

# **A smooth NDIS transition**

## **VCOSS Submission to NDIS Joint Standing Committee inquiry into Transitional Arrangements for the NDIS**

August 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.

This submission was prepared for VCOSS by VCOSS Policy Advisor Carly Nowell with input from VCOSS members.

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

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# Executive Summary

The Victorian Council of Social Service (VCOSS) welcomes this opportunity to comment on the Joint Standing Committee on the National Disability Insurance Scheme's inquiry into transitional arrangements for the National Disability Insurance Scheme (NDIS).

The NDIS brings a major shift in service provision for people with disability. VCOSS strongly supports the goals of NDIS: to provide eligible people with greater choice and control over their services and improve social and economic inclusion for all people with disability, their families and carers.

As with any large social reform, numerous transitional issues are emerging. While some are "teething" issues likely to disappear over time, others are more substantial. If not fully remedied, these could harm people with disability, whether eligible or ineligible for the NDIS.

VCOSS members are highly concerned people with complex needs or facing disadvantage will receive the poorest outcomes from the NDIS transition. For example, participants "experiences of the NDIS appeared strongly influenced by their circumstances,"<sup>1</sup> and "insufficient attention is being paid to promoting equity of outcomes among service users with diverse needs and circumstances."<sup>2</sup> The Productivity Commission has recognised the NDIS planning process is not inclusive, and sufficiently flexible to accommodate different participants' needs.<sup>3</sup>

Accessing and being a participant of the the NDIS relies heavily on individuals being literate, including digitally literate; understanding and navigating the system; identifying their needs and goals; having the skills to exercise choice and control when managing their plan; and the confidence to self-advocate. As it stands, many participants may not be able to successfully access and participate in the scheme. This includes people with high and complex needs, such as people with complex communication needs or mental health needs; or people facing disadvantage, such as those experiencing homeless, substance abuse, family violence and poverty. These people will require additional, and often intensive, support to understand and engage with the NDIS and receive meaningful support through their plans.

VCOSS is concerned the NDIS individual planning process is currently compromised, through individual planning occurring primarily by telephone, planners without the skills to determine suitable support, and insufficiently engaging with families, carers and advocates. Poor planning compromises the support quality and suitability, and contributes to plan underutilisation.

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<sup>1</sup> D Warr, H Dickinson, S Olney et. Al. Choice, Control and the NDIS, Melbourne, University of Melbourne, 2017, p.7  
Ibid., p.9

<sup>3</sup> Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs*, Position Paper, Canberra, 2017, p.70.

Some NDIS participants cannot access funded disability supports, due to lengthy waiting lists for certain services, an absence of local service providers or inappropriate services.<sup>4</sup> These problems appear more pronounced for people in rural, regional and outer urban areas, people with complex needs, people from culturally and linguistically diverse (CALD) backgrounds and Aboriginal and Torres Strait Islander Australians.

Service quality and availability is affected by NDIS pricing. VCOSS members report NDIS prices do not match the skills and expertise required to deliver effective support. They do not reflect the true costs of quality service delivery, including adequate administration, staff supervision and professional development.

The NDIS and other service systems are not clearly delineating or meeting respective responsibilities to provide necessary services. This is producing gaps for NDIS participants for different services, including in health, transport, education, emergency management and child protection. There is also a lack of coordination between different services making it difficult for NDIS participants to receive integrated holistic support. The vast majority of people with disability and their carers will not be eligible for an individual NDIS package. VCOSS and our members are concerned about the type and level of support remaining for these people during and after the NDIS transition. Governments have committed to providing 'service continuity', but have not detailed its content. State and Commonwealth government funding for existing programs are being "rolled into" the NDIS, meaning these services will no longer exist for people without an individual NDIS package. In particular, emerging and anticipated service gaps exist for mental health consumers, those not eligible for the NDIS, people aged 65 or over, and carers.

This submission explores these issues in more detail, and makes recommendations to improve the NDIS. In particular, we highlight emerging risks, and details actions so people facing disadvantage receive equitable assistance, regardless of their eligibility for the scheme.

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<sup>4</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.

# Recommendations

## NDIS plans and service delivery

### Provide pre-planning and pre-assessment support

- Provide comprehensive pre-planning and pre-assessment support to help people successfully enter the scheme and prepare for their planning session.

### Fund assertive outreach

- Provide dedicated funding for assertive outreach to help locate and connect people experiencing isolation or disadvantage with the NDIS.

### Expand the reach of independent advocacy

- Provide ongoing funding for independent advocacy so every NDIS participant can access advocacy support to help them navigate the system and obtain the right support in their plans.

### Provide in-depth planning meetings

- Provide in-depth face-to-face planning meetings with NDIS participants with sufficient time to explore goals and needs.
- Review information and processes so child participants have their voices heard and respected.

### Enable participants to review draft plans

- Allow people to review and agree to plans before finalisation.

### Engage with families, carers, advocates and support workers

- Include support people in planning meetings.
- Undertake carer assessments in the planning process to identify and support carers' needs.

### Train and employ experienced planners

- Employ planners with disability knowledge and skills.
- Provide comprehensive training and inductions for planners to be culturally safe, gender responsive, understand trauma, can identify violence and abuse, and understand different disability types.
- Form specialised planning teams for disabilities requiring specialist knowledge.

### Develop flexible plans

- Ensure NDIS plans can respond to episodic disabilities, and adapt quickly in changing circumstances.

### **Amend NDIS pricing to support high quality services**

- Amend NDIS prices to match the skills and expertise required for effective support.
- Amend NDIS prices to reflect the components of quality service delivery, including adequate supervision, administration and professional development.

### **Respond to thin markets**

- Explore alternative funding arrangements in thin markets.
- Provide equitable access to NDIS services in regional and remote areas.
- Cover the costs of providing support to participants with complex needs.

### **Provide culturally safe and gender responsive services**

- Provide culturally safe planning and service delivery.
- Fund and work with existing services with established rapport with local communities.
- Provide gender responsive service delivery, including capacity to identify and respond to violence and abuse risks.

## **Boundaries and interface between NDIS and mainstream services**

### **Support people not eligible for the NDIS**

- Adequately fund mainstream services outside the NDIS, so people with disability and their carers ineligible for the NDIS are not excluded from services.
- Publicly announce the services intended to be funded outside the NDIS at full scheme.

### **Increase ILC funding**

- Increase funding for information linkages and capacity building

### **Provide ongoing funding for core services**

- Reconsider the time-limited funding approach for core services.
- Provide a fair and robust grants process for equitable service coverage across Australia and for all population groups and disability types.

### **Identify and address service gaps between systems**

- Report on boundary issues at regular COAG meetings, to identify and address services gaps.

### **Educate mainstream services**

- Educate mainstream services about the NDIS process, its implications for eligible and ineligible people and services' ongoing responsibilities to provide inclusive services.

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### **Assist services to collaborate**

- Develop and embed protocols and training for service collaboration to provide integrated support for NDIS participants.
- Fund collaboration meetings so NDIS workers and mainstream services can coordinate participant supports.

### **Provide case management**

- Provide case management support for NDIS participants when required, particularly when in crisis, such as facing homeless or experiencing family violence.



# NDIS plans and service delivery

## Engage NDIS participants

### Provide pre-planning and pre-assessment support

#### Recommendation

- Provide comprehensive pre-planning and pre-assessment support to help people successfully enter the NDIS and prepare for their planning session.

VCOSS members describe the NDIS as a ‘labyrinth’, being incredibly complex and bureaucratic, difficult to understand, access and navigate. People remain confused about NDIS eligibility, access and participation procedures. VCOSS members describe the application process as time-consuming and confusing for some participants. For example, services in the Barwon launch site report providing substantial support to mental health consumers to complete NDIS forms, but could not bill the NDIA for this assistance.<sup>5</sup>

People experiencing disadvantage or with complex needs face additional barriers to accessing information about the scheme. For example, the NDIA has limited physical presence and relies heavily on online information distribution. But people with disability or on low incomes are more likely to be “digitally excluded”, including by having limited access to the internet, lower digital literacy and facing cost barriers to technology.<sup>6</sup> VCOSS members report information is often not accessible for children and young people participating in the scheme, and limited information was provided to some people during their transition processes. For example, some people with cognitive disability were transitioned to the scheme without receiving enough information about the NDIS, and not being presented with information in an accessible format.<sup>7</sup>

The NDIS is causing a profound shift in the way services are provided. Some participants, especially people who have been institutionalised, have had a lifetime with little or no say in their services. Many avoid complaining or asserting their rights due to real or perceived threats of reprisal, including having their services withdrawn.<sup>8,9</sup> The NDIS intends to provide “choice and control” in services to meet a person’s goals, and not merely their immediate needs. While this is

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<sup>5</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>6</sup> J Thomas, J Barraket, C Wilson, S Ewing, T MacDonald, J Tucker and E Rennie, *Measuring Australia’s Digital Divide: The Australian Digital Inclusion Index 2017*, RMIT University for Telstra, Melbourne, 2017.

<sup>7</sup> D Warr, H Dickinson, S Olney et. Al. *Choice, Control and the NDIS*, Melbourne, University of Melbourne, 2017, p.26

<sup>8</sup> Parliament of Victoria, Family and Community Development Committee, *Inquiry into abuse in disability services*, Final Report, 26 May 2017.

<sup>9</sup> Victorian Ombudsman, *Reporting and investigation of allegations of abuse in the disability sector: Phase 2 – incident reporting*, December 2015, p.18.

an incredibly positive change, VCOSS members report many participants require substantial assistance to understand and benefit from this new approach. They have provided participants with unfunded assistance hours to identify and articulate their goals. This requires educating participants, their families and carers in their NDIS and mainstream service entitlements.

VCOSS members are distressed the NDIA appears to disregard many launch site lessons. For instance, the proposed rollout does not feature the successful pre-engagement work undertaken in Barwon launch site, nor the individual grants available in the Australian Capital Territory launch site to engage a planner to assist with pre-NDIS preparation and support.<sup>10</sup> Services providers identify many potential participants needing pre-planning support.<sup>11</sup> The Productivity Commission similarly identified inadequate pre-planning assistance leaves many participants unprepared for their NDIS planning session.<sup>12</sup>

Funding pre-engagement services will help people successfully apply for the scheme and be empowered to take control and choice in their services. Assisting participants to undertake comprehensive meeting preparation can help better articulation of their goals and aspirations, and get the right mix of support. VCOSS supports the Productivity Commission's recommendation for Local Area Coordinators to be in place six months in advance, specifically to assist participants with pre-planning in relation to readiness to transition to the NDIS.<sup>13</sup> Having more highly visible, publicly accessible NDIS information centres may also help to reach people more comfortable engaging face-to-face or cannot access information online.

## Fund assertive outreach

### Recommendation

- Provide dedicated funding for assertive outreach to help locate and connect people experiencing isolation or disadvantage with the NDIS.

VCOSS members advise many people eligible for the NDIS will not engage in the scheme without active assistance. These people may be isolated, not accessing existing services or have multiple or complex needs. For instance, up to a third of people experiencing severe mental health issues are unlikely to engage with services.<sup>14</sup> People experiencing homelessness are likely to face many difficulties accessing the NDIS.<sup>15</sup>

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<sup>10</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), accessed 8 August 2017.

<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>12</sup> Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs*, Position Paper, Canberra, 2017, pp. 2, 27.

<sup>13</sup> *Ibid.*, p. 56.

<sup>14</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

<sup>15</sup> Council to homeless persons, *Homelessness and the National Disability Insurance Scheme – Challenges and solutions*, 2017.

Even people currently receiving disability services can face substantial transition difficulties. For example, VCOSS members identify some people did not receive letters about transitioning because they did not have access to a post box, had changed their address, or did not respond to transition letters due to poor literacy or limited English language skills.<sup>16</sup>

Undertaking assertive outreach can help identify and reach isolated people and communities who cannot otherwise engage in the NDIS, especially those not currently accessing services. This requires funding for skilled and experienced workers, and can take substantial time to effectively identify and build trusting relationships with potential participants.

VCOSS members advise block-funded services are currently undertaking some of this work, but there is no identified funding for outreach once funding is individualised. While Local Area Coordinators (LACs) could provide outreach, they have limited current capacity due to their heavy plan development role.

### Expand the reach of independent advocacy

#### Recommendation

- Provide ongoing funding for independent advocacy so every NDIS participant can access advocacy support to navigate the system and obtain the right support in their plans.

Independent disability advocacy can help people access and navigate the NDIS, articulate their needs and goals and receive meaningful plans. Disability advocacy can also help people make a complaint or request a plans or decision review. It is particularly important for people with complex needs or facing disadvantage, or those with limited informal supports or networks.

VCOSS warmly welcomes funding for the National Disability Advocacy Program (NDAP) to continue operating until 30 June 2020.<sup>17</sup> Governments can build on this commitment by providing ongoing funding certainty beyond the NDIS rollout, so every NDIS participant can access independent advocacy if needed. VCOSS members also suggest including a standard protocol in the NDIA planning process so every participant is aware of advocacy services, and staff refer participants to a service when requested.

More resources are needed to expand disability advocacy service coverage across Australia, particularly in rural and remote areas, and improve access for people likely to be underserved. For example, access can be increased for Aboriginal people, people from CALD) backgrounds, people identifying as lesbian, gay, bisexual, transgender and intersex (LGBTI), people with complex communication needs, and people with an intellectual disability or mental health issue.

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<sup>16</sup> Council to homeless persons, *Homelessness and the National Disability Insurance Scheme – Challenges and solutions*, 2017.

<sup>17</sup> Hon Christian Porter, *Media Release: Turnbull Government investing \$60 million in disability advocacy*, 9 August 2017.

All disability advocacy models (self-advocacy, individual advocacy, family advocacy, citizen advocacy, systemic advocacy and legal advocacy) should be available to participants as each has a different purpose and is suitable under different circumstances.

People ineligible for NDIS packages also require independent disability advocacy to protect their rights and access other service systems. Disability advocacy also addresses broader inclusion objectives beyond the NDIS such as access to mainstream services, the built environment, public transport, housing, education, employment, justice and information and communication systems.

## Deliver quality plans

### Provide in-depth planning meetings

#### Recommendations

- Provide in-depth face-to-face planning meetings with NDIS participants with sufficient time to explore goals and needs.
- Review information and processes so child participants have their voices heard and respected.

VCOSS members find the NDIS planning process is not person-centred. They observe the NDIA appears more focused on achieving operational targets to transition people into the scheme quickly, rather than on developing quality plans.

In particular, VCOSS understands most planning meetings now occur by telephone, impeding good communication and discussion which potentially leads 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 requiring assistance to articulate their needs and aspirations due to their disability, such as participants with complex communication needs, or an intellectual disability.

VCOSS members also report people have not been forewarned of planning conversations, experience rushed conversations, and have plans approved without consultation. For example, a VCOSS member reported a case of a participant given a plan without any meeting. As a result, their plan provided support for vision impairment, not their primary disability, only because the planner had a past record of their connection to a vision impairment organisation.

Poor planning processes have also been identified by the Productivity Commission. VCOSS supports the Commission's draft recommendations for planning process improvements and provision of more in-depth planning conversations.<sup>18</sup> VCOSS members also report people cannot

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<sup>18</sup> Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs*, Position Paper, Canberra, 2017 p. 56.

develop an ongoing relationship with their planner. Often, participants only see a planner once, and at their next review have to re-tell their story to a new planner.

VCOSS members also believe the perspectives of children who are participants in the scheme are often not understood. Staff need skills to help identify and articulate the goals and needs of children at different cognitive and developmental stages. VCOSS members suggest reviewing existing information and processes so children's voices are heard and respected.

Poor planning processes compromise the quality and suitability of support, and contribute to plan underutilisation. They can also affect NDIS participants' access to mainstream services. For example, a VCOSS member reported a case of a participant facing eviction due to behavioural concerns resulting from insufficient NDIS supports. The NDIS evaluation identified some NDIS participants receive reduced support after NDIS entry.<sup>19</sup>

We believe face-to-face conversations should be offered by default, with telephone conversations only for participants preferring this alternative. Face-to-face planning meetings allow time for people to explore their aspirations and develop suitable plans. In some cases, planning may need several sessions. To be properly prepared, participants require clear information about planning conversation expectations. Advance discussion also allows people to arrange relevant support people to be present.

## Enable participants to review draft plans

### Recommendation

- Allow people to review and agree to plans before finalisation.

VCOSS members report planners often do not provide participants the opportunity to review their plans and provide feedback before finalisation. This can disempower and create anxiety, as people are left uncertain to their entitlements until receiving the plan by mail. It also prevents any problems being rectified early in the process. Currently, if a participant is not satisfied, they must apply for a lengthy internal review process, and if necessary, escalate it to the Administrative Appeals Tribunal. VCOSS members report this process can be confusing and time-consuming, taking months to resolve. Over 70 per cent of complaints before the Administrative Appeals Tribunal relate to participant's plans, with most resolved in the participant's favour.<sup>20</sup>

Giving participants an opportunity to review and discuss plans before finalisation can help avoid unnecessary and costly reviews, alleviate stress, and improve outcomes for participants and the

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<sup>19</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>20</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.

scheme. VCOSS also support the Productivity Commission's recommendation for minor plan amendments without a formal review process.<sup>21</sup>

## Engage with families, carers, advocates and support workers

### Recommendations

- Include support people in planning meetings.
- Undertake carer assessments in the planning process to identify and support carers' needs.

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

VCOSS members report the planning process does not adequately engage carers or consider their needs. Advocates and support workers are often excluded from planning meetings, even when participants have explicitly requested their presence.

Many carers in the trial sites report felt they received insufficient information about the NDIS and were unaware they could submit a carer statement describing the support they currently provided and the additional assistance needed to sustain their caring.<sup>22,23</sup> The NDIS evaluation identified carer needs and were not addressed during planning.<sup>24</sup> Some carers report cuts to respite care and other support.<sup>25,26</sup>

Active engagement requires informing carers of their option to submit a carer statement, and providing information about carer support available through the NDIS.<sup>27</sup> Identifying the nature and extent of carer support can be difficult if participants do not fully understand the support provided by families and carers. Ideally, carers would receive their own assessment during planning to identify supports required, as occurs in the United Kingdom.<sup>28</sup>

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<sup>21</sup> Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs*, Position Paper, Canberra, 2017, p.56.

<sup>22</sup> Ibid.

<sup>23</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>24</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>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.

<sup>27</sup> Carers Australia and Mental Health Australia, *Mental Health Carers and the National Disability Insurance Scheme, Issues Paper*, January 2016.

<sup>28</sup> National Health Services, Carers' assessments, <http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/carers-assessment.aspx>, accessed 14 August 2017.

## Train and employ experienced planners

### Recommendations

- Employ planners with disability knowledge and skills.
- Provide comprehensive training and inductions for planners to be culturally safe, gender responsive, understand trauma, can identify violence and abuse, and understand different disability types.
- Form specialised planning teams for disabilities requiring specialist knowledge.

VCOSS members are concerned some planners have limited skills and experience in working with people with disability. They report this contributes to poor quality, unsuitable plans. For instance, one organisation reported five people with similar disabilities living together recently had their NDIS plans developed. The plans were virtually identical and did not reflect the participants' highly divergent individual goals and aspirations. NDIS participant surveys and the Productivity Commission also document this variability in planner skills, experience and training, and limited disability experience and understanding, as hindering the ability to formulate good plans.<sup>29,30</sup>

VCOSS members believe planners do not receive consistent training and induction. They report the planning process is variable and highly dependent on the individual planner. VCOSS members suggest providing all NDIS planners with comprehensive training including:

- a person-centred approach to the planning process
- undertaking a holistic assessment of people's goals and needs, such as employment, housing and social engagement, not just considering disability services
- understanding different disability types
- trauma informed practice
- identifying and responding appropriately to signs of violence and abuse, including family violence
- cultural safety
- gender responsive practices, including being sensitive to the needs of people identifying as LGBTIQ.

In some cases, conflicts of interest risks arise between participants and service providers or family members and carers. Some participants do not want their family members involved in the planning process due to family violence. Planners must be comprehensively trained to carefully manage these risks, including identifying and responding to family violence. For example, a VCOSS member gave an example of a woman with disability experiencing family violence advised by her planner to receive informal care from the perpetrator. The planner not only failed to refer her to an appropriate service, but placed her at greater risk of harm.

For people with certain disability types, such as people with psychosocial disability or complex needs, VCOSS members believe planners should have specific expertise. This allows planners to

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<sup>29</sup> Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs*, Position Paper, Canberra, 2017 p.147.

<sup>30</sup> D Warr, H Dickinson, S Olney et. Al. *Choice, Control and the NDIS*, Melbourne, University of Melbourne, 2017, p.52

better understand effects on everyday functioning, and consequently identify suitable support. We support the Productivity Commission’s recommendation for NDIS planners to understand different disability types, form specialised planning teams, and use industry expertise for disabilities requiring specialist knowledge.<sup>31</sup>

## Develop flexible plans

### Recommendation

- Ensure NDIS plans can respond to episodic disabilities, and adapt quickly in changing circumstances.

Participants report plans do not respond to the fluctuating nature of some disabilities.<sup>32</sup> VCOS members also report cases of people being “too positive” about their capacity or future ability to undertake certain activities, and found support was removed from their plans as a result.

For example, a VCOS member spoke about one man with disability, able to sometimes catch public transport, but otherwise required private transport to move around. During his planning session, the man spoke positively about his goals for using public transport more in the future. Upon receiving his NDIS plan, he found the planner had removed all funding for transport services.

Because of these experiences, people feel pressured to ‘paint the worst case scenario’ during planning meetings so support is available if needed. This deficit-based approach directly contradicts the goals of the NDIS and is disempowering for participants.

There are early indications underutilised services are being removed from plans at the next review on the basis they are not required.<sup>33</sup> This approach fails to understand many participants can experience variable health and wellbeing levels, particularly those with episodic disability. Certain services may not have been used, but may still be required in future. NDIS plans must be sufficiently flexible to quickly and adequately respond to participants’ fluctuating needs. Circumstances change: people lose informal supports, experience family violence or homelessness, and plans must adapt. This view is reinforced by the recent review of NDIS services for people by psychosocial disabilities.<sup>34</sup>

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<sup>31</sup> Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs*, Position Paper, Canberra, 2017, p.56.

<sup>32</sup> D Warr, H Dickinson, S Olney et. Al. *Choice, Control and the NDIS*, Melbourne, University of Melbourne, 2017, p.8

<sup>33</sup> D Warr, H Dickinson, S Olney et. Al. *Choice, Control and the NDIS*, Melbourne, University of Melbourne, 2017, p.31

<sup>34</sup> Joint Standing Committee on the National Disability Insurance Scheme, *Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition*, August 2017, p.xiv



## Quality service delivery

### Amend NDIS pricing to support high quality services

#### Recommendations

- Amend NDIS prices to match the skills and expertise required for effective support.
- Amend NDIS prices to reflect the components of quality service delivery, including adequate supervision, administration and professional development.

NDIS pricing policies directly affect service quality and diversity for NDIS participants. VCOSS members report current prices impede recruitment and retention of adequately qualified workers, capable of providing effective support and therapeutic services, particularly for people with complex needs and people with psychosocial disability.<sup>35</sup> For example, a community service organisation providing psychosocial services under the NDIS felt compelled to make highly qualified staff redundant, and hired less qualified staff to remain financially viable. Participants express concerns services are employing “less qualified and less experienced staff to reduce costs.”<sup>36</sup>

The NDIS pricing model is based on paying staff at level 2 in the *Social, Community Home Care and Disability Services Industry Award 2010*.<sup>37</sup> VCOSS members report the majority of existing staff assisting people with psychosocial disability are employed at level 4 or 5. Services operating in NDIS trial sites identify mental health services, one-to-one community participation and services for people with complex needs as underpriced.<sup>38</sup>

VCOSS members also report NDIS prices are inadequate to cover costs of quality service delivery including training, travel, supervision, and administration, such as using the NDIS portal. A recent Social Policy and Research Centre report confirms this, finding NDIS prices do not recognise the time needed to deliver quality services.<sup>39</sup>

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<sup>35</sup> VCOSS, [VCOSS submission to the NDIS 2017 Price Controls Review](#), April 2017.

<sup>36</sup> D Warr, H Dickinson, S Olney et. Al. Choice, Control and the NDIS, Melbourne, University of Melbourne, 2017, p.28

<sup>37</sup> NDIS, 2017 *Price Controls Review: Consultation on NDIS pricing arrangements, discussion paper*, March 2017.

<sup>38</sup> K Mavromaras, M Moskos, S Mahuteau, *Evaluation of the NDIS, Intermediate Report*, National Institute of Labour Studies, Flinders University, Adelaide, September 2016.

<sup>39</sup> N Cortis, F Macdonald, B Davidson and E Bentham, *Reasonable, necessary and valued: Pricing disability services for quality support and decent jobs (SPRC Report 10/17)*, Social Policy Research Centre, UNSW Sydney, Sydney, 2017.

*Prices for disability support work set by the NDIA according to the 'Reasonable Cost Model' do not enable minimum Award conditions to be met, and prevent employers who offer above-Award conditions from meeting their legal obligations. Prices do not account for what is required to deliver high quality services, and arrangements are not fully enabling disability support workers to deliver services which are personalised, co-ordinated, responsive or safe. Quality is likely to diminish in the process of NDIS expansion.<sup>40</sup>*

VCOSS recommends amending the pricing structure to accommodate the skills and expertise required to deliver effective support, and reflect the real costs of providing quality NDIS service delivery. VCOSS supports in principle the Productivity Commission's recommendation to transfer the NDIA's pricing powers to an independent price regulator. We believe this will provide a more fair and transparent process for price setting.

## Respond to thin markets

### Recommendations

- Explore alternative funding arrangements in thin markets.
- Provide equitable access to NDIS services in regional and remote areas.
- Cover the costs of providing support to participants with complex needs.

As a market-based system, the NDIS depends on a viable level of supply and demand for adequate service coverage and provider diversity. However, the market is not meeting many participants' needs and risks create inequitable service delivery. The NDIS intermediate evaluation found many NDIS participants experience difficulty accessing funded disability supports, primarily due to "lengthy waiting lists for some providers or support types, lack of local providers, and lack of quality provision".<sup>41</sup> If participants do not access funded services, even because they are not available, they risk losing funding because planners are using this as evidence the supports are not required.<sup>42</sup>

In rural and regional areas, and some outer urban areas, VCOSS members report there are not enough local services to provide people with the funded supports, let alone choice of providers. For example, there are early indications some people cannot find suitable local service providers, particularly in regional areas, or for specialised needs.<sup>43</sup> In these cases, participants must travel to services, or pay extra for service staff to travel.<sup>44</sup> The intermediate NDIS evaluation found NDIS

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<sup>40</sup> N Cortis, F Macdonald, B Davidson and E Bentham, *Reasonable, necessary and valued: Pricing disability services for quality support and decent jobs (SPRC Report 10/17)*, Social Policy Research Centre, UNSW Sydney, Sydney, 2017.

<sup>41</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.

<sup>42</sup> D Warr, H Dickinson, S Olney et. Al. *Choice, Control and the NDIS*, Melbourne, University of Melbourne, 2017, p.8

<sup>43</sup> D Warr, H Dickinson, S Olney et. Al. *Choice, Control and the NDIS*, Melbourne, University of Melbourne, 2017, p.8

<sup>44</sup> D Warr, H Dickinson, S Olney et. Al. *Choice, Control and the NDIS*, Melbourne, University of Melbourne, 2017, p.8

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>45</sup>

The NDIS also risks creating disincentives to assisting participants with complex needs or those perceived as 'difficult', such as people displaying challenging behaviour. This could result in services 'cherry picking' participants or services withdrawing from providing more intensive support, leaving some people without services. Workers supporting these participants are likely to require much higher management supervision and support levels than the 'standard needs' ratio of 1:15. In some cases, two workers are required for staff safety or to adequately manage a participant's behaviour. These participants are also more likely to require assertive outreach, contact outside of scheduled appointments, and workers with more specialised skills. The Productivity Commission identified people with complex, specialised or high intensity needs, very challenging behaviours, or an acute and immediate need, as at risk of service shortages and poorer participant outcomes, due to "thin markets".<sup>46</sup>

Without effective intervention, the NDIS is likely to create or perpetuate inequitable service coverage for some NDIS participants, particularly those facing multiple disadvantage. We believe alternative funding arrangements may be required to intervene in thin markets. Depending on the circumstances, different approaches may be required, such as block funding core services, retaining 'a provider of last resort', and leveraging or building the capacity of established community organisations, such as health service providers.

The NDIS pricing model should be revisited to fund the support provision costs for participants with complex needs. We support the recommendations of the recent review of people with psychosocial disability in the NDIS for governments: to develop a strategy to address service gaps for rural and remote communities; and provide details of provider of last resort arrangements for all NDIS participants unable to find a suitable service provider.<sup>47</sup>

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<sup>45</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.

<sup>46</sup> Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs*, Position Paper, Canberra, 2017, p.227.

<sup>47</sup> Joint Standing Committee on the National Disability Insurance Scheme, *Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition*, August 2017, p.xv

## Provide culturally safe and gender responsive services

### Recommendations

- Provide culturally safe planning and service delivery.
- Fund and work with existing services with established rapport with local communities.
- Provide gender responsive service delivery, including capacity to identify and respond to violence and abuse risks.

People with disability from CALD and Aboriginal and Torres Strait Islander communities face extra barriers to accessing and receiving NDIS services, and are at greater risk of poor outcomes. They may mistrust government services, be unaware of the NDIS, be unable to navigate it, have low English proficiency levels, feel uncomfortable sharing personal information, or have a reluctance to access services due to cultural attitudes and stigma towards disability and mental health.<sup>48,49,50,51,52</sup> The Productivity Commission has identified the risk of thin markets and poorer outcomes for participants from CALD and Aboriginal communities.<sup>53</sup>

Providing culturally safe service information, planning and service delivery can better assist people from Aboriginal and CALD communities participate in the NDIS. This includes using culturally appropriate concepts and language around disability, such as focusing on 'health and wellbeing'<sup>54</sup> and demonstrating inclusive practice, such as working with carers or extended kinship networks. 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 services' cultural safety.

Aboriginal people and people from CALD backgrounds are more likely to engage with trusted contacts, and existing community networks with whom they have already built rapport, such as Aboriginal Community Controlled Organisations and CALD-specific health and disability services. Resourcing and working with local CALD and Aboriginal communities to develop engagement strategies, undertake outreach, and deliver services, could help increase their NDIS access and participation.

Providing accessible and culturally appropriate information in different languages can also help reach more people. Existing information about the NDIS has been identified as too generic and not

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<sup>48</sup> Ethnic Communities Council of Victoria, *Talking Disability; under-representation of culturally diverse communities in disability support*, 2014.

<sup>49</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>50</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>51</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>

<sup>52</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>53</sup> Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs*, Position Paper, Canberra, 2017, p.227.

<sup>54</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.

easily accessible to Aboriginal and CALD communities.<sup>55</sup> Providing access to qualified interpreters, with good NDIS knowledge, also assists. VCOSS members report people can access interpreters and translating services through the initial planning process, but experience difficulty and inconsistencies having interpreters included in their plans for accessing services.

Providing gender responsive services, and ensuring practices are sensitive to the needs of LGBTI people, can help the NDIS be accessible and safe for everyone. This includes allowing participants to select their support worker's gender, 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. Building the skills of NDIS planners, other agency staff, and disability services can provide early intervention and help prevent violence or abuse from occurring. This includes the skills to identify and appropriately respond to family violence and risks of abuse, neglect and violence in all their forms, including emotional, physical, sexual and financial.

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<sup>55</sup> Ibid.

# Boundaries and interface between NDIS and mainstream services

## Support people not eligible for the NDIS

### Recommendations

- Adequately fund mainstream services outside the NDIS, so people with disability and their carers ineligible for the NDIS are not excluded from services.
- Publicly announce the services intended to be funded outside the NDIS at full scheme.

NDIS individual funding packages target people with severe and permanent disability, or children aged under 6 with early intervention requirements. The vast majority of people with disability will not be eligible for an NDIS individual package.

VCOSS and our members are concerned few services will remain for people ineligible for an NDIS package. Governments have committed to providing 'service continuity', however, there are limited details about the exact services intended to continue. Funding for many existing state and federal programs are being 'rolled into' the NDIS, leaving few services left for people not qualifying for an individual package. In particular, emerging and anticipated service gaps exist for mental health consumers, people not eligible for the NDIS, people aged 65 or over, and carers.

It is crucial people with disability and carers receive high quality services meeting their needs, regardless of their eligibility for NDIS packages. Without adequate support, people's physical and mental health is at risk, and will likely increase pressure on other health and social services, including the acute health, welfare and justice systems, at potentially greater cost. Inadequate support for people with disability may also increase reliance on family and carers. Federal, state and territory governments are all responsible for an adequately funded mainstream service system outside the NDIS, so people with disability and their carers ineligible for the NDIS do not miss out on services.

VCOSS supports the Productivity Commissions' recommendation for governments to publicly declare the services intended to continue, beyond supports provided through NDIS individual packages.<sup>56</sup> This will help to identify services gaps and the actions required to provide service continuity. This position is also supported by the recent review of people with psychosocial

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<sup>56</sup> Productivity Commission, op. cit., p.57

disability receiving services under the NDIS, which recommends conducting an audit of all Australian, state and territory services, programs and associated funding available for mental health, and making public the service plan for people with a psychosocial disability not participating in the NDIS.<sup>57</sup>

## Service gaps for people ineligible for the NDIS

### Mental health consumers

Many mental health consumers with moderate or severe conditions will not meet NDIS eligibility criteria. Many mental health services are being “rolled into” the NDIS, including Victorian community based psychosocial rehabilitation services and some federally funded services. This leaves a large emerging service gap.

The 2017 Federal Budget included \$80m over three years for community mental health to support people with severe mental illness ineligible for the NDIS.<sup>58</sup> However, this is “contingent upon states and territories contributing funding”<sup>59</sup> and the Victorian Government has not yet made a commitment. The Victorian Government recently announced an additional \$20m for clinical mental health services,<sup>60</sup> but has not made clear the funding distribution mechanism. More detail is provided in our submission to the Joint Standing Committee’s inquiry into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition.<sup>61</sup>

### People aged 65 and over

People with disability aged over 65, or Aboriginal and Torres Strait Islander people aged over 50, at the time the NDIS commences in their region will not be eligible for the NDIS, and will instead be directed to seek support from the aged care system.<sup>62</sup> Many of these people may have lived with disability for much of their lives, their needs are unrelated to ageing, and the aged care system may not provide appropriate support. The age cutoff creates inequities between NDIS participants and those accessing aged care support, particularly for people aged 63 or 64 in regions where the NDIS will not be available until they are over 65.

From 1 July 2016 older people in Victoria receiving home-based care through Home and Community Care (HACC) transitioned to the Commonwealth Home Support Program managed through the aged care system. VCOSS members are concerned people who transitioned may receive fewer support hours and reduced care levels to remain in their home. VCOSS members also raise concerns about the potential service gap if state government disability services do not continue until people are successfully transitioned to the Continuity of Support Program (CoS).

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<sup>57</sup>Joint Standing Committee on the National Disability Insurance Scheme, *Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition*, August 2017, p.xiv.

<sup>58</sup>Australian Government Department of Health, *Prioritising Mental Health – Psychosocial Support Services – funding* <http://www.health.gov.au/internet/budget/publishing.nsf/Content/budget2017-factsheet28.htm>, accessed 30 June 2017.

<sup>59</sup> Ibid.

<sup>60</sup> Victorian Government, Media release, *Greater Access to Mental Health Help – Sooner*, 29 June 2017.

<sup>61</sup> VCOSS, *Delivering high quality services for all mental health consumers: VCOSS submission to the Joint Standing Committee on the NDIS*, February 2017.

<sup>62</sup> NDIS, Continuity of support, <https://www.ndis.gov.au/people-disability/continuity-support>, accessed 10 August 2017.

## Young people with disability ineligible for the NDIS

VCOSS members also raise concerns about the availability of services for young people with disability not eligible for NDIS packages. For example, around three quarters of younger people currently receiving HACC are unlikely to be eligible for NDIS package, based on the experience at the Barwon trial site.<sup>63</sup> While the 'HACC services for younger people' program will continue to be available throughout the transition, it is not clear if this support will continue beyond the full rollout.

## Carers

VCOSS members raise concerns at inadequate support for carers of people both eligible and ineligible for NDIS. In particular, VCOSS members report are significant shortfalls in available respite care. Funds from existing carer support services such as the Mental Health Respite: Carer Supports are being redirected to the NDIS, raising questions whether services will remain for carers of people ineligible for the NDIS.

VCOSS members report reduced support is being provided even for carers of people are deemed eligible for the scheme. The NDIS planning process does not assess carers' needs and the supports listed in plans, including respite, are framed largely from the participant's perspective. The NDIS interim evaluation has found support for carers, both inside and outside the NDIS, has reduced since the introduction of the NDIS.<sup>64</sup> Early indications about the integrated Carer Support Service suggest it will not provide carers with adequate support.

Carers often provide extensive support to people with disability, substantially reducing carers' social and economic participation.<sup>65</sup> Carers often face disadvantage themselves. Over one-third of primary carers have a disability, and are twice as likely to live in a low income household as non-carers.<sup>66</sup> To support carers' health and wellbeing, all carers must have access to appropriate levels of carer specific support and services to 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.

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<sup>63</sup> Victorian Government Health and Human Services, ACC in Victoria and the NDIS, <https://www2.health.vic.gov.au/ageing-and-aged-care/home-and-community-care/hacc-and-ndis>, accessed 10 August 2017.

<sup>64</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>65</sup> ABS, *Disability, Ageing and Carers, Australia: Summary of Findings, 2015*, Cat.No. 4430.0, October 2016.

<sup>66</sup> ABS, *Disability, Ageing and Carers, Australia: Summary of Findings, 2015*, Cat.No. 4430.0, October 2016.



## Information Linkages and Capacity Building

### Increase ILC funding

#### Recommendation

- Increase funding for information linkages and capacity building

Information Linkages and Capacity Building (ILC), formerly tier 2 of the NDIS, intends to assist the approximately 4.3 million people with disability nationally,<sup>67</sup> their families and carers, regardless of their eligibility for individual packages. It aims to make the community and mainstream services more accessible and inclusive of people with disability and to build the capacity of individuals and their families to fully participate in social and economic life.

The ILC will build up slowly over the NDIS transition to \$119m nationally in 2019-20.<sup>68</sup> This comprises less than one percent of the \$22b allocated for the NDIS. VCOSS members report funding is dramatically inadequate to fill the service gap for the large number of people ineligible for NDIS packages and achieve the ILC's aims. As an example, \$14m was recently allocated for 39 projects as part of the ILC national readiness grants<sup>69</sup> yet we understand around 368 grant applications were made, a success rate of only 10 per cent. In ACT, the first jurisdiction to receive jurisdictional grants, we understand \$3m was allocated to 22 projects,<sup>70</sup> out of 99 funding applications.

In theory, LACs are meant to spend approximately 20 per cent of their time supporting people with a disability ineligible for NDIS support packages and building community capacity.<sup>71</sup> However, VCOSS members report LACs' have been directed to prioritise planning over other functions due to the large workload, leaving limited capacity to perform other aspects of their role.

Bruce Bonyhady, former chair of the NDIA board has stated "*currently only \$132 million (excluding LAC support) 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.*"<sup>72</sup> The Productivity Commission also indicated it is "a false economy to have too few resources for ILC activities, particularly during transition when it is critical to have structures in place so people with disability are adequately connected with appropriate services".<sup>73</sup>

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<sup>67</sup> ABS, *Disability, Ageing and Carers, Australia: Summary of Findings, 2015*, Cat.No. 4430.0, 18 Oct 2016.

<sup>68</sup> NDIS, *ILC Commissioning Framework Consultation*, <https://www.ndis.gov.au/communities/ilc-home/ilc-commissioning-framework-consultation>, accessed 7 August 2017.

<sup>69</sup> NDIS, *ILC National Readiness Grants*, <https://www.ndis.gov.au/communities/nr-grants.html>, accessed 10 August 2017.

<sup>70</sup> Ibid.

<sup>71</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>72</sup> B Bonyhady, Letter to Minister Christian Porter, 22 December 2016, pp.3-4.

<sup>73</sup> Productivity Commission, op. cit., p.181.

We support the Productivity Commission's recommendation for ILC funding to be increased to the full scheme amount for each year of the transition.<sup>74</sup> We further recommend the amount of ILC funding should be increased as a percentage of the overall NDIS budget and indexed annually.

### Provide ongoing funding for core services

#### Recommendations

- Reconsider the time-limited funding approach for core services.
- Provide a fair and robust grants process for equitable service coverage across Australia and for all population groups and disability types.

The ILC is a grants-based program and currently will not provide long-term funding for services. The NDIS will hold annual grant rounds and have verbally indicated grants will be available for up to 12 months but organisations will have the option to apply for an extension of up to two years.

For many existing ILC-type services, such as those providing information and referral, time-limited projects are not suitable, as they are approached by new individuals and families every year seeking information and assistance. Many services have highly qualified staff with expertise developed over many years. Services are concerned precarious, year-to-year funding will undermine their ability to retain staff, plan ahead and or make financial commitments such as signing leases for premises.

Grant-based projects may also have limited geographic coverage, introducing uncertainty about equitable coverage within and between states and territories. It is also unclear whether ILC funding will be equitable for people with different disability types and from different population groups.

By their nature, ILC activities require strong networks, collaboration and relationships built up over time, but annual competitive grants undermines these connections, and instead pits organisations against one another in perpetual competition for scarce and unstable short-term funding. Moving to a competitive grants process creates a risk ILC services will not adequately engage with hard-to-reach groups and people most at risk of being underserved. The NDIA should re-think its mechanism for ILC funding, and move to a system that facilitates collaboration and funding stability, so the scope of ILC activities will meet the needs of all people with disability, their families and carers.

Some Victorian-based disability services providers have already been informed by the Victorian Government their funding for information services will cease from 30 June 2019 due to the ILC rollout. It is also unclear if these organisations will be successfully in receiving funding under the competitive grants-based program. Uncertainty remains over whether many existing Victorian

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<sup>74</sup> Ibid., p. 291.

based services providing ILC-type services will continue to be funded or will be expected to apply for ILC type funding, such as RuralAccess, MetroAccess and DeafAccess services.

VCOSS members are highly concerned valuable services will be lost in the transition to the NDIS. Providing ongoing funding for effective ILC-type activities and services, particularly those providing core services to people with disability, so service coverage is equitable and consistent.

## Provide NDIS participant with holistic, integrated services

### Identify and address service gaps between systems

#### Recommendation

- Report on boundary issues at regular COAG meetings, to identify and address service gaps.

VCOSS members are concerned about service gaps created between the interface of NDIS and other mainstream services. The ‘principles to determine the responsibilities of the NDIS and other service systems’ (the principles) agreed by COAG provide some clarity about funding responsibility across 11 areas.<sup>75</sup> However, in some circumstances, funding arrangements are still unclear given the complex nature of the supports required, such as when participants have interrelated health and disability issues and other co-morbidities. In other cases, the distinction between funding responsibilities is clear but remains problematic because mainstream service systems are not meeting their obligations to support people with disability. The NDIA’s position is “if another system is responsible for support, the NDIS cannot fund that support, even if the system responsible does not provide it.”<sup>76</sup> The NDIS does not impose obligations on other service systems, therefore, if other systems are not meeting their obligations, people with disability may face service gaps.

We believe the Federal and the State and Territory Governments have a joint responsibility to identify service gaps and to take action to address them, so NDIS participants are not left without crucial supports. We support the Productivity Commission’s recommendation for COAG to report on boundary issues, including identifying gaps and actions taken at quarterly meetings.<sup>77</sup>

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<sup>75</sup> COAG, [Principles to determine the responsibilities of the NDIS and other service systems](#), November 2015.

<sup>76</sup> NDIA, *The NDIS and mainstream interfaces How the NDIS works with other mainstream systems*, January 2014.

<sup>77</sup> Productivity Commission, op. cit., p.57

## Educate mainstream services

### Recommendation

- Educate mainstream services about the NDIS process, its implications for eligible and ineligible people and services' ongoing responsibilities to provide inclusive services.

VCOSS members report many mainstream services have limited NDIS knowledge and the implications for people with disability, whether eligible or ineligible for individual packages. For example, a participant in receipt of income support was consistently bulk-billed for Medicare services by his regular general practitioner, however, after becoming an NDIS participant the doctor claimed he no longer required bulk-billing. VCOSS members report some mainstream services have started to withdraw services as the NDIS rolls out in their area or as participants apply to the NDIS, but before their NDIS plans are in place. This potentially leaves people without services or are left paying out-of-pocket expenses for supports previously funded. The Productivity Commission identified similar issues with reports of mainstream services 'refusing entry to people likely to be eligible for the NDIS.'<sup>78</sup>

Many health professionals need to provide diagnostic information and evidence of the functional impact to assist people to become NDIS participant and receive appropriate support. VCOSS members report too often health professionals have limited understanding of the processes involved and the type of information required, creating difficulties for people with disability trying to enter the scheme and obtaining relevant support. It is crucial other service systems fully understand their responsibilities to assist people with disability, whether eligible or ineligible for the NDIS. Mainstream services, especially health services, also require adequate knowledge of the NDIS so they know the appropriate time and procedure to refer clients to the NDIS. We believe the NDIA and state and federal governments have a role in educating mainstream services.

### Mainstream health services withdrawing services and lacking NDIS knowledge

John\* recently applied to become an NDIS participant. He has multiple interrelated health and disability conditions, and requires regular support from his local hospital. John is legally blind, is in the final stages of renal failure and has a below the knee amputation. He requires a wheelchair and support to travel to and from his hospital appointments.

Upon learning John had applied for an NDIS package, the hospital started withdrawing services, claiming the NDIS will cover these supports, including the wheelchair which John uses continually. This occurred before John was deemed eligible for the NDIS and before he received a plan outlining his entitlements.

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<sup>78</sup> Ibid., p.200.

When Sacred Heart Mission learned of these issues, they advocated on John's behalf for the hospital to maintain services until NDIS plan was in place.

As part of the NDIS application process John's doctors needed to complete the NDIS Supporting Evidence Form to help identify the severity and permanency of his disability and its impact on his life. The completed form contained limited information and used a large number of medical acronyms such as 'BKA'. The information focused solely on the physical and medical aspects of John's conditions such as the medication he takes, rather than highlighting the functional impact of John's amputation and blindness. The lack of information could have resulted in John being refused entry to the scheme, leaving him without support or forced to undergo a lengthy appeals process.

When Sacred Heart Mission saw the inadequate form they intervened and included additional information based on their knowledge of John's functional impairment. They then provided this draft document to the Doctors to review and sign.

\* Name has been changed to protect individual's identity

## Assist services to collaborate

### Recommendations

- Develop and embed protocols and training for service collaboration to provide integrated support for NDIS participants.
- Fund collaboration meetings so NDIS workers and mainstream services can coordinate participant supports.

Even when all service systems are meeting their obligations, the differences between systems can create fragmented services. NDIS participants may have to access multiple systems to receive support, which may not be integrated or seamless. VCOS members report many NDIS participants find it challenging to navigate different service systems to meet all their needs.

*"participants also expressed frustration with system boundaries that limited the ways in which support and resources from different systems could be accessed and integrated to achieve optimal outcomes for people living with disabilities"*<sup>79</sup>

People with disability need to be treated holistically and receive integrated support to achieve their aspirations. Funding 'collaboration meetings' during service planning and delivery can assist NDIS and mainstream services to discuss and coordinate supports. Establishing protocols for services to work together could also help clarify roles and responsibilities of different service systems and providers.

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<sup>79</sup> D Warr, H Dickinson, S Olney et. Al. Choice, Control and the NDIS, Melbourne, University of Melbourne, 2017, p.54

## Provide case management

### Recommendation

- Provide case management support for NDIS participants when required, particularly when in crisis, such as facing homeless or experiencing family violence.

VCOSS members report people with disability have varying abilities to manage services, particularly across multiple services systems. This can be particularly difficult for people with complex issues or in crisis, such as facing homelessness or experiencing family violence. VCOSS members highlight the limited assistance provided by support coordinators under these circumstances, and believe more intensive support is required. The Productivity Commission also identifies a gap in crisis responses for some NDIS participants.<sup>80</sup> Access to case management when required, can provide maximum benefit from the NDIS, especially when participants need intensive support to stay connected to services.

### Case management required for NDIS participants with complex needs

Jean\* is a 62-year-old woman with a long history of mental illness, living in supported housing in Melbourne's northern suburbs. Two weeks after becoming an NDIS participant Jean's mental health deteriorated. She became violent towards the other women she lived with and left the house, sleeping rough for a few weeks and ending up in a psychiatric hospital.

Jean approached Sacred Heart Mission's Women's House in St. Kilda, which provides crisis support for women experiencing homelessness. Sacred Heart identified the woman as an NDIS participant and contacted her support coordinator for assistance to help find stable housing and manage her mental health concerns, but was advised this case management type work is not in scope for support coordinators.

As a result, Sacred Heart Mission provided hours of unfunded case management for this participant, helping her to find temporary housing, assisting her to attend appointments and coordinating many services including the hospital, support coordinator and housing provider.

This example highlights the need for funded case management to assist participants with complex needs and for NDIS plans to be flexible to assist people facing crisis. It also highlights the transient nature of some NDIS participants with complex needs, moving from the North Eastern Melbourne Area (NEMA) where the NDIS rolled began on July 2017 to an area not due to receive the NDIS until April 2018.

\*Name changed to protect identity

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<sup>80</sup> Productivity Commission, *op.cit.*, p.200.

## Services gaps for NDIS participants

VCOSS members report concerns about the interface between the NDIS and other service systems, including two areas not covered in the principles document – energy and emergency management.

### Education

The principles stipulate Education Departments and schools are responsible for providing supports primarily related to a student’s educational attainment.<sup>81</sup> However, education systems and schools are not meeting the needs of all children and young people with disability.

For example, VCOSS members report cases of children with complex communication needs enduring their entire schooling without any means of functional communication, such as access to equipment, or speech therapists with expertise in specialist communication methods. In Victoria, the Program for Students with Disabilities only supports around four per cent of the student population.<sup>82</sup> However, around 20 per cent of children have additional health and development needs and require additional supports to achieve their potential at school.<sup>83</sup> The Victorian Equal Opportunity and Human Rights Commission’s recent update on their *Held Back* report identifies “there is significant unmet need for support service in schools including integration aides, occupational therapists and speech therapists” and “some parents were contributing financially to the provision of specialist supports in schools to address gaps in the system.”<sup>84</sup> Without the NDIS or education systems fully funding supports, children and young people will continue to miss out on receiving assistance required to reach their educational goals.

Interface issues also extend to situations when funding is available. For example, VCOSS members report examples of schools not allowing therapists funded by the NDIS to enter classrooms or school grounds. This is supported by early findings from the recent Melbourne University study of participant’s experiences with the NDIS.<sup>85</sup>

### Health

Many people with disability experience complex health needs interrelated with their disability. While the NDIA acknowledges this, a clear demarcation between the NDIS and health system remains.<sup>86</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>87</sup>

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<sup>81</sup> COAG, *Principles to determine the responsibilities of the NDIS and other service systems*, November 2015, p.12.

<sup>82</sup> PSD Review Team, *Program for Students with Disabilities Review: In-person Targeted Stakeholder discussions*, 2015, p. 3.

<sup>83</sup> S Goldfeld, M O’Connor, M Sayers, T Moore, F Oberklaid, ‘Prevalence and correlates of special health care needs in a population cohort of Australian children at school entry’, *Journal of Developmental & Behavioral Pediatrics*. 2012; 33(4):319-327.

<sup>84</sup> Victorian Equal Opportunity and Human Rights Commission, *Held back: the experiences of students with disabilities in Victorian Schools – Analysis paper*, Carlton, August 2017, p.22.

<sup>85</sup> D Warr, H Dickinson, S Olney et. Al. *Choice, Control and the NDIS*, Melbourne, University of Melbourne, 2017, p.40

<sup>86</sup> NDIA, *The NDIS and mainstream interfaces How the NDIS works with other mainstream systems*, January 2014.

<sup>87</sup> COAG, *Principles to determine the responsibilities of the NDIS and other service systems*, November 2015.

The distinction between whether something is primarily a health or disability issue not always clear, leaving questions over which system is responsible and potentially creating funding gaps. For example, a VCOSS member reports an example of an NDIS participant with aphasia, severely affecting her speech production, unable to access certain therapies under the NDIS, such as a psychologist or speech therapist, as these were deemed the responsibility of the health system. The participant is currently paying for these services herself despite the therapies being required to help her accept and manage her acquired brain injury.<sup>88</sup>

### Mental health

People's mental and physical health can also be interrelated, such as when a person's mental illness reduces their ability to manage their physical health, particularly chronic health conditions. VCOSS members question whether NDIS participants with co-morbidity will be properly supported under the NDIS. A VCOSS member gave the example of a person with complex mental illness and chronic diabetes previously receiving support to manage their diabetes and administer insulin under their Victorian Individual Support Package. When transitioning to the NDIS, they were informed their NDIS package would no longer support assistance to manage diabetes, which was the responsibility the health system.<sup>89</sup>

The NDIS will not fund rehabilitation and recovery services as these are deemed the responsibility of the mental health system.<sup>90</sup> However, with the loss of community based psychosocial rehabilitation – whose funding is committed to the NDIS – there will be a gap for NDIS participants requiring this support.

### Justice

The COAG principles indicate the NDIS will support people involved in the criminal justice system in the community, but will not provide supports upon entering prison, whether on remand or during a custodial sentence.<sup>91</sup> This creates a lack of service continuity for people in the justice system, particularly given the limited supports available for people with disability in the justice system. Disrupted care may comprise their health and wellbeing and increase their chance of reoffending.<sup>92</sup>

VCOSS members also report other access issues for NDIS participants in custody including difficulties accessing the NDIS portal to plan for re-entering the community, due to limited computer and internet access.<sup>93</sup> Providing people with continuity of care before, during and after any custodial sentence can improve outcomes for these people and improve community safety.

VCOSS members report two cases of NDIS participants having intensive psychology treatment cut as a result of moving to the NDIS. In both cases, the individuals were receiving funding through their Victorian Individual Support Packages for psychological services to help reduce offending

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<sup>88</sup> VCOSS, *Funding the NDIS in full*, VCOSS submission to the Productivity Commission's review of NDIS costs, April 2017, p.27

<sup>89</sup> VICSERV, *Submission on Transitional arrangements for the NDIS Joint Standing Committee on the NDIS*, August 2017

<sup>90</sup> COAG, *Principles to determine the responsibilities of the NDIS and other service systems*, November 2015, p.6.

<sup>91</sup> COAG, *Principles to determine the responsibilities of the NDIS and other service systems*, November 2015, p.21.

<sup>92</sup> J Young and S Kinner, *Prisoners are excluded from the NDIS – here's why it matters*, the Conversation, 14 March 2017.

<sup>93</sup> Jesuit Social Services, *Submission to the Productivity Commission study, into the National Disability Insurance Scheme costs*, March 2017,



related behaviour and promote pro-social behaviour and broader life skills. The NDIA has ruled this support is not 'reasonable and necessary' on the grounds it relates to offending behaviour. However, the COAG principles states the NDIS will cover "supports to address behaviours of concern (offence related causes) and reduce the risk of offending and reoffending such as social, communication and self-regulation skills..."<sup>94</sup> Some service providers specialising in forensic support services to people with disability have also been informed they cannot provide this support under the NDIS. It is unclear if they will continue to receive state-based funding. Without these support these people risk becoming entrenched in the criminal justice system.

## Transport

In Victoria people with limited mobility are provided with subsidised taxi fares through the Multi-Purpose Taxi Program (MPTP). However, VCOSS understands the NDIA and Victorian Government intend to ultimately 'fully transition' NDIS participants out of the Multi-Purpose Taxi Program (MPTP) and 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>95</sup>, but the structure of the MPTP provides people with 'uncapped' subsidies. This means any current MPTP members moving to the NDIS may experience a reduction in their entitlements. In addition, NDIS participants are not eligible to receive the federal government's Mobility Allowance.<sup>96</sup>

VCOSS members report inconsistent and inadequate travel funds included in participant 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 budgets.<sup>97</sup> The independent evaluation of the NDIS also found transport was not always included in participants' plans.<sup>98</sup> As a result, some participants "regularly paid out-of-pocket expenses for services such as transportation."<sup>99</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>100</sup>

## Emergency management

The 2009 Bushfire Royal Commission found, of the 173 people who died as a result of the fire, 44 per cent were found to be more vulnerable to bushfire because of age, ill health or a combination

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<sup>94</sup> Council of Australian Governments, *Principles to determine the responsibilities of the NDIS and other services systems*, 27 November 2015, p.23

<sup>95</sup> NDIA, *Participant transport funding information*, <https://www.ndis.gov.au/document/participant-transport-funding-informati.html>, accessed 28 March 2017.

<sup>96</sup> NDIA, *Mobility Allowance and the NDIS*, <https://www.ndis.gov.au/document/mobility-allowance-and-ndis>, accessed 9 August 2017.

<sup>97</sup> R Browne, *NDIS planning process leaves people with a disability fighting for support*, Sydney Morning Herald, March 2017.

<sup>98</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>99</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>100</sup> Victorian Council of Social Service, *Improving transport for Victorians with limited mobility*, December 2015, p.18

of both. Following a series of recommendations by the Royal Commission, the Victorian Government developed a *Vulnerable People in Emergencies Policy* designed to improve the safety of vulnerable people in emergencies.

Agencies funded to provide personal care, support and case management services to people living in the community have a key role in relation to the safety and welfare of clients. This includes agencies providing personal care, support or case management services in home or community settings, to people living in the community, and includes services such as home and community care, personal care or disability day programs. All service providers funded by the Victorian Department of Health and Human Services (DHHS), are required to plan for a diversity of emergencies affecting people.<sup>101</sup> This includes events caused by weather or natural emergencies, human health, animal health, failure of infrastructure and security emergencies. Providers have contractual obligations to act immediately when becoming aware of a risk or actual emergency such as relocation in the case of extreme risk bushfire areas on Code Red days.

VCOSS members raise concerns about where the responsibility for emergency planning will lie with the transition to the NDIS. Providers in areas where the NDIS is available report they have not been provided with templates or documents prompting thought about emergency planning or preparedness for people. The health and wellbeing of people with disability will be at risk without adequate emergency services planning and clear lines of responsibility for their care or evacuation during an emergency event.

### Energy bills

Some people with disability have conditions which make them more susceptible to thermal illness or limits their ability to regulate their temperate.<sup>102</sup> This may require them to maintain stable environmental temperatures to manage their health. The consistent heating or cooling of their home can lead to costly energy bills. VCOSS members report some people received energy subsidies under their Victorian Individual Support Plans, but this does not appear to be available under the NDIS.

The Victorian Government has a medical cooling concession but this is only available for people who have a condition which affects their ability to regulate temperature<sup>103</sup> and there are no medical heating concessions available. VCOSS and ACOSS members are also concerned about the potential loss of the Energy Supplement which will affect people on income support including people with disability on the Disability Support Pension.<sup>104</sup> Without adequate financial support

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<sup>101</sup> Victorian Department of Health and Human Services, *Emergency preparedness policy for clients and services*, October 2016.

<sup>102</sup> P C William, 'Thermoregulatory disorders and illness related to heat and cold stress', *Autonomic Neuroscience* Vol 196, April 2016, pp 91-104.

<sup>103</sup> Department of Health and Human Services, *Medical Cooling Concession*, <http://www.dhs.vic.gov.au/for-individuals/financial-support/concessions/energy/medical-cooling-concession>, accessed 14 August 2017.

<sup>104</sup> ACOSS, *ACOSS rejects Federal Government's latest attempt to cut incomes of people living in poverty. The energy supplement must stay*, [http://www.acoss.org.au/media-releases/?media\\_release=acoss-rejects-federal-governments-latest-attempt-to-cut-incomes-of-people-living-in-poverty-the-energy-supplement-must-stay](http://www.acoss.org.au/media-releases/?media_release=acoss-rejects-federal-governments-latest-attempt-to-cut-incomes-of-people-living-in-poverty-the-energy-supplement-must-stay), 26 July 2017.

these people may face large out of pocket expenses and potentially put their health at risk if they cannot manage costs.

### Child and family services

The NDIS will only provide support for children, families and carers directly related to a child's or parent's disability.<sup>105</sup> 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. VCOSS members the child protection system is not providing adequate support for families at risk of entering the child protection, where a child or parent has a disability.

The Victorian Equal Opportunity and Human Rights Commission's report *Desperate measures* found families with children with disability cannot 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>106</sup> Lack of appropriate supports, prejudice and lack of understanding from practitioners also contributes to the high rate of parents with intellectual disability being involved in the statutory system.<sup>107</sup> Having the flexibility to support the family unit, and strengthen their capacity to remain together could achieve better outcomes for children and families. VCOSS members also highlight a lack of support for children with disability who are ageing out of care, placing them at risk of poor health and wellbeing.

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<sup>105</sup> COAG, [Principles to determine the responsibilities of the NDIS and other service systems](#), November 2015.

<sup>106</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>107</sup> A Lamont and L Bromfield, *Parental intellectual disability and child protection: Key issues*, AIFS, 2009.

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