when block funding ended."<sup>47</sup>

## Support a qualified and experienced workforce

## Recommendation

 Review the pricing structure to ensure it is funded at a rate commensurate with the skills and expertise required to deliver effective support.

VCOSS members are concerned current NDIS pricing structure will not sustain adequately qualified workers who can deliver effective support and therapeutic services. They suggest the standard hourly rate of \$42.79 and the high intensity rate of \$45.17<sup>48</sup> are too low to employ specialised or appropriately qualified workers and may result in employing less qualified staff. For instance, providers may not be able to pay staff award rates due to NDIA pricing constraints.<sup>49</sup> This in turn may affect the quality and effectiveness of service delivery.

This issue has been raised across the disability sector, but particularly for the skills and qualifications required to deliver mental health support and rehabilitation services, assist people with complex needs and deliver best practice<sup>50</sup> transdisciplinary early childhood interventions<sup>51</sup> For instance, Community Mental Health Australia's workforce research noted pricing was too low to employ skilled staff to undertake cognitive behavioral interventions.<sup>52</sup> Services operating in NDIS trial sites identified mental health services, one-to-one community participation and services for people with complex needs as under-priced.<sup>53</sup>

<sup>&</sup>lt;sup>47</sup> K Mavromaras, M Moskos, S Mahuteau, *Evaluation of the NDIS, Intermediate Report*, National Institute of Labour Studies, Flinders University, Adelaide, September 2016, p.53.

<sup>&</sup>lt;sup>48</sup> NDIS, NDIS Price Guide VIC/NSW/QLD/TAS, Valid from: 1 July 2016, 11 July 2016.

<sup>&</sup>lt;sup>49</sup> K Mavromaras, M Moskos, S Mahuteau, *Evaluation of the NDIS, Intermediate Report*, National Institute of Labour Studies, Flinders University, Adelaide, September 2016, p.48.

<sup>&</sup>lt;sup>50</sup> Early childhood Intervention Australia, National Guidelines: Best Practice in Early Childhood Intervention, 2016.

<sup>&</sup>lt;sup>51</sup> Early Childhood Intervention Australia Victoria/Tasmania, Submission to the Productivity Commission Review of NDIS Costs, 2017.

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.
 K Mavromaras, M Moskos, S Mahuteau, Evaluation of the NDIS, Intermediate Report, National Institute of Labour Studies, Flinders University, Adelaide, September 2016.

## Reflect quality services in prices

#### Recommendation

 Review prices to reflect quality service delivery, including adequate supervision, administration and professional development.

VCOSS members report the fee-for-service model makes it challenging for providers to employ staff on a permanent full-time or part-time arrangements, as they have to take on a financial risk of paying workers for 'non-billable' hours. The NDIS evaluation found working conditions were generally being maintained but "increased levels of precarious employment (in the form of casual and contract work) were reported for support workers". <sup>54</sup> A more casualised workforce may result in participants receiving a range of different workers rather than being able to build ongoing relationships with particular workers.

VCOSS members report the pricing caps and funding structure do not adequately cover the costs associated with ongoing professional development for staff, adequate supervision, rent, and administration required to deliver services under the NDIS. This is compounded by problems plaguing the NDIS portal. <sup>55,56</sup> Providers continue to report the portal is not user-friendly and they are still performing large quantities of unfunded work to manage the administrative and financial components of the NDIS, and to assist participants to use the NDIS portal. <sup>57</sup> It is particularly difficult for smaller providers to absorb these administrative costs. The funding structures do not allow services to perform outreach, collaboration with other service providers and secondary consultations, which are currently managed through block funding arrangements.

### Case study: 16 hours of unfunded support to assist a new participant

Paul\* was referred to Jesuit Social Services by the NDIA for support coordination. Paul has numerous, overlapping complex issues and an intellectual disability. At the time of referral Paul was 16-years-old, was in residential care and involved with the youth justice system.

Jesuit Social Services were required to meet with Paul to arrange a service agreement and begin providing support coordination. This meant registering Paul on the MyPlace NDIS participant portal (the portal). Regular and ongoing attempts were made to meet with Paul either at his residential home or at his school to facilitate this process, but he continuously absconded and avoided contact.

<sup>&</sup>lt;sup>54</sup> K Mavromaras, M Moskos, S Mahuteau, *Evaluation of the NDIS, Intermediate Report*, National Institute of Labour Studies, Flinders University, Adelaide, September 2016, p.46.

For PWC, National Disability Insurance Scheme, MyPlace Portal Implementation Review – Final Report, 31 August 2016
 ANC News, National Disability Insurance Scheme computer glitch hits services and payments, <a href="http://www.abc.net.au/news/2016-07-28/ndis-teething-problems-hit-system-and-online-payments/7667292">http://www.abc.net.au/news/2016-07-28/ndis-teething-problems-hit-system-and-online-payments/7667292</a>, accessed 28 March 2017.

<sup>&</sup>lt;sup>57</sup> K Mavromaras, M Moskos, S Mahuteau, *Evaluation of the NDIS, Intermediate Report*, National Institute of Labour Studies, Flinders University, Adelaide, September 2016, p.47.

Paul was then taken into custody and held on remand at a youth detention facility where he remained for several weeks. Further attempts to register Paul on the portal were made from the youth detention centre but restrictions around computer use, internet access and printing made this very challenging. Eventually the youth detention centre approved Paul's Jesuit Social Services worker bringing in a laptop to enable Paul to register on the portal.

After Paul was released from custody he forgot his log in details. These were retrieved after multiple contacts with his Jesuit Social Services worker.

At no point was the worker able to access Paul's plan, with the information necessary to establish a service coordination relationship on the NDIS portal. Paul faced various impediments to registering himself correctly on the portal, meaning he could not share his plan with his worker. As a result, Paul, had to read the plan aloud to share basic details.

To begin delivering support co-ordination, the worker spent approximately 16 hours of unpaid preparation and support work with Paul.

\*name changed to protect identity

## Resource the NDIS to support participants with complex needs

#### Recommendation

• Cover the costs of providing support to participants with complex needs.

VCOSS members report pricing limitations are particularly inadequate to meet the costs of delivering services to participants with complex and high support needs. For instance, in some cases two workers are required for staff safety or to adequately manage a participant's behaviour. Staff also require more specialised skills when supporting participants with complex needs, such as people with dual diagnosis, those who have experienced trauma and have challenging behaviours. Staff may also require higher levels or supervision and support from management.

People with psychosocial disability and complex needs may require more assistance to engage in services, such as outreach and more contact outside of scheduled meetings. They are less likely to attend scheduled appointments. Cancellation fees can only be charged eight times each year for personal care and community access support, and cannot be changed for therapeutic support.<sup>58</sup> This means organisations must absorb the costs.

<sup>&</sup>lt;sup>58</sup> NDIS, NDIS Price Guide VIC/NSW/QLD/TAS, Valid from: 1 July 2016, 11 July 2016.

Without adequate resourcing, the NDIS risks create disincentives for providers to assist participants with complex needs. This could mean services 'cherry pick' participants and leave some people with disability without services.

Some people, particularly those with complex needs or psychosocial disability will require ongoing assistance to help them manage their care and support by appropriately trained or experienced practitioners. Funded 'support coordination' is available under NDIS plans but this support is 'time-limited'.<sup>59</sup> Extending the time period participants are able to access support coordination, including the highest level of support: 'specialist support coordination' can better assist these participants.

## Adequately fund travel to deliver services

#### Recommendation

Adequately fund travel costs to enable high quality, equitable service delivery.

VCOSS members report NDIS pricing does not cover travel associated with service provision in some cases. Where support workers travel to a participant to deliver assistance with self-care activities, community participations and other supports, they can claim up to 20 minutes of travel time. VCOSS members report travel, even in metropolitan areas, can be up to an hour in between participants and providers are left to cover these costs. Inadequate travel costs may restrict participants' access to services.<sup>60</sup>

Different travel rules apply to therapeutic support, in recognition services may need to be engaged from outside the participant's geographical area. This travel is paid at the hourly rate, up to a maximum of \$1000 per year and remote travel will be paid in accordance with the NDIS pricing information.<sup>61</sup> The independent NDIS evaluation, identified concerns that funding limits for therapist travel may lead to reduced frequency of appointments for particularly those living in outer metropolitan areas.<sup>62</sup>

Travel costs associated with program of supports, including the transdisciplinary early childhood intervention are not payable as additional items<sup>63</sup> as they are considered to be included in the fixed cost. Again, VCOSS members also report the pricing limits are often inadequate to cover travel. <sup>64</sup> Best practice for early childhood early intervention involves delivering services in children's everyday environments, such as the home and community. Funding reasonable and necessary travel costs is essential to delivering effective early intervention supports to 0-6 year olds.

<sup>&</sup>lt;sup>59</sup> NDIA, NDIS Price Guide VIC/NSW/QLD/TAS, Valid from: 1 July, 11 July 2016, p. 37.

<sup>&</sup>lt;sup>60</sup> K Mavromaras, M Moskos, S Mahuteau, *Evaluation of the NDIS, Intermediate Report*, National Institute of Labour Studies, Flinders University, Adelaide, September 2016, p.53

<sup>61</sup> NDIS, Provider travel information, https://www.ndis.gov.au/provider-travel-information, accessed 28 March 2017.

<sup>&</sup>lt;sup>62</sup> K Mavromaras, M Moskos, S Mahuteau, *Evaluation of the NDIS, Intermediate Report*, National Institute of Labour Studies, Flinders University, Adelaide, September 2016, p.39-40.

<sup>63</sup> NDIS, Provider travel information, https://www.ndis.gov.au/provider-travel-information, accessed 28 March 2017.

<sup>&</sup>lt;sup>64</sup> Early Childhood Intervention Australia Victoria/Tasmania, Submission to the Productivity Commission Review of NDIS Costs, 2017.

# Improve the interface between the NDIS and mainstream services

Over one quarter of NDIS participants need to access unfunded services.<sup>65</sup> The most commonly accessed supports include therapies or behaviour and specialist interventions, leisure activities outside the home, group activities in the community and transport. The full list is included in figure 1 below. These supports were generally paid for by the family (50 per cent) or the participant directly (23 per cent)<sup>66</sup> highlighting service gaps for NDIS participants. This is particularly problematic for participants facing disadvantage who do not have the means to cover these costs. If mainstream services are not adequately resourced, there is also a risk people ineligible for individually funded packages will be worse off following the transition to the NDIS.

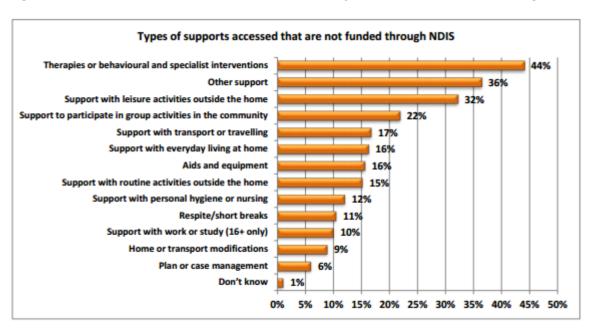


Figure 1: Non-NDIS funded supports accessed by NDIS participants of all ages

Source: K Mavromaras, M Moskos, S Mahuteau, *Evaluation of the NDIS, Intermediate Report*, National Institute of Labour Studies, Flinders University, Adelaide, September 2016, p.50.

<sup>&</sup>lt;sup>65</sup> K Mavromaras, M Moskos, S Mahuteau, *Evaluation of the NDIS, Intermediate Report*, National Institute of Labour Studies, Flinders University, Adelaide, September 2016, p. 50.

<sup>&</sup>lt;sup>66</sup> K Mavromaras, M Moskos, S Mahuteau, *Evaluation of the NDIS, Intermediate Report*, National Institute of Labour Studies, Flinders University, Adelaide, September 2016, p.29.

# Provide service continuity for ineligible people with disability and their carers

#### Recommendation

 Adequately fund mainstream services outside the NDIS, to ensure ineligible people with disability and their carers do not miss out on services.

NDIS individual funding packages are targeted at people with severe and permanent disability, or children aged under 6 years of age who meet the requirement for early intervention. VCOSS members fear many people with disability, who are ineligible for the NDIS will 'fall through the cracks'. Following the NDIS trial and early rollout sites some non-NDIS participants report receiving fewer services and others have received no supports at all.<sup>67</sup> Particular concerns were raised for mental health consumers and carers of people deemed ineligible for support.

## **Community based mental health services**

A large number of mental health consumers with moderate or severe conditions will not meet the eligibility criteria for the NDIS. These people will continue to require support, but it is not yet clear what services will be available, or how this will be funded.<sup>68</sup> 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 be included in the NDIS. An additional 321,000 people with episodic mental illness may also require some support.<sup>69</sup>

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

Adequately resourcing community mental health services outside the NDIS is a joint federal and state government responsibility. Without adequate support, people with mental health conditions' recovery and mental wellbeing is at risk. It will likely increases pressure on other health and social services, including the acute health, welfare, alcohol and other drugs and justice systems. Inadequate support is also likely to increase reliance on family and carers. This will cost much more in the longer term than adopting the 'insurance' approach of the NDIS.

<sup>&</sup>lt;sup>67</sup> K Mavromaras, M Moskos, S Mahuteau, *Evaluation of the NDIS, Intermediate Report*, National Institute of Labour Studies, Flinders University, Adelaide, September 2016, p.xvii.

<sup>&</sup>lt;sup>68</sup> VCOSS, Delivering high quality services for all mental health consumers: VCOSS submission to the Joint Standing Committee on the NDIS, February 2017.

<sup>&</sup>lt;sup>69</sup> Australian Government Actuary, Review of National Disability Insurance Scheme Costings, p. 13-14.

## Support and respite for cares

Carers provide an estimated 1.9 billion hours of support to people with disability and mental health conditions evert year, allowing many people to remain living in their own homes and communities. 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>70</sup>

VCOSS members report concerns the NDIS may result in reduced respite and other carer specific support to carers of people who are eligible and ineligible for the NDIS. 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. The NDIS evaluation has found support for carers, both inside and outside the NDIS has reduced since the introduction of the NDIS.

To support mental health carers' wellbeing, all carers must have access to appropriate levels of carer specific support and services that meet their needs, irrespective of whether the person they care for is eligible for an NDIS individual funding package. This includes access to general carer support, carer advocacy, counselling, and carer respite services.

## **Information Linkages and Capacity Building**

The goals of the ILC, formerly known as tier two, are to promote full inclusion in social and economic life. It is intended to support people who are ineligible for individual funding packages and their carers. However, VCOSS members report ILC funding is insufficient to fill the service gap. At full scheme in 2019-20, there will only be \$132 million available nationally for ILC activities, compared with an estimated \$22 billion for the entire NDIS. Bruce Bonyhady, former chair of the NDIA board has stated "currently only \$132 million (excluding LAC support) has been has been allocated to the ILC. This is not sufficient and means that one of the key foundations on which the NDIS is being built is weak." ILC funding is grant-based which also means particular programs and services may have limited coverage across Australia and be time-limited.

Uncertainty remains about the continuity of existing ILC type services and highly specialised programs supporting people with disability and mental illness, such as RuralAccess, MetroAccess and Deafaccess services, the 'Slow to Recover' program, and the 'Disability and Family Violence Crisis Response Initiative'. Providing ongoing funding for effective ILC-type activities and services would help ensure equitable access and consistent coverage of services.

<sup>70</sup> Australian Bureau of Statistics, Disability, Ageing and Carers, Australia: Summary of Findings, Cat. No. 4430.0, 2012.

<sup>&</sup>lt;sup>71</sup> K Mavromaras, M Moskos, S Mahuteau, *Evaluation of the NDIS, Intermediate Report*, National Institute of Labour Studies, Flinders University, Adelaide, September 2016, p.xvii.

<sup>&</sup>lt;sup>72</sup> B Bonyhady, Letter to Minister Christian Porter, 22 December 2016, pp.3-4.

The largest investment in the ILC is Local Area Coordinators (LACs). In theory, LACs are meant to spend approximately 20 per cent of their time supporting people with a disability who are ineligible for NDIS support packages and building community capacity.<sup>73</sup> However, VCOSS members report planning is the predominant feature of LACs' roles due to the large workload, leaving limited capacity to perform other aspects of their role.

# Provide coordinated supports across the NDIS and mainstream services

#### Recommendations

- Better coordinate the interface between the NDIS and all mainstream service and guarantee funding for services deemed outside the NDIS so participants can receive all necessary and reasonable supports.
- Fund collaboration meetings to enable NDIS workers and mainstream services to coordinate participant's supports.

State and Federal governments have agreed to key principles to determine whether the NDIS or another mainstream system should fund supports for individuals.<sup>74</sup> The NDIA's overarching position is "*if another system is responsible for support, the Scheme cannot fund that support, even if the system responsible does not provide it.*"<sup>75</sup> This arrangement creates a risk neither system will fund particular supports, leading to service gaps for participants. A lack of clarity also remains about which system is responsible for funding supports in certain cases. VCOSS members raise concerns about a wide range of mainstream systems which interface with the NDIS, but we have highlighted a few particular examples in the areas of transport, health, child and family services, education and justice.

To help people with disability achieve their aspirations, they need to be treated holistically and receive coordinated support. This is particularly the case for NDIS participants who face range of complex issues such as experiencing chronic health conditions, homelessness, family violence, child and family services and substance abuse.

There is a role for state and federal governments to better coordinate mainstream systems with the NDIS and to meet their commitment under the National Disability Strategy 2010-2020. The Building the capacity of mainstream services to better support people with disability and guaranteeing funding for services deemed outside the scope of the NDIS will help NDIS participants receive all necessary and reasonable supports. Funding 'collaboration meetings' within the NDIS planning stage and on an on-going basis would assist NDIS and mainstream services to discuss and coordinate supports for NDIS participants.

<sup>&</sup>lt;sup>73</sup> National Disability Insurance Scheme, COAG Disability Reform Council Quarterly Report, December 2016, Version 1, National Disability Insurance Scheme Launch Transition Agency, January 2017, p.84.

<sup>&</sup>lt;sup>74</sup> COAG, <u>Principles to determine the responsibilities of the NDIS and other service systems</u>, November 2015.

<sup>&</sup>lt;sup>75</sup> NDIA, The NDIS and mainstream interfaces How the NDIS works with other mainstream systems, January 2014.

<sup>&</sup>lt;sup>76</sup> National Disability Strategy, https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/government-international/national-disability-strategy

## **Transport**

NDIS support packages include funding to pay for a person's specialist transport needs due to their disability. VCOSS understands the NDIA and Victorian Government intend to ultimately 'fully transition' NDIS participants out of the Multi-Purpose Taxi Program (MPTP), and that their specialist transport costs will be fully met from their NDIS funding. This proposal means once NDIS participants have received a support package, they will no longer be eligible for the MPTP.

The current structure of the NDIS provides 'capped' travel budget at three levels of support which can be individually managed by participants<sup>77</sup>, but the structure of the MPTP provides people with 'uncapped' subsidies. This means that any current MPTP members moving to the NDIS may experience a reduction in their entitlements, and no longer have access to an uncapped transport subsidy should their travel requirements exceed those predicted.

VCOSS members report inconsistent and inadequate travel funds included in plans, reducing their ability to engage in activities. For instance, there are reports of people with disability experiencing substantial cuts by up to 'three quarters' of their travel.<sup>78</sup> The independent evaluation of the NDIS also found transport was not always included in participants' plans.<sup>79</sup> As a result some participants 'regularly paid out-of-pocket expenses for services such as transportation'.<sup>80</sup>

Travel costs in plans should support people's economic and social inclusion. At a minimum, people with disability should not experience a reduction in their entitlements as a result of transitioning to the NDIS.<sup>81</sup>

## Health

Many people experience complex health needs which are interrelated with their disability. While the NDIA acknowledges this, a clear demarcation between the NDIS and health system remains. <sup>82</sup> The health system retains responsibility for the treatment of health conditions. The NDIS is responsible for funding supports required "due to the impact of a person's impairment/s on their functional capacity and their ability to undertake activities of daily living". <sup>83</sup> VCOSS members report establishing which system is responsible for funding health related supports related to a disability is creating challenges for NDIS participants. People with disability require flexible, coordinated disability and health services to support their health and wellbeing.

<sup>&</sup>lt;sup>77</sup> NDIA, Participant transport funding information, <a href="https://www.ndis.gov.au/document/participant-transport-funding-informati.html">https://www.ndis.gov.au/document/participant-transport-funding-informati.html</a>, accessed 28 March 2017.

<sup>&</sup>lt;sup>78</sup> R Browne, NDIS planning process leaves people with a disability fighting for support, Sydney Morning Herald, March 2017.

<sup>&</sup>lt;sup>79</sup> K Mavromaras, M Moskos, S Mahuteau, *Evaluation of the NDIS, Intermediate Report*, National Institute of Labour Studies, Flinders University, Adelaide, September 2016, p.35.

<sup>&</sup>lt;sup>80</sup> K Mavromaras, M Moskos, S Mahuteau, *Evaluation of the NDIS, Intermediate Report*, National Institute of Labour Studies, Flinders University, Adelaide, September 2016, p.35.

<sup>&</sup>lt;sup>81</sup> Victorian Council of Social Service, *Improving transport for Victorians with limited mobility*, December 2015, p.18

<sup>82</sup> NDIA, The NDIS and mainstream interfaces How the NDIS works with other mainstream systems, January 2014.

<sup>&</sup>lt;sup>83</sup> COAG, <u>Principles to determine the responsibilities of the NDIS and other service systems</u>, November 2015.

## Case Study - Lack of integration with health system and inappropriate supports

Sally\* is an NDIS participation with Aphasia, severely affecting her speech production. At her planning meeting Sally identified she wanted access to speech therapy to help improve her speech, and psychology to help accept and manage her acquired brain injury.

The planner stated these therapies could not be included in the plan as they should be covered by the health system. Instead the planner focused on providing access to an attendant carer to help Sally 'get out of the house' and improve her social inclusion.

Despite Sally and her advocate, from Leadership Plus, stating attendant care was inappropriate to meet Sally's needs, they were unsuccessful in having speech therapy and neuropsychology supports included.

With the help of her advocate Sally is now in the process of undergoing an internal review of the decision, but to date the issue has not been resolved. Sally's speech therapist and neuropsychologist provided written letters of support, as part of the application for a review of a reviewable decision. While the acknowledgement and response to the request has been relatively prompt, the NDIA have requested more information about Sally's 'functional goals' and how these relate to the request for funding therapies, before a decision can be made to review the plan.

In the meantime Sally's plan is underutilised because the supports are largely unsuitable. Without funding through the NDIS, Sally has to meet the costs of the psychologist and speech therapist.

Even with the assistance of an advocate the planning process failed to meet Sally's needs.

\*name changed to protect identity.

## Child and family services

Children with disability<sup>84</sup> and parents with intellectual disability<sup>85</sup> are overrepresented in the child protection system. Lack of appropriate supports, prejudice and lack of understanding from practitioners contributes to the high rate of parents with intellectual disability being involved in the statutory system.86 The Victorian Equal Opportunity and Human Rights Commission's report *Desperate measures* found families with children with disability are not able to access sufficient and timely supports to care for their child, which can lead to families feeling they have no choice but to relinquish the care of their child.<sup>87</sup>

<sup>&</sup>lt;sup>84</sup> Victorian Equal Opportunity and Human Rights Commission, Desperate measures: The relinquishment of children with disability into state care in Victoria, Carlton, VEOHRC, May 2012.

<sup>&</sup>lt;sup>85</sup> A Lamont and L Bromfield, *Parental intellectual disability and child protection: Key issues*, AIFS, 2009.

<sup>86</sup> A Lamont and L Bromfield, *Parental intellectual disability and child protection: Key issues*, AIFS, 2009.

<sup>&</sup>lt;sup>87</sup> Victorian Equal Opportunity and Human Rights Commission, Desperate measures: The relinquishment of children with disability into state care in Victoria, Carlton, VEOHRC, May 2012.

The NDIS will only provide support for children, families and carers directly related to a child's or parent's disability. 88 However, some families may have a range of vulnerabilities placing them at risk of entering the child protection system, but with the right support could remain safely together. Having the flexibility to support the family unit, and strengthen their capacity to remain together could achieve much better outcomes for children and families. VCOSS members suggest NDIS support coordinators could potentially play this role, provided they had appropriate qualifications and experience. Referrals to funded programs may also be required.

#### **Education**

Students with disabilities continue to face substantial barriers to their educational attainment, including funding limitations, lack of specialist supports, restrictive practices, inadequate disability knowledge and training among teachers and discriminatory attitudes. For instance, over half the parents surveyed by VEOHRC report their child was unable to fully participate at school because the necessary supports were not available or because teachers lacked the time or capacity to modify their teaching to accommodate their child.<sup>89</sup> Disability advocates report education related complaints and requests for assistance are the most common issue raised by people with disability.<sup>90</sup>

The NDIS will not fund supports primarily related to education attainment. It will only fund supports related to the functional impact of student's disability on their activities of daily living, such as personal care and transport. Education departments and schools are deemed responsible for providing support for children in schools, including making reasonable adjustments, personalising learning and support for students relating to their educational attainment. This rigid demarcation creates issues for children and young people. For example equipment, such as assistive technology, which could directly benefit a student's education will not be permitted under the NDIS, and similarly equipment provided by education jurisdictions is not meant to be used outside educational settings.<sup>91</sup> Members also report uncertainty remains about which system has responsibility for funding certain resources and supports.<sup>92</sup> This creates the risk children and young people will continue to miss out on receiving assistance required to reach their educational goals.

<sup>&</sup>lt;sup>88</sup> COAG, <u>Principles to determine the responsibilities of the NDIS and other service systems</u>, November 2015.

<sup>89</sup> Victorian Equal Opportunity and Human Rights Commission (VEOHRC), Held Back: The experiences of students with disabilities in Victorian schools, VEOHRC, Carlton, 2012, p. 10.

<sup>&</sup>lt;sup>90</sup> Disability Advocacy Resource Unit, *Disability Advocacy by the Numbers Statistics from the 2012-2013 Victorian Office for Disability Advocacy Program Quarterly Data Collection*, June 2014.

<sup>&</sup>lt;sup>91</sup> B Whitburn, J Moss and J O'Mara, <u>The Policy Problem: The NDIS and Implications for Access to Education</u>, Deakin University, Probono Australia, 7th February 2017.

<sup>&</sup>lt;sup>92</sup> B Whitburn, J Moss and J O'Mara, <u>The Policy Problem: The NDIS and Implications for Access to Education</u>, Deakin University, Probono Australia, 7th February 2017.

## **Justice**

People with disability, particularly those with intellectual disability, are over-represented in the justice system. However, the NDIS will not fund supports for people serving a custodial sentence, and will only support people who are on bail or serving a community based order. Disrupting care for people with disability serving a custodial sentence may comprise their health and wellbeing and increase their chance of reoffending. Providing people with continuity of care before, during and after any custodial sentence can improve outcomes for these people and improve community safety.

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<sup>93</sup> AIHW, The health of Australia's prisoners 2015, Cat. no. PHE 207, AIHW, 2015, p.80-81.

<sup>&</sup>lt;sup>94</sup> COAG, Principles to determine the responsibilities of the NDIS and other service systems, November 2015.

<sup>&</sup>lt;sup>95</sup> J Young and S Kinner, *Prisoners are excluded from the NDIS – here's why it matters*, the Conversation, 14 March 2017.



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