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Drawing from Global Experiences: Developing a National Autism Strategy for Australia



Prepared by: Global Consulting Group



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Executive Summary

This report serves as a research foundation for the development of the Australian National Autism Strategy, identifying priority areas (services and support, early intervention, life outcomes (including employment and adults), health and mental health, and education) that require focus to ensure that Autistic individuals receive the necessary support and services to lead fulfilling lives.

A gap analysis was conducted to identify where current policies and strategies fall short in meeting the needs of Autistic individuals and their families. The report highlights the areas where improvements are necessary across the priority areas.

Research on international jurisdictions was conducted in New York, Denmark, Northern Ireland, Wales, Scotland, Hungary, and Malta to gain a broader perspective. A matrix was developed to provide an overview of what these countries had in common regarding the support and services available to Autistic individuals. The report provides a detailed analysis of each jurisdiction's support and services available to the autism community, highlighting successes and areas where improvements are necessary.

To conclude, it has been identified that a coordinated approach across different service providers is necessary to ensure that Autistic individuals receive comprehensive and integrated support. Therefore, the report recommends that the government work with stakeholders to address the priority areas identified in the report and develop a comprehensive strategy that addresses the needs of Autistic individuals and their families.



Context

Background of the Autistic Community in Australia

Autism Spectrum Disorder (ASD) affects over 736,000 people in Australia. Additionally, it is estimated that over 1.2 million Australians are connected to the disability through caring for someone they know with ASD¹. In particular, autistic individuals experience elevated levels of anxiety compared to their typically developing peers, with up to 84% of individuals with autism meeting the criteria for clinically diagnosed anxiety disorders. In addition, individuals with autism face various difficulties in schooling and employment, requiring assistance and supervision in many aspects of daily life, as revealed in the 2016 Census. Autism diagnosis is also linked to a variety of other disabilities, including intellectual, psychiatric, specific learning, speech, physical, and neurological disabilities.

The Australian autism community is supported by several organisations, including Autism CRC, A4, Aspect Australia, and Autism Awareness Australia. These groups cater to the different needs of people on the autism spectrum, such as early years, students, and adults. Autism CRC offers services to children in their early years, students, and adults, including online webinars targeting anxiety in the classroom and providing foundation practices for early career teachers². A4 is a grassroots organisation that advocates for policy and programs that aim to benefit both autistic people as well as their careers³. Aspect Australia is the largest autism-specific service provider in the country, delivering evidence-based solutions in partnership with people of all ages on the autism spectrum and their families⁴. Finally, Autism Awareness Australia provides a variety of services, including self-assessments, face-to-face workshops, online training, and advertising to raise awareness of autism to the public community⁵.

¹Australian Bureau of Statistics (2016) 2016 Census. <u>http://www.censusdata.abs</u> (Accessed: 11 May 2023).

² Autism CRC, n.d. <u>https://www.autismcrc.com.au/</u> (Accessed: 11 May 23).

³ Autism Aspergers Advocacy Australia, n.d. <u>https://a4.org.au/</u> (Accessed: 11 May 2023).

⁴ Aspect Australia, n.d. <u>https://www.autismspectrum.org.au/</u> (Accessed: 11 May 2023).

⁵ Autism Awareness Australia, n.d. <u>https://www.autismawareness.com.au/</u> (Accessed: 11 May 2023).



Problem

Identified through international and domestic research, the focus is on providing accessible and appropriate services and support to Autistic individuals and their families, tailored to their unique needs, with a coordinated approach across different service providers.

1. Services & Support:

This priority area focuses on providing accessible and appropriate services and support to Autistic individuals and their families, including early diagnosis, interventions, and ongoing support throughout their lifespan. It also encompasses the need for a coordinated approach across different service providers to ensure that Autistic individuals receive comprehensive and integrated support.

2. Early intervention:

Early intervention is crucial for Autistic individuals to improve their developmental outcomes and maximise their potential. This priority area includes the provision of evidence-based interventions that are tailored to the individual's needs, delivered in a timely manner, and with a focus on family involvement.

3. Life outcomes, Employment and Adults:

This priority area focuses on ensuring that Autistic individuals have equal opportunities to participate in society and achieve positive outcomes across their lifespan. This includes supporting individuals to access employment, education as well as strengthening each individual's financial independence.

4. Health and Mental Health:

Autistic individuals may have specific healthcare needs, including sensory sensitivities, communication difficulties, and co-occurring conditions such as anxiety and depression. This priority area includes the provision of accessible and appropriate healthcare services that are responsive to the unique needs of Autistic individuals.



5. Education:

This priority area aims to ensure that Autistic individuals receive an education that is inclusive, evidence-based, and tailored to their needs. This includes supporting educators to develop the knowledge and skills required to support Autistic students effectively.



Gap Analysis

In the context of autism advocacy organisations, a gap analysis was conducted by examining the common themes identified across their inquiries into autism to the parliament and challenges of previous autism strategies. The goal was to identify the areas where current strategies and policies fall short amongst services and support, early intervention, employment, health and mental health, policy implementation, and education of the autism community.

Priority Areas	Problems		
Services & Support	Limited rights protection and access to legal services		
	Policies and procedures exist for people with disability and families to challenge disability services on the grounds of human rights; however, individuals within the autism community do not have the capacity to use them without assistance and do not know about such mechanisms. For example, the Disability Standards are legally binding under the Disability Discrimination Act, but enforcement relies on individual complaints regarding non-compliance ⁶ .		
	Protection against violence and abuse in institutions		
	Stakeholders have voiced their concerns to the Senate inquiry into abuse, neglect, and violence against persons with autism in institutions. This includes a recommendation for the Royal Commission to look into this issue ⁷ .		
	Access to and affordable housing is lacking		
	Low availability of affordable housing in the autistic community, which includes government-supported housing options. Stakeholders have expressed the need to make housing more accessible and that autistic individuals have control over who they live with, who comes into their home, and where they live.		

⁶ Davy, L. *et al.* (2018) *Review of implementation of the National Disability Strategy 2010–2020, Department of Social Services, Australian Government.* Available at: https://www.dss.gov.au/review-of-implementation-of-the-national-disability-strategy-2010-2020 (Accessed: 11 May 2023).

⁷ Davy, L. *et al.* (2018) *Review of implementation of the National Disability Strategy 2010–2020, Department of Social Services, Australian Government.* Available at: https://www.dss.gov.au/review-of-implementation-of-the-national-disability-strategy-2010-2020 (Accessed: 11 May 2023).



	Furthermore, ensure the natural and built environment is accessible by enabling residents to use transport, buildings, playgrounds, and parks ⁸ .
	Policies not reflecting voice of autistic community
	Majority of stakeholders expressed insecurity about funding of advocacy services, including self-advocacy, individual advocacy, and systematic advocacy. Because the State and Territory governments focused on whether to fund advocacy in the future, the voices of autistic individuals were not sufficiently heard in the past, despite considerable changes in disability policies that improved their access to mainstream services and specialists ⁹ .
	Assistive technology policies were designed without consultation
	Stakeholders have commented on the recent technological advancements within the autistic community, which should have been reflected in previous strategies and considered in the future strategy. Also, stakeholders reiterated the importance of gathering feedback from autistic individuals during the design stage of future policy initiatives regarding assistive technology to ensure it meets their needs ¹⁰ .
Early	Long wait times to receive formal diagnosis
Intervention	Stakeholders have expressed concerns over long wait times of those seeking autism assessment and diagnosis through the public system (on average two years), with regional and remote autism communities having to wait longer ¹¹ . Consequently, the age of diagnosis is delayed. Amongst children, the critical access to the early window to influence the developing child's brain is delayed as well.

⁸ The strategy and supporting documents (2022) Australian Government | Disability Gateway. Available at: https://www.disabilitygateway.gov.au/ads/strategy (Accessed: 11 May 2023).

⁹ Davy, L. et al. (2018) Review of implementation of the National Disability Strategy 2010–2020, Department of Social Services, Australian Government. Available at: https://www.dss.gov.au/review-of-implementation-of-the-national-disability-strategy-2010-2020 (Accessed: 11 May 2023).

¹⁰ Inquiry into autism by the Australian parliament (2020) Australian Autism Alliance. Available at: https://australianautismalliance.org.au/inquiry-into-autism/ (Accessed: 11 May 2023).

¹¹ Inquiry into Autism by the Australian parliament (2020) Australian Autism Alliance. Available at: https://australianautismalliance.org.au/inquiry-into-autism/ (Accessed: 11 May 2023).



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Employment	Employment has declined despite targeted interventions
	Despite the introduction of new employment strategies for persons with autism across many jurisdictions, stakeholders reported the economic security of autistic individuals has deteriorated in recent years. Specifically, the employment of persons with autism requiring a high degree of support and services had declined ¹² .
	Gender inequality in labour market
	From a gender perspective, the labour participation of women with autism has not improved over the last two decades ¹³ .
	Disability discrimination at work
	Stakeholders wanted the discrimination at work of people with disability to be a priority focus, stating that it is the most frequent and common complaint the Australian Human Rights Commission received ¹⁴ . Stakeholders addressed concerns over the lack of anti-discrimination measures and complaints mechanisms for people with autism in the workplace.
Health and Mental Health	Health care environments often cause anxiety and sensory overload
	Stakeholders reported challenges in accessing healthcare due to anxiety caused by the environment and challenges related to sensory sensitivities. Furthermore, stakeholders identified the need for more preparation to help reduce anxiety associated with autism and incorporation of these practices into health services. Policies, for children specifically, lack initiatives to simulate the environments that children are in, the sensory

¹² Davy, L. et al. (2018) Review of implementation of the National Disability Strategy 2010–2020, Department of Social Services, Australian Government. Available at: https://www.dss.gov.au/review-of-implementation-of-the-national-disability-strategy-2010-2020 (Accessed: 11 May 2023).

¹³ Davy, L. et al. (2018) Review of implementation of the National Disability Strategy 2010–2020, Department of Social Services, Australian Government. Available at: https://www.dss.gov.au/review-of-implementation-of-the-national-disability-strategy-2010-2020 (Accessed: 11 May 2023).

¹⁴ Australian Human Rights Commission 2020-21 Complaint Statistics (2021) Australian Human Rights Comission. Available at: https://humanrights.gov.au/sites/default/files/2022-02/ahrc_ar_2020-2021_complaint_stats.pdf (Accessed: 11 May 2023).



	aspects of those environments, and having an example of the procedure shown to the child ¹⁵ .
	Access to healthcare is challenging
	Stakeholders identified barries to accessing healthcare, which include systematic chasms between key mental health and health services, long wait times, low confidence in health professionals understanding of autism, and communication difficulties (i.e., health professionals not equipped to handle social interactions with people on the autism spectrum) ¹⁶ .
	Systematic approach to upskilling health professionals is needed
	Stakeholders voiced concerns over the lack of understanding of autism amongst health professionals such as general practitioners. In Australia, over 80% of health professionals providing care to autistic people desired further training in behaviour, communication, and mental health management ¹⁷ . For example, health professionals not equipped to handle social interactions with people on the autism spectrum. Despite the range of resources and tools that are available to upskill health professionals on autism, uptake is not widespread.
Education	Lack of inclusive environment for students with autism
	Although education has received considerable focus throughout the life of past strategies, stakeholders emphasise on further reform to establish initiatives focused on building an inclusive educational environment. Stakeholders address concerns over the lack of training to develop the capabilities of school leaders to create an inclusive school environment for students with autism. Furthermore, current policies lack the

¹⁶ Inquiry into autism by the Australian parliament (2020) Australian Autism Alliance. Available at: https://australianautismalliance.org.au/inquiry-into-autism/ (Accessed: 11 May 2023).
 ¹⁷ The Autism Dividend (2020) Australian Autism Alliance. Available at:

¹⁵ Inquiry into autism by the Australian parliament (2020) Australian Autism Alliance. Available at: https://australianautismalliance.org.au/inquiry-into-autism/ (Accessed: 11 May 2023).

https://www.australianautismalliance.org.au/wp-content/uploads/2020/09/comprehensive-submission-

Australian-Autism-Alliance-Senate-Inquiry-into-Autism-Aug-2020.pdf (Accessed: 11 May 2023).



	delivery of educational programs to educate all staff and students of the benefits of inclusion ¹⁸ .
Policy Implementation	State/Territory-specific context influenced National Disability Insurance Scheme (NDIS) rollout
	In some States, the rollout of NDIS was less progressed. For example, the different legislative basis of each state and in some States the local government disability implementation plans were non-mandatory. Contextual factors have impacted the implementation plan on a national level ¹⁹ .
	The diversion of most funding to the NDIS by State and Territory governments has been a contributing factor in the weakening of governance arrangements
	While the NDIS has played an important role in centralising disability services and promoting a more consistent approach across jurisdictions, there was widespread that government focus on the establishment and implementation of the NDIS has resulted in limited policy attention placed on implementing other aspects of previous strategies ²⁰ . The 2017 Senate submissions indicated that some State and Territory governments were divesting their funding responsibility for wider disability issues in response to the NDIS implementation, reflecting a trend towards centralisation of disability services ²¹ . However, not all governments followed suit and some continued to fund and provide disability services outside of the NDIS framework.
	NDIS interface issues with disability services

¹⁸ Davy, L. et al. (2018) Review of implementation of the National Disability Strategy 2010–2020, Department of Social Services, Australian Government. Available at: https://www.dss.gov.au/review-of-implementation-of-the-national-disability-strategy-2010-2020 (Accessed: 11 May 2023).

¹⁹ Davy, L. et al. (2018) Review of implementation of the National Disability Strategy 2010–2020, Department of Social Services, Australian Government. Available at: https://www.dss.gov.au/review-of-implementation-of-the-national-disability-strategy-2010-2020 (Accessed: 11 May 2023).

²⁰ Davy, L. et al. (2018) Review of implementation of the National Disability Strategy 2010–2020, Department of Social Services, Australian Government. Available at: https://www.dss.gov.au/review-of-implementation-of-the-national-disability-strategy-2010-2020 (Accessed: 11 May 2023).

²¹ Delivery of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities (2017) Home – Parliament of Australia. Available at:

https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/AccessibleCommuniti es/Report (Accessed: 11 May 2023).



The issues identified mainly pertained to the relationship between services that are funded through the NDIS, other specialised disability services, and mainstream services. For instance, some States have decided to continue offering specialised disability services outside of the NDIS following its full rollout, while others have not ²² . This could potentially create access and equity barriers experienced by the autism community.
Implementation lacking methodology and measurable outcomes
No systematic, consistent approach to the implementation of strategies across Australia. Despite providing details about new programs and policies, there is little detail on how they were implemented and their outcomes ²³ .
Rural and remote locations disregarded
Stakeholders raised concerns and issues regarding strategy implementation in rural and remote locations. Stakeholders commented that rural and remote areas face additional challenges in strategy implementation because of factors such as limited workforce and disability advocacy due to smaller populations ²⁴ . Particularly, the shortage of skilled staff to provide necessary support and services to persons with autism. Stakeholders emphasised the need for support on a national level to remote and rural areas through organisational capacity building, funding, and staff training ²⁵ .

²² Davy, L. et al. (2018) Review of implementation of the National Disability Strategy 2010–2020, Department of Social Services, Australian Government. Available at: https://www.dss.gov.au/review-of-implementation-of-the-national-disability-strategy-2010-2020 (Accessed: 11 May 2023).

²³ Davy, L. et al. (2018) Review of implementation of the National Disability Strategy 2010–2020, Department of Social Services, Australian Government. Available at: https://www.dss.gov.au/review-of-implementation-of-the-national-disability-strategy-2010-2020 (Accessed: 11 May 2023).

²⁴ Davy, L. et al. (2018) Review of implementation of the National Disability Strategy 2010–2020, Department of Social Services, Australian Government. Available at: https://www.dss.gov.au/review-of-implementation-of-the-national-disability-strategy-2010-2020 (Accessed: 11 May 2023).

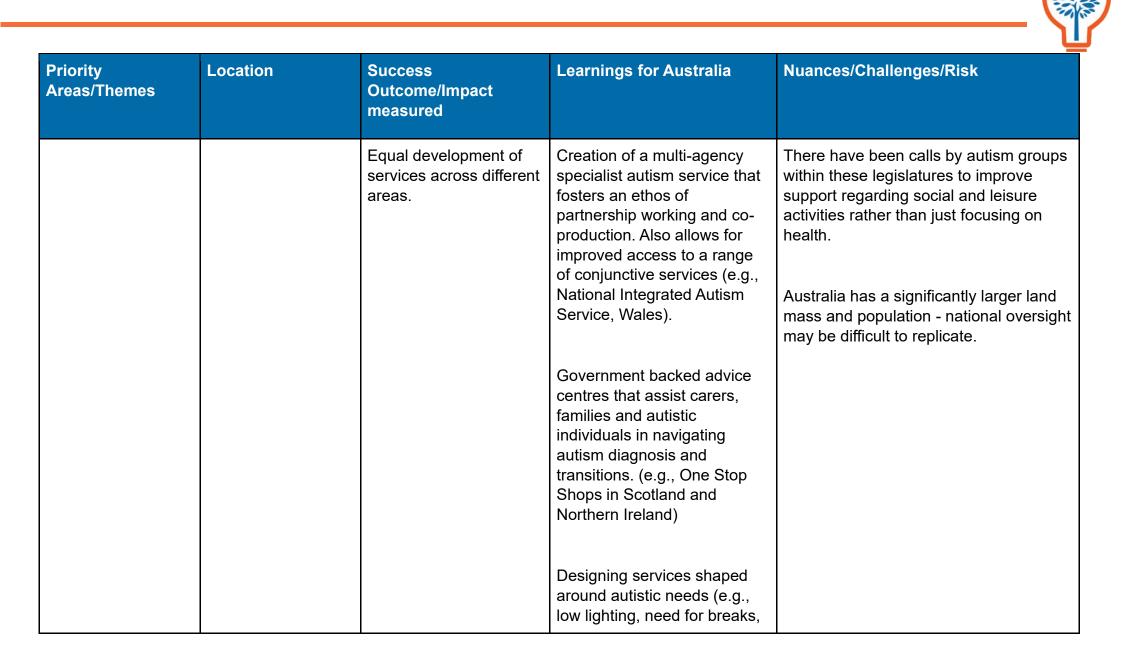
²⁵ Davy, L. et al. (2018) Review of implementation of the National Disability Strategy 2010–2020, Department of Social Services, Australian Government. Available at: https://www.dss.gov.au/review-of-implementation-of-the-national-disability-strategy-2010-2020 (Accessed: 11 May 2023).

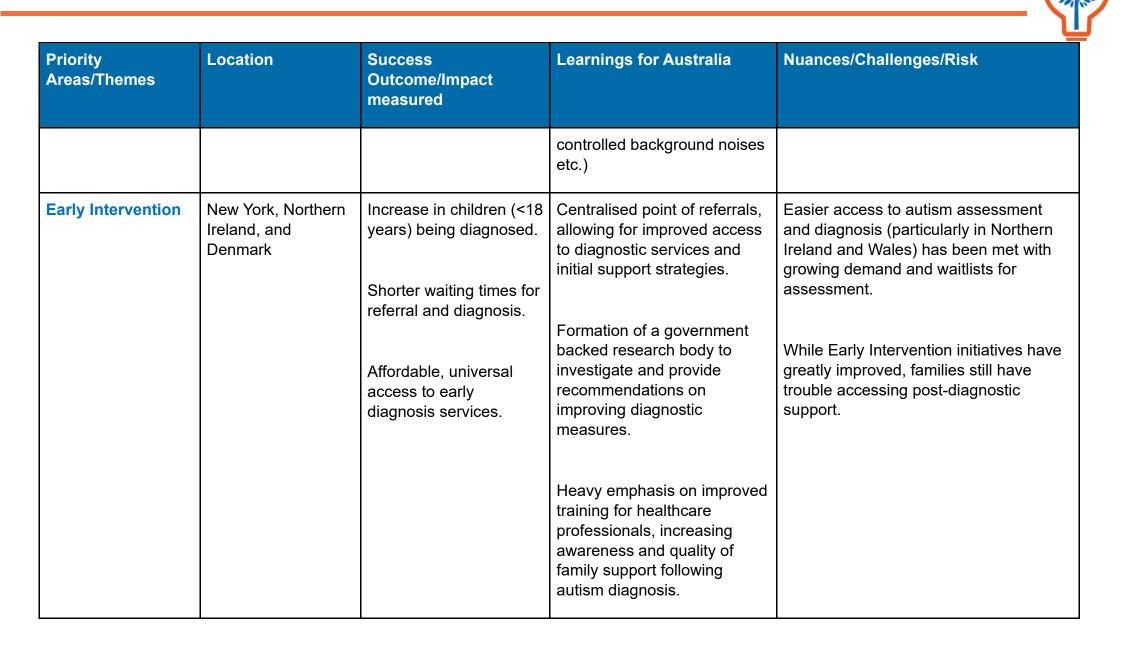


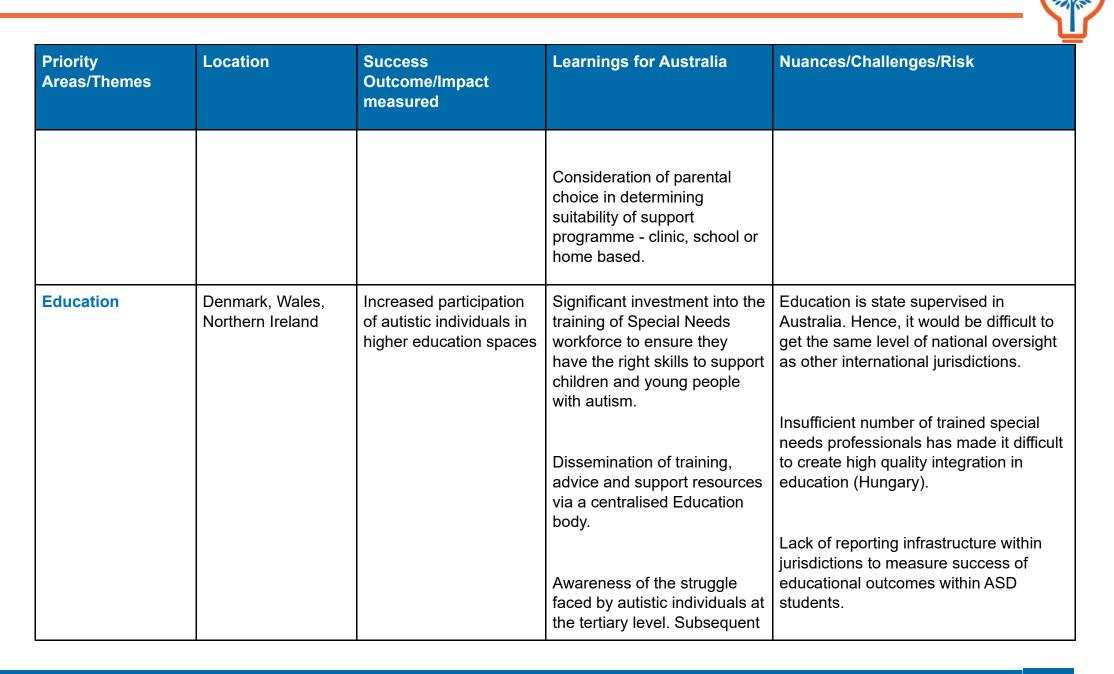
Findings

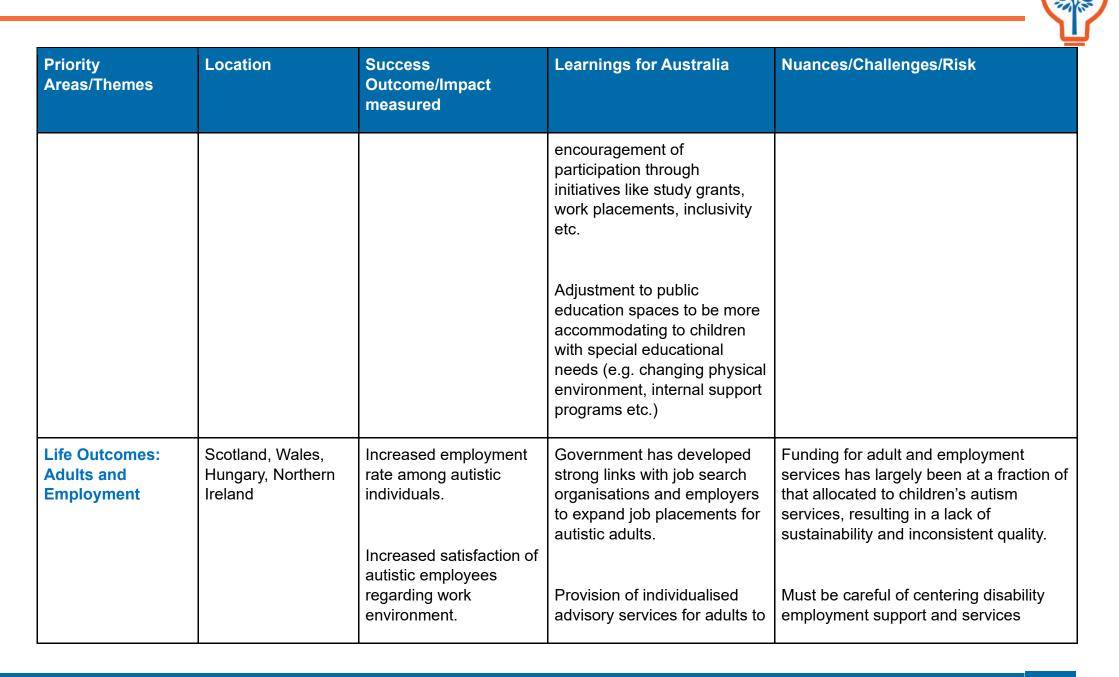
Matrix: Key insights on what was successful amongst external jurisdictions

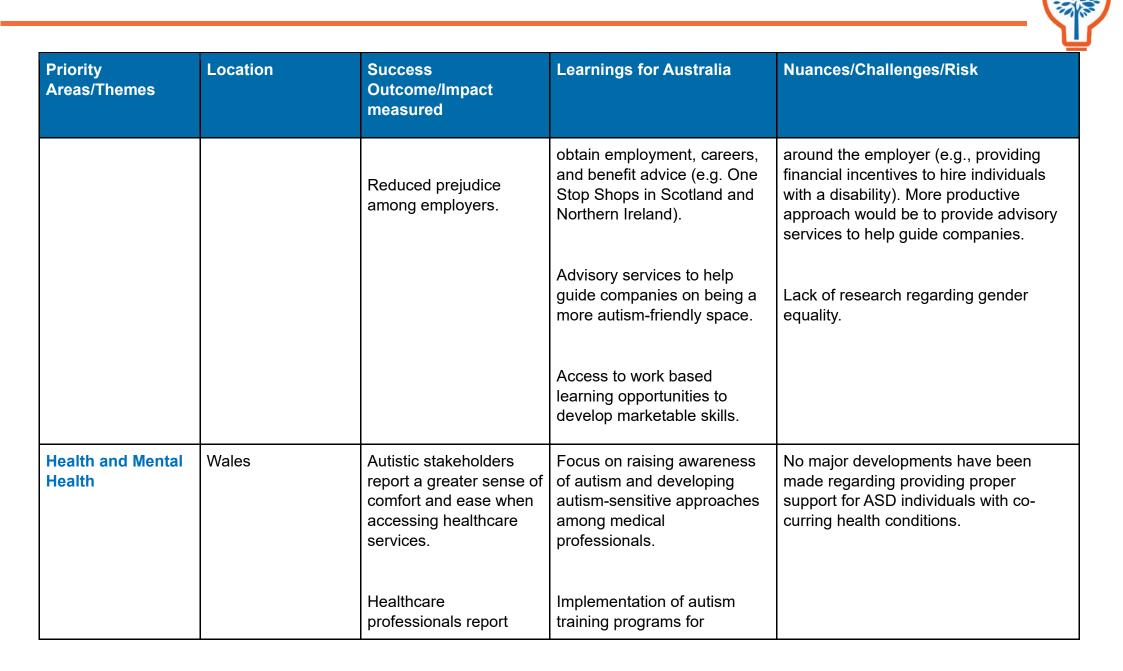
Priority Areas/Themes	Location	Success Outcome/Impact measured	Learnings for Australia	Nuances/Challenges/Risk
Services and Support	Wales, Scotland, Northern Ireland	Increase in adults seeking diagnosis. Acknowledgement and involvement of key stakeholders within the autism community when designing and delivering services. Centralised point of information/access to services and support.	Establishment of a dedicated administrative post (e.g. Autism Commissioner, Ireland) to monitor the implementation and improvement of services and support. Focusing on designing and delivering services at the local level while also monitoring them from a national perspective - ensuring one area is not more deprived than the other.	Increased societal awareness has correlated with growth in demand of autistic services, placing strain on existing infrastructure. Inconsistent funding by these legislatures has resulted to a crisis- management style of support rather than long-term or strategic plans for the commissioning of services. Long-term support for adults has still not yet been fully achieved by these legislatures.













Priority Areas/Themes	Location	Success Outcome/Impact measured	Learnings for Australia	Nuances/Challenges/Risk
		greater confidence and success when dealing with autistic patients.	healthcare professionals to close the communication gap.	
			Codification of autism in Mental Health/Health legislation.	



Country Experiences with National Autism Strategy

NEW YOR	ĸ
Context	 The New York State Department of Health established the Early Intervention Program (EIP) in 1993²⁶.
	• The mission of the EIP is to empower families and give them the skills and knowledge so that they can use everyday learning opportunities to engage the child in activities that can help the child develop to the best of their potential.
	• The EIP is based on the idea that parents are the best teachers for their children because they are around their children every day. However, many parents feel disconnected from their child when they are offered therapy services as they feel that they are not involved in the process.
	 Young children (birth to 3 years) who are not learning, playing, growing, talking, or walking like other children their age qualify to receive training and support under the EIP.
Elements	 The EIP provides young people and their families access to training and qualified personnel.
	• The EIP employs an embedded coaching approach ²⁷ . During this process, health professionals visit family homes and interact with the parents in their natural environment to suggest activities that they should engage in with their children. Therefore, the services provided to the family are individualised for the child.
	 Families work with health practitioners to set meaningful goals for their child and create a service plan to achieve these goals.
	• The NY state department have worked together with several universities and their centres of Developmental Disabilities to develop 30 trainings to enhance family-centred practices in early intervention service delivery, for families and providers. In 2018,

²⁶ Early Intervention Program Training (2023) New York State Department of Health. Available at: <u>https://www.health.ny.gov/community/infants_children/early_intervention/training.htm</u> (Accessed: 11 May 2023).

²⁷ Going Deeper with Embedded Coaching (2021) *Instructional Coaching Group*. Available at: <u>https://www.instructionalcoaching.com/going-deeper-with-embedded-coaching</u> (Accessed: 11 May 2023).



	they published a Clinical Practice Guideline on Assessment and Intervention for Young Children birth to three years of age.
	 The state funds several Centres for Autism and Developmental Disabilities Research and Epidemiology sites, which conduct research on autism and provide information and resources to families.
	 In the past, funding for the EIP has been supported by various grants, such as from the Robin Hood Project of up to \$1.6 million in 2021, and legislation signed by New York Governor, Kathy Hochul, creating \$40 million for the EIP last year²⁸.
Impact	 High-quality early intervention for young people is a strong economic investment for families and the community.
	• A report from the American Academy of Paediatrics specifically identifies the economic benefit for early intervention at "\$8 return on every dollar invested, and estimates that 80% of the benefits were directly applicable to society in general". This is because of more efficient use of public-school services, opposed to private, and less use of criminal justice and other public systems.
Lessons	Australia can translate key initiatives into their national autism policy. This could include:
	 Employing embedded coaching techniques to involve families in the early intervention process and restoring the sense of connection between parent and child.
	 Allocating funding to several Australian health providers and independent professionals to research and implement family- centred programs specific to Australian families.
	However, they can also address gaps that were not fulfilled in New York's EIP
	• The issue in New York is that children no longer qualify for the support they used to receive when they age as the EIP is targeted for only infants, toddlers, and young children. At 18-19 years of age, a person with autism will age out of the services that are provided or covered by insurance. Although this age range was intentionally chosen because children are at a critical

²⁸ Brian, T., 2021, \$1.6 Million Grant Will Increase Access to Early Intervention for Children with Developmental Delays and Disabilities, Fund for Public Health in New York, Inc., viewed 11 May 2023. https://fphnyc.org/blog/1-6-million-grant-will-increase-access-to-early-intervention-for-children-with-developmental-delays-and-disabilities/



DENMARK		
Context	• The National Autism Plan ²⁹ is a strategy first put together in 2006 by the Danish Ministry of Health; the National Board of Social Services under the Ministry of Social Affairs, Children and Integration; and autism representative organisations, such as the Danish Autism Society.	
	 The NAP adopts a lifelong approach, providing guidelines for diagnosis, care, and treatment for people with autism in all stages of life from children to the elderly. 	
Elements	The National Autism Plan in Denmark is based on several key objectives:	
	 Improving access to intervention services for children, adults, and elderly with ASD. 	
	 Providing better support for adults with ASD, including housing, education, and employment opportunities 	
	 Increasing awareness and understanding of ASD in society to reduce stigma and discrimination 	
Impact	 The guidelines and action plans that have been put into place in Denmark is aimed to ensure that people with functional disabilities, such as ASD, are not put in a position of disadvantage regarding their participation in society. 	
Lessons	Australia should focus on improving access to early intervention services for children with ASD.	

²⁹ Della Fina, V., 2015. Domestic Laws and National Plans or Strategies for the Protection of the Rights of People with Autism: An Appraisal, in: Della Fina, V., Cera, R. (Eds.), Protecting the Rights of People with Autism in the Fields of Education and Employment: International, European and National Perspectives. Springer International Publishing, Cham, pp. 25–77. <u>https://doi.org/10.1007/978-3-319-13791-9_3</u>



 In Denmark, inclusive schooling is both a political priority and a clear aim for schools³⁰. Legislation now also clearly explains how schools can reach these goals and where they are responsible for implementation (the Danish Act on Special Education and Social Measures for Children and Young People enacted in 2018). The concept of special needs education is restricted to only those students who have a need for extensive support in a major part of the teaching periods.
 Australian public schools can no doubt become better in creating a more inclusive environment and delivering quality education. However, there is still room for more integration between the curriculum for students with differences in development abilities and those without.

NORTHE	RN IRELAND
Context	Ireland's National Autism Strategy (2013-2020) was drafted in response to the Autism Act (NI) 2011 which prescribed that the Strategy must:
	 Set out how the needs of people with autism are to be addressed throughout their lives including (but not limited to their educational, health and social needs)
	 Set out how the needs of families and carers of people with autism are to be addressed; and
	Contain proposals for prompting autism awareness campaign.
	The development of the strategy sought to heavily involve the autistic community with pre-consultation engagement events across Northern Ireland that gathered the views of people with autism, their families and carers on the key issues they wanted to be addressed in the Strategy and Action Plan. An online questionnaire was also launched which specifically targeted a wide range of people with autism. Finally, the community had the opportunity to give feedback on the draft Strategy and Action plan via public consultations ³¹ .

³⁰ Systems of support and specialist provision (2020) *European Agency for Special Needs and Inclusive Education*. Available at: <u>https://www.european-agency.org/country-information/denmark/systems-of-support-and-specialist-provision</u> (Accessed: 11 May 2023).

³¹ Autism Act (Northern Ireland) 2011. Acts of the Northern Ireland Assembly. Available at: <u>https://www.legislation.gov.uk/nia/2011/27/contents/enacted</u>. (Accessed: 11 May 2023)



	Creation of a refreshed, longer-term autism strategy (2023-2028) is currently underway. Due to pandemic interruptions, an interim report (2021-2022) was published following the earlier Autism Strategy (2013- 2020).
Elements	The 2013-2020 strategy was based on 11 key themes ³²
	• Key aims of the 2013-2020
	 To promote awareness and better understanding of the challenges faced by people with autism;
	 Support people with autism, their families and carers to become well informed about accessing the services they need;
	 Encourage social inclusion of people with autism and work to address discrimination/stigmatisation; and
	 Tailor services and support to meet the changing needs of people with autism over the course of their lifetime.
	 Main objective: develop a more integrated approach to the planning, commissioning, and management of services within and across public sector organisations and the independent, community and voluntary sectors.
	The 2020-2021 interim strategy is arranged under the following three strategic outcome areas ³³ .
	 A healthy life with access to services on an equal and timely basis
	 "We will provide improved pathways of care enabling timely access to early intervention and support which best meets emotional, and wellbeing needs for individuals and families."
	2. A life with opportunities to live as an active citizen
	• "We will support autistic people, their families and carers as they participate in all aspects of community and society through continued support in education and employment as they transition through life stages."
	3. An independent life supported by greater societal understanding and choices.

 ³² The Autism Strategy (2013-2020) and Action Plan (2013-2016). Northern Ireland Executive. Available at: https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/autism-strategy-action-plan-2013_0.pdf. (Accessed 11 May 2023)
 ³³ Autism Interim Strategy 2021-2022. Department of Health. Available at: https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/autism-strategy-action-plan-2013_0.pdf. (Accessed 11 May 2023)



	 "We will provide opportunities for autistic people to live safe and independent lives within our communities and have equal access to services where they are met with respect and understanding."
	Funding (2021-2022 Strategy):
	 An additional £2 million has been invested to children's autism services on a recurrent basis since 2018
	 Total annual investment in autism services is around £6.5 million (according to 2018 progress report)
	Implementation (2021-2022 Strategy)
	 An HSC Regional Autism Co-ordinator was recruited by the Health and Social Care Board to encompass a cross- departmental remit in terms of managing and co-ordinated reporting.
	• The Autism Strategy Regional Multi-Agency Implementation Team (ASRMAIT) comprised of a range of agencies representing health, social care, education, justice and employment, is responsible for directing, coordinating and managing the implementation of the strategy on a cross- departmental basis.
	 Autism Strategy Inter-Departmental Senior Official Group (ASISOG) provided a governance and oversight role on behalf of each government department.
	• Regional Autism Fora is composed of clinicians, service users, community, and voluntary sector. Inter-departmental representatives were deployed to each Health Trust to encourage opportunities for service user development and interagency partnership.
	 Northern Ireland Autism Strategy Research Advisory Committee (NIASRAC) ensures that the most recent findings are available to ASISOG to inform implementation of the strategy and action plans.
	 A Regional Multi-Agency Implementation Team monitors the implementation of the strategy and commission input from relevant Departments regarding the development of three yearly progress reports.
Impact	Northern Ireland's government reports key achievements from the initial strategy that include:



 Increased societal awareness which has led to adjustments to many institutions (education, legal/prison system, workplaces) as well as a growing number of children and adults seeking diagnosis³⁴
 Development of a robust Single Point of Entry process that has improved the efficiency and effectiveness of Early Intervention programs³⁵.
 To mitigate the effect of long waiting times, families are offered core workshops as an initial point of contact. This allows for quick access to a professional who can suggest strategies early into the child's journey.
 Following diagnosis, families have access to a health improvement nurse that can help develop health and wellbeing programmes or refer them to specialist services.
 Grants and financial support are available to ASD students via the Additional Support Fund, administered by the Department for the Economy, has enabled further education colleges to provide additional support and advice for students with autism³⁶.
• The Registered Intermediary Scheme was introduced to the Justice Sector, enlisting the help of communication expects as intermediaries to assist vulnerable victims, witnesses, defendants or suspects with severe communication deficits to communicate their answers more effectively during police interview or trial. The Registered Intermediary Scheme was introduced to the Justice Sector, enlisting the help of communication experts ³⁷ .
 Department for Communities (DFC) main employment programme Steps 2 Success provide autistic individuals with individually tailored support to help overcome any barriers they may face entering employment.

³⁴ The Autism Strategy (2013-2020) and Action Plan (2013-2016), Progress Report September 2015. Department of Health, Social Services and Public Safety. Available at: <u>https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/autism-strategy-progress-report-2015.pdf</u>. (Accessed: 11 May 2023)

³⁵ The Autism Strategy (2013-2020) and Action Plan (2013-2016) Second Progress Report 2018. Department of Health. Available at: <u>https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/autism-strategy-progress-report-2015.pdf</u>. (Accessed: 11 May 2023)

³⁶ The Autism Strategy (2013-2020) and Action Plan (2013-2016) Second Progress Report 2018. Department of Health. Available at: <u>https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/autism-strategy-progress-report-2015.pdf</u>. (Accessed: 11 May 2023)

³⁷ The Autism Strategy (2013-2020) and Action Plan (2013-2016) Second Progress Report 2018. Department of Health. Available at: <u>https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/autism-strategy-progress-report-2015.pdf</u>. (Accessed: 11 May 2023)



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	However, they also note that diagnostic services have been struggling to cope with the rising demand resulting in longer waiting times ³⁸ . Appropriate funding distribution has long been an issue with Northern Ireland's services and support with the Adult Care pathway being allocated less than a ¼ of that given to children's autism services. Lack of appropriate funding for autism services has led to a crisis-management style of support rather than long-term or strategic plans for the commissioning of services ³⁹ .
Lessons	Reflections from the 'Broken Promises Report'6
	 Increased awareness, while positive in tackling the stigma associated with autism has resulted on a knock-on effect on public expectation and consequently demand for services.
	 In 2017/18, the number of referrals – 4,097 in total – was close to three times the number the current system was designed to deal with
	 Hence, Australia must also concurrently ensure services are adequately positioned to cope with rising demand. This includes employing a greater number of trained staff (psychiatrists, clinical psychologies, autism intervention therapists, speech and language therapists etc.)
	 Lack of funding and unfair allocation limited the Strategy's ability to improve outcomes for adults.
	 Aspects of autism services provided by Northern Ireland's six Health and Social Care (HSC) Trusts were highly variable and were not consistent across the region, depriving individuals in some Trusts from accessing the services they needed.
	 There have been complaints at the lack of involvement of parents, carers, autistic adults and the autism sector in the oversight of the Strategy's Implementation.

³⁸ The Autism Strategy (2013-2020) and Action Plan (2013-2016), Progress Report September 2015. Department of Health, Social Services and Public Safety. Available at: https://www.healthni.gov.uk/sites/default/files/publications/dhssps/autism-strategy-progress-report-2015.pdf. (Accessed: 11 May 2023)

³⁹ The Autism Strategy (2013-2020) and Action Plan (2013-2016), Progress Report September 2015. Department of Health, Social Services and Public Safety. Available at: <u>https://www.health-</u> ni.gov.uk/sites/default/files/publications/dhssps/autism-strategy-progress-report-2015.pdf. (Accessed: 11 May 2023)



"Only 8% of survey respondents in the Broken Promises report felt as if services for children had gotten better, compared to 46% who felt they had got worse. For adults, even fewer, 4%, felt that services are better, whereas 35% say they have gotten worse.⁴⁰"

Nevertheless, Northern Ireland is well-regarded compared to other countries for their structured implementation and evaluation of the Strategy with designated national departments overseeing different areas of the Strategy. It is recommended that Australia follows this national oversight approach.

WALES	
Context	Wales was the first country in the UK to develop a national approach and publish a strategic plan for people with autism. The Autism Spectrum Disorder Strategic Action Plan for Wales was initially published in 2008 and expected to run until 2018. However, it was 'refreshed' early, with a new version issued in early 2016 which is still current.
	Aim of the refreshed Strategic Action Plan is for: Children, young people and adults with autism and their family and carers to have their needs understood, to be supported to achieve their own wellbeing outcomes and to lead fulfilling lives.
	Consultation occurred with people with autism, their family and carers as well as with the ASD Stakeholder Advisory Group.
Elements	The Autism Strategic Action Plan 2016 addresses three key themes:
	 Awareness raising, information and training
	Assessment and diagnosis
	Meeting support needs

⁴⁰ Broken Promises (Feb 2016). The National Autistic Society Northern Ireland, Autism NI. Available at: <u>https://static1.squarespace.com/static/5cf788f054106a000185c13a/t/5dcc23e5c27c4f1cd261089c/157365963030</u> <u>8/Autism+NI+Broken+Promises+Report+%283%29.pdf</u>. (Accessed: 11 May 2023)



An integral initiative of the refreshed strategy is the plan to roll out an all-age National Integrated Autism Service (NIAS) for Wales ⁴¹
• The service was developed from evaluating existing assessment and preventative gaps in existing models of autism and support services. The result was the creation of a multi-agency specialist autism service with staff from health and local authority.
 Each Integrated Autism Service works in partnership with local Health Boards and authorities. The service also links
 Ensures the provision of a range of functions including diagnosis, advice, and professional services as well as sector capacity development.
 Backed by 6 million pounds.
Funding ⁴² :
 The first Autism strategy committed an annual £40,000 grand to each local authority to develop autism services.
 After the formation of the ASD Diagnosis Task and Finish Group, additional funding of £2 million annually was committed to improving neurodevelopmental services.
Implementation ⁴³ :
 The Welsh Government established an Implementation Advisory Group to monitor progress and delivery of the specific actions within the Strategic Action Plan and Delivery Plan.
 An annual report reviewing the progress of specific actions within the Strategic Action Plan and Delivery Plan will be published. This will include performance information and timelines of assessment and diagnosis.
• Regional Partnership Boards will report on the progress in relation to meeting the care and support needs of people in their area.

⁴¹ Evans, R. (2016). *Refreshed Autistic Spectrum Disorder Strategic Action Plan*. Department of Social Services and Public Health. Available at: <u>https://www.gov.wales/sites/default/files/publications/2019-03/refreshed-autistic-spectrum-disorder-strategic-action-plan.pdf</u>. (Accessed: 11 May 2023)

 ⁴² Holtom, D., Lloyd-Jones, S. (2019) *Review of the Demand, Capacity and Design of Neurodevelopmental Services: Summary Report.* Welsh government. Available at: <u>https://www.gov.wales/sites/default/files/statistics-and-research/2022-07/review-of-the-demand-capacity-and-design-of-neurodevelopmental-services-summary-report.pdf</u>. (Accessed: 11 May)
 ⁴³ Evans, R. (2016). *Refreshed Autistic Spectrum Disorder Strategic Action Plan.* Department of Social Services

⁴³ Evans, R. (2016). *Refreshed Autistic Spectrum Disorder Strategic Action Plan*. Department of Social Services and Public Health. Available at: <u>https://www.gov.wales/sites/default/files/publications/2019-03/refreshed-autistic-spectrum-disorder-strategic-action-plan.pdf</u>. (Accessed: 11 May 2023)



	 Independent evaluation of the refreshed Strategic Action Plan and National Integrated Autism Service will take place. A report has already been released in 2019.
Impact	Wales' 2019 review of the Refreshed Autism Strategy and NIAS discusses key achievements to include ⁴⁴ :
	 Increase of children and adults seeking diagnostic assessment of autism as a result of increasing awareness and establishment of a dedicated diagnosis research/implementation group dubbed the ASD Diagnosis Task and Finish Group.
	 Development of links with JobCentre Plus and Career Wales which provides specialist advice to businesses, enabling local staff to develop knowledge and skills to support people with autism into employment.
	 Significant investment into the special needs workforce to ensure they have the right skills to support children and young people with autism.
	 Specific chapter in the Mental Health code of practice about people with learning disabilities and/or autism that sets out recommendations for the training of staff.
	 In accordance with the Social Services and Mental Health Act, local health boards and authorities are also required to undertake a population needs assessment with learning disability/autism being a core theme. This assists in the development of key support services.
	Establishment of an ASD website recognised by the Autism Europe International Congress for their excellent provision of the resources available to the autistic community.

SCOTLAN	ND
Context	The Scottish Strategy for Autism, launched in 2011, was divided into three parts:

⁴⁴ Holtom, D., Lloyd-Jones, S. (2019) *Evaluation of the Integrated Autism Service and the Autism Spectrum Disorder Strategic Action Plan*. Available at: <u>https://www.gov.wales/sites/default/files/statistics-and-research/2019-05/evaluation-of-the-integrated-autism-service-and-the-autism-spectrum-disorder-strategic-action-plan-final.pdf</u>. (Accessed: 11 May)



	 Foundations (by 2 years),
	 Whole-life journey (by 5 years) and
	 Holistic-personalised approaches (by 10 years)
	Some goals will principally be for one discipline to deliver whilst others will require a multi-disciplinary response.
	In 2015, the strategy was refreshed and reframed so that it was outcome focused, under four key areas – "a Healthy Life, Choice and Control, Independence, and Active Citizenship". It was further refined and re-launched in 2018 with the four key outcomes continuing as the guiding themes for the final phase of the strategy (2018-2021). ⁴⁵
Elements	From 2011
	• The first iteration of the strategy contained 26 recommendations organised across six themes. The early foundation years focused on consolidation and preparation, creating frameworks for assessment, diagnosis, and training, commissioning research and producing resources.
	 Investment underpinning this early stage of the strategy gave £1.12 million to support the development of local authority action plans and the Autism Development Fund awarded almost £5 million to 53 projects to support autistic people and their families/carers and deliver elements of the strategy.
	From 2015
	Activity was focused around four strategic outcomes . Once again, the delivery of the strategy's priorities was reinforced with funding through the Autism Innovation and Development Fund, which distributed £2,097,526 to 41 projects (2015-18), and the Understanding Autism Fund, which disbursed £435,801 to nine projects (2019-21). These funds were administered and managed by Inspiring Scotland, which also provided capacity-building support to projects throughout this period.
	The Scottish Government committed £13.4 million over four years to improve the lives of autistic people and their families. They conducted a mapping exercise to coordinate local autism services and invested
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⁴⁵ The Scottish Government (2010) The Scottish Strategy for Autism, Scottish Government. Available at: <u>https://www.gov.scot/publications/scottish-strategy-autism/documents/</u> (Accessed: 11 May 2023).



	\pounds 35,000 per local authority to develop local autism strategies. They also set aside \pounds 4.5 million for Autism Development Funds to encourage the development of projects to improve the delivery of local autism services.
Impact	 Scottish achievements since 2015 include: Developed and promoted the Autism Training Framework "Optimising Outcomes" for health and social care professionals. Invested over £2 million in 40 autism charities/projects benefiting 6,000 autistic people and their families. Invested in Autism Network Scotland and National Coordination Project to promote good practices and develop local autism strategies. Piloted One Stop Shops for early intervention support and improved diagnostic practices. Launched a 'Knowledge Hub' and supported the 'Right Click' program for women and young girls. Developed Principles of Good Transitions 3 and promoted the Autism Toolbox for teachers. Developed employment resources through the Employment Network.⁴⁶
Lessons	To have a greater impact, the services and support need to have greater reach, become embedded and be sustained. Integration authorities play a crucial role in the degree of strategic impact because most services are designed and delivered at a local level. Until appropriate provision is commonplace, there will be a lack of accessible and relevant local autism services. Systemic change can only be realised in true partnership with autistic people and through collaboration across services and sectors. The current nature of engagement and tension between different interest groups spills into the way in which they can work together. This needs to be recognised and addressed for future collaboration to be effective.

⁴⁶ The Scottish Government (2018) The Scottish strategy for autism - Outcomes and Priorities 2018-2021, gov.scot. Available at: <u>https://www.gov.scot/binaries/content/documents/govscot/publications/corporate-report/2018/03/scottish-strategy-autism-outcomes-priorities-2018-2021/documents/00533392pdf/00533392-pdf/govscot%3Adocument (Accessed: 11 May 2023).</u>



There are lessons from the implementation of the ten-year strategy that can inform decisions about the future policy.
The Government could:
 narrow the focus of future work so there is more likelihood of effective delivery and sustainability;
 provide clarity about actions and implementation;
 explore what evidence or data could be routinely collected to inform the local and national picture;
 provide clarity on where autism sits within government policy;
 consider focusing on areas that need to see the greatest change diagnosis, transitions, support for autistic adults, employment;
 place stronger requirements on local authorities to deliver;
 review who is contributing to the discussions and influencing policy; and
 build on the positive relationships that exist. ⁴⁷

HUNGARY	
Context	The National Autism Strategy (2008-2013) from Hungary was developed by the Ministry of Social Affairs and Labour, in cooperation with other relevant ministries, experts and civil organisations. ⁴⁸
Elements	The strategy focused on five key areas:
	 Early diagnosis and intervention: Ensure early and accurate diagnosis of ASD, implement national screening program, provide intervention services to children with ASD and their families.

⁴⁷ Cross-Party Group (CPG) (2020) *The Accountability Gap*, *Scotland Autistic Society*. Available at: <u>https://www.autism.org.uk/what-we-do/news/scotland-cross-party-group-on-autism-report</u> (Accessed: 11 May 2023).

⁴⁸ SZMM (Ministry of Social and Labour) (2008) Országos Autizmus Stratégia (The National Autism Strategy), National Association of Autists. Available at: <u>https://aosz.hu/wp-content/uploads/2014/12/oasvegleges-2008-2013.pdf</u> (Accessed: 11 May 2023).



 Total Funding for initiatives in this area from 2008-2010: ~HUF 48,000 (~AUD 212)
Responsible Parties: EüM (Ministry of Health), National Institute of Child Health, ASZM (Autism professional Workshop)
2. Education and employment: Improve education and employment prospects of individuals with ASD, ensure access to inclusive education, provide vocational training and employment support, encourage employers to hire individuals with ASD.
 Total Funding for initiatives in <u>Education</u> from 2008-2010 HUF210,000 + HUF 275,000 for each employed academic p.a. (~AUD 927 + AUD1214pp/yr)
Responsible Parties: OKM (Ministry of Education and Culture), ASKM (Autism professional Workshop), SZMM (Ministry of Social and Labou
2. Total Funding for initiatives in <u>Employment</u> from 2008-2010: HUF1000+ HUF 300,000 (Taken from Labour Market fund, estimated employment of 100 persons living with autism x HUF 3,000/person employment cost.
 Employment of an Autistic Individual per annum is estimated to be HUF 3 Million (~AUD13,252.72).
Responsible Parties: SZMM (Ministry of Social and Labour)
3. Access to services: Ensure access to appropriate services an support, develop a comprehensive network of services, create a national database of service providers.
1. Total Funding for providing autism-specific professional from 2008-2010:
 HUF 5000 for providing basic training 10 carers (~AUD 22.09)
 Postgraduate training of at least 30 people (HUF 250/person/semester x 30 people x 4 semesters): HUF 15,000/ academic year, total HUF 30,000 (~AUD132.52)
Responsible Parties: OKM (Ministry of Education and Culture), ASKM (Autism professional Workshop), SZMM (Ministry of Social and Labour
4. Awareness-raising: Raise public awareness of ASD, reduce stigma and discrimination, implement public awareness campaigns, promote positive and accurate portrayal of individuals with ASD in media, organise public events and activities.



	5. Research and development: Promote research and development in the field of ASD, support research on causes, diagnosis, and treatment of ASD, establish a national research centre for ASD, encourage international cooperation and collaboration on ASD research.
	The ultimate goal of the strategy was to promote the rights and well- being of individuals with autism and to reduce the stigma and discrimination they face in society. ⁴⁹
Impact	The employment rate of disabled people remarkably improved to 48.3 %. ⁵⁰
	The government adopted the long-term concept for the deinstitutionalisation of social institutional care facilities for 2019-2036. Statistics show the transition from large-scale institutions to small-scale institutions (i.e., more tailored services for individuals with disabilities).
	Hungary was the first country in Europe which offered since the academic year 2012/13 bachelor's degree students to pursue an autism pedagogy specialisation course. In short, one can say that Hungary follows a progressive disability strategy. Even though it does not clearly distinguish between integrative and inclusive education, Hungary always followed an integrative education path.
Lessons	The Hungarian Autism Strategy highlights the importance of understanding the objectives throughout different services, coordinating responsible individuals, and setting clear deadlines for effective implementation.
	The strategy also emphasises the need for data mapping, targeted delivery to local decision-makers, and disclosure of data to improve the coordination and delivery of services for autistic individuals. Additionally, the strategy promotes the general coordination and standardisation of training for professionals across services throughout an autistic individual's lifetime.

⁴⁹ Pál, B. et al. (2011) Az Országos Autizmus Stratégia. Felülvizsgálatának Terve (The National Autism Strategy. Review Plan)gy, Docplayer.hu. Available at: <u>https://docplayer.hu/2646752-Az-orszagosautizmus-strategia-felulvizsgalatanak-terve.html</u> (Accessed: 11 May 2023).

⁵⁰ Gyulavári, T. et al. (2021) European Semester 2020-2021 country fiche on disability equality, European Disability Expertise (EDE). Available at: <u>https://ec.europa.eu/social/BlobServlet?docId=26080&langId=en</u> (Accessed: 11 May 2023).



MALTA ⁵¹	
Context	Malta's first national autism strategy was co-created between the government and the autism community by collecting input from the public since 2018, which included the following:
	 Organised meetings with service providers in the autism sector
	 Collected feedback from schools and University Campuses
	 Organised town hall and other sessions for persons on the autism spectrum
	 Collected concerns of persons on the autism spectrum and their families, holding one-on-one meetings, to gauge the situation and factor in their experiences and wishes
	 Spoke to practitioners and professionals
	 Considered international perspective by attending discussions and events abroad, including United Nations and European Union, by listening to other views, present Malta's current experience, and engage in mutually beneficial debate
	It is important to note that the strategy focuses on social and empowerment aspects within the Autism Community, and much less on the medical aspects. The current Maltese society lacks awareness, acceptance, respect, and inclusion towards people on the autism spectrum. Subsequently, the strategy will play a substantial role in educating the general public on what autism really is about.
Elements	Through the consultations conducted, Malta's Autism Advisory Council have grouped the concerns put forward into 7 main categories, and worked on providing specific action points in respect of each, after laying out a summary of the main concerns raised for every category. Concerns expressed by the Autism Community is laid out, side-by-side, with what Malta's Autism Advisory Council intends to achieve over the next 10 years of the strategy.
	What is autism (including acceptance and awareness strategies)
	Early identification and autism interventions
	Education

⁵¹ Malta National Autism Strategy 2021-2030 (2021) Public Consultation Government of Malta . Available at: https://meae.gov.mt/en/Public_Consultations/MISW/Pages/Consultations/MaltaNationalAutismStrategy202120 30.aspx (Accessed: 12 May 2023).



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	Employment
	Advocacy, Self-Advocacy and Outreach
	Autism and Adulthood
	 The Autism Advisory Council (outlining the coordinating bodies for the strategy).
	Before implementation, the strategy will be finalised through public consultation. Within three weeks, 185 responses were collected from NGOs, governmental organisations, parents and persons on the autism spectrum. Submissions by the public included feedback mainly on:
	 The issue of necessary therapies and the need for further initiatives to support parents
	 Further focus on participation in sports and leisure activities by autistic persons
	Accessibility to education as well as full inclusion of children
	 Develop analytic indicators (i.e., quantifiable outcomes) when implementing the strategy
	Implementation plan independently reviewed by external experts before actioning
	The Maltese Government plans to utilise the National Coordination Mechanism , which operates under the Directorate for Disability Issues (DDI) established under Article 33(1) of the United Nations Convention on the Rights of Persons with Disabilities. This mechanism will facilitate a smooth implementation process, including identifying the specific responsibilities of different stakeholders and setting timeframes for the execution of the Strategy's initiatives. The Coordination Mechanism enables coordination among various entities and ministries involved in the disability sector, making it "best placed" for bringing together diverse stakeholders required to implement the Strategy's comprehensive initiatives.
Impact	It is too early to observe the impact of Malta's strategy.
Lessons	Within Australia, stakeholders have expressed the critical need for a national autism strategy to be coproduced from end to end between governments and the autism community. Despite being Malta's first national autism strategy, government officials have conducted extensive consultation that included collecting input from the autism community for three years and lessons learnt from external jurisdictions



regarding national autism strategy. Subsequently, Australia's national autism strategy could draw inspiration from Malta's approach to 'coproduction' with the autism community.

Malta's strategy implementation will be guided by an international framework (National Coordination Mechanism), with the input of the Autism Community throughout each stage of strategy implementation. Australia currently lacks a comprehensive strategy for addressing autism, resulting in an unsystematic policy and program landscape. Instead, small and fragmented initiatives have been implemented across multiple service systems such as education, health, disability, and social services, at all levels of government over time. To address this issue, Australia could potentially learn from Malta's approach to strategy implementation through the National Coordination Mechanism. It is recommended that over the next few years, Australia observes and evaluates the effectiveness of the National Coordination Mechanism in delivering a structured policy response to various autism initiatives. By doing so, Australia could benefit from a more coherent and streamlined approach to national autism strategy.

This policy brief has been prepared by the Global Consulting Group in collaboration with Autism Aspergers Advocacy Australia (A4).

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