



Secretariat
Joint Standing Committee on the NDIS
Parliament House
Canberra ACT 2600

Via email mark.fitt@aph.gov.au

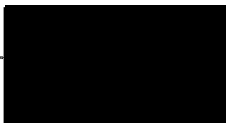
Dear Mr Fitt

Thank you for the opportunity to participate in the Committee's hearings on Friday 27 March. It was an important opportunity to share the experience of ADACAS advocates and clients in the NDIS in Canberra, to discuss the role of advocacy and to hear what others experiences of the NDIS have been.

During the hearings I undertook to provide the Committee with ADACAS's written input. The attached notes formed my speaking notes on the day, some of which you heard and some of which was not raised during the hearings.

If I can be of further assistance to the Committee, please don't hesitate to contact me.

Yours sincerely



Fiona May
CEO

30 March 2015

ADACAS Talking Points for the Joint Standing Committee on the NDIS

March 2015

Begin by saying that the NDIS is making a huge difference to many families, for some there is a sense of excitement about what the scheme may mean. Unfortunately for many others that excitement is tempered by considerable anxiety about the process.

ADACAS is engaging with the NDIA in the ACT on a number of levels:

We are actively engaging in the policy development processes happening at a national level.

ADACAS and other disability advocacy organisations meet semi-regularly with the local site. These meetings are helpful to keep channels of communication open.

ADACAS is the EMRS support organisation for the ACT. We are providing a lot of education and awareness-raising to local groups, through conference presentations and to individuals about people's rights under the NDIS. We are aware that at this early stage, people are not often ready to hear this information and are looking for more specific information about the process of accessing the scheme.

Access

ADACAS is providing intensive support to people to access the NDIS:

- There has been a lot of confusion about the 'my access checker' and its role in registering for the scheme. It clearly isn't fulfilling that function because families tell us that they completed it and got a registration number but then when they contact the Agency there is no record of them in the system so they are not receiving their access packs without asking for them. This is concerning, particularly if they are not currently receiving any other service.
- We are also getting regular although not yet busy calls seeking information on how to go about the process and their rights. People are valuing this one on one advice that matches to their circumstances as opposed to more generic information which is often at too high a level to be useful for them. People are seeking more information which is practical, based on experience of those who have gone before, and speaks directly to the process that they are expecting to engage in. People have also told us that the pre-planning sessions offered by the Agency are not meeting their needs. The volume of information is both confusing and overwhelming for many people.
- The amount of NDIS work we are doing is growing quickly. This week at intake we considered 11 requests for advocacy assistance, 6 of which were NDIS issues including 2 internal reviews. In addition we were contacted by 1 person who is seeking support to appeal an NDIS decision. This will be the first cases going to

appeal in the ACT. So more than half of our new work this week is directly related to the NDIS.

We have supported one person to seek an internal review of an eligibility decision. The advocacy support was crucial in getting a successful outcome for this participant. We are concerned that some 43 people have now been found ineligible in the ACT but of those only 1 has made contact with us for help to seek a review of decision. We are concerned that the information about rights of review and appeal is not presented in such a way as to encourage people to test the decision making process of the agency. No analysis is being undertaken to explore why people are choosing not to seek reviews or appeals. We know anecdotally that for some people it is that they are simply too worn down to continue the fight but it would be interesting to explore this further.

We have heard from some medical professionals about numerous families whose applications have been turned down. They are both so disappointed about the decision at a time and also feeling so overwhelmed by the needs they are facing because of the behaviours of the young person with disability that they do not have the energy to fight the decision. It is very concerning that they are giving up, when, in the opinion of one medical professional to whom I was speaking, they would expect them to be eligible for the scheme.

While the data on numbers of internal reviews is provided in quarterly reports (albeit hard to find!) there is no information about changes of decision that are made as a result of internal review requests. We are therefore unable to be clear about the extent to which these processes are being used and are working. As they are core elements of the scheme which are built into the Act, the Standing Committee might be interested in looking into this further.

ILC

As the Information Linkages and Capacity Building layer of NDIS has not yet rolled out, people who are ineligible for the scheme are not getting any additional support or advice to link to mainstream services. This is compounded by the rolling of planner and support coordinators into one role in the ACT site. This is not currently working well because they are overwhelmingly focussing on developing new plans. This is a significant issue because the whole of the ACT will be rolling into the scheme by July next year.

We have a number of cases where people need to access the scheme early (out of turn in the transition plan) and they are left in very difficult situation. The rules for early access are too stringent, even when there are extenuating circumstances some people are being told they just have to wait.

Planning

People have mixed views about the planning process. Mostly they are finding the planners attentive, and engaged and have welcomed their flexibility to hold planning meetings at the person's home rather than in their office.

However the plans themselves are very difficult to understand. Translating the series of line items and amounts into something they can understand in terms of what it means across a week or a month or a year is, for complex plans, taking our advocates many hours of work. Without this support the participants are finding it impossible to fully comprehend what the draft plan actually includes.

While the NDIA is reporting targets for planning timeframes, from the perspective of many of our clients the timeframe is less important than making sure that the plan is right. People need time to reflect and understand what is in the plan and what else they might need – the planning timeframe should be guided by the needs of the person not the NDIA.

Overall, we are finding that clients need to have an advocate with them as they are finding it very hard to self-advocate and ask for what they need, particularly true for our CALD and indigenous clients.

We are hearing anecdotally that people are finding the process is lengthy, and some are eventually so grateful to get anything that they are not pursuing the additional things that they feel that they should also have been eligible for. Essentially people are settling for the bare minimum which is not the intent of the scheme as envisioned.

We are also aware of some cases where the natural supports that are engaging in the planning process with the person with disability are ensuring the plan includes the things that they think the person needs rather than ensuring that the person's voice is actually at the centre of the planning process. This again highlights the need for greater access to independent advocacy.

Some of the other issues clients are encountering include:

We are aware of cases where the NDIA has not been meeting the legislated timeframe for consideration of access requests (even when no further evidence is being sought). These long delays are very stressful for people.

Eligibility assessments seem to focus on each disability a person lives with in isolation from the other conditions they also have. As a result an assessment about whether a single disability meets the threshold for functional impairment is made rather than considering the cumulative impact of a number of disabilities on the person's functional impairment. This is a cause for concern, particularly where there is a mix of disabilities and health conditions (some of which are eligible and some are not). The eligibility needs to include an assessment of the whole person and the functional impairment not only breaking assessments down into individual conditions.

Interface with other systems is still not clear – particularly the boundaries between health and education and the NDIS. The Agency appears to be taking a hard line which is not responsive to the individual needs of people.

Additional assessments in plans – default requirement to use Therapy ACT is introducing delays, and assessments are being included for items that it would actually be cheaper to just do – this involves a lengthy, frustrating delay for participants and is not efficient use of the funds.

Like costly assessments, the NDIS is including in plans more costly items that could be resolved differently. We have one client who wishes to self-manage however he does not have a personal computer and internet connection. Rather than approve funding for these items which would enable him to log in and acquit his funding, they are approving a plan manager to do these tasks on his behalf. In the long term, the equipment would certainly be cheaper than the ongoing costs of plan management.

It is going to take years for people to actually maximise the outcomes they can achieve through the NDIS. They are too used to thinking only about what they need to sustain life. The dreams and aspirations of most people are not yet developed and we urge governments to keep this in mind as they look for short term evidence of the impact of the scheme.

Other transition rules are also impacting on people's ability to exercise choice and control. Those who live in group housing for instance are required to agree on a single provider to deliver service to all residents. This reduces genuine control and choice.

People are still struggling with the way respite is cast in the planning process. While we have heard that the NDIA intends to address this, nothing has yet changed and families are feeling like they will not get the respite that they need. The requirement that they start to talk the NDIS language in order to qualify for things that they need is a barrier.

Psychosocial disability continues to get a poor response. Little information is available that is directed towards people living with psychosocial disability, they find it hard to prepare because they cannot access information relevant to them and are not even clear about whether they may be eligible. There is uncertainty about what they may be eligible for.

We have heard of numerous plans where amounts of therapies (psychology, speech therapy, OT) offered only 1 per month or less where the person actually needs much more intensive therapy for it to meet their needs. This approach by the NDIS to therapy is causing concern for many families.

There are no indigenous specific service providers in the ACT which is of concern to our indigenous clients who are seeking culturally appropriate service.

Advocacy

It is not clear the extent to which the NDIA staff are proactive in identifying and referring for advocacy support, those who need it. ADACAS has had 1 client referred to us in this way but potentially there are many more who need this extra support but they are not supported to access it.

Advocacy in the context of the ILC and Quality and Safeguards policy work that is currently underway, is not clearly present or articulated. Advocacy has a key role to play in both of these agendas. It is concerning that a number of elements of the role of advocacy are being identified as being appropriate within ILC or Quality and safeguards (such as information and advice, capacity building, mentoring and peer support) but that the role of independent rights based advocacy is missing.

There is a strong argument for both Australian and state/territory jurisdictions to continue to fund independent advocacy. Much of the work of advocates is not about access to service in the NDIS context. The demand for advocacy around other issues including access to housing, education, justice, health and interactions with the care and protection systems, will continue to be high.