

South West Autism Network (Inc)



South West Autism Network

Submission to the National Disability Insurance Agency (NDIA) Consultation on Interventions for Children on the Autism Spectrum

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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 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.

A note on language

Most autistic people prefer to use identity-first language (ie 'autistic person') rather than person-first language (ie person with autism). The language used in this submission reflects this preference from the majority of the autistic community.

Introduction - About Us

The South West Autism Network (SWAN) is grateful to the NDIA for making available this opportunity to provide feedback on the proposed changes to NDIS funding for autistic children.

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.

Submission Feedback

Promoting best practice

1. Which of these would you use to find information about choosing and accessing best practice interventions (or services) for children on the autism spectrum?

- NDIS website
- NDIS Operational guidelines
- Participant decision making guides (not yet developed)
- My usual NDIS or NDIS partner contact
- Autism organisations or peak bodies
- None of these

None of these. Best outcomes are achieved when families of autistic children reach out to autistic led organisations and peer support groups including Disabled Persons and Families Organisations (DPFOs) to find information about choosing and accessing best practice interventions.

Peer support is key in finding out which providers are safe, effective and supportive in the local community, including who is providing best practice therapy which is not harmful to autistic children, and who is not.

2. Where else would you like to find information about accessing best practice interventions (or services) for children on the autism spectrum?

Sourcing information from people with lived experience (other autistic people) and autistic led organisations (including peer support groups) ensures that the best interests of the child are kept at the forefront of any advice, rather than consideration of financial profit. Access to these types of supports are primarily available online via social media. However, where there are autistic people in the local community active in peer leadership roles and autistic led organisations, these are vital in ensuring that relevant information and support is available, especially in considering the unique issues affecting people in a community, such as geographic isolation. Research articles inclusive of autistic participation are also helpful sources of information.

Provision of specialist information about supports and services is a specialised field and must be undertaken by trusted professionals or peer supporters. Outsourced Independent Assessors, NDIS staff and LACs are not qualified or experienced in this area, and it is unsuitable to rely on them for this information. Rather, it is appropriate and in the best interests of autistic children to rely on advice from autistic people and autistic led organisations and the allied health professionals engaged in working directly with the individual autistic child when making decisions about providing best practice therapy and support to meet their individual needs.

The therapy and supports chosen by families of autistic children should be evidence based; however families must be given the choice to provide that evidence themselves, with peer review where possible. The Autism CRC report must not be used to limit access to only those therapies or interventions it reviewed. As this report was commissioned by the NDIA, this is a clear conflict of interest. Other sources of existing and future research into the effectiveness and outcomes of therapies and supports for autistic children must be taken into consideration by NDIA when deciding on whether or not to fund requested supports, such as:

- Sandbank, M., Bottema-Beutel, K., Crowley, S., Cassidy, M., Dunham, K., Feldman, J. I., Crank, J., Albarran, S. A., Raj, S., Mahbub, P., & Woynaroski, T. G. (2020). Project AIM: Autism intervention meta-analysis for studies of young children <https://www.researchgate.net/publication/337517081> [Project AIM Autism Intervention Meta-Analysis for Studies of Young Children](#)

Note: Please use the phrases ‘therapy’ or ‘support services’ rather than ‘interventions’. The term ‘intervention’ is harmful to the autistic community, demeaning and emphasizes that something is intrinsically ‘wrong’ with autistic children, thus requiring ‘intervention’. This contributes to stigma and discrimination in the community against autistic people, and is harmful to mental health and self-esteem.

3. Holistic planning is a part of the proposed funding framework for early intervention for children on the autism spectrum. A description of “holistic planning” is included in Section 7.4. How can we help families to find and connect with other supports outside of NDIS?

It is unacceptable and deeply concerning to see NDIA pressing ahead with requiring families to ‘connect with other supports outside of NDIS’. These occur naturally, as they would for any child who does not have a disability.

As per the NDIS Act 2013 and the COAG agreement, NDIS is required to fund all reasonable and necessary supports related to an individual’s disability. This includes provision of reasonable and necessary supports to autistic children.

Page 19 of the Autism Consultation Paper refers to ‘situations where we will not fund an early intervention support or require further evidence of the potential outcome’. Holistic planning must also include funding of holistic supports. We direct your attention to the following concerning points raised in the Autism Consultation Paper:

- *“more than one provider is engaged and their recommendations overlap or duplicate supports”*

Autistic children and adults, like all people with disability, require access to holistic support. Support needs are frequently due to more than one contributing factor inherent in autism as well as co-occurring conditions. Difficulties with communication, emotional regulation, executive function, sensory processing, theory of mind (understanding that another person’s experience of the world is different than one’s own), social skills, motor planning, control and low muscle tone can all trigger meltdown, and it is often a combination of these factors which lead to autistic children and adults becoming overwhelmed, anxious, frustrated and lead to meltdown and/or behavioural difficulties. Difficulties with emotional regulation, for example, are frequently due to difficulties with understanding, recognising and expressing emotions, sensory processing, theory of mind, and may also be due to difficulties with social interaction. To build capacity in regulating emotions, best practice is to work with both a psychologist and an occupational therapist; and where children also have communication difficulties, a speech pathologist should also be engaged, preferably as part of a multidisciplinary team working together to best meet the child’s needs.

Denial of funding for holistic support to meet needs will lead to poorer outcomes for autistic children, and result in higher costs to the NDIS over the individual’s lifetime. To achieve maximum outcomes, funded supports must also include assistive technology and sensory equipment to enable autistic children to generalise skills gained during therapy. It is

important to note that where funding is provided for assistive technology and sensory equipment to aid autistic people with managing executive function, sensory and emotional regulation, the cost of therapy provision over the long term is reduced. Assistive technology and sensory equipment can be used regularly by autistic people as highly effective tools which assist with improving independent living skills, self-regulation and self-management. Access to these tools substantially builds capacity, and reduces reliance on both informal and funded supports.

- *“a provider’s goal and a child’s goal are different and do not align. For example the child and parent want to use interventions to support building capacity in natural setting and the providers goals are based on practicing interventions in a clinical or closed environment”*

This statement is misleading, and not always practical. Whilst it may be preferred that therapy is provided in natural settings, where travel is involved (particularly in regional and remote areas), and where there are thin markets with high demand, requiring all therapy be provided in natural settings rather than clinical seriously compromises the capacity of therapists to provide therapy to all clients. For example, where a therapist must travel an hour to provide therapy to one client, NDIS is charged for that travel time, and that is an hour during which the therapist could have provided therapy to another client. In areas such as south west WA where waitlists for therapy range from 7 to 18 months (depending on age), and there are towns and NDIS participants located more than 1 hour (one way) from the nearest therapy provider, requiring this is not only impractical but detrimental to other NDIS participants in the community.

- *“there is weak or no evidence that the intervention will support an increase in developmental or functional skills, independence or social participation. For example an intervention has been in place for 12 months and there has been no capacity building gains”*

Many autistic children experience periods of skill development and regression, dependent on a range of factors. There are also autistic children who require significant repetition of skills over long periods of time in order to build capacity.

- *“there is no evidence that the support will increase the child’s participation in mainstream and community settings or the child is being withdrawn from educational settings to receive supports”*

This statement is particularly alarming. Therapists are only able to offer two therapy sessions per day outside of school hours. Throughout Australia, and particularly in regional and remote areas, there are insufficient allied health professionals available to meet demand. Limiting therapists to only providing therapy after school hours will directly result in many children with disability completely losing access to any therapeutic supports. Additionally, autistic children require therapeutic support to build self-help and daily living skills, not just to participate in mainstream and community services.

- *“the request does not take into account the role of informal supports and parental responsibility”*

NDIS must fund support for autistic children that meet their needs, with recognition of the needs of their family. Parent responsibility must be considered in relation to the responsibilities of parents of non-disabled children. For example, non-disabled children

typically sleep through the night after the toddler years, whereas autistic children may sleep as little as 2-4 hours per night. Sleep deprived parents are then expected to transport their children to numerous medical and therapeutic appointments; learn how to provide therapy and autism-specific supports within the home, understand, navigate and case-manage the various mainstream and disability systems and professionals engaged in their child's supports; and advocate for their child, all on minimal or no sleep. Parents of non-disabled children do not experience such intensity of support or "*parental responsibility*". Additionally, autism is genetic, with many families having two or more autistic children. Parents of autistic children may also be autistic, or have other disabilities. Managing the needs of multiple children with disabilities is an added layer of complexity which needs to be recognised and taken into consideration when making funding decisions.

- "*there is no evidence that the support will build the family's capacity*"

We reiterate - NDIS must fund support for autistic children that meet their needs, with recognition of the needs of their family. NDIS funded supports must consider the individual needs of the child, not merely whether the support will build the family's capacity. The most important way of building the capacity of the family is to ensure that the disability related needs of their autistic family member(s) are fully and holistically funded.

Autism is a lifelong neurological difference and disability which requires flexible supports which directly benefit the individual. Holistic planning must be individualised in order to adequately meet the needs of children and families in regional and remote areas, as well as Aboriginal and Torres Strait Islander (ATSI) people and people from Culturally and Linguistically Diverse (CaLD) backgrounds. Holistic planning also takes into consideration that many autistic people have co-occurring conditions, often multiple co-occurring conditions which complicate support needs. The Autism Consultation Paper shows that this issue is one of many given no consideration when designing the proposed changes.

Importantly, autism is a lifelong condition. The support needs of autistic children and adults may fluctuate due to various factors. Support needs commonly increase during periods of transition, family and/or social pressures, health and/or mental health difficulties can also impact on the disability related support needs of autistic children and adults. Examples include transition times such as puberty, starting school, high school, leaving school, seeking employment, parental divorce, illness (including mental illness) or death of a loved one, and trauma as a result of experiencing stigma, discrimination, violence, abuse and/or neglect. NDIS funding must give consideration to these environmental factors.

Reasonable and necessary

4. Building from the Autism CRC research the consultation paper outlines specific principles that the NDIS considers as early intervention best practice for young children on the autism spectrum (Section 6.1.) Is there anything you would like to add?

Autism is not a behavioural condition which causes 'tantrums' (as described in the Autism Consultation Paper). Autism is a lifelong neurological condition and disability requiring flexible and individualised support to meet needs. This includes NDIS funded support. Autism cannot be 'cured', despite the claim made in 7.1 of the Autism Consultation Paper:

"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.”

It is clearly evident in the consultation paper that the NDIS understanding of autism is deliberately selective, and has been manipulated for the purpose of proceeding with the proposed changes – inclusive of reduced and limited funding for autistic children and to remove autistic children from the NDIS as rapidly as possible. The Autism CRC has released a public statement regarding the consultation paper:

“Autism CRC was not involved in the development of the NDIA’s consultation paper, including the proposed levels of funded support it contains; and the Interventions Evidence Report did not consider matters of funding.”

<https://www.autismcrc.com.au/news/latest-news/autism-crcs-interventions-evidence-report>

Professor Andrew Whitehouse also wrote to SWAN to advise:

“I have just read your excellent [blog post on LinkedIn](#)... At no point does the [Autism CRC] Report mention children growing out of autism, and it is certainly not something I would endorse. While the consultation paper does summarise some of the Report that I led, the consultation paper is the work of the NDIA and I have had no input into it. (I hadn’t seen it prior to it being published)... I also have concerns about some of the details in the consultation paper, and have expressed these to the NDIA, and more broadly as well. I’ll continue to do so.”

As evidenced by Professor Whitehouse’s statements above and the Autism CRC statement, the autism consultation paper is not accurately reflective of the Autism CRC Report, and has been manipulated to meet the NDIA’s cost-cutting agenda, risking the safety and wellbeing of autistic children.

The Autism CRC Report should not be used to limit funded supports for autistic children to only those reviewed and found to have evidence of efficacy in the Report. Evidence of positive outcomes of therapeutic interventions is continuously evolving rather than static.

While there may not be significant evidence in favour of a type of therapy, this does not indicate that the therapy is ineffective, just that a large-scale research study of the therapeutic support has not been conducted and published. Research studies are costly, and reliant on grant funding to undertake.

5. Building from the Autism CRC research the consultation paper outlines specific standards that the NDIS considers as early intervention best practice for children on the autism spectrum (Section 6.2.) Is there anything you would like to add?

Best practice early intervention for autistic children involves provision of holistic therapy supports, usually involving a multidisciplinary team incorporating psychologist, speech pathologist and occupational therapist with the addition of physiotherapist where children have difficulties with motor planning, coordination, control and low muscle tone. Best practice also includes funding of low cost low risk assistive technology, including sensory equipment to enable autistic children to generalise and practice skills learned in therapy, thus improving independence and quality of life.

With regard to 6.6 *The benefits outweigh any costs (including risks)*, NDIS must take this into consideration with regard to low cost low risk assistive technology, including sensory equipment. Funding these items can provide significant benefit to autistic children and adults by building capacity to self-regulate and improve executive function. This reduces the need for intensive and/or long-term therapy supports, thus clearly cost effective.

Another example given is regarding weighted blankets and sleep. Whilst there may not be sufficient evidence of improvement in sleeping (which may be due to insufficient research), weighted blankets can be beneficial for many autistic children and adults in reducing the severity and length of meltdowns, improving self-regulation and capacity to engage in other activities. [Smaller studies](#) have evidenced that deep pressure can assist autistic children and adults.

6. “Reasonable and necessary” is a term from our legislation. Appendix one of the consultation paper includes case studies which might be used to explain reasonable and necessary. Do these case studies help you to understand what we mean by “reasonable and necessary”?

The case studies in the consultation paper show a complete lack of understanding of autism, the impact of autism on function, and the reason families request particular supports be funded for their children. The terminology used minimises autistic symptoms, repeatedly referring to meltdowns as ‘tantrums’. The case studies also minimise the distress experienced by autistic children and focuses instead on the impact of the child’s ‘tantrums’ on parents and other community members. We find this extremely concerning.

The first case study is regarding a request for funding for private swimming lessons, and is particularly concerning. NDIA is failing to take into consideration the impact of the disability and the risk of harm in refusing to fund this type of support. 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 swimming is a complex skill to learn, and many autistic children are unable to learn in the group setting and require significantly higher intensity of lessons to gain and maintain the necessary life-saving skills.

Many autistic children require private swimming lessons ongoing throughout the year, often for many years in order to learn and retain this vital skill. Autistic children are often drawn to water, have limited or no understanding of risk or protective behaviours, and many are described as ‘runners’. Autistic children are at a [significantly higher risk of drowning than their peers](#). All behaviour is communication, and it is clearly indicated by ‘Jenny’s’ meltdowns and behaviour that she is not yet able to cope with group with lessons and learn in that environment. Forcing her to do so actively causes harm and can inflict trauma, which would further reduce Jenny’s capacity to undertake this and other similar activities in future. The decision by NDIA in this instance completely ignore Jenny’s needs. This is clearly a reasonable and necessary disability-related support which must be funded for autistic children who are unable to learn to swim in group classes, as is defined in the NDIS Act 2013. It is very difficult to understand how NDIS could view this as anything other than reasonable and necessary.

The second case study again reflect NDIA’s lack of understanding of autism. Many autistic children experience anxiety due a range of factors directly related to their disability, including:

- Difficulties with emotional and sensory regulation

- Difficulties with communication, including comprehension
- Difficulties with transitions
- Difficulties with executive function

The third case study refers to the parents of a 3 year old child who has been denied funding for 20 hours of intervention for at least one year. ABA literature often recommends 20 hours of intervention per week for a minimum of 12 months (often longer). We agree that this is inappropriate, and do not support funding of ABA interventions by NDIS.

However, this is not what is stated in the case study, and it indicates 20 hours of therapy for the year. We concur with the parents that 20hrs of funded therapy for 12 months for a 3 year old autistic child is completely insufficient. This does not permit multidisciplinary therapy, and once assessments and NDIA required reporting have been undertaken by the therapist (funding would only enable one therapist), would enable little more than one hour of therapy per month. Such minimal therapy would do nothing to build any child's skills and capacity.

7. Do you have any other feedback about how we explain “reasonable and necessary?”

NDIS must take into consideration the rights of people with disability, including autistic children, as outlined in the United Nations Convention on the Rights of People with Disability (UNCRPD). Reasonable and necessary supports are supports which act to bridge the gap between a life with disability and a non-disabled life.

Holistic planning means that reasonable and necessary must be informed by the individual's life circumstances, taking into consideration factors such as:

- Co-occurring conditions experienced by the individual, such as Intellectual Disability, Down Syndrome, Epilepsy, Ehler's Danlos Syndrome / Hypermobility Spectrum Disorder etc.
- Multiple people with disability in the family.
- Family carers with reduced capacity to provide informal support eg mental illness, health issues, undiagnosed disability, lack of extended family etc. Consideration must also be given to family carer's capacity to understand and navigate mainstream and disability systems, and provide funded support to address this inequity.
- Geographic location, including people who are regional and/or remote.
- Access to services, including thin markets and areas with extensive wait times to access services due to demand exceeding supply.
- Aboriginal and Torres Strait Islander or CaLD status.
- Low socio-economic status and other factors impacting the person with disability, including discrimination, stigma, barriers to community and mainstream access, trauma, and experience of violence, abuse and/or neglect.

8. Table 2 (0-6 years) and Table 3 (7-12 years) are an example of how we might explain Indicative level of funded support for children on the autism spectrum (Section 7.5.) Do these table/s clearly explain the indicative levels of funded supports?

Disturbingly, the consultation paper suggests 4 levels of funding, with the minimum amount of funding allocated for an entire year being a measly \$4000 for children aged 0-6 years, and \$2,400 for children aged 7-12 years.

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. \$2,400 equates to a maximum of 12hrs of therapy – by the time assessments and reports are written, that equates to less than 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 0-6 years, the maximum funding amount proposed is \$35,000, and for children aged 7-12 years, the maximum funding amount proposed is \$21,000. These maximums are for an indicative level of funded support of Level 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 high behaviour support needs.

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' within the first 12 months.

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 7 years and over are typically only allocated between \$5,000 and \$9,000 per year for therapy, substantially lower than funding amounts in other regions of Australia. An allocation of \$5,000 is only sufficient to see a single therapist fortnightly, whereas autistic children typically require therapeutic intervention from a multidisciplinary team including psychologists, occupational therapists and speech pathologists 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.

Capping funding for autistic children is counter to the intentions of the NDIS Act 2013, is a breach of reasonable and necessary supports, ignores their inherent rights under the UNCRPD, and is one of the dangers of the robo-planning model. Moving away from individualised funding and supports for autistic children will result in increased rates of relinquishment of autistic children, and risks increased violence, abuse and neglect of autistic children. The proposed funding rates and other changes outlined in the consultation paper will directly lead to poorer outcomes for autistic children, and over the long-term,

higher costs to the NDIS in supporting autistic adults who did not receive reasonable and necessary support as children.

We are also highly alarmed by many of the planned changes outlined in NDIA's 'Early Childhood Early Intervention (ECEI) Implementation Reset: Project Consultation Report. Of particular concern is the plan to assess all children aged 0-6yrs under Section 25 (early intervention only) of the NDIS Act, rather than Section 24 (access to full NDIS) for eligibility (except for children with very significant disability, such as quadriplegia). Autism is a lifelong disability, with autism level 2 and 3 being included on List A for permanent NDIS eligibility in recognition of this fact. Coupled with the extremely low levels of funding proposed and planned exiting of autistic children from NDIS supports as rapidly as possible, this is clear evidence of NDIA's cost-cutting agenda and lack of understanding of autism and its impact on function.

9. Do you have any other feedback about how we explain the indicative levels of funded supports?

Prior to NDIS, Helping Children With Autism (HCWA) funded up to \$12,000 for early intervention, at a maximum of \$6,000 per year. A significant portion of that funding was able to be used by families as they saw fit – to purchase equipment and supports to meet their child's needs – inclusive of sensory equipment and items such as trampolines, iPads and communication devices.

In Western Australia, the state government also funded 4 hours of early intervention therapy per week for all autistic children until they turned 6 years of age. People were also able to access some therapy supports through the WA 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 federal government and NDIA proceed with these proposals, there is an extremely high risk of increased relinquishment of autistic children to state care, and that these children will require much higher support in adulthood throughout their lifespan than if their support needs been adequately funded in childhood. The NDIS changes are, in fact, counter to insurance and early intervention principles, and will result in greater cost to government overall.

10. There may be situations where families or carers need extra NDIS supports such as during first plans, or where plans reduce in value due to the impact of mainstream services. What do we need to consider in those situations?

Extra NDIS supports must be included during first plans. This is not occurring in south west WA, and results in poorer outcomes and significant stress and distress in participants and families, except where people are connected to autistic led organisations and peer support. The current review process is far too slow and inflexible to adapt to changing needs. There needs to be increased flexibility and/or contingency funding provided by NDIS for periods involving transition, such as starting school, puberty, entering high school and moving from the education system to adulthood.

Funding needs to be more flexible, whereas this consultation paper details a significant reduction in flexibility, in addition to reduced funding. The Early Childhood Early Intervention (ECEI) Implementation Reset: Project Consultation Report also indicates that families of

autistic children will only be able to access NDIS registered providers, and the NDIA's plans to phase out Self-Management (also stated in meetings by NDIA senior staff) and Plan Management. These proposed changes deny choice and control to participants and families, and seriously limit access to therapeutic supports, especially in regional and remote areas and locations with thin markets. There are many towns in WA with no NDIS registered providers. Either NDIA will need to allocate significantly more funding to enable NDIS registered providers to travel to these locations (many areas will require travel by plane, and would reduce service provision to the region they are travelling from), or will need to permit funding being used to access reasonable and necessary supports through non-registered providers. Being able to use non-registered providers is vital to ensuring participants are able to access reasonable and necessary supports to meet their needs, exerting choice and control, and building their capacity to make decisions in all areas of their lives.

All disability related needs must be taken into consideration when deciding reasonable and necessary supports, as per the NDIS Act 2013, the COAG Agreement and the UNCRPD. Whilst there are some mainstream services which provide support, the Mental Health Care Plan (MHCP) is not a suitable mainstream support for autistic children and adults. Autism is not a mental illness, and is not an eligible condition to gain referral to a psychologist via the MHCP. A general psychologist is not suitable, and autistic children and adults need access to psychologists with experience in respectfully working with and supporting the needs of autistic people. Additionally, there is a significant gap fee to pay when claiming on the MHCP, ranging from \$80-\$140 per 1 hour session.

As per the NDIS Rules (recently removed from the NDIS website):

10.8.1 Health (excluding mental health)

... "NDIA plans are developed to cover the full cost of supports (e.g. physiotherapy or OT services to build function) where these are considered Reasonable and Necessary for the participant. As a result, there should not be a "gap" fee required to be paid.

Participants should not make claims under private health insurance policies for 'Reasonable and Necessary' supports in their plan that the participant will also claim from the NDIS. Participants may choose to use private health insurance to fund services and treatments that will not be funded under their NDIS plan. In the rare cases where a support being delivered may be claimable under either the participant's plan or private health insurance, the participant may choose whether to use NDIS funds or make a claim under their private health insurance, but they cannot make a claim under both in respect to the same support."

Shifting this disability-related cost onto participants and families (many of whom already experience significant financial disadvantages) to pay huge gap fees is unreasonable, unnecessary and unfair.

Supporting parents and carers to exercise choice and control

11. We want to support children and parents with implementing plans using the Autism CRC research and best practice. In Section 8.2 there is a suggested list of questions for parents and carers. These can be used to understand the best intervention for a child and their family and how a provider is delivering an intervention. Are these questions helpful for parents and carers when selecting providers?

Whilst the example questions could be helpful for families, the limited funding NDIA plans to allocate for these supports will seriously limit how much training and/or guidance therapy providers will be able to provide to families and carers, as well as seriously limit what therapy options will be offered to meet needs.

12. What other guidance or tools do families need to feel confident to implement plans in line with the Autism CRC research and best practice?

Other guidance questions which would be important to include are:

- How will this therapy ensure positive mental health outcomes and the wellbeing of the child?
- What does my child need (not limited to behaviour management)?
- Is the therapeutic intervention respectful of autistic needs, or is it based on behavioural programs designed to train children to behave like non-autistic peers?

Conflicts of interest

13. This question relates to Section 8.3 of this paper: “Addressing conflicts of interest.” How can we support families and carers to feel confident to make decisions about what is in the best interest of the child and family?

In south west WA, Konekt (owned by APM) has been appointed as one of the Independent Assessment providers. APM is the LAC Partner in Community for this region. In a meeting with APM’s senior management staff, we were advised that Konekt Assessors will be operating out of the APM offices, which are open plan design. This means that Independent Assessors will sit side by side with LACs, a clear conflict of interest that also risks poorer outcomes for NDIS participants in this area. Complaints regarding this issue have been lodged with both NDIA and the NDIS Quality and Safeguards Commission. The Commission claim that Independent Assessors are not within their remit, and redirect complaints to NDIA, and NDIA have failed to respond to or acknowledge any of the four complaints lodged since 4th March 2021. A further complaint has since been lodged with the Ombudsman.

In order to address conflicts of interest, the NDIA must lead by example and address actual conflicts of interest with its chosen partners in community and contractors.

The NDIA has repeatedly misrepresented the recommendations in the Productivity Commission Report, the Tune Report (which was also amended by NDIA, thus not an independent review), and now the Autism CRC Report. The NDIA reports on the previous three consultation papers were also grossly misrepresentative of the actual feedback, as evidenced by both the published submissions to NDIA and the submissions to the Joint Standing Committee Inquiry into Independent Assessments. The feedback questions in this ‘consultation’ paper are again leading, and do not allow for meaningful co-design and feedback on the proposed changes, and likely harm that they will incur. Conducting ‘consultation’ in this manner is a perfect example of how to prevent empowerment of people with disability and their families, and destroy trust in and respect for the NDIS as a system and the NDIA staff and processes.

To support families and carers to feel confident to make decisions about what is in the best interest of the child and family, NDIA must:

- Act to meaningfully engage people with disability and families in co-design of all proposed changes, respond to feedback, and make changes which actively improve safety and outcomes for people with disability, as per the original intent and design of the NDIS Act 2013.
- Properly train NDIA staff, LAC partners and ECEI partners to understand autism and disability-related needs.
- Ensure that NDIS participants and families are empowered with choice and control, including the options of Self-Management or Plan Management of NDIS funding, and ability to use non-registered providers.
- Empower the NDIS Quality and Safeguards Commission to impose fines and strip registration from providers engaging in unsafe practices or demanding that participants and families use only their service for all supports.
- Ensure that parents and families are informed of all available provider options to suit needs, rather than referring participants and families to a single provider. SWAN staff have witnessed this occurring on numerous occasions when advocating for participants and carers at NDIS planning and review meetings.
- Support families to link with autistic led organisations and peer support.

Conclusion

South West Autism Network urge the NDIA and the Government to reconsider this approach. The agency must abandon plans to cap funding for autistic children and subsequently reduce funding drastically each subsequent year (if the child has not been ejected from the scheme), and return to the person-centred individual planning process with recognition of the complex needs and co-occurring conditions of autistic children.

We remain deeply concerned about the use of the flawed Independent Assessments to determine the level of funding that people with disability will be allocated, especially having heard from a parent who participated in the Independent Assessment trial, and at the end of the three hour assessment, the assessor had not identified that the child was not able to use spoken language. There was no observation of the child conducted (the IA process does not require it), and the chosen assessment tools do not have capacity to assess whether an autistic child is able to communicate verbally or not.

We also urge the NDIA and the Government to provide ECEI partners in community with greater discretion to determine reasonable and necessary funding levels for autistic children not based solely on a single functional assessment, but with consideration of the many other factors which impact on the need for early therapeutic and disability supports.

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