



NATIONAL DISABILITY INSURANCE AGENCY

Access and Eligibility Policy with independent assessments

Submission from:

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Introduction

About Scope

Scope (Aust) Ltd (Scope) is a leading provider of services to people with disability in Victoria, and one of the largest not-for-profit organisations in Australia. Our origins stretch back to 1948, when a group of parents who wanted better lives and opportunities for their children with disability established the Spastic Children's Society of Victoria.

Scope's mission is to enable each person we support to live as an empowered and equal citizen.

Scope provides services including Supported Independent Living, Short Term Accommodation, Therapy and Lifestyle options to more than 7,000 people and their families across metropolitan and regional Victoria. Scope also works with corporate and community organisations to improve inclusiveness for people with disability.

Our response

We have provided feedback both based on the discussion paper and directly in response to the consultation questions.

Scope feedback

(a) General issues

A key issue with independent assessments is that they will be conducted within a short period of time (up to 3 hours on average depending on the person's disability and age) by someone who does not know the applicant. This creates a significant risk that the applicant's needs/ functional capacity will not be adequately captured. Understanding the person, their disability, and the impact their disability has on them is unlikely to be achieved in a short session by someone who does not have an existing relationship with the applicant. Such an approach will disadvantage the applicant and have an impact on the plan developed by the Agency.

The outcomes for individuals with complex disability are likely to be even more seriously affected. Complex disability can include any combination of disability and physical health/ medical conditions, mental health problems, challenging behaviour, alcohol or drug issues¹⁻², contact with the criminal justice system, Aboriginal or Torres Strait Islander background, use of augmentative and alternative communication, a history of being placed in (or leaving) state care (i.e., child protection services)³, homelessness or being at risk of homelessness. Any of these factors may influence the way that an applicant presents during the independent assessment, including: trust issues owing to previous negative experiences with authority figures; inability to participate fully owing to use of augmentative and alternative communication devices that are unknown to the assessor or rely on

¹ St Vincent's Hospital. (2013). Young Adult Complex Disability Service [Brochure]. Melbourne, Australia: Author.

² Disability Justice Project. (2017). Support planning for people with complex needs. Retrieved from <http://www.disabilityjustice.edu.au/supporting-people-with-complex-needs>.

³ Department of Family and Community Services. (2014). *Leading clinical practice and supporting individuals with complex support needs in an NDIS environment*. New South Wales, Australia: Author.

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the involvement of a familiar communication partner; or assessor uncertainty about how the interaction of multiple disabilities impacts on the applicant's functional abilities.

There needs to be careful consideration of how an applicant's individual circumstances, notably any complex disability, will be addressed within the time being allotted for them to complete an independent assessment.

Insufficient time to understand a person and their needs is not the sole issue. It is unclear how inconsistency in information obtained during the assessment will be addressed. For example, what will happen if the applicant responds to questions or provides different information than a family member? Further, it is unclear how information for the proxy measures will be collected, if the applicant does not have a support person who knows them well enough.

(b) Independent assessment tools

The administration of the various independent assessment tools requires further interrogation prior to full implementation owing to the potential for unintended consequences.

The Vineland Adaptive Behavior Scales is administered to a proxy and the developers of the Craig Hospital Inventory of Environmental Factors (CHIEF) caution against proxy completion because of the poor inter-rater reliability.⁴ Appointing a support person, as suggested in the draft policy, will not address the issues as these supporters will not know the applicant and could not respond accurately for the applicant (see also comments above in relation to complex disability).

The aim of independent assessments is to better understand an individual's functional capacity and environment. The assessments, however, do not seem to consider the episodic nature of some disabilities sufficiently. For example, the WHODAS 2.0 asks people to respond in relation to the last 30 days. This may not be sufficient for some disabilities that tend to be episodic or where the functioning fluctuates, particularly in relation to what is happening in the environment (for example, autism). Similarly, The Lower Extremity Functional Scale asks applicants to respond in relation to today (i.e., "Today, do you or would you have any difficulty at all with...").

3.1 Principles of the assessment outlines that others can be involved in the assessment (e.g., family/carers). Page 19 mentions that the Agency will initiate a process to help identify an appropriate person/s (if requested by the applicant) if no support person is nominated. It is not clear who these people might be (e.g., will they be Agency employees), their qualifications and experience in disability, and the exact nature of their role. How will the Agency ensure that these people will be able to provide adequate support, particularly since they are unlikely to know the person? We maintain that any such person needs to be known to and trusted by the applicant, as well as having appropriate background information and knowledge of their disability, in order to be involved.

The toolkit⁵ refers to "participant interaction". It is unclear what the assessors are observing and/or assessing during these interactions. Clarification is required.

(c) Cost reduction as a motivation for the introduction of independent assessments

One of the motivators for introducing independent assessments as outlined in *2.1 Current Challenges* is to avoid applicants bearing the cost of seeking information from health and disability

⁴ <https://craighospital.org/uploads/CraigHospital.ChiefManual.pdf>

⁵ <https://www.ndis.gov.au/participants/independent-assessments/independent-assessment-toolkit/assessment-tools-toolkit>

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professionals⁶ to demonstrate reduced functional capacity. It is posited that without managing these costs, it can mean “that access to the NDIS is influenced by a person’s ability to gather and pay for enough evidence” (p.5). However, it would seem that even with the introduction of independent assessments, applicants will still be required to bear significant costs. As a result, access to the NDIS will continue to be partly influenced by the applicant’s ability to pay for enough evidence to demonstrate eligibility.

Section 3.3 Information provided before an independent assessment, states that applicants will be required to provide information from their treating health professional as to whether their impairment or impairments are, or are likely to be, permanent. This information is to include “information and clinical judgement that a disability or disabilities are:

- attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments, or
- attributable to one or more psychiatric conditions (or as proposed through legislative amendments, to a psychosocial condition)”.

There is also a tacit assumption here that the applicant already has a treating health professional who is well-informed about the nature and trajectory of the applicant’s disability. This may not necessarily be the case, and for a person with a lifelong disability, the health or disability professional who is best placed to provide that information may no longer be actively involved in treating the applicant. While the emphasis remains on obtaining current information from health professionals there is the possibility that some of the richer information about an applicant’s disability diagnosis may be overlooked.

Health professionals will “also be required to provide information about what interventions or supports have been considered and, where applicable, all reasonable supports and treatments have been identified and/or administered” (p.13). While it is acknowledged that the Agency will work to make it “simple and easier” (p.14) for health professionals and applicants to provide this information, it will still remain a costly exercise for applicants because it will require multiple sessions with a health professional. A health professional would require at least several hours to create or gather information about the most appropriate treatment/s and the functional capacity of the person (as outlined in 2.2.2), the cost of which will still be borne by the applicant.

Further, during the independent assessment (p.19), the applicant can nominate who will support them to complete the assessment. One of the examples provided is the treating professional. This cost will presumably be borne by the applicant. The argument that independent assessments will ensure that a person’s access to the NDIS is not influenced by their ability to gather and pay for enough evidence” (p.5) is flawed.

(d) Review of independent assessments findings and appeals

Independent assessments will be used to determine eligibility and to develop a NDIS plan. It seems that there will not be an opportunity for those involved in the assessment to review the assessment findings before the plan is finalised. Not allowing the results of the assessment to be reviewed is a missed opportunity to confirm the accuracy of the assessment.

⁶ We have used the term disability professional throughout to denote allied health professionals with extensive disability experience including psychologists, physiotherapists, speech pathologists and occupational therapists.

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It is unreasonable that the independent assessment results are not directly reviewable (3.11. *Administrative Appeals Tribunal*). This means that only one person, the assessor, is the decision-maker and their view cannot be questioned. The argument presented is that “Disagreeing with the results of an otherwise sound and robust independent assessment is not sufficient for the NDIA to fund another assessment”(p.23).

It is assumed that each and every assessment will be sound and robust, however, this cannot be the case as there is always the potential for human error, even with the quality assurance framework that is being developed. Moreover, no tool is perfect. For example, some of the test-retest reliability statistics that have been reported (Kostanjsek & Rehm, 2010) for the WHOSDAS 2.0 (36-item) are considered low. Low test-retest reliability means that different results can be obtained even when the same assessor repeats the assessment on the same applicant only days apart.

These differences could result in different interpretations being drawn about the same applicant, even though the same assessor conducted the assessment. Similarly, some research has found that the inter-rater reliability for the CHIEF is below the threshold of what is considered to be adequate.⁷

This means that two assessors assessing the same applicant could end up with different results. Given that the independent assessment will be used to make decisions about eligibility and the participants’ plans (i.e., a “high stakes” assessment), applicants (and their supports) must be given the opportunity to dispute the results if they believe that they are not accurate.

Consultation questions

Learning about the NDIS

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

The full range of information about independent assessments should be made available to applicants. This includes information about:

- What to expect
- Why the assessment is needed
- Who is involved
- Where applicants can get more information
- Who can support the applicant
- Where the assessments can be conducted
- How long the process will take
- What the assessment decision means

The information is best provided in plain language (English and community languages) and a range of accessible formats, including pictograph and Easy English. There should be an accompanying guide in plain language, targeted at those who may be supporting applicants through the process.

Accessing the NDIS

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

⁷ <https://rtcom.umn.edu/database/instruments/chief>

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The access lists were primarily developed as a means to ensure that people who had been receiving services and supports from state-based disability systems were able to transition to the NDIS with minimal disruption. The same 'no disadvantage' principle should apply to the removal of the access lists and the implementation of independent assessments. There will continue to be applicants/participants who have yet to transition to the NDIS and their experience should not be impacted by revisions to administrative processes such as the removal of access lists.

The access lists were informed by the accumulated knowledge and experience of health and disability professionals working within state-based disability systems. There was always the opportunity for practitioners to consider the nuances of each individuals' disability diagnosis; and, where applicable, to respond to the interplay of multiple disabilities and underlying health conditions in planning for individual services and supports. By codifying the knowledge and experience of health and disability professionals through the access lists, the opportunity to review individual circumstances was diminished, and there is an even greater risk that the unique aspects of each individual's disability do not form part of the conversation about what is reasonable and necessary.

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?

It would be preferable to incorporate an established diagnostic tool as the *starting point* for decision making about an applicant's disability on their functional capacity, and whether their disability is likely to be permanent or lifelong. The International Statistical Classification of Diseases and Related Health Problems (ICD) maintained by the World Health Organisation (WHO) is used for a range of automated decision support in health care and is complemented by the International Classification of Functioning, Disability and Health (ICF) (10th ed, 2018).

WHO has completed the eleventh revision of the ICD, which will come into effect on 1 January 2022.

We believe, however that the ICD and ICF should only be used as part of a broader array of evidence. However, direct engagement of treating health and disability professionals is always preferable to reliance on a diagnostic tool.

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

The ICD should provide useful tools for defining chronic, acute or palliative health conditions. For some people with complex and multiple disabilities, however, the distinction between their health conditions and disability is not easily made. For example, an older person with both intellectual and psychosocial disabilities may develop dementia-like symptoms that require medical intervention, but the distinction of these symptoms from the pre-existing disabilities may not be readily discernible.

Similarly, it is important to ensure that there is no diagnostic overshadowing by health professionals in assessing newly recognised chronic, acute or palliative health conditions in individuals.

Undertaking an independent assessment

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

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The Agency has stated that all assessors will be trained experts, for example, occupational therapists, physiotherapists, psychologists and other health and disability professionals. While there are many such professionals who might be considered experts, they may have never worked with people with disability. It is strongly recommended that the assessors have substantial and demonstrated experience working directly with people with disability and their families/carers, as well as formal qualifications. They will need to understand disability (and the sector), including specific disabilities, their impact and trajectory, have a positive attitude towards disability, and respect and know how to work with carers/ others who may attend the assessment.

Minimum standards for assessors should be developed, published and monitored.

Communication access is fundamental to accessibility so that “everyone gets their message across, people are respectful and responsive to individuals with communication disabilities, and strategies and resources are used to support successful communication” (Solarsh et al, 2013). For applicants with complex communication needs, skilled communication support partners may be required for them to participate in independent assessments. The assessors will need to be confident in working alongside these communication partners and appreciate that they do not speak for the applicant; rather, the role of the communication partner is to facilitate the involvement of the applicant in the process.

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

For it to be accessible, the assessment should be held at a location of the applicant’s choosing with their chosen support people. Accessibility will be improved if the assessment is conducted by a person who has an existing relationship with the applicant and is trusted. To improve accessibility, it will also be useful to provide copies of the tools to the applicant and/ or their supporters prior to the assessment so that they can better understand the questions that they may be asked and have the opportunity to consider their responses. The applicant and their supporters should also be made aware of the nature of “participant interaction”⁸ and what, if anything, is being observed and assessed.

We have serious concerns about the artificiality of situations in which applicants are intended to meet with assessors. While meeting ahead of time may alleviate concerns that individuals may have about the process, and in particular about meeting new people with ‘power over’ decisions that affect their future, many applicants are nevertheless going to be self-conscious and withdrawn.

Exemptions

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

Where the person has a severe or profound intellectual disability, or another disability which means that they are not able to respond to the questions themselves AND there is no supporter available who has an existing relationship with the person and knows them well enough to accurately describe their functional capacity and needs.

⁸ <https://www.ndis.gov.au/participants/independent-assessments/independent-assessment-toolkit/assessment-tools-toolkit>

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In section 3.7 *Exemptions from independent assessments*, it states “The delegates decision not to grant an exception for an independent assessment will not be a reviewable decision” (p.21). As with our recommendation to make the results of the independent assessment reviewable/open to appeal because of the “high stakes” nature of the assessment, we urge the Agency to do the same with decisions about exemptions.

Quality assurance

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

First and foremost, feedback from applicants and their supporters, including service providers, is required, as is ongoing support and mentoring for assessors.

In addition, to monitor the quality of assessments, a random sample of applicants who have progressed to the independent assessment stage should be selected soon after their assessment and the assessment repeated by the same assessor (without referring to the first assessment). This repeat assessment will enable the Agency to better understand how consistent the results are (i.e., test retest reliability). The plans that are developed from each assessment should also be compared.

Further, a random sample of applicants should be assessed at the same time by different assessors. The plans arising from each assessment should also be compared. This process will allow the Agency to better understand the consistency of the assessments, results, and plans (inter-rater reliability). For a random sample of applicants, the assessment should be conducted with the applicant and a proxy (separately). Conducting the assessment with two different people will enable the Agency to better understand the applicant-proxy agreement.

Communications and accessibility of information

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

The assessment results should be provided in a language and format that is accessible to the applicant. This may include information in Easy English or pictograph form. It should be relatively simple to develop templates that can be tailored for individuals. The complicating factor comes with a person who may rely on family members or others to receive and interpret communication. If that is the case, the communication preferences/ arrangements for applicants should be noted by the assessor. The family members or others who receive the communication should be provided with a guide that leads them (and by proxy the applicant) through the decision.

Summary

Scope maintains there are significant problems with independent assessments still to be resolved. At the heart of these problems lies the need to balance the involvement of applicants, participants, and families in determining access and eligibility, along with gathering the objective evidence of how a person’s disability impacts on their daily life. That evidence may come from those who know the person best, including disability and health professionals. The associated processes should always put the person with disability ahead of other considerations. This will require greater flexibility than is outlined in the policy. We have provided a set of recommendations below, drawn from this submission, that suggest how independent assessments could be made more person-centred.

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Scope recommendations

Make provision during independent assessments for the deeper involvement of people who are known to applicants, in particular for people with complex disability.

Allow sufficient time for assessors to understand applicants, their disabilities, and the impact their disabilities have on their lives.

Develop guidelines for responding to assessment results that contradict information provided by health and disability professionals and family members.

Further interrogate the proposed independent assessment tools prior to full implementation to prevent potential unintended consequences.

Consider payments to participants required to obtain evidence from health and disability professionals to inform independent assessments (that is, for appointments participants would not otherwise schedule).

Amend the policy to institute an appeals mechanism in relation to access and eligibility decisions that are based solely on independent assessments.

Provide the opportunity for applicants and their supporting health and disability professionals to review the findings of independent assessments prior to finalisation.

Ensure that communications addressed to applicants and participants are always tailored to their communication needs, which may include translation into community languages or use of accessible formats.

Consider use of the International Statistical Classification of Diseases and Related Health Problems (complemented by the International Classification of Functioning, Disability and Health) as an adjunct to decision making about a person's disability while also undertaking direct engagement with health and disability professionals.

Establish the prerequisite for assessors to have substantial and demonstrated experience working directly with people with disability and their families/carers, as well as formal qualifications.

Facilitate independent assessments at locations applicants choose while ensuring that they have the opportunity to invite their chosen support people to attend.

Preference assessors that are known to and trusted by applicants and participants.

Amend the policy to institute an appeals mechanism for decisions not to grant exemptions from independent assessments.

Conduct random sampling of applicant outcomes to monitor the effectiveness of independent assessments.