



8 November 2019

NDIS Consultations  
Department of Social Services  
By email: [NDISConsultations@dss.gov.au](mailto:NDISConsultations@dss.gov.au)

Dear NDIS Consultations,

### Submission to the Review of the NDIS Act and the new NDIS Participant Service Guarantee

Thank you for the opportunity to provide a submission to the Review of the NDIS Act and the new NDIS Participant Service Guarantee. We understand the purpose of this review is to assess the operation of the *National Disability Insurance Scheme Act 2013* (NDIS Act), with a focus on streamlining National Disability Insurance Scheme (NDIS) processes and removing red tape for participants and providers. We welcome the opportunity to support and improve the experiences of NDIS participants and providers.

The Australian Capital Territory Human Rights Commission (ACT HRC) is an independent agency established by the *Human Rights Commission Act 2005* (ACT) (HRC Act). Its main object is to promote the human rights and welfare of people in the ACT. The ACT HRC includes the President and Human Rights Commissioner, the Public Advocate and Children and Young People Commissioner (PACYPC), the Discrimination, Health Services, Disability and Community Services Commissioner (DHSDCSC), and the Victims of Crime Commissioner (VOCC).

The President and Human Rights Commissioner is responsible for managing the administration and governance of the ACT Human Rights Commission. The role also includes advising government on the impact of laws and government services on human rights, including obligations of public authorities to comply with human rights.

The PACYPC has legislative responsibility for protecting and promoting the rights and interests of people in the ACT whose situation or condition (includes their experience of disability) gives rise to vulnerability and the risk of abuse, exploitation and/or neglect. The PACYPC also holds functions in relation to fostering the provision of services, supporting the establishment of organisations, and encouraging the development of programs that benefit people with disability. The responsibilities of the PACYPC are underpinned by a range of functions including individual and systemic advocacy, representation, investigation, and monitoring.

The DHSDCSC has a mandate to consider complaints about the provision of services for people with disability and/or for their carers; complaints about unlawful discrimination (for example, being treated unfavourably in the provision of goods or services on the grounds of disability); to promote improvements in the provision of services for people with disability and their carers; and to promote an awareness of the rights and responsibilities of consumers and providers.

The VOCC delivers frontline services to help individuals and their families deal with the effects of violent crime, including the provision of financial assistance, brokered counselling and other therapeutic services, court support, safety planning, and linking victims with appropriate community-based supports. The VOCC performs a range of functions in relation to family violence, with statutory appointments as the ACT Domestic Violence Project Coordinator for the ACT

Domestic Violence Prevention Council and as the Chair of the Family Violence Intervention Program Coordinating Committee. The VOCC and Victim Support ACT work closely with people with disability given they are impacted by disproportionately high rates of violent crime.

The nature of the ACT HRC's contact with NDIS participants and their families is often related to issues of concern and complaints. While it is acknowledged that there are many people in the ACT who report strong outcomes from their participation in the NDIS, our submission will focus on the concerns and complaints raised by a wide range of participants and organisations representing people with disability.

We have endeavoured to address a number of the terms of reference by drawing from information and feedback we receive through our various functions, including advocacy, complaints resolution and support for victims of crime.

### Overarching comments

The National Disability Insurance Agency's (NDIA) published information sets out "that the National Disability Insurance Scheme will provide all Australians under the age of 65 who have a permanent and significant disability with the reasonable and necessary supports they need to enjoy an ordinary life."

The NDIS Act sets out a number of objects including to:

- support the independence and social and economic participation of people with disability
- provide reasonable and necessary supports, including early intervention supports, for participants
- promote the provision of high quality and innovative supports that enable people with disability to maximise independent lifestyles and full inclusion in the community
- give effect to certain human rights obligations. [NDIS Act s3(1)(c)(d)(g)]

At this time, the ACT HRC considers the intent of the scheme, as set out in legislation, is yet to be fully realised in the ACT. The ACT HRC has identified a number of key factors that impact on the full achievement of these outcomes, as follows:

- the current NDIS processes are complex, bureaucratic and not user-friendly
- there is a lack of accessible complaints management and resolution, particularly in relation to NDIA decisions
- there is limited assistance to access and navigate the system, which places an increased burden on informal supports and other service systems, and results in some vulnerable people not accessing the scheme
- the approach to plan approval appears to apply standardised or benchmark levels of support rather than consideration of the individual's reasonable and necessary supports as required by the legislation
- delays in processes, inaccessibility of NDIA staff and the limited accountability of the NDIA impact on participant outcomes
- the developing disability services market in the ACT is not yet able to fully meet participant's needs and deliver quality supports across the sector
- interfaces with other service systems such as health and public housing are not streamlined having a direct impact on participants' quality of life.

## Process issues

### Communication with NDIS participants

The objects and principles of the NDIS Act assert that people with disability should be provided with reasonable and necessary supports and "...should be supported in all their dealings and communications with the Agency so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances...".

The PACYPC regularly receives concerns from NDIS participants, their families/carers and/or support/service providers indicating that communication with participants is not being conducted in a way that appropriately takes into account the person's disability and communication support needs. Further, a common complaint received by the ACT HRC relates to the lack of communication between the NDIA and NDIS participants, their families/carers, and their support/service providers. ACT HRC staff also experience this difficulty when attempting to engage NDIS staff to respond to issues raised.

*Case example 1:* Sue has Down syndrome, an intellectual disability and hearing impairments. As a result of her communication needs, communication should be in person wherever possible. Concerns were raised that Sue's supports coordinator was isolating her from her support network. More specifically, it was alleged that Sue's supports coordinator had advised the support/service providers that were in place that they were no longer needed. Further, Sue had ceased her part-time employment and had become socially isolated. Concerns were also raised about not being able to speak with Sue without the supports coordinator present, and that the supports coordinator would listen in on phone calls and tell Sue what to say. The concerns about the supports coordinator's conduct were reported to the NDIS for investigation. Despite raising the communication needs of the participant with NDIS, including by advising what Sue needs to communicate effectively, the investigation was conducted with Sue over the phone.

These communication issues also impact on the implementation and review of NDIS plans, meaning that there are often delays between old plans expiring, the scheduling of a review, and new plans being approved. As a result, service providers may go into debt if they continue providing the NDIS participant with the supports they need. Others will cease providing services, leaving vulnerable NDIS participants without the required supports, which in some cases has led to homelessness.

*Case example 2:* John's NDIS plan was due to expire in six weeks. John's guardian tried to follow up in relation to setting a date for a review meeting as no review planning meeting had been arranged. The guardian, supports coordinator and service provider all sent numerous emails and phone calls to the NDIA to try and arrange the review meeting. No response was provided by the NDIA. There were concerns that if the review was not scheduled, the plan would expire leaving John without funding for the 24/7 support that he required. With the date of expiry of the plan fast approaching, the guardian attended the local NDIS office and sat there for several hours until someone spoke with her and arranged a review meeting.

### Lack of consistency and clarity in information provided by the NDIA

A recurring theme in many cases that the ACT HRC becomes involved in has been the lack of consistency and clarity in information provided by the NDIA. This is also a common complaint from NDIS participants, their families, advocates and service providers.

Differing answers are often provided in response to the same question, depending on the NDIA staff member who is contacted. Reports from participants and service providers indicate that this inconsistency often means they are passed from team to team within the NDIA, and sometimes also to external organisations. This is particularly true when it comes to enquiries about the cost of repairs and modifications to properties. The lack of a decisive and accurate response often means that people with disability are left living in unsafe accommodation due to significant delays in obtaining approval for necessary home modifications.

*Case example 3:* Shelly has significant and complex disability support needs and has been waiting for repairs and modifications to be made to her property. The repairs that are required have arisen due to damages that have occurred as a result of behaviours associated with Shelly's disability needs. The house is owned by Housing ACT and headleased by a non-government organisation. Repairs and modifications have not occurred due to the differing and contradictory information being provided by both the NDIA and Housing ACT.

### Responding to complaints

Under the HRC Act, the ACT HRC is able to receive complaints about a disability service provided in the ACT for people with disability or their carers. Disability services include services that provide assessment or referral of support needs, coordination, case management and brokerage, and also include services that provide home help, personal care, rehabilitation, advocacy, etc.

Since the rollout of the NDIS in the ACT, the ACT HRC has received numerous disability service complaints about the NDIA. The ACT HRC has attempted to seek a response from the NDIA in relation to the concerns raised in complaints received, however the NDIA has refused to participate in the ACT HRC's complaints resolution process.

The NDIA has presented several different arguments for not participating in the ACT HRC's process, including that the NDIS Act prevents the ACT HRC from compelling the NDIA to provide information in relation to complaints the ACT HRC has received about the NDIA. The NDIA has relied on the protection of information provisions in the NDIS Act, in particular section 67G which provides that the NDIA cannot be required to produce documents or disclose information to a court or other authority that has power to require the production of documents or the answering of questions.

The ACT HRC's view is that the NDIS Act is not a barrier to the NDIA complying with the Commission's requests for information in the exercise of its complaints investigation functions in relation to disability services provided in the ACT. In particular, the discretionary powers contained in sections 60 and 66 of the NDIS Act allow the disclosure of information if done so for the purposes of the Act or with the express or implied consent of the person to whom the information relates, or to a number of authorities and agencies (at Commonwealth, State and Territory levels) for the purposes of those authorities.

These provisions, however, have not in our experience been exercised by the CEO in favour of people with disability, and the ACT HRC has met a lot of resistance from the NDIA in engaging in our complaints resolution process. This refusal would appear to be inconsistent with the objects and principles of the NDIS Act, which include giving effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities (CRPD), such as the obligation to ensure effective access to justice for persons with disability on an equal basis with others in order to facilitate their effective role as direct participants. It also does not appear to be consistent with the principle that people with disability have the same right as other members of Australian society to pursue any grievance.

The ACT HRC has, in previous public submissions, called for the amendment of section 67G to clarify that Commonwealth, State and Territory bodies exercising lawful functions in relation to complaints about disability services continue to have the power to request or require the production of documents or the answering of questions. This would ensure that existing State and Territory independent external complaints bodies, including the ACT HRC, are able to provide a means for local resolution of matters regarding the provision of disability services by the NDIA, including plan preparation, coordination, review of plans, strategic and referral services to people with disability, and generally providing support and assistance to prospective participants and participants in relation to doing things or meeting obligations under, or for the purposes of, the NDIS Act.

The NDIS Quality and Safeguards Commission commenced operating in the ACT on 1 July 2019. The Commission is able to receive complaints about NDIS service providers. Importantly, it does not have the power to investigate complaints arising out of the services provided by the NDIA. The ACT HRC is supportive of this jurisdictional exclusion on the basis that oversight of the NDIA ought to be done by separate independent bodies, however, the effect of this in practice is that existing independent external complaints bodies have been unable to exercise complaint investigation powers in relation to the NDIA to assist people with disability to enforce their legal rights.

The ACT HRC remains concerned that ACT NDIS participants have had their rights of redress reduced and are not able to exercise the right to pursue any grievance as stated in the objects of the NDIS Act, and are not being supported in all their dealings and communications with the NDIA so that their capacity to exercise choice and control is maximised. The only redress mechanisms available at a federal level to individuals are the Commonwealth Ombudsman who is limited to investigating government administrative actions and the Australian Human Rights Commission which is limited to receiving disability discrimination complaints. Unlike the ACT Human Rights Commission, neither of these bodies is able to receive complaints about disability services more broadly and offer alternative dispute resolution as a way to resolve a complainant's concerns.

Alternative dispute resolution (ADR) offered by the ACT HRC fills a gap that currently exists in the options that are available to NDIS participants who wish to make a complaint about the services they have received from the NDIA. ADR provided by the ACT HRC is an informal and flexible process that allows the parties to a complaint to tell their side of the story and determine any mutually agreed outcomes for resolving the complaint or finding a way forward, with the help of a neutral and independent third party.

ADR is an important part of equal access to justice, to ensure that people have the option to choose a process that is less intimidating or legalistic, inexpensive, empowering, and better able to flexibly and creatively respond to their individual needs in a process that is generally quick, confidential and non-adversarial. Further, ADR has a documented high rate of successfully resolving complaints and assisting with maintaining ongoing relationships in circumstances where the parties choose to or are required to have an ongoing relationship of some nature.

### Limited availability of service providers

The objects of the NDIS Act include a focus on promoting the provision of high quality and innovative supports while the principles indicate that people with disability should have certainty that they will receive the care and support they need.

For people with complex needs, access to and the availability of supports, particularly accommodation, is extremely difficult. Service providers will often pick and choose the participants who they are willing to provide support to. People whose needs are harder and more complex regularly experience great difficulty in securing accommodation support.

The PACYPC has been involved in several cases where the accommodation placements of NDIS participants have broken down and where the complexity of the participant's needs has been cited by the service provider as the reason. This leaves people with complex needs with no accommodation options despite often having sufficient NDIS funding. This is particularly true for people with psycho-social disability.

Concerns have been raised that service providers choose to only support NDIS participants who are considered 'easy' to support. Conversely, concerns have also been raised about service providers who take on complex cases but do not have the skills to meet the support needs of the person.

*Case example 4:* Tom is facing homelessness after his current service provider ceased providing accommodation support as a result of his complex needs and behaviours. This is the third time that a service provider had ceased providing accommodation support due to Tom's complex needs. Tom's support coordinator has spoken to multiple service providers about providing accommodation support, however none of the service providers would accept Tom due to his behaviours and complex needs.

The case example above highlights the need for providers of last resort, which would allow a safety net for participants at risk of homelessness. Given the complex needs and behaviours of some NDIS participants, it also emphasises the importance of a skilled workforce that can appropriately respond to and meet the needs of people with disability who have complex behavioural needs.

### Access to employment supports

Where a participant has not initially sought employment supports during the plan creation process, seeking those supports at a later stage can be a time-consuming and burdensome process. The ACT HRC is aware of situations where participants have become successful in a job application and need employment supports to assist them in their employment, however by the time the employment supports have been approved into their plan, they have lost their employment due to the lack of support at the critical times needed.

It is also not clear that employment goals are routinely discussed as part of the planning process. We consider that employment supports should be included in NDIS plans for all participants over 18, unless the participant expressly chooses otherwise. The lack of employment supports at the key times at which participants need them is creating unnecessary barriers and additional red tape for participants and inhibiting their full participation in their communities. The right to participate in employment, recognised in the CRPD, should be reflected in the standard NDIS planning process.

### Interface with housing and health systems

The ACT HRC has numerous examples of people experiencing delays in assessments and approvals for housing modifications leading to people being unable to be discharged from ACT hospitals or living in properties that are not suitable and/or have not been safely adapted to their needs. We have also had a number of cases of people paying for modifications due to the delays and then being unable to be reimbursed for those costs. While housing modifications must be carefully assessed, delays in assessment and approval are causing distress to participants, their families and carers and contribute to 'bed block' where the person is in a hospital or health setting and is unable to be discharged at a clinically appropriate time due to NDIA process delays.

We note also that information sharing between the NDIA and health care teams where a person has a behaviour support plan in place or requires communication or other supports should be streamlined to reduce the impact on a person with a disability arising from inconsistent approaches to communication or behaviour support when they enter a health setting.

## Issues affecting specific cohorts

### Children and young people involved with child protection services

Parents and carers of children and young people involved with the child protection system are often unable to initiate the uptake of service provision in a timely manner and/or to utilise the child/young person's allocation within the required timeframe. This can occur for a variety of reasons including children being removed from their parents' care, and/or parents being unwell and unable to manage their child's NDIS package.

In some situations, this results in a need to reapply for access to the NDIS. In others, the inability to fully utilise the funding allocation is interpreted by the NDIA as an 'over-allocation', which impacts decision-making about future funding and can result in less funding being made available to the child/young person.

It needs to be recognised that there are times where the carers'/parents' inability to utilise the child/young person's allocation is due to systemic constraints that affect timeframes, as opposed to the child or young person not having a need for the allocated supports.

### People with disability experiencing family violence

Research indicates that people with disability are disproportionately affected by family and sexual violence.<sup>1</sup> The reasons for higher rates of family violence amongst those with disability are varied and complex, and include social isolation, lack of specialised services and supports, dependence on others for care and support and group living situations. Family violence victims with disability require access to specialist support services that are trauma-informed. In particular, when family structures break down as a result of family violence there is the need for immediate, flexible supports to meet changing individual requirements. This will often include disability accessible crisis accommodation.

The following case examples highlight the issues faced by NDIS participants experiencing family violence and the impact their experiences with the NDIS can have on their safety and wellbeing. These examples also emphasise the important need for NDIS participants in these situations to be able to access urgent interventions and for their NDIS funds to be available to meet immediate needs that promote their personal safety (for example, accommodation, alternate care arrangements, relocation, care for children, etc).

*Case example 5:* Mary has an acquired brain injury and epilepsy. She contacted Victim Support ACT requiring urgent access to crisis accommodation after being subjected to sustained physical and sexual abuse by her husband. After contacting all of the available crisis services in the ACT, Mary was advised that none were able to support her need to have a support worker with her in case she had a seizure. Mary had an NDIS plan and asked NDIS if she could use her funding for emergency accommodation. She was told this was not possible as she was required to have a behavioural assessment in order to reside in supported accommodation settings, however she was not able to have the required assessment due to not being in stable accommodation. Mary was also not eligible for mental health respite as she was unable to get a mental health assessment. This gap in support services left Mary in an incredibly vulnerable situation and as a result she remained homeless and became increasingly unwell. As Mary's health deteriorated she spent time in and out of the Adult Mental Health Unit and was finally remanded in custody at the Alexander Machonochie Centre.

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<sup>1</sup> Australian Institute of Health and Welfare, 'Family, domestic and sexual violence in Australia: continuing the national story,' 2019, p91.

Family violence greatly impacts NDIS participants and their ability to access and use their plans. Circumstances can change quickly and there is a need for the NDIS to be able to be responsive to these changes in circumstances.

*Case example 6:* Jennifer has an intellectual disability and an NDIS plan. She escaped her husband who was physically abusing her. Jennifer was successful in securing temporary crisis accommodation. However, now Jennifer is on her own, she requires extra support for basic living needs (for example cooking and cleaning) that the crisis services are not able to provide. Jennifer does not have adequate funding in her NDIS plan for these supports and her health has deteriorated as a result. Jennifer was supported to initiate a 'Change of Circumstance' review but was informed it would take several months for an outcome. During this time Jennifer considered moving back in with her husband as she was unable to access additional NDIS supports when she needed them. It took Jennifer four months until her request was reviewed.

*Case example 7:* Rebecca's husband is in custody after being charged with family violence offences. Rebecca remains at home with two young children with disability who receive NDIS supports in the home. Rebecca is now the children's sole carer and had to leave her job in order to meet their specific care needs. Rebecca initiated a 'Change of Circumstance' review for her children's plans in order to access increased supports, such as respite. Rebecca is faced with a lengthy wait for these requests to be reviewed and, in the meantime, she is experiencing extreme financial pressure as a result of having to pay for private support services to meet the children's needs.

### People with psychosocial disability

The impact of psychosocial disability is often episodic in nature requiring different levels of support at different times. Effective NDIS plans need to be able to respond to this variable pattern of need without frequent reviews, for example by including higher level of supports for estimated time periods based on past patterns of need. However in practice, the focus on plan funding levels not exceeding benchmarks means that the level of funding for reasonable and necessary supports may not be achieved for people with episodic high support needs.

The NDIA advises that if a person's need increases, a review of the plan can be instigated. However NDIA representatives also suggest using the available funding fully before seeking a review. Many people are concerned that if they use the funding as needed for periods of high support they may be denied additional supports in a subsequent review. In practice, there have also been significant delays in plan reviews and participants and their families frequently report that reviews result in decreased levels of funding.

For people and their supports coordinators, funding uncertainty leads to using a lower level of supports throughout the plan in order to retain capacity to respond to high need times. This is counter-intuitive to the focus on maximising social and economic participation, and does not support the principles of recovery-orientation. The recovery model takes account of the uniqueness of the individual and what recovery means to them and works to build capacity. Concerns have been expressed that NDIS plans for some people with psychosocial disability focus more on maintenance and keeping things as they are than on recovery.<sup>2</sup> Further, the lack of adequate NDIS supports also impacts on other support systems, particularly mental health services, as people find themselves in crisis due to not being able to access the supports they need at the time they need them.

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<sup>2</sup> Mental Health Community Coalition ACT (2018) When the NDIS came to the ACT: A story of Hope and Disruption in the Mental Health Sector, Canberra, ACT, Australia



### People with a Disability in Aged Care

People with disability in the ACT who are NDIS participants and who are supported by specialist disability service providers fall within the remit of the ACT Official Visitor (OV) scheme. Having formal entry rights to visitable sites where people with disability live provides the ACT disability OVs with a means of ensuring the safety and wellbeing of people with disability, and provides an avenue for people with disability to raise concerns.

To date, the lack of an effective means of providing information about people with disability in aged care facilities means that these people have fewer protections in the ACT as they are not easily visible to the OV's. We encourage the NDIA to review its approach to information sharing with the ACT OV's, who are statutory appointees, to ensure the safety and wellbeing of people with a disability living in aged care facilities in the ACT.

### Concluding comments

The ACT Human Rights Commission welcomes this review and the opportunity to be a part of any workshops that may take place.

Should you have any questions in relation to this submission, please contact the ACT HRC via email to [HumanRights@act.gov.au](mailto:HumanRights@act.gov.au) or by phoning 02 6205 2222.



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