



SWAN Submission to the NDIS Access Changes Consultation

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Acknowledgements

SWAN acknowledges the traditional owners of the land on which this submission was produced, the Wardandi Noongar people. We acknowledge their deep spiritual connection to this land and extend our respects to community members and Elders past and present.

About SWAN

South West Autism Network (SWAN) is a not-for-profit, charitable organisation that has been supporting autistic individuals and their families in the south-west region of Western Australia for the past 17 years. We are a Disabled Persons and Families Organisation (DPFO) with more than 2,000 members, and we provide free support to many more people with disability and their families. All staff, volunteers, and Board members either have a disability or are family members of someone with a disability.

Our primary role in the community is to provide information, peer support, advocacy, and connections to mainstream and disability services. We build the capacity of people with disabilities and their families to navigate disability and mainstream systems to meet their needs and participate in their local communities. We support people seeking diagnosis, post-diagnosis, and across their lifespan, and provide autistic-safe space group programs for autistic children, teens, and young adults through our peer social group programs. We also deliver Youth Mental Health First Aid training to the wider community.

As a regional not-for-profit Disabled Persons and Families Organisation (DPFO) providing information, peer support and advocacy, we are able to draw on 17 years' experience supporting autistic individuals and their families, carers, support workers, allied health professionals, and the wider community. Our submission aims to include the voices of everyone who will be impacted by these proposed changes to NDIS Access and Eligibility.

Executive summary

SWAN supports an NDIS access process that is fair, clear, consistent, timely, accessible and grounded in human rights. However, the proposed removal of diagnosis-based access lists and the introduction of a standardised functional capacity assessment as the universal gateway to the NDIS are unsafe, unworkable and likely to create major inequity.

The consultation paper proposes that, from 1 January 2028, NDIS access would be based on a standardised assessment of functional capacity, with current participants reassessed over a three-year transition period. It also proposes removing diagnosis lists as a means of entry to the Scheme. These changes would affect both future applicants and people who have already been found eligible for the NDIS.

SWAN strongly opposes any requirement to reassess all current NDIS participants for eligibility. Current participants have already established that they have a permanent and significant disability and require NDIS supports. A mass reassessment program would be extraordinarily costly, administratively burdensome and clinically impracticable. It would divert scarce allied health and NDIA resources away from providing supports and timely access to people who need them.

The proposed approach also carries a serious risk that people with permanent disability will be incorrectly excluded or removed from the NDIS. Loss or delay of essential supports can lead to homelessness, family breakdown, preventable hospitalisation, institutionalisation, self-harm, neglect and premature death. These are foreseeable risks, particularly for people with complex disability, high support needs, degenerative conditions, psychosocial disability, cognitive disability and people without family support.

There is no single functional capacity assessment tool that is valid, reliable, culturally safe and appropriate across all disability types. Functional impact is not experienced or observed in the same way for every disability cohort. A tool that is appropriate for one person or one disability type may be inappropriate or actively misleading for another. A standardised assessment undertaken without specialist disability knowledge risks privileging what is easily visible, measurable or verbally reported over a person's actual day-to-day support needs.

The Government has not committed to funding functional capacity assessments free of charge. If applicants or participants must pay for such assessments, the NDIS will become less accessible to people who are already living in poverty or facing financial hardship. In regional and remote communities, even a funded assessment is likely to be unavailable within a reasonable distance or timeframe.

SWAN strongly recommends that the current NDIS List A be retained and expanded, including the addition of Down Syndrome. People with conditions on List A should be presumed eligible for the disability requirements and should not be required to undergo a functional capacity assessment merely to prove what is already clear: they have a permanent and significant disability.

We also have grave concerns for people with degenerative and life-limiting disabilities, including Motor Neurone Disease. Adding a new bureaucratic hurdle of requiring that applicants undergo functional capacity assessment to gain access to the NDIS creates dangerous delays to critical supports. The access process must be fast-tracked for clearly

eligible cohorts, especially people with degenerative, catastrophic and life-limiting disabilities.

Key recommendations

SWAN recommends that the Australian Government and Technical Advisory Group:

1. Retain diagnosis-based NDIS access lists, including List A, as a streamlined and presumptive access pathway where permanence and significant functional impact are already clear.
2. Add Down syndrome to List A and establish a transparent, regular process - co-designed with Disabled People's Organisations, clinicians and disability-specific experts - to review other conditions suitable for presumptive eligibility.
3. Do not require people on List A or other clearly eligible cohorts to complete an additional functional capacity assessment merely to establish NDIS eligibility.
4. Reject a single universal functional capacity assessment as the gateway to NDIS access. Where functional evidence is genuinely required, use disability-specific, proportionate and independently validated assessment approaches that are accessible, culturally safe and equitable for the relevant cohort.
5. Do not conduct a blanket reassessment of current NDIS participants' eligibility. Existing participants should retain eligibility unless there is a clear, individualised and evidence-based reason for review, with procedural fairness and continuity of supports throughout any review or appeal.
6. Establish urgent and fast-tracked access pathways for people with degenerative, life-limiting, catastrophic and clearly permanent disabilities, including Motor Neurone Disease, spinal cord injury resulting in quadriplegia, paraplegia or tetraplegia, traumatic brain injury with permanent significant impairment, permanent bilateral blindness, major amputation and congenital absence of two limbs.
7. Set a target for urgent decisions within days, not months, where diagnosis, permanence, urgent functional impact and foreseeable risk of harm are clear; provide interim supports where delay would create a foreseeable risk of harm.
8. Fully fund all evidence and assessment requirements imposed by government, including the assessment itself, travel, interpreters, communication supports, advocacy and support-person costs. No person should be denied, delayed or discouraged from access because they cannot afford the process.
9. Require assessors and decision makers to have relevant disability-specific expertise and trauma-responsive practice, including knowledge of the person's disability type, communication needs, cultural context and life stage; allow applicants reasonable choice of suitably qualified assessor where an assessment is required.
10. Before any access changes commence, publish an independently costed national implementation plan, including workforce demand and supply modelling, regional and remote access arrangements, disability-specific assessor competency standards, and a

plan to prevent assessment work from reducing access to therapy, rehabilitation and clinical care.

11. Pilot and independently evaluate proposed access arrangements before national implementation, with public reporting of outcomes by disability cohort, location, age, gender, First Nations status, cultural and language background, socioeconomic status, assessment cost, wait time, access decision, review outcome and support interruption.
12. Measure and publicly report the full end-to-end time to an access decision, starting from a person's first contact with the NDIA or an NDIS partner - not merely from the point a NDIS partner actions the Access Request in the system.
13. Require NDIS partners to accept, register and promptly progress Access Requests, and prohibit mandatory Community Connections Plans, or similar processes, from delaying or preventing an Access Request being lodged and decided.
14. Ensure no person is refused NDIS access on the basis that another system is more appropriate unless that service is demonstrably available, affordable, accessible, timely, culturally safe and capable of meeting their disability-related needs in their local area.
15. Co-design all future access arrangements with Disabled People's Organisations, families and carers, First Nations disability organisations, culturally and linguistically diverse communities, regional and remote communities, and people with diverse disability types and communication needs.

Contents

Acknowledgements	2
About SWAN	2
Executive summary	3
Key recommendations	4
Response to consultation questions.....	7
1. Do the draft guiding principles provide the right foundation for a future NDIS access process?	7
2. Should any principles be added, removed or changed?	7
3. What should be considered when designing an access decision-making process that is fair, consistent, transparent, disability-informed and evidence-based?	8
4. How could the access process and referral pathways reduce burden and be easier and more equitable for people with disability, families and carers?	9
5. What should be considered to ensure the process works well for all disability cohorts, including people with communication, cultural, cognitive, degenerative, fluctuating, episodic or complex support needs?	10
6. What factors and evidence should be considered when determining whether an impairment is permanent or likely permanent, including whether appropriate treatment is likely to improve functional impact?	12
Conclusion.....	15
Contact.....	17

Response to consultation questions

1. Do the draft guiding principles provide the right foundation for a future NDIS access process?

The draft principles provide a useful starting point. SWAN supports the stated commitments to human rights, lived experience, evidence, person-centred practice, equity, accessibility and continuous improvement.

However, the principles are not sufficient if the proposed model removes streamlined diagnosis-based pathways, imposes a universal functional capacity assessment and reassesses all existing participants. A process cannot be described as person-centred, proportionate, accessible or safe if it requires people with clearly permanent and significant disability to repeatedly prove eligibility through a burdensome assessment process.

The principles must have practical force. They should set enforceable limits on assessment burden, delay, the risk of support interruption, and be provided free of charge. They should also require that the evidence demands placed on a person are proportionate to the issue that actually needs to be decided.

For example, a person diagnosed with Motor Neurone Disease should not face the same evidentiary pathway as a person whose functional impact requires further exploration. Requiring both people to complete the same assessment would not be consistent or fair. It would be unnecessary, expensive and dangerous for the person with a progressive and life-limiting condition.

2. Should any principles be added, removed or changed?

SWAN recommends adding the following principles.

No unnecessary reassessment or duplication

People should not be required to repeat evidence, assessments or eligibility testing where permanence and substantial functional impact have already been established. Current participants should not be subjected to a wholesale eligibility reassessment program. The NDIA already conducts approximately 1,200 to 1,250 eligibility reassessments each week on participants they believe may no longer meet eligibility requirements. Forcing all current participants to yet again prove they have a permanent and significant disability is brutally unfair, burdensome and distressing.

Proportionality and presumptive eligibility

The level of evidence required must be proportionate to the circumstances. Where a diagnosis or existing clinical evidence clearly establishes permanent and significant disability, access should be streamlined. The system should retain diagnosis-based lists and presumptive eligibility pathways.

No cost barrier to access

No person should be denied, delayed or discouraged from NDIS access because they cannot afford evidence, assessments, travel, communication supports, interpreters or advocacy. **Any assessment required by Government must be provided free of charge.**

Timeliness and continuity of support

Access decisions must be made quickly enough to prevent avoidable harm. People must not lose or have supports interrupted while an access reassessment, review or appeal is underway. Access arrangements must include urgent, low administrative burden pathways for people at risk of hospitalisation, homelessness, violence and abuse, neglect, self-harm, institutionalisation or death.

Actual availability of alternative supports

A person must not be redirected to another system unless the alternative support is demonstrably available, accessible, appropriate, timely and sufficient in the person's local area. **A theoretical service is not an available support.**

Disability-specific expertise

Any assessment of functional impact must be conducted by a person who is appropriately qualified and has relevant expertise in the person's disability type, communication needs, cultural context and life stage.

3. What should be considered when designing an access decision-making process that is fair, consistent, transparent, disability-informed and evidence-based?

A fair access process must recognise that consistency does not mean treating every person identically. Fairness requires different, flexible pathways for different circumstances, with common safeguards and clear decision-making.

The proposed universal functional capacity assessment model is not ready for implementation. There is no single assessment tool suitable for all disability types. Disability can be physical, sensory, intellectual, cognitive, neurological, psychosocial, developmental, episodic, fluctuating, degenerative, invisible, cumulative or affected by trauma and environment. Some people can perform a task in one structured setting but cannot safely, reliably, repeatedly or independently perform the same task in other settings. Some people mask their disability in appointments, a common trauma-response. Many others are unable to accurately or comprehensively describe their functional impacts because of communication, cognitive, psychosocial or trauma-related barriers that are themselves part of their disability.

Functional capacity is also not the same as support need. A narrowly standardised assessment conducted in an artificial setting fails to capture the practical support a person needs at home, at school, at work, in the community, during periods of fluctuation, or when informal supports are unavailable.

The design must therefore include the following safeguards:

- Retain List A and other diagnosis-based streamlined pathways for clearly permanent and significant disabilities.
- Use functional evidence where it is genuinely required, rather than as an additional mandatory hurdle for everyone.
- Ensure that assessments are culturally safe and provide free language interpretation services.

- Accept existing treating practitioner reports, diagnostic assessments, hospital discharge summaries, school evidence, support worker evidence and lived-experience evidence where appropriate.
- Ensure a person can provide information in ways that work for them, including with assistance from family, carers, advocates, nominees, interpreters and communication supports.
- Require assessors to consider variability, fatigue, pain, sensory overload, executive functioning, safety, informal support arrangements, environment and the reliability with which a person can undertake activities.
- Require assessors and decision makers to have disability-specific expertise rather than relying on generic assessment knowledge.
- Ensure that assessors are trained in trauma-responsive assessment, and appropriately skilled to rephrase and ask probing questions to accurately assess the functional impact of applicants, particularly where applicants have disabilities that impact their ability to communicate how their function is impacted; including:
 - Autism
 - Intellectual Disability
 - Acquired Brain Injury
 - Psychosocial Disability
- Give applicants a clear written explanation of the evidence considered, the reasons for the decision, review rights and how to obtain accessible assistance.
- Provide an accessible, timely and independent review process, with supports continuing while a review is being decided where interruption would create a risk of harm.

A decision-making process should also be tested before implementation through transparent pilots co-designed with people with disability. Any pilot must publish outcomes by disability cohort, location, gender, age, First Nations status, cultural and language background, socioeconomic status, decision outcome, review outcome, assessment cost and waiting time. Access changes should not proceed nationally unless it is shown to improve equity and reduce burden without excluding clearly eligible people.

4. How could the access process and referral pathways reduce burden and be easier and more equitable for people with disability, families and carers?

The most effective way to reduce burden is not to make every person complete another assessment. It is to avoid unnecessary assessments, remove duplication and accept reliable evidence that people already have.

SWAN is extremely concerned that the proposed changes will add a functional capacity assessment to existing access requirements rather than genuinely simplifying the process. This would create another bureaucratic hoop for people who are already managing disability, poverty, caring responsibilities, treatment, employment, housing instability and navigating complex service systems.

A person with disability should not have to become an expert in their own bureaucratic presentation in order to receive support. Functional capacity assessments frequently rely on a person, family member or carer being able to explain clearly how disability affects daily life. For many people, being unable to understand, recall, communicate or articulate this

information is part of their disability. This is particularly relevant for autistic people, people with intellectual disability, acquired brain injury, psychosocial disability, communication disability, trauma histories and people who use augmentative or alternative communication.

The Government must also address the real delays already occurring before the NDIA formally records an Access Request. SWAN has supported many people who have waited three to six months for an initial meeting with a relevant NDIS partner. We are aware of access requests being held for months before being actioned by the NDIS partner, and of people being required to complete a Community Connections Plan before their Access Request progresses. In some cases, the period between a person first seeking access and the Access Request being approved by the NDIA eligibility team can be 12 months or longer.

Currently, the NDIA only measure the wait time for access applications from the date when NDIS partners hit the submit button. This means reported NDIA processing times significantly understate the real timeframe people are wait for access. Measuring only the period after a NDIS partner sends an application to the NDIA does not measure the person's actual experience.

SWAN recommends:

- Start the official access application timeframe clock on the date a person first asks the NDIA or a NDIS partner for help to access the NDIS.
- Require NDIS partners to accept, register and progress an Access Request promptly.
- Prohibit any requirement to complete a Community Connections Plan before an Access Request is lodged and progressed. Community Connections Plans must be optional for applicants whose access request was denied.
- Provide a single, accessible access pathway with direct NDIA lodgement available at all times, rather than redirecting applicants to NDIS partners.
- Assign a named contact person or navigator for applicants with complex needs and degenerative disabilities.
- Make all forms, evidence guidance and communications available in Easy Read, plain English, Auslan, community languages and accessible digital formats.
- Fully fund independent advocacy and allow advocates, supporters and carers to support a person throughout the access application process. Currently most disability advocacy providers nationally have closed their waitlists for NDIS advocacy because the Department of Health, Disability and Ageing has refused to increase NDIS advocacy funding to meet demand.
- Provide a no-wrong-door approach service, so that a person is helped to apply rather than being turned away or left to navigate multiple systems alone.
- Establish clear, easy to navigate and rapid escalation pathways for people experiencing crisis, hospital discharge delays, homelessness, violence, carer breakdown or risk of harm.

5. What should be considered to ensure the process works well for all disability cohorts, including people with communication, cultural, cognitive, degenerative, fluctuating, episodic or complex support needs?

A one-size-fits-all tool or assessment pathway will **not** work for all disability cohorts. The design must reflect the diversity of disability experience and avoid creating a system that favours people with specific disability types, who can attend appointments, describe their needs fluently, access private clinicians, travel long distances, afford reports and present

consistently in a short assessment. Applicants must be able to **choose** their assessor from a range of options, regardless of where they live. This is critical to ensure that the assessments are culturally safe, trauma-responsive and appropriate to the applicant's disability type. A generic assessment process assigning physiotherapists to assess autistic and intellectually disabled people and speech pathologists to assess people with spinal cord injury will fail to accurately and appropriately assess functional impact. The qualifications of the assessor must be appropriate to the disability type, and the applicant must be able to choose their preferred assessor. Another example is that of rape survivors, who may be traumatised by being forced to undergo an assessment by someone of the same gender as their rapist. This is particularly critical for the autistic population, every adult autistic female SWAN has engaged with is a survivor of sexual assault. Shutdown and losing the ability to communicate is a common response to trauma triggers in autistic people.

For autistic people, functional impact can be hidden, masked or misunderstood. An autistic person may appear capable in a short and highly structured appointment but be unable to sustain functioning at home, school, work or in the community. Sensory overload, social communication demands, executive functioning difficulties, burnout, co-occurring mental health conditions and the effort involved in masking are unlikely to be visible to a generic assessor using a standardised assessment tool in a short space of time.

For people with psychosocial disability, symptoms can fluctuate and periods of apparent stability may depend on substantial informal support, treatment, housing security or other supports that are not guaranteed. A moment-in-time assessment of what a person can do on one day in one environment risks overlooking the ongoing and episodic nature of disability.

For people with intellectual disability, acquired brain injury or communication disability, the assessment process itself may be inaccessible. The person may need supported decision-making, extra time, trusted supporters, alternative communication, multiple appointments, observation in real-world environments or information from people who know them well.

For people with degenerative conditions, delay is particularly harmful. A person's support needs may increase rapidly while they wait. Requiring them to wait for an assessment timeslot, complete a lengthy functional capacity assessment, apply for access, wait for access to be approved, then wait for a support needs assessment and budget allocation before accessing support turns a manageable situation into an emergency.

For regional, remote and very remote communities, assessment availability cannot be assumed. People will face long waiting lists, limited disability-specific allied health services, high travel costs and substantial distances. A process that is technically national but relies on services concentrated in metropolitan areas is inequitable in practice.

The process must therefore:

- Retain fast-track and presumptive eligibility pathways (list A) for clearly permanent, degenerative and life-limiting conditions.
- Provide assessment options that are local, telehealth-enabled where appropriate, flexible and culturally safe, without assuming telehealth is suitable for every person.
- Fund travel, interpreters, First Nations and CaLD liaison, communication supports, advocacy and support people where needed.
- Include evidence from trusted treating practitioners, disability organisations, schools, hospitals, carers and support workers.

- Use supported decision-making and never treat communication difficulty as evidence of lower credibility or lower need.
- Assess disability over time and in context, rather than relying on a single appointment or narrow task-based assessment.
- Create specialist assessor pathways for particular disability cohorts, rather than expecting generalist practitioners to assess every disability type.

6. What factors and evidence should be considered when determining whether an impairment is permanent or likely permanent, including whether appropriate treatment is likely to improve functional impact?

Permanence should be determined using the current eligibility list A diagnoses (with the addition of Down Syndrome), reliable clinical evidence, the nature and course of the impairment, prognosis, the views of appropriately qualified treating practitioners and the person's actual experience over time. The process must not require a person to exhaust 'every' possible treatment, intervention or rehabilitation option before they can access the NDIS.

Treatment may improve symptoms, comfort, skill development or functioning in some contexts without removing a person's disability-related support needs. For example, a non-speaking autistic person may gain the ability to communicate verbally by having weekly speech pathology sessions for ten years, yet there is no access to weekly speech pathology outside the NDIS. A person with Ehler's Danlos Syndrome may be able to maintain their current level of function with multiple physiotherapy sessions per week. Medicare only provides a maximum of five Medicare claimable physiotherapy sessions per year, which provides little to no support to maintain current function.

Improvement is not cure. A person should not be denied support because a treatment "might" help, particularly where treatment is unavailable, unaffordable, clinically inappropriate, risky, inaccessible, has unacceptable side effects or has already been tried without resolving the functional impact. Currently the NDIA require that applicants with Postural Orthostatic Tachycardia Syndrome (POTS) provide evidence that they have tried weekly hospital-based intravenous hydration to improve their condition. This treatment is not available in Western Australia, and it is unreasonable to require applicants to travel interstate to try treatment options that the Government and NDIA deem necessary before access will be granted. Likewise, it is unreasonable to require applicants in regional and remote communities to travel to the metropolitan area to access treatment options before NDIS access will be granted. In WA there are towns located as far as 33 to 38 hours of continuous driving away from Perth (Kununurra is 3,196km north of Perth).

The test must recognise that appropriate treatment is individual, free and locally available. It depends on the person's medical circumstances, informed consent, culture, location, cost, waiting times, trauma history and willingness to undertake a treatment. People with disability must not be compelled to pursue unwanted, experimental, unaffordable or inaccessible treatment as a condition of receiving disability support.

For conditions known to be permanent, degenerative or life-limiting, the process should rely on diagnosis and appropriate clinical confirmation rather than requiring repeated functional capacity assessment. This includes, but is not limited to:

- Motor Neurone Disease.

- Spinal cord injury resulting in quadriplegia, paraplegia or tetraplegia.
- Major amputation or congenital absence of two limbs.
- Permanent bilateral blindness.
- Down Syndrome
- Autism level 2 or 3
- Intellectual Disability
- Other conditions already recognised through List A and comparable diagnosis-based pathways.

SWAN recommends that the Government retain List A, add Down syndrome, and establish a transparent process for regularly reviewing eligible conditions with disability organisations, clinicians and people with lived experience. This is a more humane, proportionate and administratively efficient approach than requiring every person to complete a functional capacity assessment.

Workforce and implementation risks

The Government must not proceed on the assumption that there is a sufficiently large, skilled and available workforce to conduct functional capacity assessments for all future applicants and existing participants.

The consultation paper proposes that current NDIS participants be reassessed over three years. At the same time, all new applicants from 1 January 2028 would be required to complete functional capacity assessments. This would create an enormous demand for qualified assessors at a time when regional and remote communities already face severe allied health workforce shortages.

The issue is not only the number of assessors. The assessment must be performed by someone with the appropriate qualification, disability-specific expertise and understanding of how the person's disability affects function. A generic assessor cannot safely or accurately assess all disability types. For example, an assessment of an autistic person, a person with psychosocial disability, a person with quadriplegia, a person with acquired brain injury, a deafblind person and a person with progressive neurological disability may each require different expertise, approaches and evidence.

A poorly designed reassessment program would shrink the allied health workforce available for therapy, rehabilitation, diagnosis and direct clinical care – particularly in regional and remote communities where there are already major workforce shortages. Clinicians may be drawn away from service provision to prepare reports and undertake assessments for NDIS access. This would increase costs, extend waitlists and worsen outcomes across health and disability systems.

Before any implementation decision, the Government should publish:

- An independent workforce demand and supply analysis.
- The number, qualifications and disability-specific competencies of assessors required by region and disability cohort.
- A plan to prevent assessment work from reducing access to essential therapy, rehabilitation and clinical care.
- A full cost estimate to Government, participants and families.
- A plan for regional, rural, remote and very remote communities.

- Independent validation evidence for each assessment tool and cohort before the tool is used for access decisions.
- A staged pilot and evaluation process with transparent public reporting.

Without this work, implementation risks creating a large, expensive bottleneck that delays access to essential supports and shifts costs to hospitals, emergency departments, mental health services, aged care, education, housing, child protection, justice systems and unpaid family carers.

Current participants must not be reassessed en-masse

It is unreasonable and unfair to reassess eligibility for all current NDIS participants. They have already established that they meet the NDIS disability requirements. A blanket reassessment assumes that the problem lies with participants rather than with system design, decision quality, inconsistent administration and service gaps.

A mass reassessment would also cause unnecessary distress and uncertainty. People with disability and families would once again be required to gather evidence, find clinicians, attend assessments, explain intimate details of their daily lives and wait for a decision that could determine whether they can remain safely housed, receive personal care, leave hospital, participate in work or education, or remain connected to their community. Many participants, particularly older cohorts, no longer have their original diagnostic reports from 20, 30 or 40 years ago. There are already reports of NDIA requiring new, expensive genetic testing to prove that older adults with Down Syndrome still have Down Syndrome, because they do not have a genetic test on file and will not accept evidence from General Practitioners (GPs).

The consequences of an incorrect decision are not administrative inconvenience. A person who loses access to essential disability supports may experience rapid deterioration, carer breakdown, homelessness, avoidable hospital admission, institutionalisation, neglect, self-harm, violence and abuse or death. The Government must treat this risk as the core implementation and human rights issue that it is.

If the Government considers transition arrangements, they must protect existing participants through the following minimum safeguards:

- Existing eligibility remains in place unless there is clear, individualised and evidence-based reason for review.
- No automatic loss of eligibility based solely on a new tool, a missing report, inability to afford an assessment, failure to attend an inaccessible appointment or difficulty communicating with the NDIA.
- No interruption to supports while any reassessment, internal review or external review is underway.
- Free assessments, advocacy, communication supports, interpreters and travel assistance.
- Decisions made by appropriately qualified staff, with disability-specific expertise and accessible written reasons.
- Full review and appeal rights, including timely access to independent merits review.
- Public reporting on reassessment outcomes, including disability cohort, location, demographic equity, reasons for removal, review outcomes, support interruptions and serious incidents.

The need for urgent access pathways

For some conditions, every delay causes harm. The NDIS must have urgent, streamlined pathways for people whose disability is clearly permanent and whose support needs are immediate or increasing.

Motor Neurone Disease (MND) is a clear example. It is a progressive and life-limiting condition. A person diagnosed with MND cannot safely wait months for a functional capacity assessment, further evidence requirements, a NDIS access decision, then a support needs assessment before receiving a funding allocation. This risks blowing out the wait time for access to funding support to 12 months or more, particularly in regional and remote communities. The average life expectancy for people diagnosed with MND is two to three years from diagnosis. The issue is also true for many people following catastrophic injury, major amputation, permanent bilateral blindness, sudden onset quadriplegia or paraplegia, and other rapidly changing conditions.

SWAN has serious concerns that adding functional capacity assessment requirements would generate wait times comparable to, or longer than, other heavily burdened government disability and income-support systems. The wait time for Disability Support Pension applications to be assessed is typically around eight months, but periodically blows out to 12-18 months. Functional capacity assessments are time-intensive and depend on scarce clinicians. If people must wait for an assessment before an application can proceed, the delay will occur before the NDIA's formal decision timeframe begins.

The result will be that people remain in hospital longer than necessary, rely on exhausted family members, go without essential equipment or personal support, enter crisis before help arrives, or die before gaining access to the NDIS. These delays do not save public money. They transfer costs and risks to other systems and to families.

Urgent access pathways should include:

- A decision within days, not months, when diagnosis and urgent functional impact are clear.
- Acceptance of hospital, specialist or treating practitioner evidence without an additional functional capacity assessment.
- Immediate interim supports where delay would create a foreseeable risk of harm.
- A single point of contact and active coordination with hospitals, primary care, disability organisations and family supports.

Conclusion

SWAN supports genuine efforts to make NDIS access fairer and more consistent. But fairness will not be achieved by removing diagnosis-based streamlined pathways, imposing a universal functional capacity assessment and reassessing every existing participant.

The proposed approach risks making access slower, more expensive and less equitable. It risks excluding people with permanent and significant disability because they cannot afford reports, access the right assessor, travel to appointments, communicate their needs in a narrow assessment format or survive the delay. These risks are greatest for people in regional and remote communities, people with complex and fluctuating disability, people with cognitive or communication disability, and people facing crisis.

A better approach is available. Retain and strengthen List A. Add Down syndrome. Use diagnosis and existing evidence to fast-track people whose permanent and significant disability is already clear. Use functional evidence where it is genuinely necessary, but do not turn it into a universal bureaucratic barrier. Keep current participants on the Scheme unless there is a genuine, individualised reason to review access. Fund any required assessments in full. Build the workforce before imposing new requirements. Measure the real end-to-end access wait time. Ensure no person is left without support while Governments debate which system should respond.

The NDIS should be secured by improving decision quality, reducing duplication, addressing administrative delays and investing in genuinely available supports. It must not be secured by repeatedly testing, delaying or excluding the very people it was created to support.



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