



Submission

**NDIS Act Review and Participant Service Guarantee
Tune Review**

October 2019

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

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About Carers Victoria

Carers Victoria is the state-wide peak organisation representing people who provide care. We represent more than 736,600 family carers across Victoria – people caring for someone with a disability, mental illness, chronic health issue or an age-related condition.

People receiving care could be a parent, child, spouse/partner, grandparent, other relative or friend. Carers Victoria is a member of the National Network of Carers Associations, and the Victorian Carer Services Network. Carers Victoria is a non-profit association which relies on public and private sector support to fulfil its mission with and on behalf of carers.

Carers Victoria is a membership-based organisation. Our members are primarily family carers, who play an important role in informing our work, contributing to advocacy and strategic aims, and distributing information more widely to other carers.

This policy paper was prepared by Carers Victoria's Policy Team.

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Executive summary

People living with disability do not exist in isolation. Before the National Disability Insurance Scheme (NDIS), research found unpaid family and friend carers provided 74 per cent of the assistance needed to live in the community.¹

Engaging carers in a participant's NDIS plan will increase the outcomes of the NDIS – the participant's whole life will be considered rather than a narrow focus on their disability. Carers are also regularly mentioned in the National Disability Insurance Scheme Act 2013 and must be included if the Act is to be properly implemented.

Carers are crucial in supporting people with disability. Including carers and informal care in NDIS plans will help people with disability achieve their goals.

By improving the skills of workers, having better consultation, instituting reasonable time limitations on responses and providing more assistance to navigate the bureaucracy, the NDIS will be a better scheme.

The NDIS website states:

The role of families and carers is often essential in supporting people with disability to realise their goals, so it is important to include them in discussions about supports.

Carers Victoria welcomes the opportunity to contribute to the NDIS Act and Participant Service Guarantee review.

¹The Allen Consulting Group *The Future of Community Care (Report to the Community Care Coalition, Melbourne)* March 2007.

Recommendations

1. All relevant NDIS communications to be written in plain English.
2. The NDIS to provide communications in a range of accessible modalities (face-to-face, via small groups or by via video).
3. The NDIA and LACs employ people from different language and cultural groups.
4. The NDIA and the LACs perform active outreach to engage face to face with individuals and groups in their preferred language who are unlikely to use online communications.
5. NDIA and LACs appoint more staff with lived experience of disability and caring.
6. NDIA and LACs appoint more staff with qualifications in disability.
7. NDIA and LACs provide incentives for staff to upgrade their disability qualifications.
8. The NDIS and LAC have flexible workplace practices to allow for employees in caring situations.
9. Appoint dedicated NDIS Assistants who, where available, have lived experience in participants' conditions. These case managers must be independent of assessment and planning and easily accessible. For example, co-locating them in NDIA and/or Centrelink offices.
10. Either relocate the call centre to within NDIA or LACs or allocate the call centre contract to an organisation with demonstrated skills in disability who must work closely with the NDIA and LACs.
11. Adopt a process whereby call centre staff to communicate directly with LAC and NDIA staff while participants or nominees are on the line.
12. The NDIA/LACs to provide intensive individual support to people requiring access assistance.
13. Where it is appropriate, provide an extra step before assessment where the application is discussed with the participant, their carer and treating health professional to ensure the correct information is submitted.
14. Clarify the respective obligations of health care and NDIS services.
15. The NDIA and LACs are to work closely with the health sector to appropriately support people to manage health conditions limiting their ability.
16. Review information provided by the NIDA to treating health professionals.
17. Phase in minimum qualifications and experience to develop LAC planning as a career.

18. During induction, LAC planners must spend time in service provider organisations.
19. During induction, LAC planners must receive training in caring / informal care.
20. LAC planners to refer carers requiring face-to-face supports to carer organisations to assist with understanding the NDIS.
21. Before a planning meeting, communicate with participants and their nominees in the most appropriate method which may include booklets, face-to-face meetings, via small group training or video.
22. LAC planners must consider informal support and carer roles in plan development.
23. LAC planners must consider Carer Statements in plan development.
24. LAC planners must include sustaining caring relationships in plans.
25. Participants and their nominees must receive appropriate and timely notification of a review, which contains recommendations on how to prepare.
26. Perform an NDIA organisational review and lift the staffing cap to meet demand if required.
27. Service providers to receive a minimum of four weeks' notice of a plan review.
28. There be no plan reviews for assistive technology equipment prescriptions and home modifications.
29. Put all relevant aspects of an NDIS package online and accessible to participants and their nominees so service providers are notified of pertinent changes.
30. Where appropriate, refer carers to outsourced face to face, small group training and/or online video supports. Information must be plain English and in various languages.
31. Provide participants, nominee and training facilities with a test copy of the 'myplace' application for practice/training purposes.
32. Appoint dedicated appeals managers who are contactable by participants.
33. Reviews to occur within an agreed reasonable and quick time limit.
34. Advocacy services be funded to assist with the NDIS appeals process.
35. Carer advocacy services be funded to assist carers in the NDIS appeals process .
36. NDIS rejection letters must refer to the NDIS Act and be specific to the participant's situation.

Introduction

The NDIS is a revolutionary and positive step in making Australia a fairer society. Participants are being supported to live more dignified, active lives and will have the opportunity to exercise choice and control by purchasing supports according to their needs and preferences.

To help participants achieve their goals, Victoria has 736,600 family and friend carers. One in eight Victorians is an unpaid family or friend carer. These carers provide approximately \$15b worth of support annually.²

Carers are the social lifeblood of many people with disability.

Including carers and informal care in NDIS plans will produce better outcomes for participants.

Carers can experience significant personal and financial costs through providing care. Carers can lose \$50,000 - \$60,000 in lost superannuation for a 10-15-year period out of the workforce.³

The Centrelink Carers Payment, with all supplements, is \$933.40 per fortnight. The current Australian minimum wage for the same period is \$1481.60. Someone in a full time caring role earns 37% less than the minimum wage. How society values people taking care of those with disability has been monetised as being worth less than two thirds of the minimum wage. Increasing social inclusion in the workplace is estimated to add an extra \$12.7b a year to the Australian economy.⁴ Making the NDIS more effective will free up the earning potential of both carers and participants.

Australian and international research has documented the positive and negative aspects of caring and identified mixed effects. Studies have found that carers report positive aspects of caring, such as companionship, fulfilment, enjoyment and satisfaction, as well as the negative effects on psychological health, such as depression, anxiety and burden.⁵ A key study in Australia in 2007 identified carers as having 'the lowest collective wellbeing of any group we have yet identified.'⁶

² Deloitte Access Economics, 'The economic value of informal care in Australia in 2015', <https://www.carersaustralia.com.au/storage/access-economics-report3.pdf>.

³ Nepal, B., Brown, L., Ranmuthugala, G. and Percival, R., 2008. Lifetime health and economic consequences of caring: Modelling health and economic prospects of female carers in Australia. Commonwealth Financial Planning, Commonwealth Bank of Australia, pp 27.

⁴ Deloitte "The economic benefits of improving social inclusion" Deloitte Access Economics 2019

⁵ Bauer, J.M., and Sousa-Poza, A, 'Impacts of Informal Caregiving on Caregiver Employment, Health, and Family', *Journal of Population Ageing*, 8(3):113-45, 2015, doi: 10.1007/s12062-015-9116-0 in Hill, T., Broady, T, 2019, "Understanding the social and emotional needs of carers: Final report (SPRC Report 2/19)". Sydney: Social Policy Research Centre, UNSW Sydney, <http://doi.org/10.26190/5c59202697201>, p.14.

⁶ Cummins, R., Hughes, J., Tomy, A., Gibson, A., Woerner, J., and Lai, L. (2007). "The Australian Unity Wellbeing Index, Survey 17.1. The Wellbeing of Australians-Carer Health and Wellbeing," Deakin University, Australian Unity and Carers Australia, Melbourne in Hill, T., Broady, T., "Understanding the social and emotional needs of carers: Final report (SPRC Report 2/19)". Sydney: Social Policy Research Centre, UNSW Sydney, 2019, <http://doi.org/10.26190/5c59202697201>, p. 14

Carer's Victoria submission focusses on Access, Planning, Review, Appeals and Decision-Making procedures of the NDIS.

Access

While the NDIS has a reported 90 per cent satisfaction rating⁷, many carers are very frustrated by the system.

Carers tell Carers Victoria's NDIS dedicated staff there are problems with how the National Disability Insurance Authority (NDIA) and the Local Area Coordinators (LACs) communicate. While NDIS forms are generally easy to read, many people have low literacy rates and need help to understand the information. Plain English is noted to improve the reader's comprehension of written materials.⁸

Recommendation 1: All relevant NDIS communications to be written in plain English.

The NDIS uses online information as its primary method of communication. While this is generally good, not all participants and carers have access to the internet. Information must be in a range of accessible modalities.

Recommendation 2: The NDIS to provide communications in a range of accessible modalities (face-to-face, via small groups or by via video).

Carers Victoria notes there have been below average NDIS uptake rates of people from Culturally and Linguistically Diverse (CALD) backgrounds and Aboriginal and/or Torres Strait Islander communities. We also note:

Specific cohorts of people with disability were identified in the qualitative interviews as particularly struggling with the complexity of NDIS processes and documentation. These included people with psychosocial disability, those with literacy problems or cognitive impairment, and people from CALD or Indigenous backgrounds. Concerns also persisted across the evaluation, that people with psychosocial disability were experiencing higher rates of ineligibility and consequently had lower levels of NDIS participation.⁹

Having a diverse workforce will help the NDIA and the LACs to manage engagement and communications with non-mainstream groups proactively.

Recommendation 3: The NDIA and LACs employ people from different language and cultural groups.

⁷ NDIS <https://www.ndis.gov.au/news/1518-ndis-data-shows-one-three-participants-are-accessing-disability-supports-first-time> 28 Oct 2019

⁸ Baldwin, C. 1999. *Plain language and the document revolution*. Washington, DC: Lamplighter Press

⁹ Mavromaris, K. et al. *Evaluation of the NDIS* National Institute of Labour Studies, Flinders University, Adelaide, South Australia Feb 2018

Recommendation 4: The NDIA and the LACs perform active outreach to engage face to face with individuals and groups in their preferred language who are unlikely to use online communications

Having disability skilled NDIA and LAC staff is essential as there are minimal opportunities to discuss an application with the NDIA. Therefore, the success of an application relies on the knowledge and skills of LAC workers. Asking a person if they need mobility assistance can be surprisingly complicated. While people with an intellectual or psychosocial disability may be physically able to move around, they may be unable to catch public transport without support.

Carers regularly report NDIS and LAC staff have a poor understanding of disability services. By employing more people with disability, the LACS and NDIA will have an informed workplace.

The NSW government reports for most employers:

- employment and induction costs are not higher for people with disability
- there are no increases in workplace health and safety problems after employing people with disability
- a person with disability can perform just as well as someone without disability in their job and tasks, and
- people with disability do not take more sick days than people without disability.¹⁰

For the disability sector, the benefits of employing more people with lived experience of disability and caring would be even higher. Employment of people with disability and carers also has the advantage of moving people from welfare into work where their experiences are valued.

Recommendation 5: NDIA and LACs appoint more staff with lived experience of disability and caring

Recommendation 6: NDIA and LACs appoint more staff with qualifications in disability

Recommendation 7: NDIA and LACs provide incentives for staff to upgrade their disability qualifications

With an ageing population, Australian employees will need more workplace flexibility to provide care for older friends and family members. Employers who support carers in the workplace report a range of benefits, including:

- attracting and retaining staff;
- improving staff morale;

¹⁰ NSW Government <https://www.seethepossibilities.nsw.gov.au/resources/benefits> 28 Oct 2019

- improving staff engagement;
- reducing recruitment and training costs;
- producing cost savings;
- reducing sick leave and absenteeism, and
- increasing productivity and improving service delivery.¹¹

One publication found, in a caring emergency “*you are not dealing with an absence, you are potentially dealing with a vacancy, if you don’t respond appropriately. The cost of recruiting is incomparable to the cost of 2–3 days’ emergency leave*”.¹²

Recommendation 8: The NDIS and LAC have flexible workplace practices to allow for employees in caring situations.

Carers report a lack of skilled support staff helping them through the application process. LACs and Support Coordinators assist applicants but have no role in decision making. Some participants need advocacy.

Recommendation 9: Appoint dedicated NDIS Assistants who, where available, have lived experience in participants’ conditions. These case managers must be independent of assessment and planning and easily accessible. For example, co-locating them in NDIA and/or Centrelink offices.

Carers report that call centre staff appear to be poorly skilled, have little disability knowledge and are unable to forward calls or contact staff within LAC or NDIA directly. Also, staff cannot provide advice over the phone.

Serco, the company running the call centre, has expertise in running prisons and detention centres and not disability. Paralympian Kurt Fearnley tweeted he was “going to assume that SERCO is currently racking their brains on how they can bring lived experience of disabilities into their workplace”.¹³ Serco’s appointment met with a mostly negative response from the disability sector.¹⁴

Serco is reported to email a query to a generic NDIA address, meaning no single person oversees complex matters. There is always a different person answering the call centre phone and often a different person answering emails at the NDIA.

¹¹ Carers UK and Employers for Carers Task and Finish Group 2013, *Employers ‘Business Benefits’ Survey*, p.1

¹² Yeandle, S Bennett, C Buckner, L Shipton, L Suokas, A *Who Cares Wins: The Social and Business Benefits of Supporting Working Carers, A Report for Carers UK*, 2006, p.14

¹³ Twitter @kurtfearnley 1.06 AM, April 23, 2018

¹⁴ Guardian Australia, *Outsourcing NDIS contact centres to Serco ‘an accident waiting to happen’* <https://www.theguardian.com/australia-news/2018/apr/23/outsourcing-ndis-contact-centres-to-serco-an-accident-waiting-to-happen> 23 April 2018

Recommendation 10: Either relocate the call centre to within NDIA or LACs or allocate the call centre contract to an organisation with demonstrated skills in disability who must work closely with the NDIA and LACs.

Recommendation 11: Adopt a process whereby call centre staff communicate directly with LAC and NDIA staff while participants or nominees are on the line.

Many people eligible for the NDIS struggle to make and keep appointments. People with intellectual and/or psychosocial disability who come from Aboriginal and/or Torres Strait Islander communities or CALD backgrounds can have trouble meeting bureaucratic requirements. Making a booking with a medical specialist, being clear on NDIS conditions, and then taking ongoing action is complex, can be costly and is beyond the capacity of some applicants.

Recommendation 12: The NDIA/LACs to provide intensive individual support to people requiring access assistance.

Recommendation 13: Where it is appropriate, provide an extra step before assessment where the application is discussed with the participant, their carer and treating health professional to ensure the correct information is submitted.

Carers Victoria regularly supports carers dealing with the interface between disability and health. Often, the NDIA defines an issue as health-related and outside of their area. The lack of demarcation clarity inhibits what “reasonable and necessary” services a person receives.

Colin Burchell is an NDIS participant with cerebral palsy which causes dysphagia. Mr Burchell cannot swallow properly and needs to consume thickened fluids. The NDIA refused to fund the fluids claiming it was a health issue. Mr Burchell appealed to the Administrative Appeals Tribunal, who found “*the funding or provision of the support takes account of what is reasonable to expect families, carers, informal networks and the community to provide*”.¹⁵

Other legitimate applications may have been rejected because of incorrect NDIA reasoning.

Recommendation 14: Clarify the respective obligations of health care and NDIS services.

Recommendation 15: The NDIA and LACs are to work closely with the health sector to appropriately support people to manage health conditions limiting their ability.

¹⁵Wade, N. *Tough to swallow: the recent decision of Burchell v National Disability Insurance Agency*
<https://www.equalitylawyers.com.au/post/burchell-and-ndis>

Carers Victoria has supported carers where their health professionals have not read the small print in an application and incorrectly filled sections out.

Recommendation 16: Review information provided by the NIDA to treating health professionals.

Planning

While most participant plans proceed well, many do not. Carers Victoria receives calls about planners' lack of disability knowledge and a refusal or reluctance to include specific supports to maintain their unpaid caring role. Participants who know little about the NDIS or lack assertiveness or language skills can end up with inadequate plans.

LAC planners are a critical part of the NDIS but do not appear to require qualifications or a good knowledge of disability.

Recommendation 17: Phase in minimum qualifications and experience to develop LAC planning as a career.

Recommendation 18: During induction, LAC planners must spend time in service provider organisations.

People with a lived experience of disability and caring and appropriate qualifications are best placed to advise with planning.

While participants and carers receive information, there is limited practical support in turning this information into an NDIS plan.

Participants are often unsure of what a planning meeting is and are therefore unprepared. While a lot of generally useful information is online, it is not accessible to some groups.

Participants require explicit instructions and significant lead times. Carers Victoria spends considerable time assisting carers in this phase. It can often take months to get a report from a bulk billing medical specialist.

Many participants and carers need independent and informed support to understand planning. Carers Victoria delivers NDIS information sessions and programs and provides direct support to carers state-wide on all stages of the NDIS process.

Carers Victoria is a peak body to support unpaid family and friend carers. We know carers must be supported to ensure participants get the most out of the NDIS.

Recommendation 19: During induction, LAC planners must receive training in caring / informal care.

Recommendation 20: LAC planners to refer carers requiring face-to-face supports to carer organisations to assist with understanding the NDIS.

Assistance with planning and better information must be a standard part of NDIA and LAC services. Better planning will reduce the amount of time the NDIA spends in appeals. Carers Victoria finds many carers prefer meeting with a person rather than being referred to a website or sent a letter. As already stated, information can be discussed face-to-face, via small group training or by video and all communications must be in plain English and in a culturally appropriate language.

Recommendation 21: Before a planning meeting, communicate with participants and their nominees in the most appropriate method which may include booklets, face-to-face meetings, via small group training or vide.

Planners often do not access informal supports or even appear to understand them very well. While the NDIS Act mentions carers, this rarely translates into a plan. The Act allows for funding of supports to enable carers to build capacity in their role.

Carers have told Carers Victoria how planners sometimes comment on parental supervision being normal for a 13-year-old. While this is correct, most 13 year olds can be left alone for short periods. However, a 13 year old with severe autism will need continuous supervision by their parents or others. The toll of 24/7 care provision is often not reflected in plans.

Recommendation 22: LAC planners must consider informal support and carer roles in plan development.

Recommendation 23: LAC planners must consider Carer Statements in plan development.

Recommendation 24: LAC planners must include sustaining caring relationships in plans.

Review

Participants sometimes experience reviews with little to no knowledge of the process which is occurring. People with psychosocial disability, or from Aboriginal and/or Torres Strait Islander communities, from CALD communities, or those with poor literacy skills are particularly vulnerable. They can be ill-prepared to participate.

Recommendation 25: Participants and their nominees must receive appropriate and timely notification of a review, which contains recommendations on how to prepare.

Carers Victoria is regularly informed of reviews taking a long time, often six months, often longer. The NDIA was initially planned to have 10,000 employees but is limited to 3,400. The fragmentation from the outsourcing of the remaining employees has had negative consequences on the processes, skill development, retention of experience and the number of reviews needed. The result of a fragmented and highly casualised service provider workforce is profound.

Recommendation 26: Perform an NDIA organisational review and lift the staffing cap to meet demand if required.

Service providers complain they are often not informed of plan reviews which results in business and income loss.

Recommendation 27: Service providers to receive a minimum of four weeks' notice of a plan review.

As some plan aspects are generally non-contentious, existing plans could be adapted instead.

Recommendation 28: There be no plan reviews for assistive technology equipment prescriptions and home modifications.

Client-centred computer software could be developed, enabling the participant or their nominee to log in and assess all aspects of their NDIS engagement. A separate component could be added notifying service providers whenever a relevant change is occurring.

Recommendation 29: Put all relevant aspects of an NDIS package online and accessible to participants and their nominees so service providers are notified of pertinent changes.

Participants and their nominees report difficulty with navigating the NDIS portal 'myplace'. The support provided by LACs varies with degree of knowledge and expertise. NDIS online resources are in written format and not accessible to all carers as they may have literacy issues, come from a non-English speaking background or be vision impaired.

Recommendation 30: Where appropriate, refer carers to outsourced face to face, small group training and/or online video supports. Information must be plain English and in various languages.

Recommendation 31: Provide participants, nominee and training facilities with a test copy of the 'myplace' application for practice/training purposes.

Appeals

Participants and carers can find appeals challenging. Often the participant or their nominee receives minimal information while a review is occurring. Again, information should be available online and the participant and their nominee must receive written notification well in advance.

Carers Victoria also notes there is no single contact point in the NDIA regarding a review.

Recommendation 32: Appoint dedicated appeals managers who are contactable by participants.

An appeal can take a long and uncertain time to occur.

Recommendation 33: Appeals to occur within an agreed reasonable and quick time limit.

LACs cannot advocate for a participant during an appeal, but they can facilitate access to advocacy. There are advocacy services, but they have long waitlists and are issues specific. A person who has autism cannot access a service which caters for people with an intellectual disability.

Recommendation 34: Advocacy services be funded to assist with the NDIS appeals process.

Recommendation 35: Carer advocacy services be funded to assist carers in the NDIS appeals process.

Decision-making

Decision-making can be slow and fragmented as the NDIA, LACs and call centre all have separate briefs. There is frequently no single person to contact about issues.

NDIA letters rejecting applications are generic and non-specific in their rationale. It is reasonable to quote which section of the NDIS Act denies an application. However, many people don't know, understand or have access to the Act to find out what this means.

Recommendation 36: NDIS rejection letters must refer to the NDIS Act and be specific to the participant's situation.

Conclusion

Carers play a critical role in the support of people with disability. Including carers and informal care in NDIS plans will help people with disability achieve their goals. The NDIS can be readily improved with structural changes: improving the skills of workers, better consultation, reasonable time limitations on responses and more assistance to navigate the bureaucracy.