

Standing Committee on Health, Ageing and Social Services
Inquiry into the NDIS in the ACT

Via email:

LACommitteeHACS@parliament.act.gov.au

Submission by ACT Disability Aged & Carer Advocacy Service

Thank you for the opportunity to provide a submission to this inquiry. ADACAS is Canberra's largest independent, individual advocacy service. Our client groups are people with disability, frail older people and their family carers. As independent advocates we take seriously our role in ensuring that our clients have their voice heard in matters that affect them. Being heard, and having your decisions respected with regard to the NDIS are fundamental human rights for all Canberrans with disability.

ADACAS strongly supports the introduction of the NDIS. We recognise that it is the result of many years of advocacy by people with disability and has the potential to transform lives. ADACAS has been working constructively with the ACT Government and the NDIA both prior to and during the trial and full scheme rollout in the ACT. We are aware that many people have had good experiences with the NDIA and have plans which are improving their lives. The nature of advocacy is of course, that the clients who seek individual advocacy are those who are less able to navigate processes and achieve the outcomes they are seeking without support. Our experience of the NDIS therefore is primarily through working with people whose experience with the NDIS has not been fully positive. Our reflections on that experience in this submission, does not diminish our commitment to the objects of the NDIS as articulated by the productivity commission and in the NDIS legislation. We continue to be committed to working closely with governments and participants in the NDIS to ensure that the scheme is the best it can be. Our aim is to ensure that people with disability can access the supports they need in a manner which upholds their rights, they feel heard and respected and the experience is a positive one. This would truly transform both the scheme and the lives of the people it supports.

"it really does feel like all I do is go off the deep end constantly and I just don't know if anyone can help or should I leave the NDIS like other disgruntled people have already." client comment 2018.

The terms of reference specifies three specific areas of inquiry. To assist the Committee, ADACAS has sought to organise our contribution within the framework set by the terms of reference. Many issues however are multi-faceted so may relate to more than one area of the inquiry. In addition we have provided feedback on the impact of the NDIA and its processes on ACT participants. We recognise that the Inquiry may have limited capacity to effect change to NDIA processes and decision making however we believe it is helpful for the Committee to understand the breadth of issues which participants and their families in the ACT are faced with as they seek to successfully have their needs met by the NDIS. Whenever their needs are not met, including through long drawn out processes of review and appeal, people are required to go without support or seek it from other ACT systems where it is available, this is particularly an

issue for the health system. Awareness of these issues then may inform the wider consideration of the Committee and Government. We also hope that the Committee may choose to provide relevant submissions to the NDIA for their consideration.

a. The relationship between the ACT Government and Australian Government in regard NDIS and National Disability Insurance Agency (NDIA) as it affects the ACT; particularly gaps or duplicate roles and responsibilities;

During transition the ACT government funded important pre-planning supports for participants who were yet to enter the scheme. These supports included Capacity Building Workshops delivered by ADACAS and partners, and important one on one work undertaken by ImagineMore and Wellways. These supports ensured that people who otherwise may not have successfully accessed the scheme were able to do so. This program ceased at the end of the ACT trial however, it is not true that all participants who may need support to access the scheme have done so.

Where people are not entering the NDIS, for a range of reasons, the ACT government remains responsible for providing support. The Community Assistance and Support Program (CASP) is unique across Australia and is the result of the ACT Government taking a considered and far-sighted approach to the dissolving of past disability support systems. The ACT should be commended for retaining the CASP program in recognition that there will be people who need support who will not be accessing the NDIS. Indeed the ACT could hold up CASP as a model for other jurisdictions who are only now grappling with the issue that they remain responsible for some disability supports even when the NDIS is fully rolled out.

For those who may be eligible for NDIS but have not entered, currently CASP providers may be able to provide some support with access requests but these providers do not necessarily have the skill or funding to provide in-depth pre-planning support which some participants require. As a result access processes can be traumatic and initial plans are often lacking fundamental supports and participants' experience of the NDIS is less than ideal.

CASP currently also continues to fund ADACAS to provide individual advocacy to people aged under 65 in the ACT. The introduction of the NDIS has significantly increased demand for independent advocacy, as people realize the difficulty they face navigating NDIS processes. This increase in demand is reducing our capacity to also advocate on other matters, such as: care and protection, housing, education, transport, health, justice, workplace discrimination, access to human rights and social isolation. A perhaps unintended consequence of the NDIS is that availability of individual advocacy has become more constrained (despite specific NDIS Appeals funding being provided by the Australian Government).

ADACAS recently took a new case for a client who the NDIS was considering exiting from the scheme. Within 4 days we had undertaken more than 40 hours of advocacy for this client in preparation for a meeting with the NDIA. While doing so, other client work had to be delayed.

The ACT continues to share responsibility for funding of independent individual advocacy. We currently receive funding under the Community Mental Health Program and the Community Assistance Support Program through the Department of Health. Both of these programs are currently flagged for procurement review and we are not certain what this means for ongoing funding of independent advocacy. This uncertainty impacts on our ability to recruit and retain quality staff at a time when advocacy has become a more urgent need for many people with disability.

Our data shows that we have insufficient resources to meet the demand for individual advocacy for people with disability. Where we are unable to take on an advocacy case because it does not meet our priority of access criteria we seek to always provide some information and strategies which will assist with self-advocacy; provide other options or referrals; and will where we can provide some brief assistance. When we analyse our work in this area it shows that we are currently denying or providing only referrals/brief assistance to more than 50% of the people who seek individual advocacy. While in some of these cases that limited assistance is sufficient, we are aware that it very often does not meet the need but we do not have resources to offer anything further. We are also aware that an environment in which individual advocacy has been a scarcity for some time then creates in the community an expectation that even if they ask for advocacy it will not be available, and therefore it is not worth asking. This is of grave concern to us as people with a genuine need for advocacy on a range of issues are unlikely to seek it and therefore struggle to have their voice heard and their rights met. Timely advocacy can avoid later crisis leading to increased impact on multiple service systems. ADACAS urges the ACT Government increase its funding of individual advocacy for people with disability

Whilst ADACAS applauds the ACT Government's ongoing support for the CASP program, the ACT Legislative Assembly Inquiry particularly asks about gaps. There is currently a gap for people who need a high level of support (above that which CASP can offer), but also where the NDIS considers that the care is the responsibility of the health (not disability) system. The NDIS is meant to be looking at disability in terms of functional capacity – however we are finding that more and more, the scheme is starting to focus intensely on diagnostic reason for disability, and use these as a reason for denying entry to the scheme. ADACAS is aware of clients who are under immense pressure after being denied entry to the NDIS, but where the level of support needed is above that which CASP can provide.

There is a family with a parent with disability, with three children (two of whom had disability) needing to interact with: the NDIS, the health system and financial support services. The two children are NDIS participants. The parent had applied for entry to the NDIS, however had their application denied. With assistance from ADACAS they appealed the decision however, the appeal was unsuccessful. It was clear from the NDIS response that further diagnostic information was needed (the information provided on functional impairment of the parent was not considered sufficient). The parent was willing to seek further diagnostic assessment (re autism), however the cost of this was prohibitive. With regard to the children's plans, the family requested that the planning meetings for both children be held together, with the same planner and at the same time of year, such that a cohesive approach to NDIS planning was possible. Unfortunately this did not occur. Planning meetings for

the children occurred 3 months apart, with different planners, which meant that the plans did not work well together, and added considerably to the stress and distress for the family. Whilst the family receives CASP services (given the parent's eligibility), due to the impact of disability for the entire family, this is not a sufficient level of support. The family needed to lean on extended family (who had limited ability to offer support). The amount of stress that the family was under contributed to a breakdown in the relationship with extended family.

One of the challenges is in working with families with multiple people with disability/ in complex situations – in a coordinated way. There is a gap in the availability of complex case coordination for families needing support across multiple service systems.

As the NDIS rollout matures, instances of interaction between the NDIS and other systems delivered by the ACT are becoming more frequent. Our advocacy indicates that the interfaces between health, education, and transport are particularly difficult. We urge both the NDIS and the ACT Government to work together to ensure that people with disability can access the support they need without long delays as cost arrangements are negotiated between systems.

We were contacted by a family with a younger person who is on the NDIS. The dispute about who pays for the housing modifications needed for the young person has caused enormous stress to the family.

ADACAS is working with a number of patients in the Canberra and Calvary hospitals who have been living in hospital for many years. With a strong relationship built between ADACAS and ACT Health and other stakeholders we have been able to increase understanding of the operational guidelines of the NDIS and support development of effective strategies to enable these long stay patients to transition into their community. Through the work of advocates, specific funding from NDIS is enabling new properties to be built in the ACT which will be suitable for complex clients with high needs supported by staff trained in their specific care needs.

b. Practical outcomes of implementation in relation to disability workforce development strategies; the Human Services Registrar; the availability of services for eligible NDIS participants; the availability of early childhood intervention services; the implementation of local area coordination; and supports for people with psycho-social disabilities;

Impact of poor NDIA decision making, and review processes on workforce, client outcomes and carers. The NDIA decision making has considerable practical implications for the lives of people in the ACT. In the past couple of years their decision making has become less consistent with significant effect on the lives of affected people.

Client had been able to access the community and had support to live independently in their home. The NDIS cut the subsequent plan by 80%. The person had to cease all community involvement and significantly cut back on support in the home. They

quickly sought a review but many months has gone by and the review has still not been undertaken.

Volunteer organisations reported recently to us that their volunteers were being asked to step into providing supports which had been undertaken by paid carers under previous plans.

NDIA processes for review of decisions have no timeframes and therefore take many months. ADACAS has numerous clients whose request for review during the first 3 months of a plan, or review because circumstances have changed, are ignored until the time of the annual review. This means the person has to live without necessary supports, workers who had previously been providing services that are withdrawn in later plans go without work, and there is additional pressure on the health system and other ACT systems. The practical outcomes are very real, with clients significantly worse off, and yet the NDIA seems oblivious to them.

The NDIA has recently significantly reduced the amount of support coordination that is funded in plans. This appears at times to be a unilateral decision which does not take into account the specific needs of individuals. The NDIA assumption that it is only needed during the first plan and that 80% of participants can have their coordination needs met by the LAC is flawed. In particular ADACAS clients with psycho-social disability have been adversely impacted by the decision to withdraw support coordination. In the absence of this funding individual advocates are being asked to undertake support coordinator roles as are other service providers. The building of capacity for those with intellectual disability is recognised as requiring additional time, repetition and practice which short term provision of support coordination denies.

Support coordination has been withdrawn from the plans of many clients leading to increased expectation on family carers to monitor and negotiate services in plans. Older family carers in particular, express their very real concern about what will happen when they are no longer able to provide this free support.

The implementation of the LAC model in the ACT has demonstrated once again that the combination of planner and LAC functions in a single role means that the LAC function is de-prioritised. The ACT Trial included the role 'plan support coordinator' with the intention that the NDIA trial the integration of these functions. During the trial phase, the ACT branch of the NDIA recognised that combining the two functions in the one role meant that the wider- LAC function did not happen because of the pressure of planning targets. Despite this lesson, the same model was rolled out at full scheme, in response to other pressures on NDIA staff numbers. Sadly this means that many participants struggle to implement their plans as the LAC are not able to provide the connection and support that participants' need. ADACAS recommends that the original model proposed by the Productivity Commission be implemented in the ACT. This would ensure that the LAC was independent of the NDIA and in a position to provide support connection for people with less complex plans as well as support people who have some disability needs but are not eligible for a plan – a group which is currently not being adequately supported by any services as role delineation remains confused.

People with psycho-social disability often experience additional challenges in their interactions with the NDIA and ensuring good outcomes from the scheme. These continue to cause specific adverse consequences for individuals. ADACAS is supporting numerous clients with psychosocial disability with the review and appeal processes. In some cases participants are choosing to forego their right to review to get access to supports that they certainly need, simply because the process is so traumatising for them. We are also aware of people who have not entered the NDIS because it is too challenging. Ensuring support is available for people through the entry process, in addition to reducing the currently extended delays to entry and planning, would make the NDIS more accessible for this group.

A person who experiences extremely severe anxiety, affecting every aspect of life, had an application for the scheme declined. They applied for an internal review without accessing additional support to do so and without being able to provide additional information to meet the criteria. As a result the review was also declined. The client then contacted ADACAS to seek support with an AAT appeal. While it is very clear to us that the client needs high levels of ongoing support they have found the AAT process too daunting and even with advocacy support available have decided to withdraw their appeal as their psychosocial disability does not allow them to proceed. Had support for the access process been available at the outset this individual may not now be experiencing such high anxiety and be accessing the support they need.

A client has had such a difficult time with the NDIS that their suicide ideation and self harming behaviours have both significantly increased.

ADACAS clients experience difficulty finding and connecting with appropriate supports when attempting to implement their plans. This is partially a workforce issue – there are insufficient skilled workers available in the ACT, particularly to work with participants who are complex in their presentation, and given the low wages on offer. Partly it is also a market issue, there are gaps in the market, specifically for cleaning and gardening when the participants plan is NDIS managed as very few of these services have registered as providers with the agency. Similarly accessing therapy, both for adults and for children is difficult in the Canberra market. Many therapy providers, including EACH, have long wait lists. Other gaps in the market include finding competent independent plan managers and accessing transport. Community transport is difficult to get, is insufficient for the demand and requires a minimum 2 days advance notice which limits its flexibility.

We are also aware that the NDIA model does not always best support participants who are also working. The care hours provided in a plan can be used either on weekdays or weekends however if a participant is working, and therefore more of their hours need to be used at the weekends, this results in fewer hours overall because weekend rates are higher. This essentially disadvantages working participants which is counter to one of the stated aims of the NDIS which is to increase the workforce participation of people with disability and their carers.

c. Whether there are unique factors relating to the provision of disability services affected by the implementation of the NDIS in the ACT.

A significant factor impacting on provision of disability services in the ACT since NDIS implementation is the lack of availability of a provider of last resort. The NDIA are quick to confirm that they are not a crisis service and cannot be expected to ensure access to service in a crisis. However, with the ACT government no longer providing disability services, there is nothing filling this gap. ADACAS clients who have needed crisis service include:

- A person ready to exit hospital but with no alternative accommodation available and unable to return home to live alone
- A carer needing in-hospital medical treatment unable to access additional care for the person they care for
- Clients who have need for disability specific equipment and experiencing considerable delays in accessing it.
- Families with insufficient support considering or actually relinquishing care of their child because they cannot access additional support at times of high stress, including:

6 year old child with ASD and significant behavioural issues. Single parent family. Had intensive ABA therapy and access to respite in early NDIS plan. NDIS threatened that this level of support was going to be removed. The parent, at the limit of their endurance, commenced steps to relinquish the child to Care and Protection. With advocacy support the new plan was reviewed and the supports restored. The family has been able to stay together.

Young ASD teen with very high behavioural issues including self harm and violence towards other family members. The respite provider was not able to access sufficient funding for the level of care required and therefore had to withdraw support. Family considered relinquishing child however at plan review additional funding was provided to ensure that the family could stay together.

While we have not yet become aware of an instance where the lack of a provider of last resort has led to death or very significant and lasting harm, there is a very genuine risk that this may happen. Early in the trial the NDIA did commence discussions about contracts for a provider of last resort which would enable emergency supports to be put in place out of hours or on a weekend however no such system eventuated.

Unique issues arise in particular when there are in-kind supports included in NDIS plans which require the use of an existing service – such as the ACT Health or Education services. These in-kind supports mean that the participant has no choice and control over the service they receive and no transparency over the way in which the funds are used. Ideally all in-kind arrangements should be phased out enabling participants to exercise choice and control across all of their

plans. If this is going to take some time to achieve, where a participant does not wish to use the existing provider, NDIS plans should reflect this by not including the support as in-kind only.

Client receives support for management of diabetes as part of the plan however it is listed as an in-kind support provided by ACT Health. Client wants to be able to choose a different provider as the ACT Health staff are not listening to the client or achieving the goals stated in the plan, but is unable to do so because the support is in-kind.

The recent legislation change which ensures that people with disability can participate on juries on an equal basis with others will potentially introduce a new opportunity for the NDIS to interface with an ACT system. Which system will be responsible for the additional support that the juror with a disability may require? If the NDIS is already paying for a support, can that support be used while the person fulfils their civic duty or will the NDIS require the ACT Courts system to cover the cost of supports?

Interactions with the NDIA

Change of experience of participants during trial to current day.

- Intimidation/threats. On many occasions ADACAS has observed or clients have reported that the NDIA staff act in a threatening way or seek to intimidate clients. This is particularly with regard to denial of certain supports that the client believes they are entitled to, and when the client indicates an intention to seek a decision review. It is common for clients to be told 'you will lose other funding if you ask for a review'. Clearly this is inconsistent with the decision making framework outlined by the legislation and completely inappropriate behaviour by a member of the Australian Public Service.
- NDIS staff have limited understanding of participants for whom they are making decisions, this has become particularly apparent since the LAC function of gathering data to send to decision makers was introduced. Clients come to ADACAS with evidence that the data provided by the LAC was incorrect, inappropriate and/or incomplete and that this therefore leads to poor decision making. Participants want to be able to interact directly with decision makers.
- The NDIS legislation requires planning decisions to be made based on the individual circumstances of clients however many clients experience NDIS decisions being made based on general factors, based in the disability diagnosis, rather than their individual circumstances and level of functional impairment. There is an inherent tension between decision making for individual circumstances and the need for equity between plans where circumstances are similar. The NDIA has yet to achieve a balance in relation to this tension.

- Significant issues with communication have developed as the full scheme rollout got underway. Almost all communication channels have become either ineffective or less effective. Clients experience considerable frustration using both the phone line or the generic email address because issues raised are never addressed and messages left are not returned. The introduction of the 'secure email' requiring a login and limiting access to messages from the NDIS has become another barrier in communication. Similarly where staff at the front desk of the NDIA in the ACT were previously welcoming and willing to assist, more recently clients and advocates are actively discouraged from attending the office to seek resolution of issues with their plans. Communication issues are also a barrier to efficient processing of bills by the NDIS, leading to increased costs and risks for providers who are unable to be paid reliably.
- ADACAS has supported a number of adult clients who have been accepted into the scheme who have received notices that the NDIA intends to revoke their eligibility. These adults have in some cases been seeking a review of an NDIA decision and the revocation therefore appears to be a punishment for exercising their rights of review. Great distress has been caused to all clients who have received advice that the NDIS intends revoking their eligibility.

In one instance the client was simultaneously having surgeries for health issues unrelated to her disability. Given the scheme is meant to be for life, and that the participant was subsequently found to be eligible, the revoke notice and process caused a level of cruel and unnecessary stress at a time when the person was already under significant pressure.

A client had a plan and was seeking an internal review of the decision to deny home modifications. This internal review is now going to include consideration of whether the person is still eligible for the scheme. The person's anxiety and the uncertainty about whether they will continue to get funded support has stopped them from accessing supports in the current plan. As a result the person spends almost all of their time in bed, has declining health because they are not eating well and is at risk of hospitalization.

- The staffing model for both the NDIA and Ferros (as the LAC) has impacted on the continuity experienced by participants. There is very high staff turnover, often because staff are employed in short fixed term contracts rather than longer or ongoing positions. Recent changes to ACT staffing have seen most of the experienced planners re-allocated to other regions leaving participants here without ready access to NDIA staff for plan reviews, internal reviews or other decisions. This has led to very lengthy delays in resolving issues with plans which have a very real impact on the lives of participants.

ADACAS thanks the Committee for the opportunity to provide this summary of the experience of our clients with the NDIS in the ACT. In the main, the concerns raised relate to how the NDIS

is being implemented rather than significant design flaws. The attitudes, training, culture and professionalism of staff both within the NDIA, within ACT Government and working in disability service provision are the fundamental determinants of whether a client has a positive or negative experience navigating the disability and mainstream services. The willingness of each layer of the system to work collaboratively, to identify and meet the needs of each person with disability so that they can live inclusive lives in the ACT community, is core.

If we can provide any further information to support the work of the Committee please contact me at manager@adacas.org.au .

Yours sincerely

Fiona May
CEO
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