South West Autism Network (Inc)

Submission to the Joint Standing Committee Inquiry into NDIS Independent Assessments

Acknowledgements

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

Submission preparation

This submission was prepared by South West Autism Network Inc. In order to write this submission, we listened to the views and concerns of autistic people, their families and advocates, and the wider disability community. We researched current and proposed NDIS processes, the NDIS Act 2013, the Productivity Commission Report 2011, and the Tune Review report 2019.

Introduction - About Us

The South West Autism Network (SWAN) is grateful to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) for making available this opportunity to provide feedback on the National Disability Insurance Agency's (NDIA) proposal for Independent Assessments.

SWAN is a not for profit, charitable organisation supporting autistic individuals and their families living in the south west region of Western Australia for the past 12 years. We are a Disabled Persons and Families Organisation (DPFO) who are currently delivering two Information Linkages and Capacity Building (ILC) projects. All staff, volunteers and Board members either have a disability, or are the family member of someone with disability.
After campaigning for over a decade to fix the underfunded disability support system, SWAN, along with countless people with disabilities and their families, welcomed the introduction of the NDIS.

With the introduction of the NDIS Act 2013, SWAN was pleased to see a focus on human rights, seeing people with disability as equal partners in decisions that will affect their lives, and providing the right to exercise choice and control. We have supported thousands of people with disability and their families since the introduction of NDIS, to access funding, support services and interventions so that they can live the life they choose. This is the NDIS we fought for. Unfortunately, however, we have also supported hundreds of people with disability and their families who have received insufficient funding, who do not have the resources they need to navigate the NDIS, or, in extremely devastating circumstances for those involved, people with disability not being granted access to NDIS funding.

There are many issues with NDIS which need to be fixed. However, the proposed compulsory Independent Assessments and many other elements in the suite of changes proposed by the NDIA will not address these issues, but will increase inequity, reduce fairness, breach human rights and risk the safety of people with disability.

Our Concerns

We are making this submission because we are extremely concerned by the proposed changes, and the devastating impact they will have on people with complex needs, episodic disability, people with psychosocial and developmental disability, and people in regional and remote areas.

The "consultation" process NDIA has undertaken has been and is entirely tokenistic. The Minister for Disability and the NDIA decided the Independent Assessments (IAs) would be made compulsory for all new and existing participants, and sweeping changes to the "planning" process, how funding will allocated and distributed, and even transport funding were all made prior to consulting with any people with disability. Here are some of the changes that we are most concerned about:

1) The Independent Assessment Tools are NOT fit for purpose. Additionally, none of the tools are suitable for assessing people with Intellectual Disability, psychosocial disability and autism. There is also no assessment tool chosen for people with upper limb disability, only lower limb disabilities. None of the tools are suitable for assessing the impact of multiple disabilities. People's circumstances (lack of informal supports, multiple people with disability in the family, ATSI, CaLD, geographic isolation – including lack of services near them etc) are not taken into consideration in this process.

2) One of the assessment tools is the Vineland 3. This tool requires someone other than the person with disability to answer questions about their functional impact, **without the person with disability present**. This has the potential to be extremely dangerous. We know that people with disability are at high risk of violence, abuse and neglect, particularly women. So there will be people with disability having questions about their functional impact answered by their abuser, with no safeguards. This means that the abuser could sabotage the Independent Assessment by presenting the impact of the person's disability as being significantly less than it actually is – thus reducing their funded supports (and potentially resulting in their being exited from the scheme), and isolating them further from supports, trapping them in the abuse cycle. There are also people with disability whose only supports are funded services with a vested interest, and who should not be answering questions in the Independent Assessments. There are no safeguards around this, as the exemption criteria are secret, and the NDIA has sole decision-making authority on who can be exempt from undergoing Independent Assessments.

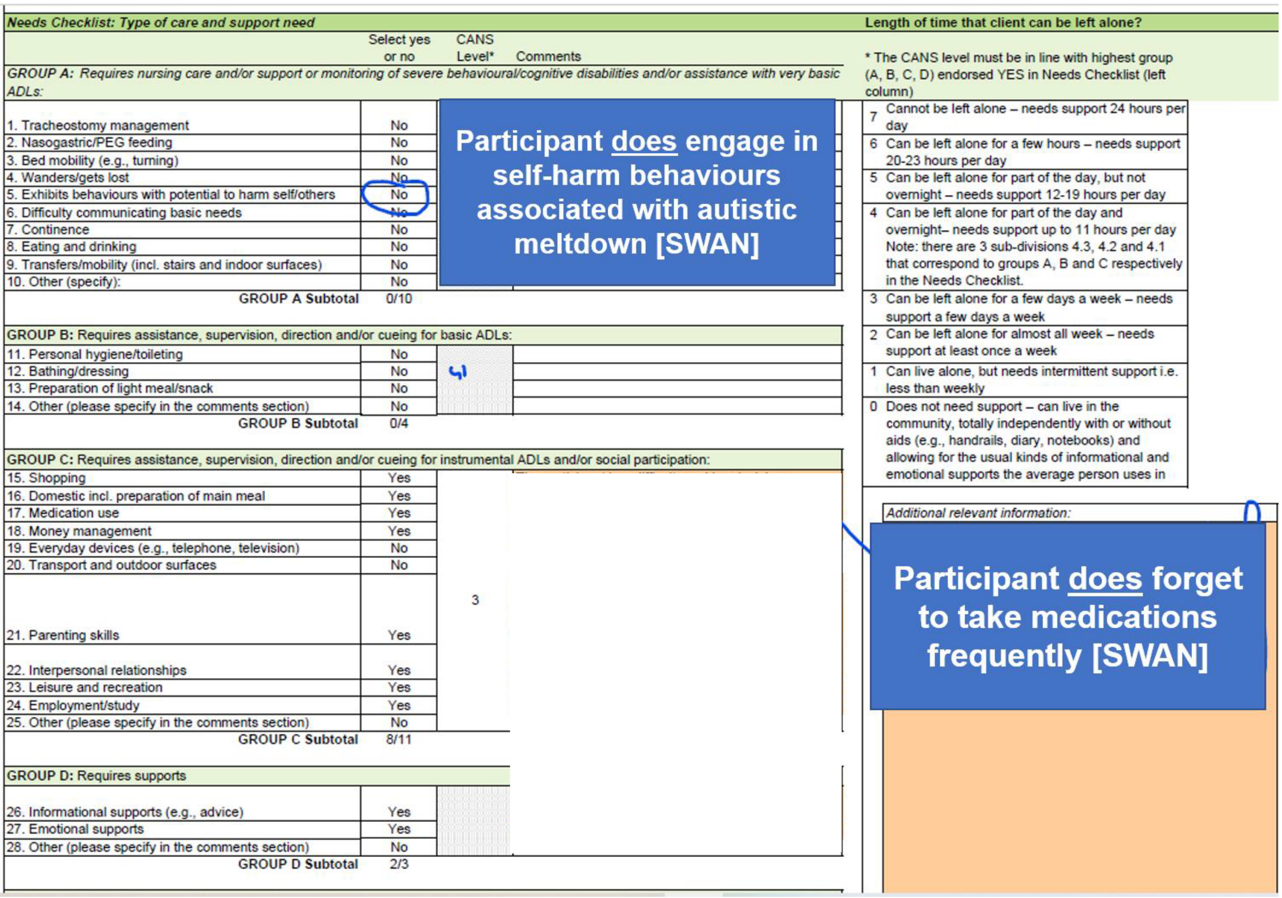
3) New people requesting access to the NDIS will still be required to obtain expensive diagnostic reports in order to gain access to an Independent Assessment which will determine whether they can gain access to the scheme. It places another hurdle in the path of gaining access to supports, and if the Independent Assessor doesn't understand your disability and how it impacts you, their report can prevent you gaining access to supports – a decision which isn't reviewable. The IAs will also be used to assess whether existing participants can remain in the scheme. This already occurs occasionally where an NDIA delegate decides that someone may not meet the disability eligibility criteria anymore, but will now be done to more than 400,000 participants at least once every 5 years. And for children and teens, the NDIA has informed us that they will be forced to undergo IAs much more frequently due to their changing needs, probably every year.

4) The Independent Assessors are not and will not be matched by qualification type to disability type. This means it will be luck of the draw as to whether you have an

Independent Assessor with any knowledge of your disability, or suitability to assess you. Physiotherapists are and will continue to assess people with Intellectual Disability, autism and psychosocial disability, despite having no expertise in these disability types. Speech Pathologists and Psychologists are and will continue to assess people with physical disability.

SWAN was provided a copy of the Independent Assessment "reports' performed by a physiotherapist on an autistic adult participating in the current trial. Concerningly, despite being promised a copy of all reports before agreeing to participate in the trial, the participant had to contact the Independent Assessor organisation multiple times requesting a copy of the reports, then contact NDIA multiple times before finally receiving a copy. Notably, the participant, who spoke out about their negative experience, also did not receive a copy of the trial feedback survey. **SWAN are aware of at least four participants in the current Independent Assessment trial who spoke out about their negative experience, and have not been provided the feedback survey. There are likely to be many more, including individuals who decided to cease the assessment part-way due to their negative experience. It is clear that the NDIA is attempting to skew the satisfaction data results from trial participants by only inviting feedback from individuals who completed the entire assessment and did not express negativity about the experience.**

The Independent Assessment report documents received by the autistic adult assessed by a physiotherapist are riddled with errors that would likely result in the person assessed being ejected from the NDIS. Here are some excerpts from the person's Independent Assessment "reports":



Needs Checklist: Type of care and support need

	Select yes or no	CANS Level*	Comments
GROUP A: Requires nursing care and/or support or monitoring of severe behavioural/cognitive disabilities and/or assistance with very basic ADLs:			
1. Tracheostomy management	No		
2. Nasogastric/PEG feeding	No		
3. Bed mobility (e.g., turning)	No		
4. Wanders/gets lost	No		
5. Exhibits behaviours with potential to harm self/others	No		
6. Difficulty communicating basic needs	No		
7. Continence	No		
8. Eating and drinking	No		
9. Transfers/mobility (incl. stairs and indoor surfaces)	No		
10. Other (specify):	No		
GROUP A Subtotal	0/10		
GROUP B: Requires assistance, supervision, direction and/or cueing for basic ADLs:			
11. Personal hygiene/toileting	No		
12. Bathing/dressing	No	4	
13. Preparation of light meal/snack	No		
14. Other (please specify in the comments section)	No		
GROUP B Subtotal	0/4		
GROUP C: Requires assistance, supervision, direction and/or cueing for instrumental ADLs and/or social participation:			
15. Shopping	Yes		
16. Domestic incl. preparation of main meal	Yes		
17. Medication use	Yes		
18. Money management	Yes		
19. Everyday devices (e.g., telephone, television)	No		
20. Transport and outdoor surfaces	No		
21. Parenting skills	Yes	3	
22. Interpersonal relationships	Yes		
23. Leisure and recreation	Yes		
24. Employment/study	Yes		
25. Other (please specify in the comments section)	No		
GROUP C Subtotal	8/11		
GROUP D: Requires supports			
26. Informational supports (e.g., advice)	Yes		
27. Emotional supports	Yes		
28. Other (please specify in the comments section)	No		
GROUP D Subtotal	2/3		

Participant does engage in self-harm behaviours associated with autistic meltdown [SWAN]

Length of time that client can be left alone?

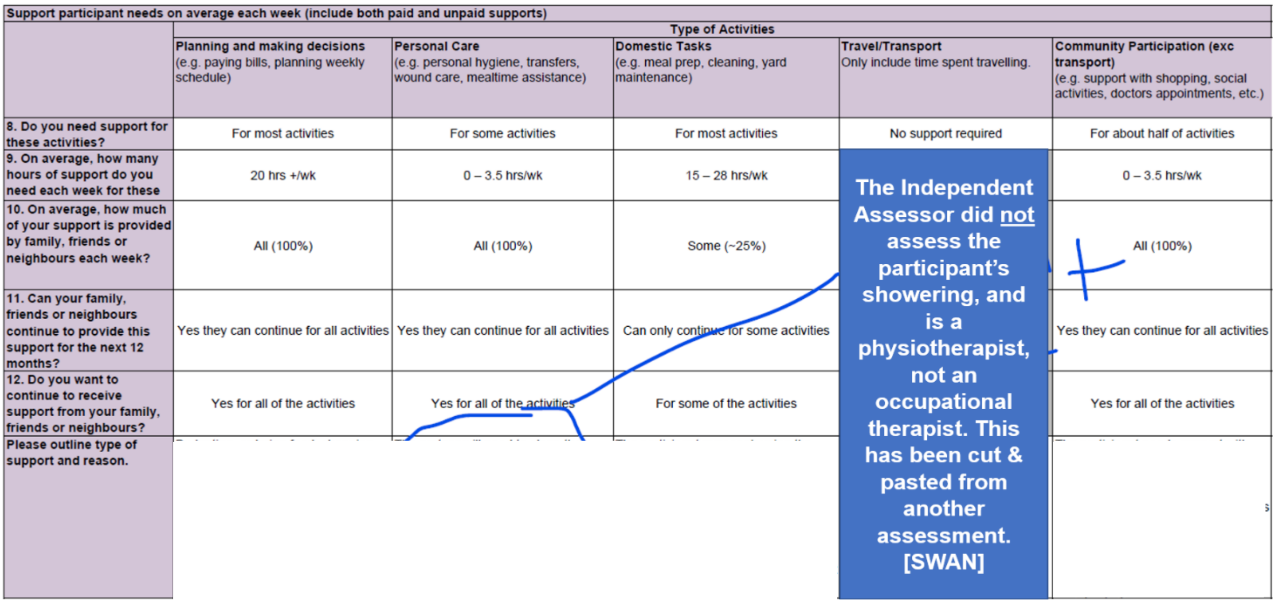
* The CANS level must be in line with highest group (A, B, C, D) endorsed YES in Needs Checklist (left column)

7	Cannot be left alone – needs support 24 hours per day
6	Can be left alone for a few hours – needs support 20-23 hours per day
5	Can be left alone for part of the day, but not overnight – needs support 12-19 hours per day
4	Can be left alone for part of the day and overnight– needs support up to 11 hours per day Note: there are 3 sub-divisions 4.3, 4.2 and 4.1 that correspond to groups A, B and C respectively in the Needs Checklist.
3	Can be left alone for a few days a week – needs support a few days a week
2	Can be left alone for almost all week – needs support at least once a week
1	Can live alone, but needs intermittent support i.e. less than weekly
0	Does not need support – can live in the community, totally independently with or without aids (e.g., handrails, diary, notebooks) and allowing for the usual kinds of informational and emotional supports the average person uses in

Additional relevant information:

Participant does forget to take medications frequently [SWAN]

Fig.1: Screenshot of an excerpt of the Independent Assessment conducted by a physiotherapist on an autistic adult, showing some of the errors made. SWAN has inserted typed comments over the participant's hand-written notes to protect their identity.



Support participant needs on average each week (include both paid and unpaid supports)

	Type of Activities				
	Planning and making decisions (e.g. paying bills, planning weekly schedule)	**Personal Care** (e.g. personal hygiene, transfers, wound care, mealtime assistance)	**Domestic Tasks** (e.g. meal prep, cleaning, yard maintenance)	**Travel/Transport** Only include time spent travelling.	**Community Participation (exc transport)** (e.g. support with shopping, social activities, doctors appointments, etc.)
8. Do you need support for these activities?	For most activities	For some activities	For most activities	No support required	For about half of activities
9. On average, how many hours of support do you need each week for these	20 hrs +/wk	0 – 3.5 hrs/wk	15 – 28 hrs/wk		0 – 3.5 hrs/wk
10. On average, how much of your support is provided by family, friends or neighbours each week?	All (100%)	All (100%)	Some (~25%)		All (100%)
11. Can your family, friends or neighbours continue to provide this support for the next 12 months?	Yes they can continue for all activities	Yes they can continue for all activities	Can only continue for some activities		Yes they can continue for all activities
12. Do you want to continue to receive support from your family, friends or neighbours?	Yes for all of the activities	Yes for all of the activities	For some of the activities		Yes for all of the activities
Please outline type of support and reason.					

The Independent Assessor did not assess the participant's showering, and is a physiotherapist, not an occupational therapist. This has been cut & pasted from another assessment. [SWAN]

Fig.2: Screenshot of an excerpt of the Independent Assessment conducted by a physiotherapist on an autistic adult, showing some of the errors made. SWAN has inserted typed comments over the participant's hand-written notes to protect their identity.

Adaptive Behavior Area	Level Compared to Others Their Age
Communication skills	Moderately High
Daily Living skills	Moderately High
Social Skills and Relationships	High
Motor Skills	N/A
Overall Summary Score	Moderately High

Fig.3: Screenshot of an excerpt of the Vineland-3 conducted by a physiotherapist on an autistic adult.

Figure 3 above shows that the physiotherapist conducting the Independent Assessment scored the Vineland-3 in reverse to how it should have been done. These scores indicate that the autistic participant is functioning significantly higher than most of the non-disabled population in Social Skills and Relationships, and higher than average of the non-disabled population in Communication skills and Daily Living skills. These are areas of deficit in people diagnosed with autism. There are numerous other errors in the Independent Assessment Report other than those shown above.

NDIA plans to roll out the Independent Assessments process as follows:

- The Independent Assessor conducts the assessment and writes the report, with a maximum of 3 hours allocated for both the assessment and the report-writing.
- The Independent Assessor forwards the report direct to the NDIA, unseen by the person with disability and their family.
- For new people seeking access to the NDIS, the National Access Team (NAT) will decide whether or not the person is eligible, based on the Independent Assessment report. As the current eligibility lists will cease to exist, people eligible

  - under list A (automatic eligibility based on diagnosis alone) may now be deemed ineligible due to the outcomes of poorly designed, inappropriately conducted and inaccurate Independent Assessments.
  - For existing participants, the Independent Assessment Report is then fed into the Personal Budget Calculator (PBT) to calculate a funding amount for that participant.

NDIA is adamant that Independent Assessments will not be a Reviewable Decision. NDIA does state that people will be able to seek a second Independent Assessment if there is evidence that the first one was incorrect, however people will not be provided with a full copy of the assessment reports in order to contest its accuracy. Additionally, the NDIA will only accept that the Independent Assessment is unsuitable when undisclosed criteria is met.

5) Many of the organisations contracted to deliver the Independent Assessments have already breached their contracts in advertising the positions. We are finding and reporting adverts seeking new Allied Health graduates, whereas the NDIA requires that the Independent Assessors have a minimum 12mths full time clinical experience (which is also completely insufficient). Some are also advertising for physiotherapists, occupational therapists and speech pathologists – excluding psychologists – thus ensuring that no one with psychosocial disability in the areas serviced by those organisations will be appropriately assessed.

6) People will:
   - Have no choice or control over who does the Independent Assessment (choosing between 2 or 3 organisations to undertake these assessments is not choice and control, especially as people will not be able to choose the actual assessor),
   - Not be provided with a full copy of the Independent Assessment report,
   - Not be told the full name of the Independent Assessor, and may not be told their qualification (therefore unable to report them to AHPRA for working outside the scope of their expertise, or inappropriate conduct),
   - Not be able to have errors in the IA report corrected, and
   - Not be able to have the Independent Assessment decisions reviewed.

SWAN are deeply concerned that the human rights of people with disability, their goals, experience, opinions, and those of the professionals who have worked with people with disability and their families; will be ignored, as this has been our experience thus far during the trial phase. To conduct assessments which result in a secret report that can neither be seen nor appealed, and which may potentially have life threatening implications for those involved, is highly alarming to say the least.

7) The new planning process will exclude the most important things – planning and goal-setting. People will have an Independent Assessment which will then go to a Personalised Budget Tool (PBT) to calculate how much funding will be allocated to that person. None of the assessment tools are designed for this purpose. There is no information on how the PBT will work, because the NDIA has yet to decide this – despite planning to commence using it as soon as there have been 4000 participants in the current Independent Assessments trial. Participants will then have a meeting to explain how to use their funding (it's yet to be decided if this will be with an LAC or an NDIA Planner). Goals are suddenly irrelevant. So if you're a young adult living in an aged care facility with a goal to move out of facility and live independently, too bad. Your funding amount has already been decided. Ditto if you need funded supports to move

out of the house of an abusive carer. Your goal to do this, the supports you need to do so, and your circumstances will not be considered. Because the funding amount was decided by the PBT based on a poorly constructed and performed Independent Assessment.

By moving away from a NDIS funding model driven by the participant's goals and linked to the Section 34 Reasonable and Necessary part of the NDIS legislation, this change removes hope for 430,000 participants, applying a deficits-based model and cookie-cutter approach. This change will deliberately eject tens of thousands of people from the scheme, who will then need to turn to state-based systems of support – many of which are now closed or significantly defunded as part of the rollout of the federal NDIS (to which the states contribute half of the funding).

8) The NDIA Planner will have the power to increase the funding above the amount calculated by the PBT, or alarmingly, to reduce it. Whilst this is likely to be a reviewable decision, it is unlikely that the reasoning for this decision by the Planner will be disclosed to the participant.

9) The current funding support categories will be changed, and instead of Core, Capital & Capacity Building budgets, there will now be 'Fixed' and 'Flexible' budgets. Some types of funding will always be in the Fixed budget, and NDIA claim that most funding will be in the Flexible budget. However, the NDIA Planner can decide to put any funding amounts in the Fixed budget, seriously limiting how participants can use the funding to meet their needs. This is particularly concerning in our region, where NDIA Planners are not as knowledgeable as required. All but one are from the old WA state system, and have brought their preconceived notions from that system with them.

10) Funding will be released for claiming in monthly or quarterly instalments (NDIA has yet to decide which), and any unspent funds from that period rollover into the next. Currently the entire amount of approved funding is available for claiming. This means that if a participant loses their informal support, needs to go into Short Term Accommodation (respite), receives an unexpectedly large bill, or their support needs suddenly increase, they can claim the funding flexibly, and continue to have support while negotiating with NDIS to have their plan changed to better meet their needs. Under the new system, if one provider overcharges, another may go unpaid. For people self-managing their funding, if they receive an unexpectedly large invoice, they may not be able to pay their other reasonable and necessary supports – which they then lose access to, and family carers are likely to have to resign from work to provide care. People also would not be able to access Short Term Accommodation (STA) early in their plan if they need it, and would instead have to 'save up' to access this support. This defeats the purpose of STA, which must be available when people need it.

11) Transport funding as a periodic payment will cease. For many people, Transport funding replaces Mobility Allowance from Centrelink, which is also paid as a periodic payment. It's designed to enable participants to reimburse informal supports for transporting them around, as well as pay for Taxis and other forms of transport related to their disability needs. People will be required to provide receipts in order to claim transport costs. For people direct employing support workers, there will be no way to reimburse them for their fuel costs. People self-managing their funding will have to cover these costs from their own pocket, or instruct their support workers to fill up their car and provide a receipt (which would cost NDIS more).

12) The Minister and NDIA plan to pay providers direct, similar to the old block funding model. This is hugely problematic, as all evidence clearly shows that the greatest rorters of NDIS funding are NDIS registered providers. It is people self-managing their funding, and those who are plan managed who are picking up on the gross overcharging by providers, and significantly reducing costs of the scheme. And there are currently only 30% of participants self-managing all or part of their NDIS plans, as per NDIA's quarterly reports. Nowhere near the 50% claimed by the Minister. This change is especially problematic for people living in regional and remote areas of Australia. There are many towns who literally have no NDIS registered providers. Returning to this model will take us back to the days of providers receiving huge sums of funding to provide minimal support, and people with disability experiencing increased rates of violence, neglect and abuse.

Proposed Changes to Early Intervention for Autistic Children

Concerningly, the NDIA has just released another Consultation Paper on Autism and Early Intervention, only one day prior to the closure of submissions to the Joint Standing Committee's investigation into Independent Assessments, ensuring most organisations and individuals making submissions would be unable to review the document and include it in their submission. Equally concerning is the extremely short time frame for the consultation – only four weeks.

The Consultation Paper refers to a recommendation that "the people who deliver intervention know the person well and respect their feelings and views". In order for this to occur, NDIS needs to sufficiently fund therapy interventions to enable providers to build rapport, learn about the person and their needs, understand and respect their feelings and views. To do this requires **time**. When NDIS limits and reduces funding for therapeutic interventions for autistic people of all ages, this prevents the development of this rapport in order to provide suitable supports to meet the person's needs. In our region, for example, autistic children and teens aged 7yrs and over are typically only allocated between $5000 and $9000 per year for therapy. An allocation of $5000 is only sufficient to see a single therapist fortnightly, whereas autistic children typically require therapeutic intervention from a multidisciplinary team including psychologist, occupational therapist and speech pathologist on a minimum basis of fortnightly (many require weekly support) in order to develop and maintain the skills the therapy is targeting. Many autistic people also have difficulties with low muscle tone, balance, coordination, joint hypermobility and toe-walking, which need support and intervention from a physiotherapist. For autistic children aged 0-6yrs, access to multidisciplinary therapy at least weekly is needed in order to develop and retain skills.

Alarmingly, 7.1 of the Consultation paper claims that:

> *"Many children on the autism spectrum will benefit from short term early intervention that is delivered through our early childhood partners and may never need to become participants of the Scheme... Short term early intervention is generally up to twelve months."*

Autism is recognised to be a "life-long developmental disorder that affects how people behave and interact with the world around them." (https://www.healthdirect.gov.au/autism), **by the Australian government. The World Health Organisation recommends that "A broad range of interventions, from early childhood and across the life span, can optimize the development, health, well-being and quality of life of people with autism."** (https://www.who.int/news-room/factsheets/detail/autism-spectrum-disorders) **It may be mild, moderate or severe, with autistic people requiring support throughout their lifespan. Autism is not something which can be cured by 12 months of early intervention therapy.**

The Autism Early Intervention Consultation paper proposes set funding levels for two age groups, under 7yrs and 7-12yrs (pages 27-31). Disturbingly the consultation paper suggests 4 levels of funding, with the minimum amount of funding allocated for an entire year being only $4000 for children aged 0-6yrs, and $2,400 for children aged 7-12yrs. These amounts are completely insufficient to provide even a bare minimum of reasonable and necessary support. This funding amount is deemed by the NDIA to be suitable for children for whom the Independent Assessment finds one area of high need and one area of medium-low need. Note that from these tiny funding allocations, NDIA will require therapy providers to assess the therapy needs of the child, provide therapy, and write report(s) for submission to NDIA. $2400 equates to a maximum of 12hrs of therapy – by the time assessments and reports are written, that equates to less 1 therapy session per 2 months, not including any other support needs the child may need. Multidisciplinary therapy, which the NDIA acknowledges to be of the highest benefit to autistic children, is not possible with such low levels of funding.

Equally concerning are the maximum funding amounts being proposed by NDIA for autistic children. For children aged 0-6yrs, the maximum funding amount proposed is $35,000, and for children aged 7-12yrs, the maximum funding amount proposed is $21,000. These maximums are for an indicative level of funded support of Leve 4, where the Independent Assessment reflects three areas of high need with possibly one to three medium-low areas identified, or equipment needs also identified. This is the maximum funding amounts recommended in the consultation paper for children who are non-speaking, and unable to communicate their needs, inclusive of children with self-harm and aggressive behaviours.

In addition to this, NDIA proposes to drastically reduce funding in the NDIS plans of autistic children by 40-45% each year, assuming they are not 'cured' in the first 12 months.

For context, prior to NDIS, Helping Children With Autism (HCWA) funded up to $12,000 for early intervention, at a maximum of $6,000 per year. The WA government also funded 4 hours of early intervention therapy per week for all autistic children until they turned 6 years of age. Additionally, people were able to access some therapy supports through the Health Department and the Disability Services Commission. Those supports are no longer available – defunded as part of the WA Government's 50% contribution toward the cost of delivering the NDIS – designed to replace and improve on these earlier supports.

If the Government and NDIA proceeds with these proposals, there is extremely high risk of increased relinquishment of autistic children to state care, and requiring much higher support in adulthood throughout their lifespan had their support needs been adequately funded in childhood.

Of note also is the deceptive case study presented in Appendix One (p.36) of the consultation paper. NDIA presents an example of a family requesting funding for the cost of private swimming lessons for 'Jenny', who is 4 years old for the purpose of 'building community inclusion'.

Families of autistic children frequently request funding for the difference in cost between private and group swimming lessons. However, the reason for this request is because many autistic children are unable to learn the life-saving skills of swimming in group settings, and require private swimming lessons throughout the year, often for many years in order to learn and retain this vital skill. Many autistic children are drawn to water, have limited or no understanding of risk or protective behaviours, and many are ‘runners’. **Autistic children are at significantly higher risk of drowning than their peers.**

All of the changes proposed by the Government and the NDIA are being driven by a mistrust of people with disability and their families, and assumptions that NDIS participants are spending their funding fraudulently (rorting the system). We have laws regarding fraud in Australia. During the entire course of the NDS since commencement, there has not been a single NDIS participant charged with defrauding the scheme. Numerous NDIS registered providers have been charged with defrauding the scheme, and despite this fact, the Government and NDIA plan to significantly reduce funding in NDIS plans, reduce participant choice and control, and give greater powers to providers, enabling an increase in their ability to defraud the scheme.

Our Recommendations

- The proposed Individual Assessments **must not** commence in the format proposed.

- There must be no change to the NDIS Act 2013. People with disability and their families need the opposition, minor parties and the senate to block any changes to the current NDIS legislation, which reflects the original purpose, scope and goals of the scheme.

- All changes to NDIS processes and requirements must be made only after extensive consultation with disabled people and their families has been undertaken. NDIA is proposing to make sweeping, non-negotiable changes to process which will have significant and far-reaching impacts on people with disability and their families, with substantial risk of harm. These risks are entirely due to the fact that these non-negotiable decisions have been made entirely without consultation with people with disability and their families.

- There must be meaningful co-design of all NDIS processes and any changes. This means significant and widespread consultation with disabled people and their families, the disability sector, service providers and other stakeholders. This consultation needs to include the peak bodies for the various allied health professionals, with **no limitations** on feedback to be provided.

- The proposed Independent Assessments need to be thoroughly examined for negative impacts against the NDIS Act, especially with regard to the crucial area of choice and control. With special consideration given to ensuring that the human rights of people with disability is protected.

- Participants subjected to Independent Assessments must have the right to appeal the results of the Independent Assessments, including the ability to undertake a second assessment or seek some form of arbitration if for whatever reason they are dissatisfied with the assessment.

- There must be **no changes** to the NDIS legislation.

- The primary issues with NDIS are due to internal NDIA and contractor processes and systems, rather than problems with NDIS participants and families. As noted in the Tune Report prior to being amended by the NDIA and DSS. We recommend:
    - The staffing cap at NDIA must be removed, and resourced with direct employees rather than private contractors. This will aid in addressing the high staff turnover at NDIA
    - NDIA must implement meaningful training of staff – codesigned with people with disability and families.
    - Staff KPIs at NDIA and Partners in Community must prioritise quality (eg. Participant satisfaction, lower number of S100 Reviews etc) over quantity – this will have the greater reduction in AAT appeals than will the proposed changes.
    - Currently, most participant plans are drafted by an LAC before being submitted to an anonymous NDIA delegate who often removes many reasonable and necessary supports. NDIS participants <u>must</u> be provided full name and contact details of NDIS representatives making decisions affecting their supports. Anonymity breeds disrespect - there are no repercussions for harmful decisions.

- Disabled persons' organisations should be resourced to consult directly with their members and the wider community regarding:
    - Access to assessment and diagnostic services
    - Their experiences with government appointed doctors and assessors (eg. Job Capacity Assessments through Centrelink)
    - Their experiences with standardised assessment tools
    - Any other relevant issues raised

- Particular consideration should be given to the issues facing people with disability in regional and remote areas of Australia. Access to suitable therapists is severely limited in these areas, and contracting desperately needed therapists to provide Independent Assessments to the area rather than actual therapy would be extremely detrimental to people with disability.

- When rolled out, Independent Assessments must be an **option**, rather than compulsory. There is clearly a role for **<u>optional</u>** free Independent Assessments to gain access to the NDIS for people unable to afford expensive diagnostic assessments, however such assessments should not be forced on existing NDIS participants who have the right to choice and control regarding therapists performing assessments on them. It is important to note, however, that NDIA have stated that after the commenced changes, people with disability will still be required to have a formal diagnosis in order to gain access to the Independent Assessment, to <u>possibly</u> gain access to the scheme. This is likely to still be at high cost to the person with disability and their family. During the recent Senate Estimates session, NDIA CEO Martin Hoffman advised that the organisations selected to deliver the Independent Assessments will be paid per IA conducted. It's obvious that such a system of payment will result in low quality, rapid assessments churned out by the organisations, who will likely impose quantitative KPIs to ensure maximum profit. This is clearly dangerous and harmful to people with disabilities. Being forced to undergo yet another assessment which has the ability to eject people from the NDIS risks further trauma in people with disability, psycho-social repercussions, depression and anxiety further impacting their functional capacity after the assessment has been conducted.

- Funding for advocacy, the National Disability Strategy and for Information, Linkages and Capacity Building (ILC) needs to be considered. People with disability and their families rely on Disabled Persons and Families Organisations (DPFO) for independent information, support, advocacy and referral. Ensuring the sustainability of DPFOs to meet these ongoing needs of people with disability and their families is vital to improving outcomes for people with disability and ensuring the effectiveness of the NDIS.

- Management of the Information, Linkages and Capacity Building (ILC) projects needs to be returned to NDIA. The shift to having these projects managed by the Department of Social Services (DSS) severed an important feedback and communication forum between Disabled Persons and Families Organisations and the NDIA. Additionally, many of the projects require approval from NDIA to deliver various workshops, resources and other KPIs. As management of the ILC projects is now through DSS, there is no point of contact available to approve these ILC activities, undermining the beneficial outcomes of the ILC program.

- Any underspend must be returned to the NDIA and to the NDIS Quality Safeguarding Commission to improve service delivery and reduce abuse and neglect of people with disability and their families. Consideration should also be given to contributing budgetary surplus to the NDIS, and undertaking the proposed increase to the Medicare levy to ensure long-term sustainability of the scheme.

Conclusion and Contact Details

As an organisation with more than 12 years' experience negotiating, advocating and working in the disability sector, supporting and advocating for hundreds of people with disability living in regional WA, SWAN has an excellent understanding of the potential risks associated with introducing Independent Assessments in the current proposed format and are deeply concerned about the potentially dangerous consequences for people with disability and their families.

As the peak body supporting people with autism in the south west region of WA, we would be happy to talk with someone from the Joint Standing Committee regarding these issues. It is very clear that the Independent Assessments and proposed changes are driven by mistrust of disabled people and cronyism, and aimed at reducing the overall number of NDIS participants.

Thank you for investigating these issues. These changes are potentially life threatening for some people, and like 430,000 Australians with disability and their families, we are very concerned about the consequences.