Olga Tennison Autism Research Centre
School of Psychology and Public Health

Olga Tennison Autism Research Centre: Response to the 'What we have heard' report

ENQUIRIES
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Introduction

Approximately 15% of Australian children will meet criteria for a neurodevelopmental disability (NDD) resulting from differences in early brain development. These conditions, including Autism, significantly impact learning, communication, and behaviour. Many children will meet criteria for multiple diagnoses and be susceptible to poor mental health during their school years and beyond, reducing their and their family's wellbeing across the lifespan.

The world-renowned National Disability Insurance Scheme (NDIS) in Australia has the promise to ensure better lives for Australians living with a significant and permanent disability, including their families and carers. It is evident that this scheme does not have the capacity to support all families living with someone with neurodevelopmental disability.

With one in ten Australian children in the NDIS, it is clear we need to identify neurodevelopmental vulnerability early and implement necessary community-based supports, ideally within the first 1000 days of life, thereby minimising longer-term support needs, as least for a proportion of this population. It is critical that this effort is undertaken in partnership with all levels of government, with the provision of supports to all children with disability and their families being a shared responsibility.

La Trobe University's Olga Tennison Autism Research Centre (OTARC) welcomes the invitation from the NDIS Review Committee to provide a response to the Interim Report - the *What we have heard report*[1]. Established in 2008, OTARC was the first dedicated Autism research centre in Australia. Our vision is for a world where Autistic people, their families and their carers thrive. Our research is internationally recognised as making an impact not just in Australia but globally.

At OTARC, our research aligns with the United Nations Sustainable Development Goals.[2] We work to optimise impact for the Autistic and Autism communities through public accountability, community engagement, government and industry collaborations, and by using local paths to global change. Our research encompasses four program areas: Identification and Diagnosis, Supports and Practices for Daily Living, Educational and Vocational Engagement, and Health and Wellbeing.

Through our research to practice arm, we aim to support Autistic people to realise their full potential, actively participate in the community, including in education and employment, enjoy life, and make meaningful lifelong contributions based on their goals. This response to the Interim report focuses on providing evidence-based, community-driven recommendations that we hope will contribute to achieving these aims.

OTARC's recommendations draw on evidence from:

➢ Our four Research Program areas and accumulated clinical and professional expertise, including lived experience.

➢ Our embedded research to practice program at the Victorian Autism Specific Early Learning and Care Centre. We support approximately 50 Autistic toddlers and preschool aged children

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using an evidence-based program called the Group-Early Start Denver Model (ESDM) incorporated within the La Trobe University Community Children's Centre.[3]

➢ An OTARC NDIS 'Conversation Session' where we discussed the *What we have heard report* (held in July 2023) involving researchers, clinicians, NDIS service providers (La Trobe University Community Children's Centre, Centre Manager and Clinical Manager), NDIS participants and NDIS applicants.

➢ Consultation with lived experience experts within OTARC (Autistic people, parents of Autistic people, and NDIS participants).

Our recommendations are grounded in the **social model of disability** and a **human rights approach**, acknowledging the intrinsic right to inclusion and that attitudes, practices, and structures create barriers that hinder individuals from reaching their full potential and enjoying equal rights within society.[4] People living with disability encompass those with long-term physical, mental, cognitive, intellectual, and/or sensory difficulties. While our submission will primarily focus on Autism, many Autistic people have co-occurring conditions that are also disabling. Autistic people have individual support needs, strengths, priorities, and perspectives influenced by their identities, such as gender, age, sexuality, race, and cultural background. Due to these intersectional identities, Autistic people may encounter additional obstacles and inequalities. However, depending on circumstances they can thrive and make significant contributions to society.

As our research shows that Autistic people prefer using identity-first rather than person-first language,[5] we will use identity-first language (e.g. Autistic) throughout this submission.

Contents

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[3] https://www.latrobe.edu.au/otarc/margot-prior-autism-intervention-centre
[4] United Nations Convention on the Rights of Persons with Disabilities (CRPD), Commonwealth of Australia (Department of Social Services) (2021)
[5] Bury et al (2020); Kenny et al (2016)

Summary of recommendations

Recommendation 1. Provision of a streamlined multi-departmental guide for NDIS participants, educators and education service providers on the division of responsibility for service provision with direct links to detailed explanations and process guides on how to access local educational supports that are consistent nationally.

Recommendation 2. Establishment of a national community of inclusive education practice[6] to improve inclusion and accessibility in education settings, to be funded by the Department of Social Security Information, Linkages and Capacity Building program.[7] The following interest groups should be included:

- education institution administrators (public, private, and specialist schools)
- educators (public, private, and specialist schools)
- governing bodies (e.g. State and Federal Departments of Education)
- individuals with disability and their families.

Recommendation 3. Increase connection between departments responsible for disability services at all levels of government to identify service gaps and plan on how to address these gaps at the appropriate government level.

Recommendation 4. Set a national target for all early childhood education and care settings and primary and secondary schools to have access to a multidisciplinary allied health team comprising a psychologist, speech therapist, occupational therapist and physiotherapist, working together with the centre/school educational team to support the student cohort utilising a transdisciplinary approach.

Recommendation 5. The Federal Government to facilitate the generation and implementation of a national inclusive education action plan with state and territory governments to deliver inclusive school environments across Australia, modelled on universal design principles, including:

- a working definition of inclusive education in the Australian context
- a funding agreement with states and territories
- step by step implementation plan with timelines for delivery
- a plan on how to evaluate success, as defined by the student and/or their family.

Recommendation 6. Initiate a National Cabinet discussion between states and territories to reach a commitment to expand community-based individual and group services and programs for people with disability. This commitment should include:

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[6] Lave & Wenger (1991)
[7] In line with Recommendation 16 of The Senate Select Committee on Autism final report (2022)

> - an increase in community grants aimed at reducing isolation and mental ill health and increasing community participation in physical activities.

Recommendation 7. The Department of Social Security Information, Linkages, and Capacity Building program to allocate funding to develop state and territory specific resources and training for inclusion in physical activities and recreation facilities to increase community participation. These resources should be accessible, appropriate, and relevant to the target population, to be determined through community consultation, particularly in regional and remote communities.

Recommendation 8. State and territory governments to work with local councils to set low-cost entry fees for physical activities, exercise and sport to remove the cost barrier to participation for people with disability.

Recommendation 9. Promote greater connection and collaboration between Disability Employment Services providers and NDIS to reduce long-term unemployment which can further contribute to disability.

Recommendation 10. Explore and evaluate planner caseload optimisation to facilitate specialisation in:

- distinct areas of disability (e.g., neurodevelopmental disabilities; physical disabilities; psychosocial disabilities)
- physical/cognitive age groups of childhood, adolescence, adulthood, etc., to foster developmentally appropriate decision-making for clients.

Recommendation 11. Commit to training planners in their area of speciality through traditional (e.g. research) and non-traditional (e.g. direct consultation with lived experience experts) means.

Recommendation 12. Increase time allocation for individual NDIS participant/applicant decision making.

Recommendation 13. Update internal procedures to consider comprehensive profiles such as sensory processing, executive function, strengths and interest, connections to culture and community, self-care and independence skills, and social and communication skills –to determine *what* is 'reasonable and necessary' for a given individual. To facilitate this, the NDIS should develop and implement an interactive tool to be used by applicants/participants prior to a planner meeting to establish that individual's context and enable planner perspective taking.

Recommendation 14. Include provisions for people with disabilities to obtain funding for gym memberships and other community participation initiatives based on participant goals.

Recommendation 15. State and territory governments to implement Social Attention and Communication Surveillance (SACS) nationally as recommended by the Senate Select Committee for Autism via all primary health and early education and care (ECEC) professionals.

Recommendation 16. State and territory governments to promote the use of the free ASDetect app for parents.

Recommendation 17. Implementation of Recommendation 12 of the Senate Select Committee on Autism - "…the Australian Government develop guidelines on autism- friendly service design through the National Autism Strategy in order to help service providers tailor services and service environments to meet the needs of autistic individuals."[8]

Recommendation 18. Implementation of Recommendation 9 of the Senate Select Committee on Autism - "…National Disability Insurance Agency continue to improve the capacity of its staff, including Local Area Coordinators, to provide better support to autistic people. This should include a focus on both understanding and meeting autistic participants' support coordination needs".[9] In addition, we recommend:

- that this capacity building be extended to service providers delivering supports for NDIS participants.

Recommendation 19. The NDIS recommend review of the barriers to inclusion support and systematically remove or significantly reduce these barriers to facilitate more streamlined access to inclusion supports.

Recommendation 20. State, territory and local governments mandate all new developments and significant upgrades to existing developments of public spaces meet universal design principles.

Recommendation 21. Barriers to NDIS registration should be identified and minimised to facilitate registration by more providers who meet NDIS evidence-base standards.

Recommendation 22. The NDIS should introduce a more effective monitoring program of registered providers which focuses on evaluating the quality of the programs being delivered and the measurable outcomes for NDIS participants.

Recommendation 23. NDIS plan development should incorporate community participation goals and active inclusion as a priority.

Recommendation 24. States and Territory governments to engage in an active public education campaign on Autism, with the support of the Australian Government Department of Social Services, to:

- dispel myths regarding a 'right way' to engage socially.
- increase awareness and acceptance of Autistic social-communication styles, with an aim to facilitate social inclusion of Autistic people.
- facilitate access to co-produced public mental health material specific to Autistic people, such as The Suicide Response Project.

Recommendation 25. The NDIS to adopt a definition of evidence-based practice that acknowledges the intersection of research evidence, clinical practice and expertise and the clients' values and preferences, ALL underpinned by lived experience.

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[8] The Senate Select Committee on Autism (2022)
[9] The Senate Select Committee on Autism (2022)

Recommendation 26. States and territory governments to increase dedicated and ongoing financial support for non-profit organisations, prioritising those who use transdisciplinary approaches to take advantage of their deep knowledge of, and historical ties to, the disability sector.

Recommendation 27. Incorporate regular monitoring of service providers' evidence-based practice use, including active client outcomes monitoring. Expecting consumers to discern evidence-based practices that will control markets is unrealistic.

Recommendation 28. Extend service providers' registration to more allied health providers to ensure accountability through periodic audits and to promote inclusive and transdisciplinary practices.

Recommendation 29. Encourage collaborative efforts among all professionals to ensure holistic support for NDIS clients, including focusing on their families. Ultimately, this approach seeks to establish a dynamic, transparent, and diverse NDIS ecosystem that empowers individuals with disabilities and their families, ensuring their rights to quality support and well-informed decision-making.

1. Why is the NDIS an oasis in a desert?

1.1 What supports from governments, business and the community are missing?

Our researchers, clinicians and lived experience experts describe significant gaps in support available to Australians with disability during OTARC's NDIS Conversation. They especially noted the closing of numerous services previously providing supports in the following areas:

1.1.1.   [Education](#)

1.1.2.   [Community services](#)

1.1.3.   [Employment services](#)

In addition, in several of our studies of Autistic people and their parents/carers/families, participants expressed concern about the availability of services across the lifespan,[10] echoing a recent research project by the University of Melbourne. The study investigated the experiences of working-age Australians with disabilities, who were not NDIS participant's, in finding and utilising necessary supports and services in Victoria, South Australia and Tasmania.[11] Findings revealed a fragmented support landscape, inconsistent costs, eligibility criteria, and information availability. Most respondents deemed their support inadequate due to accessibility, information gaps, and unclear service paths. A significant portion had unsuccessfully applied for NDIS funding, and disparities in access emerged based on factors like location, income, and demographics.

> *We must ENSURE that nothing is taken away from those who need it or limited to a certain "population" of disabled people, WITHOUT first identifying and filling in the gaps that will be left when NDIS changes its access and eligibility criteria.*
>
> Associate Professor Josephine Barbaro – OTARC Principal Research Fellow and mother of an Autistic NDIS participant

1.1.1 Education

Around one in five children will likely have additional learning needs, but supports in educational settings are consistently being culled, even for those with a significant disability. As recently as August 3, 2023, the Victorian Department of Education announced more than 80 visiting teacher positions will be culled. These roles provide crucial services to children with additional learning needs (and thankfully this decision was reversed). Thus, even while the NDIS Review Committee is considering means of improving Tier 1 and 2 supports for people with disability, cuts to these supports continue to affect those in need of services. It is important we provide more, not fewer, resources in schools to meet the learning needs of vulnerable students.

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[10] Dissanayake et al (2020)
[11] Olney et al (2022)

In addition to needing significant learning supports, education settings can be traumatic for Autistic students, with the majority in primary school and beyond experiencing significant stigma, often resulting in bullying.[12] The Australian Broadcasting Corporation has released a summary of research indicating that students with disability endure bullying and exclusion in schools with 70% of these students feeling excluded from activities and events, and 65% experiencing bullying.[13] Only 27% of students with disability felt they received the support they needed to learn in the classroom. Feedback from education service providers, researchers and lived experience experts indicates critical gaps in support provision for students accessing education at all levels, undermining school engagement, social adjustment, and academic achievement. Students have difficulty in accessing the necessary supports to learn and participate fully in education.

A key issue is the knowledge gap regarding what is best practice inclusive education for students with diverse learning needs. While good examples of inclusive education practices exist, this knowledge is not shared and replicated. Moreover, in Victoria, the Department of Education has made accessing mainstream schools out of designated school zones (excluding specialist schools) increasingly difficult, reducing parents' ability to seek out good inclusive educational environments[14]. Carers can apply for exceptions based on compassionate grounds, but this requirement places an additional burden on them. It is therefore critical that ALL schools are supported to build inclusive practices to accommodate ALL students, regardless of their disability.

Fostering stronger connections between different types of schools within the educational landscape is hugely beneficial. A wealth of knowledge and expertise exists in special schools, providing the opportunity to equip educational settings to deliver evidence-based inclusive practices, thereby embracing the diversity of all learners and delivering equitable education. There is significant need for Departments of Education to increase, or at the very least, maintain, dedicated disability support roles which are not limited to behavioural supports alone but that have a broader focus of accommodating all learning styles.

Accessing resources to support individual students with additional needs well is also a barrier, with education providers reporting:

➢ overly complex and time-consuming applications for state-based supports

➢ lack of clarity regarding federal, state, and local government responsibilities.

Many Autistic students in mainstream education settings do not receive individual disability support funding. This means that these and other neurodivergent students (e.g. those with ADD/ADHD) face considerable learning challenges, often due to accompanying executive functioning difficulties. Consequently, without additional support, most of these students fail to thrive academically.

Proposed solutions

Education settings represent a crucial intervention point where all students can be nurtured, guided, and empowered to reach their full potential, and from an early age. These settings play a vital role in fostering growth and development for all students, regardless of their learning challenges. By offering broad-based supports, it is possible to create an inclusive and empowering educational system that helps vulnerable students overcome obstacles and succeed both socially and academically.

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[12] Dissanayake et al (2020)
[13] Australian Broadcasting Corporation (2023)
[14] The Age (2023); Schools Vic (reviewed June 2023)

An important initiative for Autistic students, their families and educators introduced as part of the Helping Children with Autism initiative, and that has been maintained is Positive Partnerships which works "together with parents, carers and educators of school-aged children on the autism spectrum to provide current, relevant and evidence informed information through workshops and online resources."[15] This highly valued and freely accessible initiative has built significant capacity across the sector to support Autistic students and is a fine example of best practice that should be built upon.

> *Just imagine what we could achieve if we provide adequate supports for all neurodivergent students within their school day for 15 years from kindergarten onwards to build capacity prior to their transition into adulthood.*
>
> Professor Cheryl Dissanayake AM - Endowed Chair in Autism research, OTARC

In 2022, the Senate Select Committee on Autism proposed that all mainstream schools work toward becoming inclusive schools, modelled on universal design principles with Springbank Secondary College given as an example based on its outcomes upon committing to becoming fully inclusive.[16] Building system capacity to deliver inclusive education is a key priority under Australia's Disability Strategy 2021-2031.

Four areas of opportunity for change are provided below regarding the provision of disability supports in education that work together to bring Australia closer to delivering inclusive education where developmentally vulnerable students can thrive.

1. Education and training

Recommendation 1. Provision of a streamlined multi-departmental guide for NDIS participants, educators and education service providers on the division of responsibility for service provision with direct links to detailed explanations and process guides on how to access local educational supports that are consistent nationally.

2. Information sharing

Recommendation 2. Establishment of a national community of inclusive education practice[17] to improve inclusion and accessibility in education settings, to be funded by the Department of Social Security Information, Linkages and Capacity Building program.[18] The following interest groups should be included:

- education institution administrators (public, private, and specialist schools)
- educators (public, private, and specialist schools)
- governing bodies (e.g. State and Federal Departments of Education)

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[15] https://www.positivepartnerships.com.au/
[16] Commonwealth of Australia (2022, pg. 4)
[17] Lave & Wenger (1991)
[18] In line with Recommendation 16 of The Senate Select Committee on Autism final report (2022)

> ▪ individuals with disability and their families.

Recommendation 3. Increase connection between departments responsible for disability services at all levels of government to identify service gaps and plan on how to address these gaps at the appropriate government level.

3. Multidisciplinary care

Recommendation 4. Set a national target for all early childhood education and care settings and primary and secondary schools to have access to a multidisciplinary allied health team comprising a psychologist, speech therapist, occupational therapist and physiotherapist, working together with the centre/school educational team to support the student cohort utilising a transdisciplinary approach.

We recommend that multidisciplinary allied health supports be available within all schools to foster learning and participation of all students. Currently, some schools have access to a psychologist, with the psychologist: student ratios frequently exceeding the 1:500 recommended as best practice by the Australian Psychological Society and the Australian Psychologists and Counsellors in Schools Association.[19] Adding speech therapists, occupational therapists and physiotherapists increases capacity for assessment and support for mental health, language and communication, social and physical development.

The allied health team would partner with educational school staff using a transdisciplinary approach to build supports for learning as well as social and emotional wellbeing and participation. Implementing such supports on a broad scale within schools creates an environment where all students, regardless of their specific needs, can access the necessary resources and assistance to thrive. This approach fosters a culture of inclusivity, empathy, and understanding, reinforcing that every student deserves an equal opportunity to succeed.

In addition to supporting all developmentally vulnerable students, this approach will reduce the number of children accessing NDIS plans whereby those with additional needs will receive the supports they need at school. Such a model of support, provided within all education settings, including in the early years, will be more economical than the alternative of children with a developmental disability accessing individualised NDIS plans. However, if the school-based supports aren't sufficient for given students, the allied health team can refer and partner with relevant external services that may require individual funding via a NDIS plan.

4. Universal supports

Recommendation 5. The Federal Government to facilitate the generation and implementation of a national inclusive education action plan with state and territory governments to deliver inclusive school environments across Australia, modelled on universal design principles, including:

▪ a working definition of inclusive education in the Australian context

▪ a funding agreement with states and territories

▪ step by step implementation plan with timelines for delivery

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[19] Australian Psychological Society (2022); Australian Psychologists and Counsellors in Schools Association (2021)

> ▪ a plan on how to evaluate success, as defined by the student and/or their family.

Currently, additional supports for individual students are funded by applying for education inclusion support. This process is complex, time-consuming, and unnecessarily singles out the student with disability. The reality, however, is that many students require additional support to learn. Financial support to schools should be estimated based on the percentage of students that are expected to require learning supports, considering the school population. This approach fosters a more comprehensive and easily accessible educational environment for all, without exclusions, and enables some flexibility in meeting all student's needs. Embracing a population-centric funding approach ensures learning requirements of all vulnerable children are met with supports delivered in an integrated, comprehensive, and equitable way. It also has the potential to eliminate the need for schools to present the "worst version" of individual student's needs to gain access to support. The NDIS would only be required to fund additional supports needed over and above this universal support structure.

1.1.2 Community services

The introduction of the NDIS has severely impacted the availability of community services for people with disability. Cuts to day programs (e.g., those run by the Melbourne City Mission) disproportionately impact adults with disability, with many losing even the limited access to the community that these programs provided. The absence of such programs also impacts on their families, with the flow-on effect being reduced family participation in work and leisure activities.

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> *So, one of the first things they took that was very important in the community was removing funding from the councils. The council used to provide support for all people with disability, whether under the NDIS or not, to improve community participation meant for people who may not be eligible for the NDIS but needed some support. That's gone.*
>
> Dr Nancy Sadka - OTARC Senior Research Associate and Mother of three Autistic NDIS participants

There is a lack of state funding for proactive and protective community services. For example, the National Disability Services expressed disappointment in the Victorian 2023-2024 budget as no targeted funding was allocated to the Victorian Disability Advocacy Program for abuse prevention. The budget also failed to allocate funding for the promotion of good practice in disability services to complement funding for regulation, which includes $12.4 million for the Victorian Disability Worker Commission and the Victorian Disability Services Commission[20].

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[20] National Disability Services (2023)

Promoting Inclusivity: Enhancing physical recreation for Autistic people

Certain groups, such as young Autistic individuals, encounter additional challenges that hinder their participation in community activities that promote exercise and social interaction. Traditional avenues like gyms and local sports and recreation clubs often do not cater to their specific needs, exacerbating their exclusion. The reduction of community services since the introduction of the NDIS has further compounded this issue, limiting their access to structured exercise opportunities.

Challenges:

1. **Limited participation:** Young Autistic individuals are less likely to participate in mainstream community activities due to the lack of accommodation of sensory, communication, and social needs. This leads to reduced opportunities for exercise and interaction with peers and poorer physical and mental health.[21]
2. **Lack of tailored activities:** The existing community activities often lack the necessary adjustments and accommodations to make them accessible and enjoyable for Autistic people, perpetuating their exclusion.[22]
3. **Dependency on structured avenues:** With limited options in the current funding structure, it is easier for Autistic individuals to use their NDIS funding to exercise with professional staff rather than with peers or friends, perpetuating the medical model of disability and hindering their right to participate on an equal basis in recreation.[23]
4. **Exercise is perceived as a luxury:** Disability is a predisposing factor to chronic health conditions such as obesity, diabetes, osteoporosis, cancer, and depression. These health issues are not inevitable and can be prevented or better managed with exercise. People with disability who do not exercise are 50% more likely to have at least one chronic health condition.[24]

Importance:

➤ **Wellbeing:** Equal access to physical activities fosters wellbeing by addressing the physical, emotional, and social needs of Autistic people. It promotes self-esteem, confidence, and better overall quality of life.
➤ **Community Integration:** Accessible activities and facilities support the participation of Autistic people into the broader community, encouraging positive interactions and reducing social isolation.
➤ **Human Rights Perspective:** Denying equal access to opportunities violates human rights principles that advocate for inclusivity and equal treatment for all members of society, irrespective of their circumstances.

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[21] Shields & Synnot (2016)
[22] McKenzie et al (2023)
[23] Shields et al (unpublished data, 2023)
[24] Rimmer & Lai (2017)

Cost, including entry fees, is consistently given as the key reason for non-participation in exercise by people with disability. By embracing an inclusive approach to physical activity, we can empower Autistic people to lead healthier and more socially connected lives.

Proposed solutions

Recommendation 6.   Initiate a National Cabinet discussion between states and territories to reach a commitment to expand community-based individual and group services and programs for people with disability. This commitment should include:

- an increase in community grants aimed at reducing isolation and mental ill health and increasing community participation in physical activities.

Recommendation 7.   The Department of Social Security Information, Linkages, and Capacity Building program to allocate funding to develop state and territory specific resources and training for inclusion in physical activities and recreation facilities to increase community participation. These resources should be accessible, appropriate, and relevant to the target population, to be determined through community consultation, particularly in regional and remote communities.

Recommendation 8.   State and territory governments to work with local councils to set low-cost entry fees for physical activities, exercise and sport to remove the cost barrier to participation for people with disability.

1.1.3 Employment services

OTARC has undertaken a large body of research on employment of Autistic people to identify barriers and enablers to sustainable employment.[25] In doing so, we have also reviewed the effectiveness of assisted employment supports within the Disability Employment Service (DES) for Autistic people, finding that effective supports had the one common factor - providers understood Autism and the needs of Autistic adults.[26] We also identified a significant knowledge gap that requires specific education and training to meet the needs of Autistic people. Moreover, one of the limiting factors in sustainable employment is the endurance of mental health issues which also requires support and understanding by employers.[27]

Proposed solution

Recommendation 9.   Promote greater connection and collaboration between Disability Employment Services providers and NDIS to reduce long-term unemployment which can further contribute to disability.

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[25] Hedley et al (2017b; 2018c; 2019; 2021)
[26] Hayward & Flower (2023)
[27] Hayward et al (2022)

1.2 Does the original vision need to be rethought because people with disability do not neatly fit into silos or 'tiers'?

The original vision of the NDIS to support people with disability, be it acquired or inherited, so that they can participate in and contribute to the community is a laudable vision. This vision was never reliant on people with disability fitting into silos or tiers but on an ambition of inclusion and available service provision.

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> *It was stated clearly that the NDIS shouldn't be the only way disabled people are supported - but that is still what happened. It again creates a dichotomy of "those who are deserving" of support/help and those who are not. Just like the Disability Support Pension (DSP), where you can miss out on support by 1 point and the allocation of those points is by and large dependent on the rater and their knowledge/understanding of your condition(s), how the condition(s) affect you, and how these interact. I think it would be better if all disabled people were supported under the NDIS, but that the supports they receive match what their needs are – the trouble being that the impact of the inaccessible environment/services has been grossly underestimated.*
>
> Dr Melissa Gilbert - OTARC Postdoctoral Researcher and NDIS participant

A scheme rethink is required to address the market failures it has spurred (see response to Question 4 for more detail), and the insufficiently nuanced processes put in place that have failed to address the diverse needs of the population with disability adequately. In addition to any market changes, the following questions need addressing:

Who should be in the NDIS?

Children and adults with disabilities who cannot be fully supported within their family and local community (including early childhood education and care settings, school, places of work, and recreation) need to be in the NDIS so that the limits their disability imposes upon them do not prevent their participation and contribution in the community.

How can we tell?

By asking the person, their family and/or care partners about their functional capacity to participate in ways that are meaningful to them. And by understanding their developmentally appropriate tasks –for example, a school aged child needs to access school regardless of their disability. If the child has sufficient functional capacity and can receive adequate support from their family and school to learn and participate, they do not need to be in the NDIS. If they need significant accommodations to do so, they will need a NDIS plan to access these accommodations.

What processes should exist?

Accessible and humane processes are needed that do not require the worst version of oneself to be presented to access a NDIS plan. Planners need to be well trained to work with people with disability and their families, to empower them, and to understand their developmentally appropriate strengths, interests and goals and how best to address these within their life context. It is critically important that the decision maker has had direct and meaningful contact with the NDIS applicant:

> *I'm very new to this whole space. I've just put in a NDIS application for myself. So haven't even had my first planning meeting. But what struck me when I was reading the report[28] was that there's a disconnect between the people who you are actually talking to and getting to know and those who are making the decisions. And I think that's where the reasonable and necessary comes in because the person has to be familiar with that particular person. To know what is reasonable and necessary for that person. So I think if we moved more of the power from the faceless bureaucrats to be, you know, dramatic, to the people who are actually connected to the participants, I think that might make a difference.*

OTARC PhD candidate and NDIS plan applicant

Proposed solutions

Please refer to recommendation/s for Question 2.1.1.

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[28] Australian Government (2023)

2. What does reasonable and necessary mean?

2.1 What frameworks or processes could help make this fundamental change?

The human rights approach[29] and the social model of disability are in alignment with the overarching aims of the NDIS and are echoed in the seven principles used to create individual NDIS plans and what is 'reasonable and necessary'.[30] In practice, however, 'reasonable and necessary' seems poorly understood by planners and decision-makers alike as well as NDIS participants.

As outlined in our Introduction, NDIS participants have individual intersectional identities (age, sex, gender, ethnicity, geographical location, language, income, family etc.) and experiences of the world. These contextual markers shape their individual goals, aspirations, and life priorities. It is essential to consider that individual's perspective to determine what is 'reasonable and necessary' for them to live a fulfilling life. This must also include recognising that the person applying for a NDIS plan, be that the person with a disability or their family/carer, is the expert on their disability experience and in defining what is 'reasonable and necessary' for them. This becomes increasingly complex in light of the decreased funding for disability supports within the community, including in education, as summarised in our response to Question 1.

> *"Reasonable and necessary" means support that allows someone to live their life like anyone else. If their disability prevents them from participating in life that they otherwise could WITHOUT supports, then this is reasonable and necessary.*
>
> Associate Professor Josephine Barbaro – OTARC Principal Research Fellow and mother of an Autistic NDIS participant

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[29] Australian Human Rights Commission
[30] National Disability Insurance Scheme (reviewed 2021)

A core issue resides is the system's failure to regard individuals as unique entities. Instead, it categorises them into a limited set of standard disability profiles, undermining the system's ability to consider each individual's distinctiveness and inherent value. The NDIS needs to redesign this process to include the intricacies and diversities within people's experiences.

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> *It (the NDIS) seems that individual employees and the NDIA as a whole seem to have this idea that there are certain types of disabled people. For example, there are people in wheelchairs, there are people with intellectual disabilities, there's maybe a handful of people that they see as disabled, and those are the kinds of supports and services that they see as reasonable and necessary. They're trying to fit everyone in a box and not looking at that individual person's needs.*
>
> Dr Melissa Gilbert - OTARC Postdoctoral Researcher and NDIS participant

Taking the perspective of persons with disability can be difficult. Unconscious assumptions and cognitive biases can lead to adverse outcomes when assessing what is 'reasonable and necessary', particularly when people mask[31] their disability to survive and avoid stigma, often to the detriment of their physical and mental wellbeing.

So, **context and perspective taking** in the processing of NDIS claims seems to be where confusion and unintentional biases appear, leading to participants feeling that decisions made are unfair or inappropriate to their circumstances. A good example of this is detailed on page 18.

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[31] Masking is the practice of concealing one's natural Autistic traits and behaviours in social situations by imitating or mimicking neurotypical behaviours. It involves suppressing or camouflaging aspects of one's true self to fit societal expectations and norms, often resulting in mental and emotional strain.

Is Exercise a Luxury for people with disability?

The NDIS does not fund gym membership because it is considered a day-to-day living cost not related to disability support needs. Exercising at the gym is a popular physical activity in Australia – 35% of adults aged 15 and older participated in this activity in the past 12 months[32] but it does not follow that the cost of gym membership is a 'day to day' living cost[33]. The NDIS perspective is that because gym membership is 'discretionary' or luxury spending for people without disability, it should also be considered as such for people with disability. However, for many people with disabilities, exercise is neither discretionary nor a luxury, it becomes a functional need and right with the reality that exercise is essential for them to maintain their physical function and overall wellbeing.[34]

"for young people with disability, access to a gym for exercise is not a luxury - if they want to continue to maintain their physical function, they need to exercise."

- Professor Nora Shields, OTARC Research Director

People with disabilities often report encountering cost-related obstacles when trying to participate in physical activities.[35] Paradoxically, an explicit NDIS policy excludes funding for gym memberships, in concert with local councils also not routinely offering alternatives for people with disability, together creating barriers to essential exercise opportunities in community settings.

Challenges:

1. **Misconception of luxury:** The prevailing notion that exercise is a discretionary activity perpetuates the belief that gym memberships for people with disabilities are unnecessary or indulgent.
2. **Exclusionary policies:** The current NDIS policy excludes gym memberships, limiting access to inclusive community exercise environments for people with disability.[36]
3. **Undervaluing public spaces:** The intrinsic value of exercising in public spaces for people with disabilities is often underestimated or overlooked.

Importance:

➢ **Wellbeing:** Physical activity is fundamental to maintaining physical function, independence, and overall wellbeing for many people with disability.
➢ **Addressing exclusion:** By revising NDIS policies to include gym memberships and promoting exercise as an essential need, we can mitigate barriers and enhance access to beneficial exercise environments. Increasing the number of adults who are physically active, including those with disability, is also cost-effective[37].
➢ **Empowering public spaces:** Recognising the value of exercising with peers in public spaces emphasises the inclusivity of such environments, encourages equal participation, irrespective of ability and promotes positive societal attitudes to disability.[38]

Equal access to exercise opportunities contributes to improved physical health, overall wellbeing, and enhanced quality of life for people living with disability.

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[32] AusPlay
[33] Administrative Appeals Tribunal of Australia (2019)
[34] Verschuren et al (2016)
[35] McKenzie et al (2023; 2021)
[36] National Disability Insurance Scheme (reviewed 2021)
[37] Eckermann et al (2022)
[38] Shields et al (2023)

During OTARC's NDIS Conversation, the following example was given: A NDIS application was refused because the person with a hidden disability could drive. Their NDIS planner stated, *"if you can drive, if you are capable of driving, then you are not disabled."* This is the type of ill-considered comment which is made to people with disability with sad regularity. The NDIS Conversation also highlighted the difficulty in allowing sufficient time to ensure that NDIS participants can communicate what is 'reasonable and necessary' for them/their dependent to their NDIS planner.

> *Reasonable and necessary. That has been my headache since the roll out of the NDIS. I have two children with high needs and considered under the scheme as profound, meaning that all their life and for the rest of their lives they will need substantial funding to be well supported. It took me a year to prepare for the planning meeting and account for every hour of every day, 365 days, 8,760 hours, and it did not stop there. What is reasonable and necessary for my children is completely different for each of them and the over 500 thousand participants accessing the scheme.*

> *I had to show the planner who initially agreed to a one hour meeting per child that we have a complex situation at hand. She was confident that we can get it all done in the time frame and from the first 15 minutes it was very apparent that we were not going to agree on what is "reasonable and necessary" for my children. Six hours later, we were still pouring over all the documents, the daily planning, the weekend, the public holidays, I even had set up the cost per line item, per hour, per day, and for the whole year.*

> *It is what is reasonable and necessary for them to thrive in the community.*

> *I didn't want the funding for a gym membership, but wanted the funding for a support worker to accompany them to go swimming because if they don't exercise, it affects their health, and they don't sleep during the night. If they don't sleep, I am awake all night, I am tired and can't go to work in the morning and will be "at risk" of losing the precious few casual hours of paid work I had at the time. By giving the repercussion and the outcome on what's going to happen if I don't get the funding and why I urgently needed, I was able to get it.*

> *After the first year I documented the application of the plan, including where we started, how did it happen, and what was the outcome. So that meant that the following year, I kept arguing I'm not adding hours to the plan. It is not my problem if the cost of the NDIS is going up; the cost of the hours is going up, but I am requiring the same amount of hours. And that's a point that is always missed when caregivers are talking with their planners. Oh, my word, your plan now is going to be over $200,000! It's not my fault if the cost rate per hour on Sunday is currently at $118 an hour to access a support service. It is not my fault. But it is reasonable*

and necessary for my son to attend his friendship group. I need my son to go swimming 4 times a week so he can sleep all night so we all can rest.

Reasonable and necessary funding should be based on the outcome for my children, for the whole family, and for the community.

"

I keep arguing and I keep advocating that my son, bless his heart, my youngest son is part of a friendship group, peer-like group with some neurodiversity, but most of them are what they consider in the world – neurotypical. He goes out with them, he goes camping, he goes Friday night, he does all that I because I was able to argue that it is his right: to be with his peers and to be loved in the community. Everybody in the community knows who my son is because he goes to the same fish and chip shop. They know who he is. They wait for him. They wait for his wallet to come out. They are empowering his social skills. They're practicing with him. He does all of that, but it's been a work in progress because I was able to argue what is reasonable and necessary for him to live 10 years from now as independently as possible.

Personally, a great outcome from the NDIS and what became support for what is reasonable and necessary for my children, translated into supporting me to commit to re-join the workforce on a fixed part-time basis.

Dr Nancy Sadka - OTARC Senior Research Associate and Mother of three Autistic NDIS participants

'Reasonable and necessary' means you can live your day-to-day life without having to go to extreme lengths to have access to things that people without disability have. See the case study on page 21 for an example.

The case for Autism-friendly Programs – swimming lessons

Autistic Children deserve equal access to essential skill-development activities like swimming lessons. Unfortunately, the absence of Autism-friendly practices in local swim centres forces parents to go to great lengths – both figuratively and literally – to ensure their child's participation. These challenges not only disrupt their child's access to enriching experiences but also place immense burdens on parents who are already navigating complex care schedules.
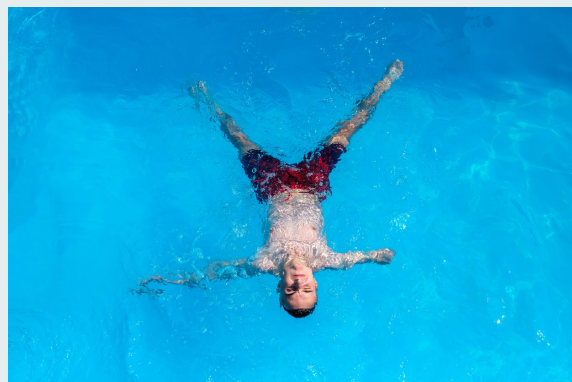
Challenges:

1. **Lack of Autism-friendly activities:** The absence of swim centres offering autism-friendly lessons leaves parents with limited options for their child's aquatic education, impeding their development and water safety skills.

2. **Burden on parents:** The need to tirelessly advocate, educate, and search for suitable facilities often leaves parents exhausted, diverting focus from quality family time and holistic child development.

3. **Safety concerns:** The inability to access swimming lessons tailored to their needs increases the risk of drowning for Autistic children.[39]

Importance:

➢ **Equal opportunity:** Autism-friendly swimming lessons ensure that Autistic children can access vital life skills and engage in activities like their peers, promoting inclusion and equal opportunities.

➢ **Empowerment for parents:** Access to nearby, tailored swimming lessons would empower parents to spend more quality time with their children and reduce the burden of advocating for basic services.

➢ **Life-saving impact:** With drowning being a significant cause of death among Autistic children, the implementation of Autism-friendly swimming lessons holds potential to save lives and foster water safety awareness.

We need to create a future where Autistic children can confidently participate in every-day activities to gain valuable skills while reducing safety risks. By addressing this pressing issue, we are not only fostering individual growth but also contributing to the overall wellbeing and safety of our communities.

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[39] Royal Life Saving Australia (2023)

2.1.1 Workload and assessment

From an administrative standpoint, it's apparent that the workload faced by NDIS planners is substantial. Understanding the full range of distinct disability profiles, let alone the different profiles within a single disability category such as Autism, presents a considerable challenge. This complexity necessitates a comprehensive understanding of diverse cases and contexts. Given these circumstances, it's understandable that planners inadvertently rely on convenient stereotypes or make hasty judgments, with the pressure to manage a demanding caseload leading to oversimplifications in their approach.

Establishing what is 'reasonable and necessary' to support a person with disabilities should be contingent upon a fundamental question: Would this level of support still be essential if the individual did not have the disability? This criterion prompts us to acknowledge that one's disability status and context do not exclusively dictate support needs. If the support would not be imperative in the absence of the disability, then categorising it as 'reasonable and necessary' is justifiable. Conversely, suppose the support would be necessary regardless of the disability. In that case, it might point to a broader need applicable to most people and more reasonable to be managed from outside of the NDIS.

> " *Speak to those with lived experience – identifying what are the "core" things that allow people to live their life like anyone else. And developing a "network tree" that identifies where there are possible blockages to "living life like anyone else" (within the possibilities based on the person's disability).*
>
> *Associate Professor Josephine Barbaro – OTARC Principal Research Fellow and mother of an Autistic NDIS participant*

There is opportunity to improve perspective-taking and to have a deeper understanding of individual context by planners. One approach is to Incorporate a planning tool to represent the diverse profile of disability of the NDIS applicant/participant. Tools exist to do just this. For example, the Positive Partnerships Planning tool[40] allows young people to focus on different areas that contribute to their experiences of everyday life based on the diversity wheel. It includes descriptions of sensory processing, executive function, strengths and interest, connections to culture and community, self-care and independence skills, and social and communication skills.

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[40] https://planningtool.positivepartnerships.com.au/
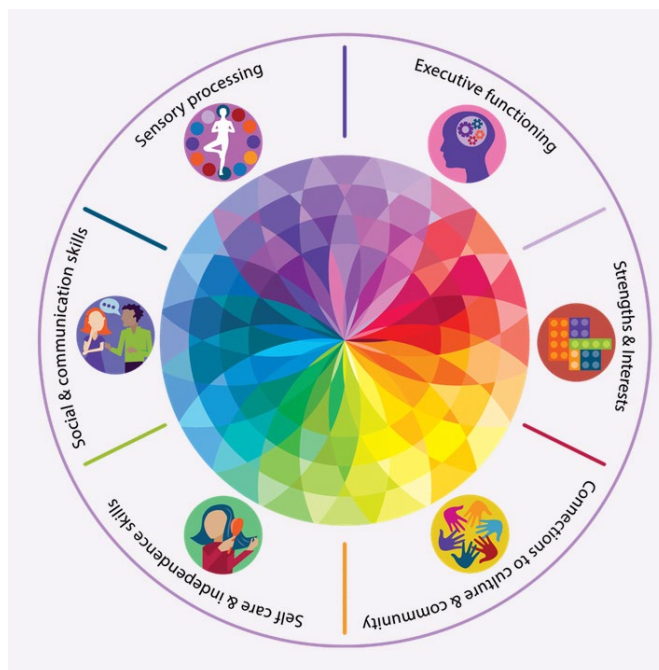
Proposed solutions

To enable fairer decision-making regarding NDIS client's needs:

Recommendation 10. Explore and evaluate planner caseload optimisation to facilitate specialisation in:

- distinct areas of disability (e.g., neurodevelopmental disabilities; physical disabilities; psychosocial disabilities)
- physical/cognitive age groups of childhood, adolescence, adulthood, etc., to foster developmentally appropriate decision-making for clients.

Recommendation 11. Commit to training planners in their area of speciality through traditional (e.g. research) and non-traditional (e.g. direct consultation with lived experience experts) means.

Recommendation 12. Increase time allocation for individual NDIS participant/applicant decision making.

Recommendation 13. Update internal procedures to consider comprehensive profiles such as sensory processing, executive function, strengths and interest, connections to culture and community, self-care and independence skills, and social and communication skills –to determine *what* is 'reasonable and necessary' the a given individual. To facilitate this, the NDIS should develop and implement an interactive tool to be used by applicants/participants prior to a planner meeting to establish that individual's context and enable planner perspective taking.

Recommendation 14. Include provisions for people with disabilities to obtain funding for gym memberships and other community participation initiatives based on participant goals.

3. Why are there many more children in the NDIS than expected?

We propose two potential answers. First, an under-estimation of prevalence of children with disabilities. As an example, the Autism prevalence data used by the Productivity Commission in planning the NDIS rollout was 1 in 150. Our research shows that Autism prevalence at the time was significantly higher, and consistent with the international prevalence data at the time of 1 in 69.[41] A more recent Australian screening and prevalence study conducted from 2013 to 2018 found that 1 in 31 children are Autistic.[42] Based on a 4% false negative rate, this is still likely to be an underestimation, but is consistent with the most recent Centers for Disease Control and Prevention data of 1 in 36.[43] Using the Longitudinal Study of Australian Children data at age 12–13 years, May et al have reported a prevalence of 4.36%.[44] The second reason is that, as Minister Shorten so frequently states, the NDIS is the only lifeboat in the ocean. Without good community supports, everyone swims to where they can find refuge.

3.1 What is the best way to support children with disability and families?

3.1.1 Early screening, identification and timely provision of supports

The most efficient way to support all developmentally vulnerable children is to identify them and commence supports within their first 1000 days. Currently, the mean age of children within the Early Childhood Approach (ECA) is between 4 to 5 years! Fewer children will need longer-terms supports if this is achievable outcome is realised. Our research supports this. We found that Autistic children who access the group-based Early Start Denver Model (ESDM) embedded in childcare for one year make significant developmental gains across a variety of early learning and care settings, increasing their chances of participation[45] in mainstream settings, with an earlier age of access bolstering their outcomes[46]. Importantly, our research also shows these children continue to make significant cognitive gains into their school years,[47] a finding we have recently replicated in new (unpublished) research. We have also found that Autistic children who receive an early diagnosis (under 2 years of age), compared to those diagnosed between 3- to 5-years-old were:

➢ 3 times less likely to have an IQ < 70 at school-age

➢ 1.3 times more likely to be in a mainstream school.

Our research has revolutionised how early childhood professionals are trained to monitor the prodromal signs of Autism in very young children. The Social Attention and Communication Surveillance (SACS) studies are the foundation of the SACS-R (11 to 30 months old) and SACS-Preschool (3.5 to 5 years old) training programs on monitoring early social attention and

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[41] Centers for Disease Control and Prevention (2023)
[42] Barbaro et al (2022)
[43] Maenner et al. (2020)
[44] May et al (2020)
[45] Clark et al (2017; 2018)
[46] Vivanti et al (2016)
[47] Vinen et al (2018; 2022); Clark et al (2023)

communication behaviours as early markers of Autism.[48] Doing so from 12 months of age and through to second year of life is efficacious, with 82% of infants and toddlers identified at 12, 18 and 24 months having a confirmed Autism diagnosis.[49] Importantly, all children who were identified but not diagnosed with Autism had other developmental delays.

In 2018, OTARC successfully tendered to train all maternal and child health (MCH) nurses in Victoria using the SACS to improve access to Autism assessment, diagnosis, and early supports. After training, MCH nurses effectively incorporated SACS-R assessments into their work practice, completing 82,581 assessments within the first six months following training.

Based on the SACS methodology, we developed a free video-led app to enable parents to identify potential signs of Autism in their children prior to age 3-years of age. With over 110,000 downloads since its launch in February 2016, ASDetect[50] is empowering parents and caregivers around the world, with the application now available in English, Mandarin Chinese, Spanish and Slovak. The app guides parents through age-appropriate assessments, using videos of Autistic and non-Autistic children to illustrate key social attention and communication milestones. Parents receive an on-screen result of either a 'low' or 'high' likelihood of Autism, and a detailed email summarising the results designed to be shared with their family doctor. This integration with healthcare professionals ensures that caregivers receive the support and guidance necessary to make informed decisions about their child's care and ongoing support.[51]
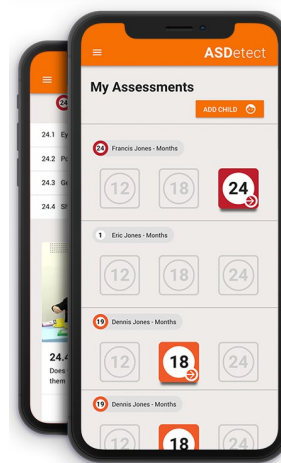
Proposed solutions

Recommendation 15. State and territory governments to implement Social Attention and Communication Surveillance (SACS) nationally as recommended by the Senate Select Committee for Autism via all primary health and early education and care (ECEC) professionals.

- All identified children are referred to the Early Childhood Approach for supports within their first 1000 days.

Recommendation 16. State and territory governments to promote the use of the ASDetect app for parents.

3.1.2 Education and training

One of the most effective approaches to supporting children with disabilities and their families is to enhance the knowledge and skills of professionals, particularly those in early childhood education and care (ECEC), through comprehensive training, including in inclusive practices. Fifty eight percent of Australian children are in ECEC by age 2-years. By enhancing their training, ECEC professionals can create supportive environments for neurodivergent children and families, fostering a sense of belonging.

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[48] Barbaro et al (2010; 2022)
[49] Barbaro et al (2022)
[50] https://asdetect.org/
[51] Barbaro & Yaari (2020)

Proposed solutions

Recommendation 17. Implementation of Recommendation 12 of the Senate Select Committee on Autism - "…the Australian Government develop guidelines on autism- friendly service design through the National Autism Strategy in order to help service providers tailor services and service environments to meet the needs of autistic individuals."[52]

Recommendation 18. Implementation of Recommendation 9 of the Senate Select Committee on Autism - "…National Disability Insurance Agency continue to improve the capacity of its staff, including Local Area Coordinators, to provide better support to Autistic people. This should include a focus on both understanding and meeting Autistic participants' support coordination needs".[53] In addition, we recommend:

- that this capacity building be extended to service providers delivering supports for NDIS participants.

3.1.3 Process streamlining and simplification

Simplifying the process for accessing inclusion support is essential within education settings like ECEC. Currently, this process can be unnecessarily complicated and time-consuming, often leading to discouragement and abandonment of the application. Streamlining these systems and making them less burdensome would ensure that families can readily access the assistance they need, and in a timely manner. A streamlined approach would save time and increase access to available resources, contributing to the overall well-being and success of children with disabilities and their families.

Proposed Solution

Recommendation 19. The NDIS recommend review of the barriers to inclusion support and systematically remove or significantly reduce these barriers to facilitate more streamlined access to inclusion supports.

3.1.5 Schooling universal supports

See Section 1.1.1 for details.

3.1.6 Universally designed public spaces

Dedicating more effort to creating universally accessible environments in schools and other spaces could significantly diminish the impact of disability. In disability-friendly environments, the extent of disability naturally decreases by removing social and environmental barriers that contribute to disability. What remains of the disability is what requires additional supports. This change would bring about a reduction in the government's financial burden.

The key is understanding that by fostering inclusive and accessible environments, we simultaneously enhance the quality of life for everyone while significantly reducing the challenges associated with disability. By striving to create environments where everyone can thrive, we pave the way for a more

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[52] The Senate Select Committee on Autism (2022)
[53] The Senate Select Committee on Autism (2022)

just and inclusive society that benefits everyone, particularly children with disabilities and their families.

Proposed Solution

Recommendation 20. State, territory and local governments mandate all new developments and significant upgrades to existing developments of public spaces meet universal design principles.

Pathway from early identification of concerns to early childhood supports

We need a national reset in the approach to early childhood, ensuring that all children have universal access to foundational supports through clearly articulated pathways. Instead of working around broken systems, those system not functioning well should be reset. This will undoubtedly have significant cost implications. However, investment in early childhood will foster longer-term positive outcomes for children and their families and, ultimately, the Australian community and its economy.

Regardless of where they live, all children should have access to a minimum number of maternal and child health (MCH) visits, where their development (social-emotional, language and physical development) and the primary caregiver's wellbeing are monitored throughout the first 3 years of life. In Victoria, these key ages and stages visits occur at 2 weeks, 4 weeks, 2 months, 4 months, 6 months, 8 months, 12-months, 18 months, 2 years, and 3.5 years.

Developmental surveillance (not screening) is critical as children develop at different rates; thus, once-off screening is ineffective in identifying developmental concerns. Moreover, the emergence of neurodevelopmental conditions varies both between and within conditions. For example, some children will show early signs of autism at 6 months. In contrast, others will have neurotypical development within the first 18 months or so, with signs of autism becoming more evident towards the end of the second year.

In addition, opportunistic contact with children, such as during immunisation, should also be used to monitor development using validated tools, including in early childhood education and care settings (ECEC). The care setting is ideal due to increasing numbers of children accessing these as early as 6 to 12 months when parents' return to work following parental leave.

Varied tools are used within different systems to monitor development (e.g. Parents' Evaluation of Developmental Status PEDS; Ages & Stages; SACS) and undertake developmental assessments once concerns are identified (e.g. Brigance; Bailey). At this point, children should be referred immediately to the ECA. A developmental assessment is an important first step to determine those areas needing initial early short-term support.

Foundational supports should be community-based, delivered in children's everyday settings (e.g., home, ECEC, kindergarten - depending on the child's age), and informed by a transdisciplinary team. Focus should not just be on the individual child but also on families to build parental capacity to support children's development. Access to information for families is critical at this stage, with excellent, free information already available (e.g. Raising Children's Network). However, hands-on support for families should also be provided by registered Early Childhood Partners.

After a fixed period (approximately 3 months), the Early Childhood Partner will have good insight into the effective and appropriate next steps for the child and their family, be this continued early supports within the current setting or referral for a NDIS plan to enable access to more intensive supports.

4. Why aren't NDIS markets working?

4.1 What needs to be done to ensure NDIS markets serve the interests of people with disability, rather than the other way round? Where will markets not work?

When designing, structuring, and supporting NDIS markets, there must be careful consideration of its impact on community services. To support people with disabilities, NDIS markets must balance convenience and inclusive community participation, fostering empowerment, well-being, and equitable access.

4.1.1 Registered NDIS services

NDIS participants want to be free to choose their own supports and service providers; however, concerns arise when this approach exposes individuals vulnerable to exploitation due to a lack of safeguards.

Requiring NDIS registration for all providers is unrealistic and creates barriers to entry for new providers, further disadvantaging consumers in regional and remote communities.

Current barriers highlighted at our recent OTARC's NDIS Conversation included:

➢ Cost

➢ Complexity

➢ Time consuming

➢ Disproportionately difficult for smaller providers

➢ Process especially difficult for neurodivergent service providers.

There is a clear need for a division of services that require oversight and those that don't. For example, it is unnecessary to be registered for providing gardening services, but for a therapy-based support program, it is important that providers are registered and audited to ensure the provision of evidence-based care and the appropriate monitoring of outcomes.

> *We're accessing non-NDIS providers. Services for my son who are very affirming and very good, but I researched to know who to choose. Still, other people may be prone to exploitation by providers who don't do the right thing. I want to know why the process of registering is so laborious. That could be fixed if everyone can be registered and the process is not as laborious.*
>
> Associate Professor Josephine Barbaro – OTARC Principal Research Fellow and mother to an Autistic NDIS participant

It is unfortunate that many specialist service providers choose not to be NDIS registered. Moreover, families are unaware of the importance of selecting registered providers because there is insufficient information regarding the importance of registration, and also the paucity of available services means

choice of services, registered or otherwise, is limited. Registered providers inform us that the monitoring of service delivery and service outcomes is rarely efficient, nor it is ambitious. The focus of monitoring is largely on administrative aspects of delivery rather than on the quality of the programs being delivered and the ensuing outcomes.

Based on the above, it is critical that the registration process is efficient, transparent and streamlined to ensure that service providers that meet the NDIS standards can register with ease to ensure the delivery of best practice.

Proposed Solutions

Recommendation 21.   Barriers to NDIS registration should be identified and minimised to facilitate registration by more providers who meet NDIS evidence-base standards.

Recommendation 22.   The NDIS should introduce a more effective monitoring program of registered providers which focuses on evaluating the quality of the programs being delivered and the measurable outcomes for NDIS participants.

4.2 How can the scheme help participants become more independent; not more dependent?

4.2.1 Increase social acceptance and community participation

Valuing and recognising the differences of Autistic people while reframing Autism as something not in need of 'fixing' is crucial for preventing systematic discrimination and stigma faced by Autistic people.[54] The fundamental social-communication differences between Autistic and non-autistic people (known as the "Double Empathy Problem"[55]), with emphasis in society that only one way of engaging in social-communication is the 'right' way (i.e. neurotypical social engagement) can play a role in segregating, ostracising, and isolating Autistic people from social and friendship circles. This can lead to feelings of loneliness and depression.[56] Loneliness serves as a transdiagnostic risk factor for suicide.[57]

Research conducted by OTARC highlights that within the Autistic population, loneliness and inadequate social support stand as risk factors for suicide.[58] Moreover, bullying is prevalent among Australian Autistic youth, affecting 58% of those without an intellectual disability and 50% of those with an intellectual disability.[59]

It is likely that discrimination and stigma significantly contribute to the mental health struggles and isolation that Autistic individuals face, which consequently results in elevated rates of suicide compared to the general population.[60] To address these challenges, promoting societal changes that improve the comprehension and acceptance of differences, combined with implementing programs that facilitate peer connections, can effectively mitigate these risk factors.

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[54] Hedley et al (2022)
[55] Milton (2012)
[56] Mazurek (2014); Rai, et al (2018a; 2018b)
[57] Glenn et al (2017); Glenn et al (2018)
[58] Hedley et al (2018b; 2018b; 2017a)
[59] Richdale et al (2022)
[60] Hedley et al (2022)

The Suicide Response Project: Inclusive approaches for an equitable society

Often, individuals with unique experiences, such as Autistic and sex/gender diverse individuals, face specific challenges that available approaches may not adequately address. In 2020, a collaborative team of researchers (two from OTARC), academics, and psychologists developed an innovative educational website focused on identifying and responding to suicide risk in others – **The Suicide Response Project**.[61]

This pioneering resource was designed with a strong commitment to inclusion, ensuring the active involvement of individuals with lived experiences of suicide ideation and behaviour, including Autistic and sex/gender diverse individuals. The project prioritised the voices and participation of marginalised communities, recognising the importance of co-designing the resource with individuals with firsthand experience with suicide ideation and behaviour. It also included input from their families and people with lived experience of being bereaved by suicide or having supported someone after a suicide attempt.

The educational website encompasses 12 comprehensive modules, integrating multimedia elements, including animated videos, to enhance accessibility. The resource underscores the importance of equitable access to vital information by catering to diverse learning styles and communication preferences. It includes resources for professionals.

OTARC research partners Aspect and Untapped have promoted the resource's utilisation, and it is now also incorporated into the RUOK website.[62] This collaborative endeavour broadened the resource's reach and impact, ensuring it was accessible to a wider audience. As the resource continues to be promoted and utilised, its potential to save lives, raise awareness, and contribute to a compassionate and understanding society is undeniable.

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[61] https://www.suicideresponseproject.com/
[62] https://www.ruok.org.au/neurodivergent

Proposed Solution

Recommendation 23.   NDIS plan development should incorporate community participation goals and active inclusion as a priority.

Recommendation 24.   States and Territory governments to engage in an active public education campaign on Autism, with the support of the Australian Government Department of Social Services, to:

- dispel myths regarding a 'right way' to engage socially.

- increase awareness and acceptance of Autistic social-communication styles, with an aim to facilitate social inclusion of Autistic people.

- facilitate access to co-produced public mental health material specific to Autistic people, such as The Suicide Response Project.

4.2.2 What is evidence-based practice?

Evidence-based practice is difficult to define. The origins of evidence-based practice stem from medicine – "*The practice of evidence-based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research*".[63] We now understand that evidence-based practice involves a combination of factors. Research evidence is crucial, but so is the knowledge gained from practical experience in the field and the depth of knowledge held by those with lived experience. Clinicians and advocates with lived experience often pioneer novel ideas and sound, person-centred practices before they're formally recognised, which often outpaces formal research by several years. **The research to practice gap is a staggering 17 years!**[64] Therefore, evidence is based on three equally important pillars[65] that should be underpinned at all times by lived experience:

1.   Research evidence.

2.   Clinical practice and expertise (trauma informed, culturally responsive, LGBTQIA+ inclusive).

3.   Clients' values and preferences and lived experience.

This combination of research, lived experience, and clinical practice creates a well-rounded conceptualisation of evidence-based practice.

To ensure informed decision-making, the NDIS should evaluate evidence for practices based on the confluence of research findings, expert clinical consensus, and learnings from lived experience rather than relying on any of these factors alone. The NDIS should also play a role in educating the broader disability network, including families and service providers, of this nuanced meaning of evidence-based practice. It is in this way that participants and planners can make informed choices.

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[63] Sackett (1997)
[64] Morris et al (2011)
[65] Victoria State Government (Department of Health) (2021); American Speech-Language-Hearing Association

Proposed Solution

Recommendation 25. The NDIS to adopt a definition of evidence-based practice that acknowledges the intersection of research evidence, clinical practice and expertise and the clients' values and preferences, ALL underpinned by lived experience.

4.2.3 Services in silos

A prevalent topic of discussion at OTARC's NDIS Conversation was the view that service providers, including allied health professionals, are siloed in their approaches. An observed trend among allied health service providers is their isolated presence in separate clinics, detached from the community and each other. Such clinic-based approaches result in a:

- ➢ lack of collaboration

- ➢ lack of skill generalisation

- ➢ failure to deliver using transdisciplinary approaches.

Proposed Solution

Recommendation 26. States and territory governments to increase dedicated and ongoing financial support for non-profit organisations, prioritising those who use transdisciplinary approaches to take advantage of their deep knowledge of, and historical ties to, the disability sector.

4.2.4 Build family capacity

Currently, the sole focus in the NDIS is on the participants, regardless of their developmental stage. Building the capacity of families is core to enhancing the participant's independence. It is critical to enable families to build upon the participant's strengths and support their goals. Supporting families with culturally sensitive information, advice and skill development through offering services for them, especially via the community health and education sectors, which promotes them as key partners in securing the best developmental outcomes for the NDIS participant, will go a long way in promoting independence.

In the context of Autism, evidence-based initiatives developed under the Helping Children with Autism Package, such as the free Early Days Program for families of newly diagnosed children, provided crucial early support for families. They fostered connections to local supports, including peer supports, for participating families. These workshops were extremely popular and highly evaluated. They consistently demonstrated positive feedback, with parents reporting that the workshops provided, among many things, practical ideas, assisted with goal planning, and a valuable opportunity to connect with other parents and carers. Unfortunately, funding for delivering these workshops was terminated, resulting in the loss of a valuable resource for families.

Proposed Solutions

Recommendation 27. Incorporate regular monitoring of service providers' evidence-based practice use, including active client outcomes monitoring. Expecting consumers to discern evidence-based practices that will control markets is unrealistic.

Recommendation 28. Extend service providers' registration to more allied health providers to ensure accountability through periodic audits and to promote inclusive and transdisciplinary practices.

Recommendation 29. Encourage collaborative efforts among all professionals to ensure holistic support for NDIS clients, including focusing on their families. Ultimately, this approach seeks to establish a dynamic, transparent, and diverse NDIS ecosystem that empowers individuals with disabilities and their families, ensuring their rights to quality support and well-informed decision-making.

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RELEVANT UNITED NATIONS SUSTAINABLE GOALS