

22nd February 2021

**National Disability Insurance Agency (NDIA) Consultation
Access and eligibility policy for independent assessments
Autism Spectrum Australia (Aspect)**

Autism Spectrum Australia (Aspect) welcomes the opportunity to provide a written feedback to the National Disability Insurance Agency (NDIA) on Access and eligibility policy for independent assessments

Aspect is Australia's leading national autism service provider & knowledge leader. Using the expertise within our own research unit (ARCAP) to identify evidence-informed practices, Aspect provides a broad range of services to support individuals & their families across their life span to achieve outcomes that are important to them by engaging with them in their communities.

These include:

- Regular services in all states & territories (except WA) & a national program of workshops & consultancies known as Aspect Practice, based on the organisation's distinctive capabilities.
- Direct services (both fee-for-service & NDIS funded) for children include diagnosis & assessment, early childhood development, behaviour support & schooling, incorporating nine specialist schools with over 100 satellite classes, education & family support, assessment & transition & educational outreach services.
- Direct services for adults (Aspect Adult Community Services, Aspect Employment) in the form of preparation for employment & community based services.
- A national resource for families & services seeking information & advice about people on the autism spectrum.

The organisation employs more than 1000 staff, many of whom are highly skilled professionals who are experts in the field of autism, including clinical psychologists, specialist teachers, speech pathologists, occupational therapists & adult services staff.

We have provided feedback that have the most relevance to our expertise, work and services.

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

To support participants through the independent assessment process there are a number of key things they will need to know. We imagine they would have a number of questions that should be answered prior to undergoing an independent assessment. These would include:

- How long will I wait for an assessment?
- Who is the assessor?
- What are the assessor's qualifications?
- What are they going to ask me?
- How do I need to respond? E.g. can I write responses or do I need to talk?
- Who can support me?
- What if I don't agree to the independent assessment?

- Do I need to prepare or provide anything?
- How long will the assessment take?
- Where will the assessment be?
- Can I choose where the assessment will be?
- What do I do if I don't understand what they're asking me?
- Can I access an interpreter?
- How do the results inform the NDIS of what I will be able to access?
- What will the NDIS do with the results?
- Can I see and have a copy of the results?
- What if I need to stop the assessment?

It is essential that the participant and their support networks can easily access information regarding the independent assessment process at any time during their journey. Participants should be given the opportunity to ask questions prior to an assessment occurring to support their understanding of what the assessment will involve. Ideally this should be with the independent assessor, which will support initial rapport building between the assessor and the participant. Information regarding independent assessments, should also be available in multiple forms to ensure all participants can access the information required. This would include videos, visual supports/stories, written materials, information provided in Easy English and information available in multiple languages. Information should be included on the NDIS website, but the agency also needs to consider how participants will access information if they do not have access to technology. Government agencies, not for profit organisations, health and education services, should all have access to the most recent information and resources, so they can support the people that access their services. Information sessions should also be offered across the sector, so that all relevant stakeholders are clear on the process.

2. What should we consider in removing the access lists?

Whilst access lists were somewhat problematic as automatic access to the scheme was determined by diagnosis and level of diagnosis, which does not always match a participant's level of functional needs - it was somewhat clear on what was required to meet eligibility to the scheme. Participants could also choose to access assessments and seek paperwork from professionals who they already had built trust and rapport with and see professionals who understood their specific needs and how these impact on their daily functioning. It is clear that the agency is trying to create a more equitable process by providing independent assessments, where participants no longer need to seek out their own assessments, which can be costly and with long wait times, however we have significant concerns around the validity of an independent assessment completed by someone who does not know the individual and who will take a snapshot in a short assessment on a particular day. We also have concerns that the independent assessors would make a judgement about an individual's functioning and level of support required without listening to and including in their assessment, information from the health professionals currently supporting the individual, who have expertise working with people with that disability/support needs and are familiar with the evidence based supports that will help that individual to participate in their valued activities and to build their skills towards identified goals. Individuals (and their carers) may not be able to advocate for themselves around the level of support they need across settings and the type of and amount of intervention that will best support them to meet their goals – this is where information from treating professionals is essential in order to determine an appropriate level of funding in their plan.

It is also not clear how the results equate to amount of money a participant will receive and there are so many variables that in the attempt to create a fair process it will come down to how the participant can answer the questions and whether they have a support network to assist and advocate on their behalf. Ideally, funding should be available for participants to access assessments through providers of their choice, who already have a relationship with them.

The removal of access lists, will also not remove the need to seek assessment and documentation from relevant health practitioners to prove their eligibility for an independent assessment. Participants may still be faced with long wait times, especially if going through the public health system and high costs if they

choose a private practitioner to enable them to be seen quicker. This will most likely still lend itself to inequities across participants.

3. 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?

The agency needs to provide relevant health professionals with clear and consistent guidelines around what the agency requires. It could be helpful to consider providing:

- A clear and consistent statement to providers for e.g. in your diagnostic reports/letters, the following sentence must be included if this is relevant: "XXX has been diagnosed with XXX. This is likely to be permanent and lifelong" OR
- A simple form for health professionals, where they "fill in the boxes" and tick the relevant statement regarding permanent and lifelong.

Clarification should also be provided around who can complete this documentation, so families know who they can approach. Clear and consistent communication to relevant health professionals regarding the requirements is essential. This should be captured on the website, written information emailed/posted to relevant professionals and options for training/information sessions provided by the agency.

4. How should we make the distinction between disability and chronic, acute or palliative health conditions clearer?

This is a challenging distinction. You only need to look at the definitions to see how this continues to be an ambiguous discussion. The *Disability Discrimination Act 1992* (Cth) defines disability as:

- total or partial loss of the person's bodily or mental functions
- total or partial loss of a part of the body
- the presence in the body of organisms causing disease or illness
- the malfunction, malformation or disfigurement of a part of the person's body
- a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction
- a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment, or that results in disturbed behaviour;

Chronic disease, as defined by the Australian Institute of Health and Welfare (AIHW), are 'long lasting conditions with persistent effects'. So a chronic disease can lead to a permanent and lifelong disability that affects an individual's everyday functioning.

It is a little clearer to see the difference between acute (generally sudden and severe onset, where the individual gets better) and palliative health conditions (which are generally lifelong with no cure), however acute conditions could also lead to longer term

The question here should be when do individuals access supports through the health system and when do they access supports through the NDIS? There needs to be better communication between the two systems and much clearer information as to where people can go for support, to ensure individuals do not fall through the cracks.

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

We would like independent assessors to:

- Be a qualified allied health professionals e.g. Occupational Therapists, Speech Pathologists, Psychologists and potentially even mental health trained social workers
 - Have experience in the disability sector
 - Have experience administering, interpreting and discussing outcomes of functional assessments And have the skill to incorporate the information gained from the standardised tools with the information
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provided by the participant and their carers/involved health professionals to get a full overview of that person's abilities across settings, and over time (not just in their home on one day).

- Have knowledge of and experience working with the disability they are assessing
- Be personable, friendly and able to build rapport easily and quickly
- Be able to respond appropriately to participants and family members during assessments
- Be professional
- Be non-judgemental
- Have knowledge and experience working with diverse communities including Aboriginal communities, Culturally & Linguistically Diverse populations, and LGBTQIA+ individuals and be open and considerate to their preferences and needs.
- Have experience working in trauma informed practice to support their decisions around exemptions
- Be truly independent – whilst they are independent assessors they are being paid by the agency to conduct assessments
- Have an understanding of the NDIS and the supports that individuals can access to support their functional needs

6. What makes this process the most accessible that it can be? For example, is it by holding the assessment in your home?

This will really come down to the individual and their own individual support needs however it will be important to consider:

- Offering assessments in the individual's environment of choice for example at home.
- Providing information in an accessible way e.g. not just online, but through other channels as well
- Providing information in a way that the individual will understand for example using Easy English and visual supports as well as recorded information that can be listened to.
- The need for a support person – if the individual is unable to participate independently in the assessment, who will assist them to engage a relevant support person?
- Making it a requirement for someone who knows the individual really well to also be part of the process with the individuals consent
- Participants should be able to provide information from their current support services and this should be taken into account during the independent assessment process.
- The timing and number of appointments required to complete the assessment. Some individuals may need multiple breaks or for the assessment to be spaced out across multiple appointments depending on what they can cope with.
- Access to AAC devices as appropriate and ensure the Assessors know how to use these
- Completing observations/assessment across settings/activities
- If there are questions that could be asked during the initial stages of booking an assessment to ascertain what the most suitable environment will be for an assessment. For example at a day program, when an individual may spend a significant portion of their time.

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

When contacting participants the Agency or Assessors should also be asking participants if there is anything that needs to be considered from a cultural perspective to ensure they can participate as comfortably and safely in the assessment as possible.

Some other things to consider are:

- Independent Assessors should have to undergo mandatory cultural training to ensure they have a basic understanding of potential cultural differences.



- Can participants have a choice around the type of assessor they have? For example gender or background.
- Access to translators who have knowledge of disability, the NDIA and assessment process
- Flexibility around day/time of assessment so it doesn't impede on cultural or religious events and or practices

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

It will be important to consider the below scenarios when determining who can be exempt from an independent assessment:

- Someone who has a background of trauma, where an assessment may cause them increased distress
- When there is a risk to the participant's or Assessor's safety for example if the individual presents with significant behaviours of concern
- A participant who is actively Psychotic
- A participant who has a severe intellectual delay and has limited or no access to support person who knows them really well
- A participant who has no insight into their abilities and challenges and who has limited or no access to a support person who knows them well
- Individuals who have suffered traumatic injuries who may find a functional assessment confronting due to their recent change in level of functioning
- Individuals who have had functional assessments completed by other professionals recently. For example the Vineland can be a confronting assessment by the nature of the questions if administered in close succession

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

We strongly recommend that you implement a much longer trial period with a wide range of participants in both metropolitan and regional areas, to ensure you have all processes in place before it is rolled out nationally.

It will be essential to conduct regular independent audits, which should include:

- Observations of Assessors completing independent Assessments with participants
- Interviews with Assessors regarding the Assessment and process and to seek their feedback on the process
- Interviews with participants and their support networks to gain feedback on how the process was for them and to discuss whether the amount of funding allocated as a result of the assessment met their functional needs

Participants will need to know that the feedback they provide will not impact on their funding as some participants may be concerned to provide feedback otherwise.

All Assessors should:

- Have access to quality support and supervision through senior practitioners.
- Have access to regular training opportunities as well as on floor coaching during assessments with experienced senior practitioners.
- Know who they can provide feedback to on how the assessments are going, especially when they have concerns



All participants should have the opportunity, after 12 months of utilising supports through an NDIS plan, to speak with someone from the Agency around whether the funding allocation based on the assessment met their functional needs.

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

Participants should be given flexibility in the way that assessment results are provided to them, however we would suggest the below is best practice:

- Face to face verbal feedback to participants and support networks (as required).
- After face to face feedback written feedback should also be provided in a way that the participant and their support networks can understand.
- Participants should be given the opportunity to ask questions during face to face feedback, but also after these meetings have concluded when they have had time to process and reflect the information that has been provided to them.
- Results should be provided within a functional context that is meaningful for the participant, not just a score or “stock standard” response.
- Follow up support should be provided by the agency to check in on participant wellbeing after receiving the results.
- All results should be presented in a way that meets the participant’s individual needs. For example in Easy English and with visual supports.

Yours faithfully



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