

## **A National Autism Strategy**

**APM Response to the Discussion Paper** 

30 October 2023



### A note on language

APM understands that language is a highly personal choice, and each person will have their own way of talking about autism and about themselves, and that there are people in the autistic community who prefer 'identity first language', people who prefer 'people first language', and people who use the terms interchangeably. For consistency with the discussion paper, and recognising that for many people, autism is a critical part of who they are and how they identify, this submission uses identity first language.

### **Photography**

Photographs used in this document are for illustration only and should not be interpreted to mean that any person or organisation whose assets are shown in them endorses this document.





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#### About APM

APM Group is a team of 14,750 people in 11 countries with a global purpose - to enable better lives.

APM started in 1994 as a small team in Perth, Western Australia, looking to provide better vocational rehabilitation for injured workers so they could recover their health and stay in their jobs.

Today APM is an international human services provider with more than 1,700 locations across Australia, the United Kingdom, Canada, the United States of America, New Zealand, Germany, Switzerland, Spain, Sweden, Singapore, and South Korea.

For people with injury, illness, or disability, as well as children and the elderly, the unemployed, and those facing hardship or harm, APM's services make a positive and lasting social impact every day.

APM takes immense pride in empowering people to realise their ambitions and aspirations through sustainable employment, independence, better health and wellbeing, and increased social participation.

Each year globally, APM supports more than 2.1 million people of all ages to improve their quality of life.

In Australia, the more than 5000 strong team deliver key services across the care economy – employment services, training, aged and disability care, community and assessment, and health and wellbeing, from more than 750 locations nationally.

Simply put, APM helps people to find employment, recover from injury and illness, improve their health, and enjoy social and economic participation in their community, no matter where they are in life's journey so that they can achieve optimal independence and wellbeing.



#### Introduction

APM appreciates the opportunity to contribute to the discussion on the development of a National Autism Strategy.

As a provider of both disability and mainstream services accessed by autistic people across the life course - including assessment, early childhood intervention, mental health and wellbeing, and employment related supports, APM supports the need for a diagnostic-specific strategy for autism.

As highlighted in evidence presented to the Senate Select Committee on Autism, Australia has notably lagged comparable countries in the development of a national autism strategy<sup>1</sup> and while overarching national disability strategies have set important policy directions and outcomes for improving the lives of people with disability broadly over recent decades, life outcomes for autistic people have not advanced.<sup>2</sup>

It is clear there are unique needs, challenges and enablers for autistic people that require a more targeted approach to foster inclusion, dignity, and full participation in all aspects of Australian society. APM welcomes the Government's commitment to developing a National Autism Strategy that is genuinely co-produced with autistic people and their families to achieve these aims.

APM's response to the discussion paper builds on the input provided at the community consultation sessions and is cognisant of the work that has been done to date including through the Senate Inquiry, the development of Australia's Disability Strategy 2021-2031 (ADS) and the Disability Royal Commission (DRC). It also recognises work that is still underway which intersects with the autism strategy, including the National Disability Insurance Scheme (NDIS) Review, the development of the national Early Years Strategy and the reform of Disability Employment Services (DES).

The following key principles also guide this feedback:

- 1. All people with disability, including those in the autism community, regardless of diagnosis, should have access to the supports and services they need to fully participate in their chosen communities and in all aspects of social, economic, and political life.
- 2. Intervening as early as possible and wrapping services around the individual and their family should be the gold standard for all supports.
- 3. Enabling better lives starts with genuine inclusion. Everyone needs to step up and play a bigger role in ensuring services, institutions, and communities are truly accessible.
- 4. Policies and programs need to be underpinned by good evidence. Research and a strong evidence base are crucial to good policy design and effecting real change.
- 5. What gets measured, gets done. Targets are key enabler to shifting the dial on employment outcomes.

<sup>&</sup>lt;sup>1</sup> Amaze (2021) *Towards a National Autism Strategy – International lessons for Australia.* Background Paper for the Senate Select Committee on Autism <a href="https://www.amaze.org.au/wp-content/uploads/2021/10/Towards-a-national-autism-strategy-international-lessons-Oct-2021-Amaze.pdf">https://www.amaze.org.au/wp-content/uploads/2021/10/Towards-a-national-autism-strategy-international-lessons-Oct-2021-Amaze.pdf</a> (accessed October 2023)

<sup>&</sup>lt;sup>2</sup> Senate Select Committee on Autism (2022) *Services, support and life outcomes for autistic Australians.* https://www.aph.gov.au/Parliamentary\_Business/Committees/Senate/Autism/autism/Report\_(accessed October 2023)



# A well-structured and comprehensive National Autism Strategy can drive genuine and meaningful systemic change.

The current approach to autism in Australia is haphazard and highly fragmented. As highlighted through the Senate Inquiry, disconnected policy and program initiatives are spread across multiple siloed service systems and varying tiers of government – primarily health, disability, education, and social services.

The lack of a coordinated, whole of government approach and the resulting poorer life outcomes achieved by autistic people comes at a significant cost to individuals, their families, and the broader community.<sup>3</sup> Improving outcomes requires genuine systemic change.

### An intentional and coordinated approach to improving outcomes across the life course.

To be effective, the National Autism Strategy needs to create an intentional and coordinated whole of government approach to improving the outcomes for autistic people across the life course. This approach should be built on a shared vision to enhance the quality of life and opportunities for autistic people while promoting understanding, acceptance, and full inclusion in society.

It is APM's experience that the current division of roles and responsibilities between levels of government exacerbates the issue of coordination on the ground. It is important that a whole of government approach acknowledges the separate but related roles of each tier of government (Commonwealth, State and Territory and Local) in the provision of services accessed by the autistic community and that the Strategy includes specific mechanisms and agreements under which these roles and responsibilities are clarified and managed. Facilitating a national approach under the Strategy that coordinates with existing services and systems also includes a coordinated approach to funding mechanisms at all levels of government.

Critically, as highlighted through the NDIS review process<sup>4</sup> the Strategy will need to consider the important role of foundational support services and how they interact and connect with specialist autism services in a fully coordinated and joined up way. Further, consideration needs to be given to the levers the Strategy will have available to ensure that mainstream services and institutions (particularly health, education, and employment) are fully inclusive and accepting of diversity. This can ensure that all autistic people are empowered, and enabled, to fully engage in and actively contribute to their chosen communities as highlighted through the Disability Royal Commission final report and recommendations related to redressing segregation.<sup>5</sup>

<sup>&</sup>lt;sup>3</sup> Synergies Economic Consulting, 2013. *Cost-benefit analysis of providing early intervention to children with autism.* <a href="https://www.synergies.com.au/wp-content/uploads/2019/09/Productivity-Commission-Cost-Benefit-Analysis-of-Providing-Early-Intervention-to-Children-with-Autism-2013.pdf">https://www.synergies.com.au/wp-content/uploads/2019/09/Productivity-Commission-Cost-Benefit-Analysis-of-Providing-Early-Intervention-to-Children-with-Autism-2013.pdf</a> (accessed October 2023)

<sup>&</sup>lt;sup>4</sup> See for example Bonyhady, B. (2023) Transcript. *Address to the Geelong Community Meeting – NDIS 2.0.* https://www.ndisreview.gov.au/resources/speech/ndis-20

<sup>&</sup>lt;sup>5</sup> Royal Commission into Violence, Abuse Neglect and Exploitation of People with Disability (2023) https://disability.royalcommission.gov.au/publications/final-report



The Strategy should promote interagency and interservice collaboration among government agencies, healthcare providers, educators, and community organisations to further ensure a comprehensive and coordinated approach to autism support.

APM also agrees with the Senate Committee that the National Autism Strategy should be person and family centred, address whole-of-life needs for all autistic people and include targeted actions to support vulnerable cohorts.<sup>6</sup> It is critical that the strategy is person-centred and based on the social rather than medical model of disability, effectively addressing the intersectional nature of autism, and ensuring that those who have not yet received a diagnosis still benefit from the Strategy.

### An effective Strategy also needs targeted actions, outcomes, and accountabilities.

The Strategy also needs to be underpinned by strategic actions, measurable outcomes, clear accountabilities for implementation and delivery, and coordinated funding if it is going to effect genuine change.

APM agrees key areas for action within the strategy should include (but not be limited to):

**Early detection and diagnosis**: ensuring early detection and diagnosis of autism to support the timely provision interventions and supports that improve life outcomes.

**Better access, integration, and coordination of services**: improving access to, and integration of, a wide range of services including healthcare, therapy, education and vocational training, and employment supports, to meet the diverse needs of autistic people.

**Education and awareness:** building an increased understanding of autism within the community, including providing training for professionals and educators. Promoting public education and awareness campaigns to reduce stigma and target misinformation, and celebrating the diversity and strengths within the autistic community.

**Family support:** support and resources for families and caregivers to support wellbeing, recognising the significant role they play in the lives of autistic individuals.

**Research, evidence, and innovation**: establishing and investing in an ongoing research agenda to better understand the needs and strengths of autistic individuals (including subpopulations and individuals with co-occurring conditions) across the life course and developing innovative evidence informed interventions and supports. This should include global collaboration to share best practice, policy learnings and latest developments in autism support, and a clearing house mechanism to support greater translation and dissemination of research information to all stakeholders including autistic people, families, advocates, services providers, and policy makers.

Like the ADS, the National Autism Strategy should be supported by a roadmap that details implementation milestones and responsibilities at all levels of government and an outcomes framework that tracks, measures, and regularly reports on the outcomes being achieved under the Strategy.<sup>7</sup> This includes the collection and analysis of clear and consistent data on the experiences and outcomes of autistic individuals to identify disparities and inform ongoing policy decisions that respect their diversity and rights.

<sup>&</sup>lt;sup>6</sup> Senate Select Committee on Autism (2022) *Services, support and life outcomes for autistic Australians.* https://www.aph.gov.au/Parliamentary\_Business/Committees/Senate/Autism/autism/Report\_(accessed October 2023)

<sup>&</sup>lt;sup>7</sup> Australia's Disability Strategy Hub <a href="https://www.disabilitygateway.gov.au/ads/strategy">https://www.disabilitygateway.gov.au/ads/strategy</a> (accessed October 2023)



The strategy should also be subject to ongoing evaluation and regular refresh to ensure it evolves as the community evolves. Reporting on progress should be done through Parliament.

## Supporting the rights, autonomy and diversity of the autistic community is multifaceted.

The discussion paper asks how the Strategy can support the rights, autonomy, and diversity of the autistic community.

A National Autism Strategy that is underpinned by a human rights-based approach ensures that the rights, dignity, and autonomy of autistic individuals are at the core of its design and implementation. The Strategy should align with United Nations Convention on the Rights of Persons with Disabilities (CRPD)<sup>8</sup> and ideally be supported by human rights legislation.<sup>9</sup>

The CRPD lays out a set of guiding principles, such as non-discrimination, full and effective participation, and respect for individual autonomy. These principles should be incorporated into the National Autism Strategy to ensure that all policies, programs, and actions respect and promote the human rights of autistic individuals through:

**Self-advocacy and decision-making**: encouraging and supporting autistic people and communities in self-advocacy, decision-making, and active participation. Promoting their right to make decisions about their own lives and well-being.

**Continued engagement**: supporting the ongoing involvement of the autistic community in the development, implementation, and evaluation of the National Autism Strategy to ensure that their voices and perspectives continue to be heard and considered.

**Full and effective participation and inclusion**: creating an equitable and inclusive society where every autistic person, regardless of their background, abilities, or characteristics, is supported to fully participate, engage, and contribute to social, economic, political, and cultural life.

**Person-centred services**: developing and delivering person-centred approaches to support that recognise the unique needs, strengths, and preferences of each individual, rather than adopting a one-size-fits-all model.

**Intersectional approaches:** recognising and respecting the diversity within the autistic community. Tailoring support and services to meet the specific needs of individuals including gender, background, culture (First Nations, cultural and linguistic diversity), age, identity (LGBTQIA+), life stage, etc.

**Peer support and mentoring:** facilitating peer support networks and mentoring programs, enabling autistic people to connect with and learn from others with similar experiences.

<sup>&</sup>lt;sup>8</sup> United Nations Convention of the Rights of Persons with Disabilities <a href="https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd">https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd</a> (accessed October 2023)

<sup>&</sup>lt;sup>9</sup> It is important to note here that while Australia has ratified the CRPD, which demonstrates the country's commitment to uphold the human rights and inherent dignity of people with disability, there remains no single legislative base at the national level for the recognition of human rights. This means that while the CRPD and other rights-based conventions may influence the interpretation of legislative provisions and/or policy, there is no Federal domestic law that can be drawn on to ensure rights are upheld in the way intended under the convention.



**Legal protections:** ensuring that legal frameworks provide strong protections against discrimination and promote the rights of autistic individuals in areas such as employment, housing, and healthcare.

**Protection from exploitation:** ensuring safeguards (including the provision of trusted information) are in place within systems to protect autistic people from exploitation, abuse, and undue influence, respecting the dignity of risk and their right to make choices based on informed consent.

## Improving access to, and integration of, services is fundamental for good whole of life support.

In considering what needs to improve so autistic people are better supported across their whole life, better access to, and integration of services, is a fundamental component of good support.

Improving access to, and integration of, services and supports is central to providing effective and lifelong support for autistic individuals. This approach recognises the evolving needs of autistic people, promotes a coordinated and person-centred model of care, and ensures that they receive the support they require at every stage of life.

Access to a wide range of services and supports is essential to addressing the diverse needs of autistic individuals throughout the ages and stages of life. Autism is a spectrum, and individuals can have vastly different strengths and challenges. Some may require early intervention services, while others may need support with education, employment, independent living, or mental health. Supporting better access to the breadth of services allows for individualised and tailored holistic care plans that can evolve as an autistic person's needs change over time.

Beyond access, the integration of services and supports is vital to provide a coordinated and seamless experience for autistic people and their families. Often, an autism diagnosis means individuals interact with multiple service systems (including, as outlined above, health and mental health care, education, social services, employment supports). An integrated approach ensures that these systems work collaboratively, preventing fragmentation and overlap, which can be overwhelming and confusing. It also helps avoid service gaps and delays, resulting in more effective and efficient care.

Integration also fosters a better understanding of the unique needs of autistic individuals across various service providers. It encourages professionals in different fields to collaborate and share knowledge, which leads to a more informed and sensitive approach to autism support. This collaboration helps identify early signs, triggers, or co-occurring conditions that may otherwise go unnoticed and untreated.

Importantly, a coordinated whole life approach to services ensures continuity of care. Transitioning from childhood to adulthood and facing other significant life changes can be challenging for autistic individuals. A seamless and well-coordinated system helps facilitate these transitions, ensuring that the support structure remains in place, regardless of the stage of life, and ultimately promotes better long-term outcomes and quality of life.

## Better social inclusion requires acceptance, understanding and accessibility.

Better social inclusion for autistic people involves fostering a society where they are treated with dignity, have access to opportunities, are supported in their unique needs, and are celebrated for their diverse perspectives and contributions to the community. It's about creating a world where everyone, regardless of their neurodiversity, can fully participate and thrive.

In practice, facilitating social inclusion means facilitating:



**Genuine acceptance and understanding**: a socially inclusive society that embraces and understands the diversity of all neurological profiles, including autism, without prejudice or stigma.

**Equal opportunities**: autistic people have equitable access to education, employment, and community opportunities, with accommodations and support provided as needed.

**Accessible environments**: public spaces, services, and information must be physically, cognitively and psychologically accessible – accommodating physical and sensory sensitivities and differences in communication styles and needs, and safe to engage with (trauma minimisation).

**Engaged and supportive communities**: communities actively engage autistic people in social and recreational activities, fostering a sense of belonging and connectedness. They are supportive, offer social networks, peer support and mentoring opportunities.

**Empowered participation**: autistic people are empowered to make choices and decisions about their own lives, how and where they participate, and have their voices heard in matters affecting them.

**Cultural competency**: professionals and service providers are trained to be culturally competent, recognising the diverse backgrounds and experiences within the autistic community.

### Genuine acceptance requires improving community attitudes towards autistic people.

Improving community attitudes is one of the most crucial steps in fostering a more accepting society and better social inclusion. Much of the current understanding of, and attitudes towards, autism is built from outdated stereotypes and misconceptions.

Education and awareness initiatives have a pivotal role to play in dispelling myths and misconceptions. Educational programs should be implemented in schools, workplaces and community organisations which are developed by, or in collaboration with, autistic people and are designed to increase the understanding of autism. These programs can provide valuable insight into the diverse experiences and strengths of autistic individuals, unpack the breadth of neurodiversity and the value of neuroaffirming approaches for all people (not just those with a diagnosis) and promote awareness and empathy, ultimately helping communities to build a foundation of acceptance.

In APM's experience, personal interaction is another powerful tool that can be highly transformative in changing attitudes. Encouraging and supporting opportunities for autistic and neurotypical people to interact, collaborate, work together, and build friendships is instrumental in breaking down barriers and fostering a sense of belonging. Organising inclusive and accessible community events and activities that celebrate neurodiversity and provide platforms for autistic individuals to share their talents and stories can help address misunderstandings and build confidence.

Additionally, the influence and role of media and popular culture in shaping public attitudes must not be overlooked. Much of the misconception and misinformation people have about autism today stems from outdated portrayals of autism in film, television, and news stories. Developing and promoting accurate and positive portrayals of autism in films, television shows, and literature can help dispel these stereotypes and create a more informed and accepting society. This can be achieved through partnerships between the industry, advocacy groups, experts, and autistic people themselves.



## Greater economic inclusion starts with equal access to opportunities.

Better economic inclusion for autistic people involves creating a supportive and inclusive environment in which they have equitable access to economic opportunities, are recognised for their unique strengths, and can participate in the workforce on an equal footing with their neurotypical peers.

APM's experience is that an emphasis on the individuals' strengths, goals and aspirations is central to a successful placement and access to decent work. With Industry 4.0, increased digitisation and the acceptance of more flexible working arrangements, opportunities are increasingly becoming available for autistic people seeking work. The lack of available workers is also challenging employers, and many are considering differing options that embrace diversity and inclusion by providing opportunities to groups previously excluded.

Just like their neurotypical peers, autistic people should have access to a wide range of employment opportunities across various industries and job types, with hiring practices that focus on skills, qualifications, and potential rather than solely on social or communication skills. However, experience shows that for many autistic people just getting through the front door of a potential employer is a key barrier to employment.<sup>10</sup>

#### A focus on unique strengths and talents is needed.

Like key barriers to social inclusion, employer perceptions, misbeliefs and common myths have a significant impact on the employment opportunities for autistic people. Challenging these misconceptions is a critical starting point to opening more doors and enabling better outcomes.

There is a strong body of evidence that autistic people bring a great range of strengths, skills, and capabilities to the workforce. There is also a sound business case for neuro-diverse workplaces, which can deliver competitive advantages related to productivity, quality, perspective, innovation, and engagement.<sup>11</sup> But there is a need to turn the traditional recruitment process on its head when supporting autistic people in work, fitting the role to a person, rather than a person to a "job".

Organisations need to work directly with autistic job seekers to identify their unique strengths, abilities, and skills. Skills and strengths need to be matched to roles and industries where individuals can contribute and feel valued. Employers need to be supported to build roles that meet the unique talents of the people they are recruiting, which in turn can lead to better productivity and employee engagement.

<sup>&</sup>lt;sup>10</sup> See for example Lopez & Keenan (2014) <u>Barriers to employment in Autism: Future challenges to implementing the Adult Autism Strategy</u> (accessed October 2023) Harmuth et al (2018) <u>Barriers and Facilitators to Employment for Adults with Autism: A Scoping Review https://doi.org/10.3928/24761222-20180212-01</u> (accessed October 2023)

<sup>&</sup>lt;sup>11</sup> Harvard Business Review (2017) *Neurodiversity as a Competitive Advantage*. <a href="https://hbr.org/2017/05/neurodiversity-as-a-competitive-advantage">https://hbr.org/2017/05/neurodiversity-as-a-competitive-advantage</a> (accessed October 2023)



#### There are a range of key enablers for good employment outcomes.

Research also tells us that there are a range of identified practices that further enable good employment outcomes for autistic people<sup>12</sup> including:

**Tailored, pre-employment, job matching and placement services**: effective pre-employment job matching and placement services that are tailored to the individual needs of autistic people and connect them with employment opportunities that align with their skills and interests. This includes access to volunteer and work experience opportunities to help develop a vocational identity, and support for entrepreneurship and self-employment where appropriate.

**Accommodations and flexibility**: providing reasonable accommodations and adaptions of work environments to meet the specific needs of autistic employees, which may include sensory-friendly workplaces, flexible work hours, modified communication and neuro-affirming supervision and management approaches.

**Awareness and sensitivity training**: employers and co-workers are provided with training to understand and respect the needs and preferences of autistic colleagues, addressing common misconceptions and fostering a more inclusive workplace culture.

**Accessible career paths**: pathways and supports that go beyond "a job" and include clear and accessible career development for autistic individuals, with opportunities for advancement, leadership, and specialisation.

**Support networks**: supporting networks and mentorship programs that connect autistic employees with peers and mentors who can provide guidance and assistance in their careers.

**Networking and social inclusion**: fostering social inclusion within the workplace by encouraging networking, social activities, and team building to build positive relationships among colleagues.

**Anti-Discrimination measures**: proper enforcement of legal protections and policies against employment discrimination based on neurodiversity, ensuring that autistic individuals rights are protected in the workplace.

### Improving education outcomes and transitions from school to post school options will also support better employment outcomes.

Young people with disability, including autistic young people, are more likely to be unemployed and have poorer mental health outcomes than those without.<sup>13</sup> They face additional barriers to transitioning from school to work and are more likely to be not in education, employment, or training, which can have lifelong effects on economic and social wellbeing.<sup>14</sup>

<sup>&</sup>lt;sup>12</sup> See for example Black et al (2020) *Multi-informant International Perspectives on the Facilitators and Barriers to Employment for Autistic Adults* <a href="https://doi.org/10.1002/aur.2288">https://doi.org/10.1002/aur.2288</a> (accessed Octoer 2023), Scott et al (2018) *Factors impacting employment for people with autism spectrum disorder: A scoping review* <a href="https://doi.org/10.1177/1362361318787789">https://doi.org/10.1177/1362361318787789</a> (accessed October 2023), Kavanagh et al (2021) *Evidence review: strategies to increase employment and economic participation for people with a cognitive disability – Summary Report.* <a href="https://mspgh.unimelb.edu.au/">https://mspgh.unimelb.edu.au/</a> data/assets/word doc/0008/3803786/1.<a href="https://mspgh.unimelb.edu.au/">UoM Employment-research Summary-report FINAL 9April2021-NDIS-copyright-disclaimer.docx</a> (accessed 2023)

<sup>&</sup>lt;sup>13</sup> Shields et al (2023) *Does employment status mediate the association between disability status and mental health among young adults? Evidence from the Household, Income and Labour Dynamics in Australia (HILDA) survey.* doi: <a href="https://doi.org/10.1136/oemed-2023-108853">10.1136/oemed-2023-108853</a> (accessed October 2023).

<sup>&</sup>lt;sup>14</sup> OECD (2022), *Disability, Work and Inclusion: Mainstreaming in All Policies and Practices.* OECD Publishing, Paris. https://doi.org/10.1787/1eaa5e9c-en\_(accessed October 2023)



Barriers to education mean many autistic people leave school early and that they are underrepresented in vocational education and training and university completions.<sup>15</sup> Given that most jobs growth is in occupations that require post school qualifications, support for improved education outcomes directly improves future employment opportunities.

Ensuring that autistic young people are supported to transition from school to post school options (further education, training and/or work) should be a priority action to improve economic inclusion.

## The role of government led incentives and targets should be considered to shift the dial on employment across the public and private sector.

In Australia, supports for improving the employment of people with disability, including the autistic community, is heavily supply-side focussed. There is no doubt that building individual capital in the labour market is crucial, but good policy must also include a clear focus on activating demand in the labour market if real impact in addressing labour market disadvantage is going to be achieved.

Despite the current tight labour market settings and the impact on demand, autistic people are still not fully benefiting from current labour market conditions that should be creating strong incentives for employers to access pools of talent they have previously ignored. More needs to be done to ensure that employers are fully incentivised to increase their engagement with potential autistic employees.

Consideration should be given to the role of targets/quotas and reporting to drive permanent cultural change in hiring approaches to people with disability – including within government and the private sector.

As the saying goes, "what gets measured, gets done."

Government should also consider the role of social procurement in creating opportunities. There could be significant returns realised through the expansion of the Commonwealth Indigenous Procurement Policy<sup>16</sup> to focus on inclusive procurement across expanded target cohorts or a new social procurement policy approach that includes a focus on employment of people with disability, including specific measures for autism.

## A nationally consistent approach to early diagnosis and intervention is critical to improving outcomes.

As the discussion paper notes, timely diagnosis is needed for early intervention and support and in Australia, it often comes too late.

Lack of early diagnosis, coupled with a diagnosis process that can be long, confusing, expensive, deficits based, and not nationally consistent<sup>17</sup> means that many autistic people and their families miss

<sup>&</sup>lt;sup>15</sup> Flower et al. (2020). What Happens After School? Exploring Post-school Outcomes for a Group of Autistic and Non-autistic Australian Youth Journal of Autism and Developmental Disorders. <a href="https://link.springer.com/article/10.1007%2Fs10803-020-04600-6">https://link.springer.com/article/10.1007%2Fs10803-020-04600-6</a> (accessed October 2023)

<sup>&</sup>lt;sup>16</sup> National Indigenous Australians Agency (2020) <a href="https://www.niaa.gov.au/resource-centre/indigenous-affairs/indigenous-procurement-policy">https://www.niaa.gov.au/resource-centre/indigenous-affairs/indigenous-procurement-policy</a> (accessed October 2023)

<sup>&</sup>lt;sup>17</sup> Autism CRC (2023) *Research Evidence and policy landscape mapping to inform the National Autism Strategy* https://www.autismcrc.com.au/our-work/general/research-evidence-and-policy-landscape-mapping (accessed October 2023)



out on neuro-affirming supports and interventions when they can have the most impact on fife better lives trajectory. 18

Further, this lag effect has flow on effects to services and systems – for example the NDIS, education and health, with young autistic people continuing to be the largest growing cohort of NDIS participants.

Shifting the age of diagnosis downwards is important - as is ensuring a nationally consistent, evidence-based and accessible approach, to guarantee an equitable experience of assessment no matter where a person lives in Australia. Supporting more professionals to follow the National Guideline for Assessment and Diagnosis of Autism and investing in system (particularly the public system) capacity to deliver is important.

### The impact of early identification and intervention on improving outcomes across the life course cannot be underestimated.

The importance of early diagnosis is well-established as it leads to early interventions, supports and adaptations that improve developmental outcomes. However, the challenges of diagnosis do not preclude the ease of early identification. Early identification, rather than diagnosis, can lead families to access the same early intervention, supports, adaptations and support positive developmental and longer-term outcomes.

It is well evidenced that early identification allows families and communities to intervene earlier, leading to more cost-effective treatment during the preschool years.<sup>19</sup> This is important given that the most effective interventions in child health and development occur with the first 1000 days. Additionally, research notes that if a gap in development emerges by age 5 and is not addressed, it is likely to remain, particularly for those children who are vulnerable or disadvantaged.

Early years points of contact – particularly child and maternal health services and general practitioners who are engaged with young children have the potential to play a much greater role in early detection, identification, and referrals to interventions. Developmental surveillance models, such as the Social Attention and Communication Study (SACS) are well-validated and have been effectively implemented across the community in Victoria<sup>20</sup> and could be easily rolled out on a national scale.

## Increasing awareness and embedding supports and services in mainstream settings can improve access.

Equitable access to early intervention ensures that all autistic people, regardless of their background or socioeconomic status, have the same opportunities to receive support and reach their full potential.

Better access and equity requires a focus on increasing awareness and education. Many in the autistic community may not be aware of the availability of early intervention services or may not know how to access them.

<sup>&</sup>lt;sup>18</sup> Clark et al (2017) *School Age Outcomes of Children Diagnosed Early and Later with Autism Spectrum Disorder.* Available at: <a href="https://link.springer.com/article/10.1007/s10803-017-3279-x">https://link.springer.com/article/10.1007/s10803-017-3279-x</a> (accessed October 2023)

<sup>&</sup>lt;sup>19</sup> US Office of Early Childhood Development <a href="https://www.acf.hhs.gov/archive/ecd/child-health-development/watch-me-thrive">https://www.acf.hhs.gov/archive/ecd/child-health-development/watch-me-thrive</a> (accessed October 2023)

<sup>&</sup>lt;sup>20</sup> La Trobe University's Olga Tennison Autism Research Centre (OTARC) <a href="https://www.latrobe.edu.au/otarc/research/autism-detection-diagnosis/social-attention-communication">https://www.latrobe.edu.au/otarc/research/autism-detection-diagnosis/social-attention-communication</a> (accessed 2023)



Increasing awareness and education through outreach efforts, community events, and partnerships with regularly accessed healthcare or other service providers can help people and families understand the importance of early intervention and how to access supports. Providing information and services in culturally appropriate and neuro-affirming ways can support autistic people from diverse backgrounds build knowledge and confidence and can reduce stigma around accessing supports.

Embedding services and delivering supports within everyday environments and community settings, for example within the home, childcare, community centres, kinder/early learning settings, healthcare or other regularly accessed services can also help identify autistic children in need of early intervention and increase access to supports, and support ordinary and inclusive childhoods which is important.

APM's experience is that this approach also encourages better collaboration and supports better ongoing engagement in, and continuity of, care.

Further, when services are accessed in mainstream settings, this can support an ongoing trajectory of engagement with mainstream services and systems – including education and employment.

#### Interventions should also be wrapped around families.

As previously highlighted, it is important that supports and resources are available for families and caregivers of individuals with autism, recognising the significant role they play in an individual's ongoing well-being and development.

Dedicated resources should include advocacy, navigation supports, accessible education/training on interventions, care strategies and access to easy-to-understand information on quality evidence-based practice.

### As a lifelong disability, supports for autistic people must continue into adulthood.

Just as early intervention is critical, recognition that autism is a lifelong disability and that people need support across the lifespan is just as important. Ensuring that autistic individuals are effectively and comprehensively supported as needed through all key life transition points (see for example school to work transition as discussed earlier in this response) is fundamental to good life outcomes and central to a person-centred model of care.

As previously outlined, transitioning from childhood to adulthood and facing other significant life changes can be challenging for autistic individuals. The Strategy must support a seamless and well-coordinated system that helps facilitate these transitions, ensuring continuity of care and that the support structure remains in place, regardless of the stage of life, ultimately promoting better long-term outcomes and quality of life for autistic people.

### **Conclusion**

As mentioned at the outset of this response, the opportunity to contribute to this important discussion on a National Autism Strategy is appreciated, and APM fully supports the government's commitment to deliver better life outcomes through a more targeted and coordinated policy approach that increases the full and inclusive participation of autistic people in all aspects of life and community.

We look forward to continuing to work with government on achieving these objectives.