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To whom it may concern

RE: Consultation papers for how the NDIS works for 7 - 65 old's

The Public Advocate (OPA), and the Disability Advocate, thanks the National Disability Insurance Agency (NDIA) for the opportunity to participate in the consultation about how the National Disability Insurance Scheme (NDIS) works for people aged between 7 and 65 years of age. In providing this response consideration has been given to the two discussion papers, Access and eligibility for independent assessments and Planning policy for personalised budgets and plan flexibility.

The Disability Advocate works closely with the Public Advocate and has consulted broadly with South Australians about their experience with the NDIS since late 2018. These consultations have provided a unique insight into the experience or people with disability, their families as well as a range of stakeholders as the NDIS has rolled out in South Australia.

The Office acknowledges that the NDIS is a complex and evolving scheme and recognises the continued work of the NDIA to improve the experience of people with disability.

We thank you once again for the opportunity to provide input into the NDIS and advocate for South Australians and look forward to future opportunities to collaborate to improve outcomes and the experience of South Australians with the NDIS.

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National Disability Insurance Agency (NDIA) Consultation Papers:

- Access and Eligibility Policy with Independent Assessments
- Planning Policy for Personalised Budgets and Plan Flexibility

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Introduction

Office of the Public Advocate

The South Australian Public Advocate is a statutory official appointed by the Governor to implement the provisions of Section 21 of the *Guardianship and Administration Act 1992*, (the GAA). The Public Advocate is supported by the Office of the Public Advocate (OPA) to assume guardianship, and provide advocacy, support, and education to people with mental incapacity and the systems and services around them. This includes speaking for and on behalf of people and their families, carers, and supporters, educating the sector and identifying areas of unmet need for reporting to the Minister.

The Public Advocate acts as guardian of last resort for people with impaired decision-making capacity, when appointed by the South Australian Civil and Administrative Appeals Tribunal (SACAT) under the GAA. The SACAT will only appoint the Public Advocate as a person's guardian if it is satisfied that no other order would be appropriate. What this means in practice is that the Public Advocate will only be appointed if there is no one else in a person's life able or willing to make necessary decisions, or if there is family conflict meaning that agreement on decisions is difficult or not possible. Consequently, the Public Advocate often must make decisions for people who have complex needs or experience complex situations and who may be without support networks.

The Public Advocate's role as guardian is to make decisions, including giving the relevant consent about a person's care, where there is the requisite authority to do so under the guardianship order. However, the Public Advocate as guardian is not responsible for arranging and coordinating a protected person's package of care and services.

Disability Advocate

The Disability Advocate is a position located within the Office of the Public Advocate and was established in November 2018. The purpose of the role of the Disability Advocate is to "ensure that South Australians with a disability and their families are getting a good deal from the National Disability Insurance Scheme (NDIS)."

Throughout 2019 the Disability Advocate attended over 150 meetings with people with disability, family advocates and carers to speak with people about their experiences with the NDIS, what was working well and areas for improvement. Regular reports were presented to Ministers and senior State and NDIA officers.

The role has since been extended with funding for the next 3 years. COVID-19 and other work (such as the Safeguarding Taskforce) made it difficult to undertake face to face meetings in 2020 but the Disability Advocate conducted over 270 meetings with external stakeholders during the year. He has also recommenced meetings with the regular reports scheduled in 2021.

General Discussion

The Public Advocate and the Disability Advocate welcome the opportunity to provide written feedback on the following NDIS Consultation Papers:

Access and Eligibility Policy with Independent Assessments¹ Planning Policy for Personalised Budgets and Plan Flexibility.²

These documents outline the planned changes to determining NDIS eligibility that flow on to the NDIS planning process. The Independent Assessment Framework (August 2020)³ clearly states the rationale behind the introduction of independent assessments. The NDIA developed a range of questions related to both policies, however these questions do not speak to the concerns that the Disability Advocate has been hearing about the roll out of this process. It would be remiss not to make general comments on those issues raised.

- By implementing the proposed system of independent assessment, the NDIA appears to be moving away from the fundamental principles of participant "choice and control".
- Those participants who can articulate their circumstances and clearly identify the parameters of their disability in language that the assessors both understand and expect are likely to get a better plan. It is highly likely that these people will be able to navigate the new system and continue to receive better outcomes.
- There is still the problem of participants portraying their circumstances in the direst way in order to stimulate better outcomes and bigger plans, which has the perverse effect of rewarding dependency rather than encouraging independence.
- The concern of the availability of suitably qualified assessors in an already "thin market", especially in rural and remote areas.
- The independent assessments process will be introduced regardless of the outcome of pilot projects and consultation. Whilst the *Review of The National Disability Insurance Scheme Act 2013 Removing Red Tape And Implementing The NDIS Participant Service Guarantee*, David Tune AO PSM December 2019⁴ (Tune Review) recommended prospective participants should undergo assessments, it specifically stated that NDIA-approved providers should carry these out. In addition, the Tune Review stated the NDIA should not implement a closed or deliberately limited panel of providers.
- The Disability Advocate acknowledges that the current access process can be costly and involve long wait times. However, in the new process the prospective participant is still responsible to pay the costs of meeting the eligibility criteria of age, Australian residency, and permanency of disability. The Disability Advocate has heard that this process can be particularly onerous for some prospective CALD participants. People have to wait lengthy times for citizenship and find difficulty gathering evidence. Obtaining a diagnosis of disability may be difficult as there may not be a regular GP who knows the person.

¹ National Disability Insurance Scheme, *Access and Eligibility Policy with independent assessments* (Consultation Paper vol. 1, November 2020).

² National Disability Insurance Scheme, *Planning Policy for Personalised Budgets and Plan Flexibility* (Consultation Paper vol. 1, November 2020).

³ National Disability Insurance Scheme, Independent Assessment Framework (Report, August 2020).

⁴ David Tune, *Review of the National Disability Insurance Scheme Act 2013: Removing Red Tape and Implementing the NDIS Participant Service Guarantee* (Final Report, December 2019).

- There are concerns that the Independent Assessment Pilot and the evaluation was based on a small cohort of participants which may not be reflective of the larger NDIS population's experience.
- There are concerns about how standardised assessment tools will translate into a dollar figure and how this will affect the plan.
- The Office of the Public Advocate and the Disability Advocate Submission to the Review of the NDIS Act⁵ stated that the rigid assessment requirements of access requests were unclear to participants and that the solution was more guidance in the assessment process for participants, families and health professionals. This was to ensure that assessment reports could better reflect the functional capacity impact.
- The Independent Assessment Framework (August 2020)⁶ references inadequate and inconsistent assessment procedures and confusion between terms such as "diagnosis", "impairment" and "functional capacity" causing difficulties in decision making. There is concern that the NDIA not been able to clear this confusion in the new Independent Assessment process?
- The planning meeting will now resemble the implementation process how to spend the money, rather than an opportunity to discuss goals.
- The NDIA has raised concerns about inconsistency and bias in the current access process. The same concerns have been raised about the independent assessments.
 - The validity of information that is provided by the assessor is this simply a "tick and flick" exercise.
 - Insufficient time for the potential participant to be observed in numerous settings such as home/school/work/hobbies and with friends.
 - Insufficient time for comprehensive report writing.
- The Disability Advocate raised the issue of the NDIA repurposing Local Area Coordination in the Safeguarding Taskforce Supplementary Report September 2020 (Safeguarding Taskforce).

"the role of the Local Area Coordinator (LAC) being to support people to access the wider community and mainstream services has been side-tracked into plan development, a role they weren't designed for and this has resulted in less community access information for people with disabilities"⁷

We need to be assured that the NDIS independent assessors will not be reassigned into other roles?

• Because the independent assessment process has occurred at the same time as NDIS "scheme viability" is being debated at the Government level, there is a justifiable suspicion that independent assessments will be the vehicle that leads to more difficult access and smaller packages so that the scheme costs do not blow out.

⁵ Ibid.

⁶ National Disability Insurance Scheme (n 3).

⁷ Kelly Vincent and Dr David Caudrey, *Safeguarding Task Force* (Supplementary Report, September 2020) Government of South Australia <<u>https://dhs.sa.gov.au/__data/assets/pdf_file/0004/90832/Safeguarding-Task-Force-Report-31-July-2020.pdf</u>>.

Feedback on the NDIA Access and Eligibility Policy with independent assessments paper.

What will people who apply for the NDIS need to know about the independent assessments process? How this information is best provided?

The Disability Advocate has met with a large number of people with disability and their families. There were many reports of the difficulties faced in navigating the very complex systems of the NDIS.

The September 2020 Safeguarding Taskforce Supplementary Report states that

"It is critical that the participants or their families know where to go to for help, with a single point of contact who is responsible for looking out for the vulnerable participants and ensuring their needed supports."⁸

It is essential that prospective NDIS participants are assigned either a NDIS worker or Local Area Coordination (LAC) partner to fully explain the independent assessment process to the participant and their support person (if required). This would include providing all information in a format that suits the communication needs of the person, including easy read or sign language. The Disability Advocate has been made aware that interpreting services are not provided until the person is an NDIS participant. An interpreter must be provided to explain the independent assessment process to any prospective participant who requires this service.

People who apply for the NDIS must have the entire independent assessment process explained to them including:

- who is the independent assessor?
- the time required
- where the meeting can take place
- the purpose of the assessment and how it affects the planning process
- how they can apply for the results and how long this will take
- avenues of review and appeal are open to them should they not be successful.

This information should be given to the person in writing (easy read if required) and an opportunity to review and consolidate the information prior to the assessment. Checking back to ensure understanding of the process and information may be required.

The NDIS Booklets on understanding the NDIS⁹, planning¹⁰ and using your NDIS plan¹¹ are very useful user guides and will need to be updated to reflect these changes.

⁸ Ibid.

⁹ National Disability Insurance Scheme, 'Understanding the NDIS', *Booklets and Factsheets* (PDF, May 2020) <<u>https://www.ndis.gov.au/media/80/download</u>>.

¹⁰ National Disability Insurance Scheme, 'Planning', *Booklets and Factsheets* (PDF, May 2020) <<u>https://www.ndis.gov.au/media/333/download</u>>.

¹¹ National Disability Insurance Scheme, 'Using Your NDIS Plan', *Booklets and Factsheets* (PDF, May 2020) <u>https://www.ndis.gov.au/media/336/download</u>>.

The NDIS Participant Service Charter¹² though a relatively recent document may need to be made clearer with these changes to access and planning (Pg. 5 The service standards you can expect).

Not everyone will want this level of guidance through the system, but for those people who do they should be afforded the opportunity.

What should we consider in removing the access lists?

In much the same way as the Section 55 data from the South Australian state government was used to streamline access to the scheme, it appears that the access lists allowed people who have certain diagnoses or received supports from past programs to have immediate access to the Scheme. It would appear logical that as most people have fully transitioned to the scheme that removal of the list would not be problematic.

However, what must be considered is the level of understanding of the assessors, planners and the delegates who sign off on the plan. The Disability Advocate still hears concerns that NDIA and Local Area Coordination (LAC) staff do not have sufficient understanding of disability types and of the issues related to the person's disability and whether this is lifelong. The access lists do serve the purpose of providing background information on disability for staff.

How can we clarify evidence requirements from health professionals about a person's disability and whether or not it is, or is likely to be, permanent and life long? How should we make the distinction between disability and chronic, acute or palliative health conditions clearer?

In 2011 The Productivity Committee recommended the establishment of both the National Disability Insurance Scheme and the National Injury Insurance Scheme (NIIS). Whilst the NIIS was developed for catastrophic injuries caused by motor vehicle accidents, workplace accidents, medical and general accidents, the NDIS has far broader criteria, i.e. support for people with permanent and significant disability that affects their ability to take part in everyday activities. Given the medical focus of the NIIS, some collaboration to clarify these tricky topics could be beneficial.

The NDIA has published the *Principles to Determine the Responsibilities of the NDIS and other Service Streams*¹³ that outline the roles and responsibilities of different sectors who deliver supports to people with disability. Revisiting, clarifying and clearly defining the above terms in this document may help the wider sector to understand these terms and use them more appropriately.

What constitutes a disability, as distinct from a chronic medical condition, has been a troubling topic for many years. The definition of "disability" regarding loss of function for an extended period (more than 6 months) is bound to be problematic. What constitutes a disability service as opposed to a health service is equally troublesome. In psychosocial disability the supports that a participant needs include the mental health supports that are the responsibility of the state.

¹² National Disability Insurance Agency, 'Participant Service Charter', *Service charter | NDIS* (Online PDF, July 2020) <https://www.ndis.gov.au/media/2623/download>.

¹³ 'Principles to Determine the Responsibilities of the NDIS and Other Service Systems', *Council of Australian Governments* (Web Page, 27 November 2015)

<https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-DetermineResponsibilities-NDIS-and-Other-Service.pdf>.

What are the traits and skills that you most want in an assessor?

How can we ensure independent assessments are delivered in a way that considers and promotes cultural safety and inclusion?

The Joint Standing Committee on the National Disability Insurance Scheme Planning Interim Report 2019¹⁴ recommends additional training and skills development to NDIA and LAC partner staff to ensure that these people become familiar with the wide range of disabilities experienced by participants and the specific needs of CALD and ATSI people.

It is recommended that assessors are trained appropriately by the NDIS to understand a range of disabilities. There is a concern that, as assessors will come from a specific discipline, that their knowledge base may not be sufficiently broad to have a sound understanding of the needs of the person they are interviewing. The assessors must also have knowledge of the specific needs of those prospective participants from CALD and ATSI backgrounds and integrate this into their processes. An appreciation of the varied communication styles of people with disabilities and a willingness to work with the individual at *their* level is essential.

What makes this process the most accessible that it can be? (e.g. holding the meeting at the person's home)

Ensuring "choice and control" by respecting and adhering to the prospective participant's wishes.

Providing the prospective participant with a variety of options that the person may not have considered.

What are the limited circumstances which may lead to a person not needing to complete an independent assessment?

The Disability Advocate has become aware that agencies representing specific cohorts of NDIS participants are recommending that their client groups should be exempt from the independent assessment process. Corrections Services and Mental Health Services believe that their client groups would be better served by an assessor who is known to the person. Individual advocacy groups are raising concerns relating to trauma and trust and whether people who have experienced trauma will be able to communicate effectively and tell their story to a stranger. There is concern that a stranger assessor will adversely affect the outcomes for a number of people.

If the numbers of cohorts requesting exemption increases, the remaining groups who are not exempt will again likely be those people, whose voice is not strong enough to be heard.

How can we best monitor the quality of independent assessments being delivered and ensure the process is meeting participant expectations?

The NDIA in their Independent Assessment Framework¹⁵ has covered governance to include:

 Centralised and consistent training of health professionals conducting independent assessments

¹⁴ Joint Standing Committee on the National Disability Insurance Scheme, Commonwealth of Australia, NDIS Planning (Interim Report, 2019).

¹⁵ National Disability Insurance Scheme (n 3).

- Research into reliability and validity of assessment tools and results in Australia
- Governance over assessor competencies
- Evaluation of feedback from participants and/or representative
- Regular cycle of evaluation against best practice-tools.

The Disability Advocate supports this process.

How should we provide the assessment results to the person applying for the NDIS?

Unless specifically requested, feedback should be given verbally- face to face in a format that suits the individual. Hardcopy information should be provided as not everyone has access to email and a printer. Results must be provided in easy English if required and an interpreter provided as required.

This information is sensitive and may cause distress to the person.

Feedback on the NDIA Planning Policy for Personalised Budgets and Plan Flexibility Paper

How should a participant's plan be set out to be easier to understand? How could we make it easier for participants to understand how their funding can be spent?

How can we support participants to prepare for a planning meeting? What might be needed to support participant decision-making?

How can the NDIS ensure positive relationships between participants and planners?

How can we best support participants to transition to this new planning model?

It is clear that the NDIS is a most welcome innovation in Australia – a universal, national, insurance-based view of disability that enshrines respect for the individual participant and their ability to exercise choice over such matters as "who provides services" and to exercise control over precisely how those services are delivered. For the majority of NDIS participants the current model of service delivery works well. However, for a smaller group of participants the NDIA approach is inherently risky. The NDIA has avoided the concept of "case management", due to concerns that it leads to disempowerment and condescension. Instead, it has created numerous players with different roles that make perfect sense to the framers in the NDIA but make precious little sense to many participants or their families. "They end up doing all of the advocacy, lobbying, chasing – up and coordination themselves." (i.e. case management isn't done away with, it has lobbed back with the participant and/or their families, to their detriment.)

There are a number of ways the NDIA could make all processes easier for the participant and their family:

- Having a "Go to Person" to guide them through all the NDIS process
- Providing an Interpreter as required
- Investing in individual advocacy
- Making face-to-face meetings the preferred method of interaction with all participants or at least to meet with the participant regularly
- Not relying on electronic communication systems
- Update user guides and booklets when changes occur.

Which supports should always be in the fixed budget? What principles should apply in determining when supports should be included in the fixed budget?

The NDIA Chief Executive Martin Hoffman advised that "they want to move away from a line by line welfare rationing culture."¹⁶ The traditional, core, capacity building and capital support categories are to be replaced by fixed and flexible budget lines. It would appear the idea of moving to this system will provide make it easier for the participant to make choices to shift monies around when purchasing supports.

Additional supports for which funding will be determined differently. These supports include:

- Specialist Disability Accommodation (SDA)
- high-cost or complex assistive technology
- home modifications
- extensive behavioural support.

However, no mention is made of Supported Independent Living (SIL), which can be the largest portion of costs for people in grouped arrangements. If these essential core supports become flexible how can the NDIA ensure that service providers will have sufficient funds left in plans for SIL services if the SIL budget can be flexibly used elsewhere?

How can we assure participants that their plan budgets are at the right level? (e.g. panels of the Independent Advisory Council that meet every six-months to review learnings and suggest improvements)

Martin Hoffman advised, "Every person is an individual. If you've got a similar functional capacity and similar life circumstances, you're going to get a similar budget."¹⁷ Goals are important in people's lives. Even if you have the same disability, your goals, your work or day activities, your relationships and where you live need to be considered during a planning process.

The participant's budget should not be solely based on the independent assessment of daily need but should take into consideration the participant's goals.

The NDIA has advised that timeframes for plan reviews will change and that reviews will occur at significant life events, change of circumstances or no longer than 5 years. Participants need to be assured that funds are indexed to accommodate for inflation.

What new tools and resources should we provide to support people using their plan and new plan flexibilities?

What ideas do you have for how people can use their plan more innovatively?

The Safeguarding Taskforce identified several gaps in relation to NDIA, NDIS Quality and Safeguards Commission and State government processes:

Safeguarding Gap 1

Potentially vulnerable participants are not routinely identified and assigned ongoing support coordination in their NDIS Plan.

Safeguarding Gap 3

¹⁶ Tom Burton, 'Redesigning the complex disability services system', *Financial Review* (online, February 11 2021) <<u>https://www.afr.com/politics/federal/redesigning-the-complex-disability-services-system-20210113-p56tq4</u>>.

¹⁷ Ibid.

Participants are not routinely linked to community activities, so they are often isolated.

Safeguarding Gap 4

Participants are not identified as potentially vulnerable by the NDIA and prioritised by LAC when carrying out the community connection role.

Safeguarding Gap 14

The State has not invested in individual advocacy to assist people with disabilities to navigate the service system and the community.¹⁸

The Disability Advocate made recommendations that Support Coordination should be included in plans of vulnerable participants and that LAC should return to their intended role of linking participants to the community. The NDIA should use these existing resources to support participants to engage with the community and use their plans more innovatively.

In addition, the Safeguarding Taskforce Report recommended that the State government invest in individual advocacy to assist individuals with accessing what they need from the NDIS and from the community. By further investment in advocacy services the NDIA could support participants to use their plans more innovatively.

A number of Information Linkages and Capacity Building (ILC) grants have been issued over time to fund projects to support education and engagement of CALD communities with the NDIS. Feedback received was that the ILC projects produced good outcomes whilst they were funded but once funding finished all the good work was lost. There should be an opportunity for projects that are working well to have funding extended and work should be showcased to enable duplication across areas. Grants may not produce outcomes within a year, three yearly grants may be more beneficial. Linking ILC with the National Disability Strategy may be an incentive for organisations to progress innovation.

What do we need to consider for children aged 7 and above in the new planning process?

Recognise the voice of the child in decision about themselves.

Support families to connect with services where it may be required. Check plan utilisation and where there are concerns check-in with families to ascertain why aspects of the plan a have not been actioned and set a plan in motion to put in additional supports.

The Disability Advocate has met with Aboriginal and Torres Strait Islander communities who voiced concerns that family and kinship arrangements were not recognised by the NDIA.

The Department of Child Protection (DCP) defines kinship care as: Any living arrangement in which a relative or someone else emotionally connected to the child take primary responsibility for raising the child. This care arrangement may be informally arranged or formally supported by the Department of Child Protection. (DCP)¹⁹

¹⁸ Kelly Vincent and Dr David Caudrey, *Safeguarding Task Force* (Final Report, 31 July 2020) Government of South Australia https://dhs.sa.gov.au/__data/assets/pdf_file/0004/90832/Safeguarding-Task-Force-Report-31-July-2020.pdf

¹⁹ 'Glossary – relative, kinship and foster care', *Department for Child Protection* (Web Page, 2021) <<u>https://www.childprotection.sa.gov.au/children-care/foster-carers-charter/glossary-relative,-kinship-and-foster-care</u>>.

Family members told the Disability Advocate that they were recognised by Centrelink but not by the NDIA. The inability to make contact with the NDIA hindered the planning progress for children under Kinship arrangement. Families reported waiting for over a year to have a DCP social worker make an access request.

NDIA need to acknowledge family and kinship arrangements.

How best to handle the timing of the release of funds into plans and rollover of unused funds?

The Disability Advocate has not explicitly sought the views of South Australians on this topic. This is also a topic that was not readily raised by those spoken to during gatherings and meetings.

How should check-ins be undertaken? Under what circumstances is a check-in needed? Who should be involved in a check-in?

How often should we check-in with participants in different circumstances?

During the COVID-19 Pandemic the NDIA identified over 5,000 participants in South Australia who were vulnerable, and these people had welfare checks conducted during this time.

The concept of vulnerability needs to be assessed on a case-by-case basis and is not static. A person may be independent and or well connected for the majority of their life, but if these circumstances change, they may find themselves more vulnerable. Conversely, people can become less vulnerable over time.

At this time the cohort for the COVID 19 vulnerability strategy included participants who:

- were receiving certain levels of core daily activities supports;
- already in the NDIA's Complex Support Needs Pathway;
- receiving disability related health supports, including community nursing, assistive technology for personal care/safety, diet management;
- receiving behavioural supports;
- aged over 55 years and with aged carers;
- in indigenous communities; and
- living in Supported Independent Living (SIL), Specialist Disability Accommodation (SDA), Younger People in Residential Aged Care (YPIRAC) or specific housing segments such as boarding houses or hostels.

This welfare checking initiative conducted under COVID 19 needs to be built on when considering criteria of "vulnerability" and measures to address the associated risks. "Living alone" is a criterion that needs to be added.

The NDIA Participant Service Improvement Plan²⁰ states that the NDIA will check in with you on how your planning is going and whether an update or review is required. The NDIA has also advised that they will provide a named contact person on all documents. Both initiatives are a good start to providing the participant with a go-to person. The NDIA must endeavour to ensure consistency of staff as one of the ongoing concerns of participants is the movement of both the NDIA and planning staff and the cast of players that they need to deal with in their NDIS journey.

²⁰ National Disability Insurance Agency, 'Participant Service Improvement Plan', *Participant Service Improvement Plan | NDIS* (Online PDF, June 2020) https://www.ndis.gov.au/media/2623/download>.

Conclusion

The Public Advocate and Disability Advocate acknowledge the ambitious task of rolling out a national scheme at such a rapid rate. In doing so this has presented challenges for people with disability and their families who formerly had a 'go to' person to assist them to navigate the system and coordinate services. As noted throughout this paper, the lack of 'case management' support coupled with a new and ever evolving scheme presents significant challenges and barriers for the person with disability to access the scheme. The independent assessor is yet another additional player in the process of accessing the scheme. For people newly entering the scheme there is benefit to having an independent assessment as this is one less cost the individual has to incur in paying for assessments. For those who are currently in the scheme the independent assessment appears to be some form of economic rationalisation to try to reform an ever growing and costly scheme. The NDIA has made a concerted effort to engage participants in the independent assessment trials and consult around the independent assessment. These attempts, whilst noteworthy, still do not reach the most vulnerable and disadvantaged people with disability. We watch with anticipation for the next move and player in the NDIA.

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