

# Submission in response to the NDIS Consultation paper: Access and Eligibility Policy with independent assessments February 2021

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#### INTRODUCTION

The Australian Community Support Organisation (ACSO) welcomes the opportunity afforded to us by the NDIS to submit a response towards the 2021 consultation on the Access and Eligibility Policy with independent assessments. ACSO has delivered disability support services for over 35 years and currently deliver a range of NDIS funded supports including outreach disability support, specialist forensic disability accommodation and support coordination to clients with cognitive disability. Additionally, ACSO is funded to deliver the Mental Health Access Project (MHAP), with funding from the state government of Victoria. This project supports eligible people with psychosocial disability to navigate entry pathways into the NDIS, targeting those who are most vulnerable within our communities and are otherwise not supported by relevant services. ACSO's suite of services target high risk, high need and complex cohorts including those defined as 'extreme complex cases', and primarily those who are engaged in, or at risk of engagement in the criminal justice system. In developing our response to the consultation questions, we have interviewed key staff from our Disability Services and Mental Health Access Project teams, who have also consulted with their clients, and consulted with an NDIS-registered member of our Lived Experience Advisory Panel (LEAP).

#### LEARNING ABOUT AND ACCESSING THE NDIS

Throughout all questions posed by the consultation paper, responses from our employees and clients highlighted the following themes:

- The need to ensure a range of approaches are available, tailored to respond to individual preference and needs.
- The critical importance and significant challenges in ensuring choice and control across all facets of the scheme.
- The right of clients to experience dignity and empathy throughout their NDIS journey.

## Individually tailored responses

Preferences regarding communication and information provision from the NDIS vary widely among participants. A range of modalities should be available, participants should be individually invited to nominate their preference for receiving information, and the scheme should increase its promotion and use of advocates and support people to ensure information

is clearly explained and understood (particularly in regard to the results of the independent assessment). Scheme participants and persons with lived experience of disability should be involved in the compiling of educational information (whether this be written, recorded, or in some other format). Independent assessments should not be a move towards a 'one-size-fits-all' approach, and recognition of various disciplines, specialties and experience in terms of clients, advocates and support persons should be much more clearly maintained through the independent assessment process.

#### Choice and control

When accessing an independent assessment, participants should be wholly informed as to their options and should feel confident that the assessment process is indeed independent, and their information will be kept confidential except for agreed purposes (including assurance that information will not be shared in child protection or other insurance matters, for example). Participants should feel confident that they have a choice in assessor (not just geographical location, but specialisation, demographics etc.) and should be fully informed as to what will occur at assessment and how the information will be used and shared. Further, transparent pathways and timelines should be available and well communicated throughout all stages of the assessment and access processes to ensure clients and their advocates and support networks know what to expect and how to challenge the results of assessment. It was also noted that there is a need for increased mechanisms to be available to seek further opinions where the participant feels poorly represented by the assessment result. Importantly, such review and appeal mechanisms should not cause extensive delays to a persons' receipt of required funding and necessary supports as clients are currently experiencing.

## Qualifying disabilities and supports

While the current documentation on the independent assessment process notes it has been designed to take the burden from individuals of providing evidence of impairments to functional capacity, it is our opinion that significant barriers still exist regarding providing proof of permanent disability. ACSO's clients are often transient and experience many complexities, including impaired memory and executive functioning. ACSO supports participants who have moved often, and who often cannot recall when or where their diagnosis was made. For those who have been provisionally diagnosed with no record; and

those who have slipped through the gaps of the service system entirely, it is next to impossible to provide the required information without significant cost, resources, and time to get new assessments and evidence compiled. In the experience of our clients and their advocates and support workers, the requirement to try alternative means of treatment prior to a successful access request frequently causes unnecessary barriers and delays to required disability support provision and is just not suitable for the required level of complex service need and complexity experienced by those in contact or at risk of contact with the criminal justice system. For many this requirement is financially prohibitive and funding to access these alternatives is not available through any other mechanisms at a state or federal level. This requirement in our opinion should be removed for complex clients and requires immediate and significant attention in terms explicit clarified and explanation in other cases. Where the NDIA holds a belief that a particular treatment may be an effective alternative to disability supports for a particular condition, this should be explicitly documented and provided in transparent guidance documents for clients, support workers and advocates.

In the case of psychosocial disability, the current NDIA published materials lacks acknowledgement that all mental health practitioners and assessors work under a recovery framework. ACSO notes that our clients and employees strongly believe that urgent guidance is needed for practitioners on how (and in which instances) this framework is compatible with the concept of permanent or lifelong disability. At present due to the apparent conflicting differences in underpinning frameworks between the NDIS and mental health models of care and delivery, many practitioners are reluctant to name a psychosocial disability as permanent which disadvantages individuals who require support and are otherwise eligible.

### UNDERTAKING AN INDEPENDENT ASSESSMENT

While ACSO supports shifting the cost-burden of functional assessment away from participants, greater transparency is required from the NDIA as to the means of selection, funding, and clinical independence of the independent assessors.

Amongst ACSO's client cohort, NDIS participants often exhibit long histories of challenging behaviours, impairments and experiences of disadvantage which are interrelated with their disability. Over many years of servicing such clients, we have developed a practice model which serves to build trust, rapport and respect with our clients. This trust and rapport is integral to providing effective supports to our cohort, who frequently have limited supports in the community and find it particularly challenging to build trust due to their extensive justice

backgrounds as well as their sometimes limited ability to understand complex NDIS processes. In our experience, it often takes months or years of rapport and relationship building, as well as seeking collateral information, to truly understand our client's experience of disability. It is not clear how this breadth of understanding, or the breadth of knowledge and understanding of treating clinicians can be replaced by a single session with an independent assessor.

In the experience of our Mental Health Access Project, participants, when questioned about their functional impairments, will frequently downplay their experiences or attempt to provide answers which they believe the access clinician is seeking. Much time is spent by our staff seeking a clearer picture of a person's circumstance, particularly through rapport building and through consultation with a range of involved professionals or informal supports. In the case of our forensic clients, consultation with involved supports frequently reveals a host of impairments, behaviours and interrelated challenges experienced over many years, often without treatment. It has not been made clear what weight will be given to the assessment and understanding of people closest to the participant (including carers, family and treating professionals) throughout the independent assessment process. Indeed it would appear that this process is a shift in policy which discourages the ability for inclusion of advocacy and any other expertise in the access request process.

Given that the results of assessment will be used to formulate the participant's draft plan and budget, all efforts should be made by independent assessors to gather and summarise existing known information about a person's condition and its effects, and participants should be encouraged to make use of advocates or support people at assessment. This collateral information gathering process MUST be more clearly noted and articulated within the current NDIA guidelines and documentation.

## Accessibility of assessments

In the opinion of our employees and clients, the same themes arose regarding the accessibility of independent assessors and assessments. Participants should have a strong degree of **choice** and control over their chosen assessor: assessors should be available from a range of culturally and linguistically diverse backgrounds, and who mirror vulnerable population groups, including those identifying as Aboriginal or Torres Strait Islander, or identifying as LGBTQI. It is noted that the use of interpreters creates a significant barrier to effective assessment, and that assessors speaking a person's own language should be available.

There should be appropriate reach of independent assessors across metropolitan, regional and rural areas; and participants should have a high degree of choice over the location and modality of their assessment. Consideration should be given to funding travel (for the participant as well as their support persons) where this is preferred by the participant, either due to a lack of local services or e.g. the preference to maintain privacy outside of close-knit rural communities. Appropriate safety planning should be undertaken where assessments are offered in-home, being cautious of the risks posed to both the assessor and participant in the absence of prior rapport-building (particularly in the forensic client group, or those experiencing domestic violence). Given the length of time taken to access the NDIS, assessors must be available to provide inreach into institutions including prisons and hospitals, ensuring participants are registered in a timely fashion and supported to exit a facility successfully. In the current system, delays of 12 months or more are common for participants involved in the justice system attempting to gain access to the scheme, often resulting in delays to their transition from institutional settings, or in substantial cost to ACSO where participant support is commenced without funding from the scheme.

### **Exemptions to assessment**

As stated above, it is ACSO's belief that the absence of extensive rapport between independent assessor and participant creates a risk of incomplete assessments lacking holistic information on a persons' functional impairment and associated challenges. It also poses a challenge to participants who experience anxiety toward new or unfamiliar situations and clients note it is likely to cause significant distress. This is particularly pertinent where a person has access to existing specialist clinicians with a holistic understanding of their condition over their lifespan. In instances where a person has their own specialist with enhanced awareness of the impacts of their condition; and where accessing an independent assessor with no relationship with the individual would present a barrier to their access to the scheme, it is recommended that this person should be exempted from the independent assessment process. It is recommended that a pragmatic approach is taken for participants with existing assessments of functional capacity which satisfy the entry requirements of the scheme, and that these participants are not unnecessarily subjected to repeated and duplicative assessments for the sole purpose of gaining access to the NDIS.

Consideration should also be given to exempting participants in prison, who frequently require NDIS access in place to be granted parole, where the significant wait times associated with

NDIS access requests presents a barrier to their liberty and community inclusion. Accessibility to the scheme is further reduced for these participants if released without support in place; as they are frequently transient with no means of contact.

## **Quality Assurance**

ACSO have previously and continue in all forums to express our significant concern regarding the high degree of discretion and interpretability in the development of client plans. Given the shift to draft plans based on the result of independent assessment alone, it is vital that transparent information is made available around how assessors are selected and appointed, and how the results of assessment are formulated into specific weighted measures and comparable funds in participants plans. Such transparency will aid in building equity and fostering trust in the NDIS system by both participants and service providers for all cohorts but is likely to have a disproportionally positive impact for the complex, justice-involved clientele ACSO supports in our programs.

Alongside this necessary transparency, the introduction of independent assessments should be accompanied by strengthened channels for feedback, review and appeal. As with any other medical opinion, participants should be afforded the opportunity to challenge the outcome of the assessment and seek a second opinion, without experiencing extensive delays to their access to the Scheme.

# **CONCLUSION**

ACSO is committed to the support and rehabilitation of people with disabilities who are engaged in the justice system or who are at risk of engagement, and those who present with complex needs and a high level of risk to self and community.

ACSO remain committed to ensuring choice and control for all clients in our service. While ACSO supports the shifting of the burden of assessment cost away from participants, concerns remain among our staff and client group around ongoing lack of transparency in this process and the qualification of independent assessors to holistically understand the needs arising from a person's disability and to provide affirming, culturally appropriate care. Clear criteria should be established regarding the necessity for independent assessment or re-assessment,

and assessments should be available in a timely manner which does not delay or introduce additional barriers to NDIS access.

ACSO strongly advocate for the introduction of transparency and consistent frameworks in the application of assessment to personalised budgets, and that these frameworks are underpinned by a comprehensive approach to gathering information about a participants' support needs from multiple services and support persons. Current delays and barriers to accessing and reviewing plan budgets should similarly be addressed in the independent assessment policy, ensuring swift channels for review and appeal of assessment results where these impede access to comprehensive supports as required by the participant.

Principles of choice and control should be maintained through the independent assessment journey, with participants able to exercise a high degree of choice over their assessor; including those catering to diverse backgrounds and those with specialist knowledge of their condition and its effects. It is crucial to the success of this policy change for forensic clients that it does not disadvantage those in institutions awaiting plan access prior to release, and that the existing expertise held by a persons' existing practitioners is surfaced and acknowledged in the formulation of assessment.

ACSO strongly recommend the implementation of a universal approach to coordinating the assessment and eligibility requirements for people with a disability in the justice system, as this is likely to significantly improve access into the scheme for this cohort.

ACSO is thankful to the NDIS for the opportunity to provide feedback to the proposed changes to the NDIS Access and Eligibility Policy and remain open to further discussion on these matters.