

Submission by the Commonwealth Ombudsman

Provision of services under the NDIS Early Childhood Early Intervention Approach

Response to inquiry by the Joint Standing Committee on the NDIS

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Introduction

The Commonwealth Ombudsman's Office welcomes the opportunity to respond to the Joint Standing Committee's inquiry into the *provision of services under the NDIS Early Childhood Early Intervention Approach*.

Background

The Commonwealth Ombudsman safeguards the community in its dealings with Australian Government agencies by:

- correcting administrative deficiencies through independent review of complaints about
 Australian Government administrative action
- fostering good public administration that is accountable, lawful, fair, transparent and responsive
- assisting people to resolve complaints about government administrative action
- developing policies and principles for accountability
- reviewing statutory compliance by law enforcement agencies with record keeping requirements applying to telephone interception, electronic surveillance and like powers.

The Commonwealth Ombudsman's unique position in the Australian administrative law system provides this Office with an understanding of the individual experiences of members of the public, who are dissatisfied with the way government has dealt with their concerns. The Office has the power to investigate those complaints by obtaining records and information from the agency that would not ordinarily be available to a person acting on their own behalf. Over time, through investigating complaints about the actions of a Commonwealth department or agency, the Ombudsman's Office can build up a detailed picture of an agency's operations.

The Office also engages with peak bodies and community representatives that have direct access to stakeholders affected by government policies and programs. This engagement provides an opportunity for the Office to develop a more holistic understanding of the public's experience of those programs, and is of particular value when affected parties (including people with disability) may be less inclined to make direct complaints.

The Commonwealth Ombudsman's Office plays an important role in safeguarding the Australian community in their dealings with Australian Government agencies. In recent years, we have focused on the way government policies and programs are administered for vulnerable and/or disadvantaged people including people with disability, Aboriginal and Torres Strait Islander peoples, and people from culturally and linguistically diverse backgrounds.

The NDIS is an important social reform that will have an impact on all the above groups, as well as the broader community. Our Office is committed to working closely with government (including the (National Disability Insurance Agency (NDIA) and the Department of Social Services), community, service providers and people with disability and their families, to understand the way the Scheme is working in practice, and to point to ways in which its delivery can be improved.

Response to Terms of Reference

This submission is based on feedback given to our Office in the form of complaints and anecdotes, by participants, families, carers, providers, advocates, community organisations and peak bodies. Most of this feedback has come from NSW.

The issues outlined in this submission have been highlighted with the NDIA, either through the investigation of complaints or by providing feedback following engagement activities. Our Office has found the NDIA receptive to feedback and willing to implement remedies when needed.

Our submission covers five of the Joint Committee's 12 Terms of Reference:

- timeframes
- adequacy of funding
- costs of services
- information
- accessibility.

Timeframes

Transition timeframes

We understand that under the Early Childhood Early Intervention (ECEI) Approach funding for direct services to children and young people will progressively transition from state and territory programs and targeted Commonwealth-funded programs to the NDIS. The phasing schedules in the bilateral agreements set out the timing in which regions transition to the NDIS.

We have received complaints from families in NSW who told us their children had lost access to services during the transition to the NDIS. Specifically, they said their child had been accessing therapies through a Commonwealth program, such as *Better Start for Children with Disability* and *Helping Children With Autism*, but when these funds were exhausted, they were unable to maintain the cost of the therapies in the absence of NDIS funds. In some cases, it appeared that children were at risk of going without therapy for up to 12 months, while they waited for their local area to commence planning under the NDIS phasing schedule.

Our investigations identified the NDIA had told the families that, as their children were not able to access NDIS funding yet, they should seek assistance from NSW Family and Community Services (FACS). When families approached FACS, they were referred to Early Link Coordinators who said they were unable to take on new clients.

In most instances the child was eventually connected to supports, either by FACS arranging services or the NDIA prioritising their planning. However, these processes took time and in the meantime it seemed there was no clear pathway for families who find themselves caught between their Commonwealth program funding running out and the commencement of an NDIS plan.

Planning timeframes

In a number of the complaints to our Office about ECEI, families were advised of their children's acceptance into the NDIS in late 2016, but had still not commenced planning by June 2017.

There was significant confusion about when the transition was occurring in NSW. Complainants stated that when informed of their child's acceptance into the NDIS, the NDIA had either advised them that they would be contacted "shortly" to arrange planning meetings or remained silent as to when this would occur. Most assumed that planning and funding packages would quickly occur following acceptance into the scheme, but for many this has not been the case.

Timeframes for accessing services

Many families, particularly in NSW, have told us there is a shortage of suitable support providers in their local area. In some instances, although families have NDIS funding, they are not able to access supports due to wait lists or because there are no providers in their local area. Families have expressed concern that, unless more providers enter the market or existing providers expand their staff, their child may go without some or all of their funded supports for extended periods.

It would be disappointing – and counter to the intent of the NDIS and the ECEI Approach – if inadequate supply of services undermined the outcomes that might otherwise be achieved by child participants. It may also increase NDIS costs if these children remain in the Scheme longer than anticipated, due to a lack of access to supports.¹

Adequacy of funding

Providers delivering specialist childhood therapies have told us they are concerned about the way the NDIA assesses children's impairment during the planning process. In particular, they are concerned about the use of assessment tools such as the Paediatric Evaluation of Disability Inventory (PEDI-CAT).² They told us this tool was developed primarily to assess children with cerebral palsy and is focused on physical impairment and equipment needs, meaning it is not well suited to assessing children with behavioural conditions such as autism. Providers have noticed that many children who they assess, using specialist diagnostic tools, as having 'moderate to severe' autism, are classed as having only 'mild' autism when the NDIA uses the PEDI-CAT tool. They believe that, as a result, many children's support needs have been underestimated and their NDIS plans underfunded.

Service providers have told us that an inadequate NDIS plan can mean that a child has little or no chance of reaching their stated goals. They cited research which indicates a minimum of 20 hours/week of intervention for young children is necessary to establish and maintain progress against developmental goals, with best practice being 30 hours/week. However, providers were aware of some children who received funding for only 10-15 hours of therapy across a year. Providers indicated these lower levels of therapy could mean the difference between participants becoming independent (the early intervention approach) and needing ongoing support.

ECEI providers also expressed frustration and concern that children in very similar situations could receive NDIS plans with vastly different types and amounts of support. They also said they

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¹ The Productivity Commission's discussion paper on the costs of the NDIS referred to the lower than expected rate of exit from the NDIS by early intervention participants. While the Commission did not reference undersupply of services as a factor, it pointed to the impact the lower exit rate could have on the future costs of the NDIS.

² https://www.pedicat.com/

had seen plans that included almost identical types and amounts of support, despite the children and families having vastly different needs.

Service providers and participants said that when they told the NDIA they were thinking of asking for a review of their plan due to lower than expected levels of funding, they were warned that a review may result in their plan supports being reduced. Families felt this was a threat designed to stop them from exercising their review rights.

Costs of services

We have heard from families that, when they complete the NDIS access process for their child (rather than transitioning directly from state services), they are often expected to obtain expensive reports to show evidence of their child's disability and associated impairment. Regardless of whether access is granted or refused, these costs cannot be reimbursed.

Many smaller service providers, and even some larger ones, have also complained about the costs and administration associated with registering with the NDIS, claiming the arrangements are more onerous than the previous state requirements. Some service providers have indicated they will not register as an NDIS provider. This may mean that only larger service providers will remain in the market, reducing supply and decreasing competition and choice for families.

These issues around cost are also echoed in our consultations with participants and stakeholders about the NDIS generally.

Information

In a recent submission to the Productivity Commission³ we detailed the problems people tell us they experience when communicating with the NDIA. We also provide direct feedback to the NDIA about these issues.

In the context of the ECEI Approach, families continue to tell us about the difficulty they have getting clear and timely information from the NDIA. This includes information about what the NDIS covers, how the planning process works, when planning will take place, and how to use the plan. Complaints to our office have also reflected long wait times on NDIA phone lines, difficulties having phone calls returned, lack of response to written communication and complaints, confusion about whether review requests are being actioned, and receiving information in bureaucratic language.

We recently sought information from the NDIA about how it will ensure that families are aware their child may be exited from the NDIS, if they are considered to no longer meet the early intervention requirements and do not qualify under the disability requirements. It will be important that the NDIS and its ECEI partners provide clear advice to families on this point, to ensure their expectations are managed and they are appropriately supported to access mainstream services if their child can no longer receive NDIS-funded supports.

³ http://www.ombudsman.gov.au/__data/assets/pdf_file/0024/43449/OCO-submission-to-PC-inquiry-into-NDIS-costs,-March-2017.pdf

Accessibility

Our Office receives few complaints from complainants who identify as being Aboriginal or Torres Strait Islander. For this reason we consult directly with stakeholders who have contact with Indigenous communities to seek input into our work. Where possible, we also conduct outreach to remote Indigenous communities to hear from participants and providers about their experience of the NDIS.

In recent discussions with stakeholders in the Anangu Pitjantjatjara Yankunytatjara (APY) Lands we were told no children living on the APY Lands are receiving disability services, as families with children who have significant care needs or behavioural issues tend to live in, or move to, regional towns where there are some services. Stakeholders further advised that, of the few families on the APY Lands who have NDIS plans, none accessed supports in their plans in the first 12 months.

In our recent submission to the Productivity Commission's inquiry into human services⁴ we outlined some of the themes in feedback from stakeholders in remote Indigenous communities. These include:

- the concept of 'disability' is often not one that Aboriginal and Torres Strait Islander people identify with, either for themselves or for a member of their family or community
- the planning process and range of plan outcomes are not sufficiently flexible to account for:
 - family and kinship arrangements in which Aboriginal and Torres Strait Islander people with disability live and are cared for
 - o participants' focus on food and housing security as immediate priorities (but neither of which are usually covered by the NDIS) which, if not met, may affect their ability or willingness to consider broader goals related to disability
- many communities have few phones and little or no internet coverage, which makes it difficult for participants to access the portal or engage directly with the NDIA
- low levels of literacy and numeracy, combined with English as a second (or third or fourth) language mean that many people find the NDIA's materials inaccessible, even when written in Easy English
- people who have received an NDIS plan are often unsure how to use it to access supports and, as a result, many have not spent any funds from the plan during the full 12-month plan period.

Our submission to the Productivity Commission also included comments on how the NDIS might be delivered more effectively for Aboriginal and Torres Strait Islander people, particularly where they live remotely.

Concluding comments

Many stakeholders speak positively about the work the NDIA and its Early Childhood partners have done to develop and implement the ECEI Approach. However, our submission points to several areas where providers and families feel that the Approach does not always work well.

⁴ http://www.ombudsman.gov.au/__data/assets/pdf_file/0023/43448/Final-submission-PC-Human-Services-Inquiry-060217.pdf

While issues, like undersupply of services, are not entirely within the NDIA's control, there are others that might be mitigated by clearer and timelier communication.

For example, the NDIA could examine whether its communication products (including letters, factsheets and online information) are readily available, and provide clear information to families:

- currently receiving Better Start and Helping Children With Autism, about how they can access supports for their child if they run out of funding before they can access NDISfunded supports under the ECEI Approach
- whose children have been/are likely to be accepted into the NDIS, about the likely timeframe for receiving a plan under the ECEI Approach
- about the focus of the ECEI Approach, including that their child may be exited from the NDIS if they no longer meet the early intervention access requirements
- about their review rights if dissatisfied with a plan.

It might also more effectively manage the expectations and understanding of providers, families and treating professionals by providing clear information about:

- what can and can't be covered by the NDIS
- the factors that are considered when developing a plan
- the reasons why plans may vary across families, living situations and disability types.

This information should be available in a variety of media, be accessible, and account for the different cultural, language and literacy needs of families.