

Disability Strategy Review Submission

Response to questions on the proposals in the Position Paper

Written by the National ADHD Consumer Forum (NACF)

The National ADHD Consumer Forum (NACF) has been created to be a national voice for the ADHD community. The NACF has reviewed the position paper within the context of representing the broad views of many ADHD community organisations. Our submission was informed by a series of national community forums conducted during the past four months.

NACF welcomes the opportunity to provide feedback for the new National Disability Strategy (NDS) and we are available to provide more detailed advice to the Department at any time to further their deliberations.

ADHD is not included on the Federal Government's *List of Recognised Disability* despite its recognition in the Disability Discrimination Act (1992), until this is addressed true equality is not possible for those living with ADHD.

Question 1 (250 words maximum)

During the first stage of consultations we heard that the vision and the six outcome areas under the current Strategy are still the right ones. Do you have any comments on the vision and outcome areas being proposed for the new Strategy?

The NACF endorses changing the vision statement to include the language "*members of the community*" to ensure this is an accessible idea for all people with a disability.

However, NDS Outcomes are not being met for people with ADHD for the following reasons:

Economic security. The ADHD community is economically disadvantaged as it remains unfunded and unrecognised in The Federal Government's *List of Recognised Disability*. Diagnosis and treatments are largely self-funded and expensive. Additionally, untreated ADHD can have long term impacts on economic security, and capacity to contribute to the community¹.

Inclusive and Accessible Communities. Members of the ADHD community consistently face exclusion within community and educational contexts² and many face harsh scrutiny of behaviours in public settings. Anecdotal evidence supports the conclusion that ADHD's exclusion from the NDIS has resulted in a redirection of services to those funded by the NDIS.

¹ The Social and Economic Costs of ADHD in Australia - Report; Deloitte Access Economics, July 2019

² Mulholland S. (2017) ADHD: The Untold Truths of the ADEP (Australian Deficit in Educational Policy), International Journal of Disability, Development and Education, 64:1, 1-18, DOI: [10.1080/1034912X.2016.1164835](https://doi.org/10.1080/1034912X.2016.1164835)

Rights protection, justice and legislation, ADHD is over represented within the criminal justice system³. Few criminal cases include expert ADHD testimony. There are limited safeguards in the workplace when compared to other ‘recognised’ disabilities.

Learning and Skills: The manifestation of ADHD neurology in children adversely impacts their ability to learn⁴. There are multiple examples of negative prejudicial treatment by teachers and other children through a lack of understanding of the condition and a lack of resources to manage the condition effectively in schools.

Health and wellbeing: For optimal outcomes ADHD needs to be identified and treated. The current health system impedes this optimal outcome.⁵

Question 2 (250 words maximum)

What do you think about the guiding principles proposed here?

Guiding Principles are important in framing policy, but they are meaningless if they are not evaluated for their effectiveness.

NACF strongly advises an annual review process that can assess the document’s efficacy.

Involve and engage: This principle is critical for the ADHD community as appropriate policy cannot be created without the input of the community for which it affects. As an unrecognised, unfunded condition, Federal and State policy makers must seek deeper engagement with those advocating on behalf of the 800,000+ people (and their families) living with the condition in Australia.

Design universally, design that is thoughtful and mindful of all capacities, cultures and orientations is fundamental to ensure appropriate policy creation and implementation.

Engage the broader community, a critical principle, engaging the broader community provides opportunities to gather input but also to educate and break down barriers and reduce prejudice.

Address barriers faced by priority populations, the word “priority” has a negative connotation. Its use implies that there are some disabilities that are more important than others. This word should not be used here. Prejudicial language should not be used in the NDS as communities that are unfunded already experience systemic neglect.

Support carers and supporters. The word “supporters” should be changed to “advocates” as this is the language more often used by the community.

³ Freckelton I. Attention deficit hyperactivity disorder (ADHD) and the criminal law. *Psychiatr Psychol Law* 2020; 26: 817-840.

⁴ Cussen A, Sciberras E, Ukoumunne OC, et al. Relationship between symptoms of attention-deficit/hyperactivity disorder and family functioning: a community-based study. *Eur J Pediatr* 2012; 171: 271-280

⁵ Deloitte Access Economics (n.24) 19.

NACF advocates for an additional guiding principle “**Best practice and evidenced based**”, supported by an Expert Advisory Committee. Policy should be designed with this principle at its core.

Question 3 (250 words maximum)

What is your view on the proposal for the new Strategy to have a stronger emphasis on improving community attitudes across all outcome areas?

The NACF agrees there needs to be strong emphasis on improving community attitudes across all outcome areas. There are many opportunities in workplaces, the justice system, the education sector and the community sector to improve understanding and attitudes. But campaigns need to be coordinated with a single, clear and easily understood central message across all disabilities, whilst remaining specific to a specific disability. Targeted specific messaging with a common theme. Most importantly, efforts to change or improve knowledge and attitudes must be led by the Communities themselves at the grassroots level.

This could include but are not limited to the following:

- Adequate teacher training to ensure they are able to cope in classroom settings with diverse needs, and are able to promote an inclusive attitude to their students
- Short training programs for employees across all sectors, and
- Training for workers and volunteers across the community sector.
- Required professional development for those in the legal and justice system.

Question 4 (250 words maximum)

How do you think that clearly outlining what each government is responsible for could make it easier for people with disability to access the supports and services they need?

Without doubt better quality information that can be easily accessed is required. Few people would know of or understand the *Principles to Determine the Responsibilities of the NDIS and Other Service or the Systems and accompanying Applied Principles and Tables of Service (APTOS)*. The Tune Report (2019) identified widespread confusion among consumers trying to access the NDIS and addressed the importance of accessible information through programs like Easy Read.⁶

Across Government agencies, at every level, there is little understanding of their roles and responsibilities within the context of the disability community. The 2019 Productivity Commission (PC) Review of the National Disability Agreement (NDA) was damning in its findings regarding a lack of clarity of Government’s responsibilities, recommending better, more accessible information about services both NDIS and mainstream (services not included in the

⁶ Tune D. Review of the NDIS Act 2013 - Removing Red Tape and Implementing the NDIS Participant Service Guarantee,. December 2019 (p.9-10)

NDIS)⁷. There is a plethora of policy (State and Federal) that is not coordinated or harmonised, leading to confusion, frustration and uncertainty for those seeking help.

Our community consultation process revealed that there is a widespread impression within the community, including the not for profit sector and some state governments, that if the disability is not funded under the NDIS then there are no available services and support and no government agencies are responsible for supporting this segment of the community.

NACF also supports the PC recommendation that a gap analysis must be conducted to inform any process that aims to make it easier for people with a disability to access the supports and services they need.

Question 5 (250 words maximum)

How do you think the Strategy should represent the role that the non-government sector plays in improving outcomes for people with disability?

For decades the NGO sector has been at the coalface in the community assisting people living with disabilities. They have consistently filled information and services gaps left by Governments, after decades of underfunding disability services, and will continue to do so in the future. Research has shown that many NGO's approach their communities with overwhelming, dedication care and concern⁸. But, the horrific and disturbing revelations from the Royal Commission speak to a desperate need to overhaul the provision of services and how they are monitored and evaluated.

The NACF is awaiting the imminent release of the interim report from the Commission and will closely examine any conclusions and recommendations contained therein.

For many disabilities, including ADHD, early intervention is pivotal to better life outcomes, and NGO's play a critical role in helping parents and carers through what is often a highly distressing and confusing time. So many disability NGO's in Australia, that provide vital information, are poorly funded and operate on the goodwill and hard graft of volunteers.

NACF advocates for a more forensic and coordinated examination of the Information Linkages and Capacity grants, which is necessary to ensure these NGO's are able to continue to fill system-wide gaps that undermine achieving the NDS outcomes.

Question 6 (250 words maximum)

What kind of information on the Strategy's progress should governments make available to the public and how often should this information be made available?

⁷ Review of the National Disability Agreement, Productivity Commission Study Report 2019 (p.12)

⁸Son, J, Debono, D, Leitner, R, et al. (2019) Pass the parcel: service provider views on bridging gaps for youth with dual diagnosis of intellectual disability and mental health disorders in regional areas. Journal of Pediatrics and Child Health 55

NACF believes an annual audit and evaluation of the NDS is necessary. An advisory group independent of the Government should compile this report to ensure its credibility and integrity.

The PC's informative and comprehensive annual Report on Government Services (ROGS) provides an excellent breakdown of Services for People with a Disability, but it lacks a qualitative analysis that a future NDS should deliver. The same could be said of the NDIS quarterly figures.

The 2020 ROGS, identifies numerous gaps in figures available to adequately report against the Framework of Performance Indicators suggesting that there are problems compiling the correct data⁹. This needs to be addressed as a matter of urgency. NACF hopes the proposed National Disability Data Asset (NDAA) will address these concerns but would suggest that providers in receipt of Government funds be compelled to provide data in the same manner that aged care providers are now required to. This new body must also include members of the Community in a consultative role. It needs to be a wider group than those selected by the PC for its NDA Review.

Any annual report needs to be in an easy-to-read format, with downloadable infographics, and audio options. This should be published and promoted on the Department's website and more broadly, with compatible formats for mobile, and commonly used social channels. It should be distributed to the relevant groups and organisations in advance for comment along with a series of assets to ensure its relevance and promotion to their own consumers.

Question 7 (250 words maximum)

What do you think of the proposal to have Targeted Action Plans that focus on making improvements in specific areas within a defined period of time (for example within one, two or three years)?

A targeted action plan could provide the framework for specific actions that have been highlighted but should not be "the be all and end all". As the strategy is implemented new opportunities to have impact will be revealed and some of the actions may become irrelevant. The plan should be a fluid document open to change when required, and with explanation of changes made, without fear of unjust ramifications, if important and necessary changes occur. Additionally, targeted action plans need to be associated with a responsible department and relevant officer to ensure that appropriate monitoring and evaluation is occurring.

Finally, the danger of picking specific areas is that these areas will be focused on to the exclusion of the areas that were not selected, hence ongoing reviews of which areas are relevant are also needed.

⁹ Report on Government Service 2020, Productivity Commission. (Chpt 15 Services for people with a disability)

Question 8 (250 words maximum)

How could the proposed Engagement Plan ensure people with disability, and the disability community, are involved in the delivery and monitoring of the next Strategy?

The engagement plan should include a strategy to ensure ongoing buy-in from the disability community. As suggested earlier, it requires a multi-layered approach utilising as many channels as possible in a coordinated way.

Including people in the plan with lived-experience is critical to success. It also needs to incorporate the employment of individuals who are specifically hired to create and manage ongoing relationships with stakeholders within this community. These individuals should be supported with appropriate marketing functions to allow them to advertise, contact and connect with those community stakeholders effectively.

The engagement plan needs to be a fluid document with an associated fluid process. Information should flow back and forth through the process. Involving the community being informed throughout the implementation process and allowing for feedback to flow back to ensure corrections and realignment occurs as necessary.

Question 9 (1000 words maximum)

Is there anything else you would like to share about the ideas and proposals in the position paper?

In addition to the comments outlined in earlier responses the NACF would also like to make the following recommendations.

The NACF believes there are three critical areas that need to be emphasised in the NDS.

As previously stated, including an **Evidence-Based - Best Practice** guiding principle must be included in the new Strategy. Ideally, this would be supported by an expert advisory panel that would shape and review this principle and any accompanying standards that are required.

Assessing functionality is a major plank of disability policy in Australia. Many disabilities have long standing guidelines, and those along with some that have been underdevelopment, for several years, are being used to determine funding. All are evidence-based and strive for best practice diagnostics, treatments and outcomes.

Of those still under development, the guidelines for ADHD have activated a rigorous national framework to anchor discussions and deliberations. The Australian ADHD Professionals Association is leading the work around establishing definitive guidelines that align with extensive work completed internationally. Their firmly stated intention is to develop a document that will be

a “living guideline” to provide a roadmap for ADHD clinical practice, research and policy into the future for the betterment of those individuals living with ADHD in Australia¹⁰.

It’s hoped that this framework may also serve a pragmatic purpose in aligning the Australian ADHD Guidelines and its recommendations more closely with the priorities of major funding agencies such as the National Disability and Insurance Scheme (NDIS) which would be a major step toward equitable access for the ADHD community.

We would also like to see more deliverables and outcomes around the **future disability workforce**. No doubt there will be a number of recommendations that will emerge from the Royal Commission but the NDS will not meet its vision or outcomes without better provision around building a skilled future workforce.

The Productivity Commission has consistently focused on the need to adequately plan for a future workforce and that as a country we are massively under-prepared for the burdens to come within the disability and aged care sectors¹¹. The Government’s recent Growing the NDIS Market and Workforce Report 2019 also recognises the urgency of the problem but offers few real deliverables.

Finally, it is worth reiterating NACF’s support for a comprehensive and meaningful engagement process with the community. The UN Convention on the Rights of Persons with Disabilities (UNCRPD) makes it clear that, when developing laws and policies relating to disabled people, governments “must closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations”. It defines “representative organizations” as those that are “led, directed and governed by persons with disabilities”¹².

One of the core aims of the NACF is to facilitate and enable the many community and consumer groups that support people with ADHD, we believe we can help facilitate a discussion around standards that could be used as a way forward to ensure ongoing community engagement with the NDS.

¹⁰ AADPA Newsletter October 2020

¹¹ Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs, Study Report*, October 2017, p. 319.

¹² United Nations Convention on the Rights of Persons with Disabilities (Article 4 - General Obligations)