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Towards a National Autism Strategy International lessons for Australia

Background Paper

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About Amaze

Amaze is a community organisation established over 50 years ago by autistic people and their families. Amaze works to build understanding of autism, influence systemic policy change for autistic people and provide independent, credible information and resources to individuals, families, professionals, government and the wider community. We are closely connected with the autistic community through our national help line Autism Connect, our peer support networks and community capacity building initiatives. Amaze is *not a service* provider.

About autism

Autism is a lifelong neurodevelopmental condition. People are born autistic. Autism is not a disease, there is no cure. Every autistic person is different, and the way autism affects each person may change over time.

Autism is highly prevalent and affects people from all walks of life. It is among the biggest disability groups in Australia. Improved recognition of autism and the reclassification of Asperger's Syndrome has contributed to a dramatic increase (217%) of people diagnosed with autism in Australia over the last decade. In 2018 the ABS reported that 1.3% of males, 0.4% of females and 3.2% of children aged 5–14 years have an autism diagnosis. Based on childhood diagnosis rates, actual prevalence in the community is likely to be 2–3%, which means that the majority of Autistic adults are yet to be formally diagnosed.

Autism frequently co-occurs with other neurodevelopment conditions (e.g. ADHD, dyslexia) and intellectual disability. Around 50-70% of autistic people also have mental health conditions.

Acknowledgment

Amaze is indebted to Monique Blakemore, Autistic researcher and advocate for generously sharing her international insights and contacts to inform this paper.

Methodology and disclaimer

The paper provides a high-level investigation into autism strategies of other countries that may be of interest to an Australian audience.

This paper does not seek to be comprehensive or represent all perspectives on the issues concerned. Most of the research was undertaken by desktop analysis of materials published by governments and major autism community organisations. Language barriers (and the absence of English language translations) was a limiting factor. We also benefited from (and are most grateful for) the input of autism experts with international experience and autism organisations in other countries, but this was limited.

We acknowledge that some errors or omissions may have arisen from these limitations and invite readers to verify and build upon the information in this paper.

For further information

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Towards a national autism strategy: international lessons

Context

In November 2019, the Australian Senate resolved to establish a Select Committee on Autism to inquire into and report on the services, support and life outcomes for Autistic people in Australia and to consider the need for a National Autism Strategy. The Committee is due to report in March 2022.

Many submissions made to the Inquiry called for a National Autism Strategy. These came from diverse interests well beyond the autism community such as the Royal Australasian College of Physicians, the Australian Association of Social Workers, various state commissioners for children, young people and families and public guardians.

In considering the need for, and scope of a potential National Autism Strategy, the Select Committee has sought advice about international comparisons. Amaze has produced this background paper to inform Senators, decision makers and the broader community about what is happening elsewhere and the lessons for Australia.

Overview

Many countries have national autism strategies

Australia is noticeably lagging behind comparable countries in the development of a national strategy for autistic people.

Amaze's research identified at least ten comparable countries that have a national autism strategy in place, with some on their second or third iteration. England, Wales, Scotland, Northern Ireland, Malta, France, United States, Spain, Denmark and Hungary are among those with dedicated national autism strategies.

Despite the talent of Australia's autistic community, life outcomes are very poor

Autism is among Australia's biggest disability group, with between 2-3% of the population likely to be autistic. Despite the talents, skills and aspirations of the autistic community, autistic people have among

the worst life outcomes of any cohort experiencing disadvantage in Australia. Autistic people experience with very low rates of educational attainment; very high unemployment off a very low base of labour market participation; high rates of social isolation; marked health inequalities; widespread mental ill-health and poor experiences in the justice system.

Outcomes are manifestly worse for autistic people than for people with disability more generally. These dire outcomes come at a huge cost to autistic people, their families, and the broader Australian community. They demand urgent and dedicated action. Cost results from inappropriate use of scarce resources, inadequate training, lack of knowledge, missed opportunities and avoidable crises, poor co-ordination of services and desperate attempts to remedy past failures of care... The reality is that poor support for autistic people results in poor choices, leading in turn to poorer outcomes. **The Autism Dividend 2020 (UK Autism**

Project)

Australia's public policy response for the autistic community is haphazard

Generic disability approaches have failed to address the discrete challenges and enablers of autistic people. While Australia has some autism specific measures, the policy and program landscape comprises a fragmented array of small and disconnected initiatives. Instead, a dedicated commitment to shifting the dial for autistic people – backed by complementary and evidence informed approaches across governments and community – is needed.

A quality National Autism Strategy would make a difference

It will be a long road ahead – however, a journey of a thousand miles starts with a single step.

Malta's Autism Strategy 2021

A national autism strategy for Australia is long overdue. While a strategy in and of itself is no silver bullet, the international evidence demonstrates that a clear bi-partisan approach builds solid foundations between governments and community that improve the life outcomes of autistic people and their families. When backed by a firm commitment to mutually reinforcing actions and adequate funding, national autism strategies can drive real change.

The Committee may hear arguments there should not be a diagnostic-specific strategy for autism and that Australia's (soon to be refreshed) National Disability Strategy is sufficient. Respectfully, we disagree. Despite the excellent work that has been done in cross-disability policy, key indicators and outcomes for autistic people in Australia have not advanced. The large numbers of autistic people, the distinct challenges and enablers our community face, and the opportunity to make significant gains with a well targeted and tailored response make an autism-specific strategy a national imperative.

The impacts of the pandemic elevate the urgency for a national autism strategy

The challenging circumstances that COVID-19 has presented to autistic people and their families is causing some countries to refresh their autism strategies to address health, mental health, community, and employment impacts. As Australia confronts the impacts of the pandemic and its aftermath, the need for a national autism strategy has never been more critical.

There is much to learn from those that have gone before us

A distinct benefit of being a late adopter is that Australia can learn from those that have gone before us. Accordingly, this paper seeks to highlight approaches in comparable countries and gain a sense of the factors behind their respective successes and shortcomings. The first part of this paper provides a synthesis of experiences from around the world in a way that aims to be instructive for an Australian audience. The second part details specific counties' approaches.

Part 1: A synthesis of what Australia can learn from national autism strategies elsewhere

National autism strategies tend to be wide-ranging

Most national autism strategies tend to include a vision and principles (see the Scottish principles in the adjacent box), as well as practical actions that cover a broad range of issues such as:

- Understanding and acceptance of autism in society (particularly England, Wales, Malta, Spain)
- Access to assessment and diagnosis

 (particularly Wales, Scotland, Malta, Spain, France)
- Education outcomes (particularly England, Malta, Spain, France)
- Employment outcomes (particularly England, Scotland, Malta, Spain)
- Health and care services (particularly England, Wales, Spain, USA)
- Government and sector leadership and coordination
 - (particularly Wales, Scotland, Malta)
- Transition into adulthood (particularly England, Malta, France)
- Training for autism sector workers and mainstream interface workforces (particularly Wales, Spain, USA)

The better strategies take a whole of life approach. England's initial autism strategy focused on adults, but its more recent strategy has been expanded to cover children, young people and adults.

Some jurisdictions including England, Wales, United States and France also have autism specific legislation to underpin their strategies and trigger periodic reviews. **Scotland's Autism Strategy** is underpinned by the following principles:

- The Scottish Government will provide strategic leadership on improving the lives of people affected by autism. It will lead on creating a strategic vision for the development of services and support for people with autism, their families and carers.
- Achieving best value for services for people affected by autism will ensure that resources are effectively targeted and that the outcomes in improving people's lives are the best we can achieve.
- 3. People with autism, and their families and carers, should be involved at all levels in decision making.
- The capacity for cross-agency working will be developed through stronger networks, best practice and training. This will help deliver cost-effective support and interventions.
- 5. For adults, getting a good quality diagnosis is the key foundation that will lead them to understanding their condition and for the best support to be made available to them.
- There are many people with autism who would like to work but who face significant barriers to getting and sustaining a job. We will support them through training, creating opportunities and improving access to the workplace.

National autism strategies deliver positive outcomes

National autism strategies provide *the* critical foundation for concerted and coordinated action. A lack of clear targets, data and outcomes reporting across many existing strategies make it difficult to track real change. However, common outcomes and impacts reported to flow from having a national autism strategy include:

- **Cost savings** when compared with the high costs of inaction or poorly coordinated action. A report by the UK's National Autism Project <u>The Autism Dividend: Reaping the Rewards of Better Investment</u> highlights that delivery of evidence driven supports create long term savings.
- Increased community awareness and understanding of autism. Community attitudes are critical for inclusion. Without changing community attitudes, nothing much else will change.
- Improved access to autism assessment and diagnosis. An autism diagnosis, at any age, can generate significant wellbeing benefits and support social, educational, and economic participation. Easier access to autism assessment has typically been met by growing demand (and therefore waitlists) for an assessment.
- Initiatives for **more inclusive and effective education** for autistic children.

"There has been significant progress. Awareness of autism has increased hugely. Every council now has an adult autism diagnosis pathway, whereas fewer than half did before the Autism Act. Today, all but a very few councils have a lead commissioner for autism. Autism is also a cross- party priority" UK Parliamentary review of ten years of the Autism Act

- Tailored initiatives to boost Autism employment outcomes.
- Better understanding and autism responsiveness in criminal justice.
- The establishment of autism responsive health and care services.

Analysis by Autism Europe found that "national autism strategies seem to bring about a positive impact and change for people on the autism spectrum, even if they do not necessarily achieve all their objectives towards the full respect of the rights of autistic people."¹

Some countries have made significant progress in some areas, while others' achievements have been more modest. Overall, the consensus seems to be that much greater progress is needed.

A <u>report</u> undertaken by the UK's All Party Parliamentary Group on Autism ten years after their Autism Act was introduced found that while there have been improvements in areas such as healthcare and social services, there is still a long way to go.²

Despite advancements, it is not uncommon for autistic people to report that some aspects of life had gone backwards. While this may reflect the reality of individual experiences and lack of opportunity, it is likely also in part a reflection of higher aspirations and expectations among the autistic community.

¹ Available at <u>https://www.autismeurope.org/wp-content/uploads/2018/02/ASDEU_State-of-the-art-autism-policies.pdf</u>

² <u>https://www.autism.org.uk/what-we-do/campaign/not-enough/about-the-autism-act</u>

A future Australian Autism Strategy should reflect lessons from experiences elsewhere

Development of a national autism strategy in Australia can benefit from what has been learnt elsewhere. Understanding what worked and why, what hasn't worked, and what is being improved upon in the second and third waves of autism strategies elsewhere is very instructive.

Drawing on advice received from those we engaged with, analysis by <u>Autism Europe</u>, and a review of key materials, we identified the following success factors for an effective national autism strategy: We want to create a society that truly understands and includes autistic people in all aspects of life; one in which autistic people of all ages, backgrounds and across the country have equal opportunities to play a full part in their communities

England's National strategy for autistic children, young people and adults: 2021-26

- ✓ Genuine co-production with the Autistic community, including representative organisations. Autism organisations and autistic advocates in other countries have underscored the importance of this approach and risks where it does not occur. Strategies perceived as being captured by service provider (commercial) interests have attracted criticism.
- An overarching commitment to advancing the human rights and inclusion of autistic people rather than a deficit-based approach to 'fixing' or 'combatting' autism or channelling autistic people into separate settings.
- ✓ Whole of life and whole of spectrum coverage. The better strategies are relevant to autistic people and their families across their life journey and responsive to different experiences, including those with more complex needs.
- Clear and tangible objectives, targets, measures and indicators are critical to enable progress to be tracked and publicly reported on. These should reflect key priorities across the life course such as: early learning; education and training; employment; community participation; community attitudes; health and wellbeing outcomes; justice, and research. Data needs to be disaggregated for key population groups (e.g. females, Cultural and Linguistically Diverse (CALD) people and First Nations communities.) Strategies without targets and measures are inherently vague; making outcomes and return on investment difficult to quantify.
- An action/implementation plan with accountabilities for delivery. Strategies that are not underpinned by implementation plans are at high risk of floundering. Feedback from key stakeholders with direct experience in the design and implementation of the UK's initial National Autism Strategy was that a lack of sufficient incentives and deterrents undermined effectiveness.
- ✓ Effective governance to drive and coordinate implementation across a vast number and range of organisations and people. This has proved challenging in some countries. To address this, an emerging trend is the establishment of an Autism Commissioner (or a dedicated administrative post) to drive and monitor implementation and maintain focus and momentum. A measure of independence is desirable. A Commissioner could establish 'strategic partnership boards' with

autistic people, families and representative organisations involved in key areas of strategy implementation (e.g. an employment partnership board).

- Adequate and coordinated funding for implementation. A common repercussion of autism strategies is that demand for autism assessment and supports accelerate as awareness of autism grows and services are expanded. Frequent monitoring, responsive funding mechanisms and early attention to workforce development would help avoid the capacity pitfalls that have affected other rollouts.
- ✓ High quality information and training is a key enabler for implementation. Training requirements and quality accreditation of training (as a response to missed quality) are common. The UK have developed a <u>national autism core capabilities framework</u> to identify key capabilities for those working with and for supporting Autistic people. A tiered approach is used: Tier 1 for those who require a general understanding of autism but may not regularly work for autistic people; Tier 2 for those who provide care and support for autistic people but are not autism specialists; Tier 3 for those who work intensively with autistic people. Significant work has been done on workforce training in different sectors including education and healthcare.³
- ✓ Coherent linkages to the broader policy context so that an autism lens is applied in areas such as education, employment, criminal justice, and disability policy. In an Australian context this would mean situating a future National Autism Strategy as complementary to the upcoming Australian Disability Strategy, and ensuring that key government policy areas (e.g. employment for people with disability) include an autism focus.
- The need to address the adverse impacts of the COVID-19 pandemic. Consistent with international experiences⁴, much of Australia's autistic community risks experiencing a long tail of post-pandemic disadvantage. Significant deteriorations in mental health, social isolation, severely disrupted learning, increased economic uncertainly and increased support needs are common.⁵

There is no doubt that the experiences of COVID-19 and lessons learned throughout this period will influence and shape the delivery of autism services for some time to come...there should be no delay in implementing actions at a time when need has never been greater.

Northern Ireland Interim Autism Strategy 2020-21

✓ Timelines for review built into the strategy. The review should be owned at Ministerial level. If there is no date for review, there is a high risk the strategy will 'sit on a shelf'. England's Autism Act obliges the government to produce a strategy every 5 years and to review progress each year.

³ In Education: Autism Education Trust <u>https://www.autismeducationtrust.org.uk/</u> and in healthcare <u>Info Hub | Leading Free</u> <u>Healthcare Resources | Skills for Health</u>

⁴ A <u>study in the United States</u> reported high levels of stress – particularly around isolation, illness, and finance. A <u>survey on the</u> <u>impact of the pandemic on autistic adults in the UK</u> found autistic people to be "particularly at risk, as a consequence of a higher prevalence of co-occurring mental health conditions, such as anxiety".

⁵ ACU/Amaze, Autistic Experience Survey 2021 (publication forthcoming); <u>2020 Survey by the Australian Autism Alliance;</u> Australian <u>research on the impact of the pandemic on autistic people</u>

Part 2: National autism strategies: experiences by country

England's Autism Act (2009) makes it mandatory for the English Government to have a Strategy for Adults
with Autism and to review it every 5 years. ⁹ It requires England's Secretary of State to issue guidance on several aspects of implementation (with ongoing relevance) to local authorities and National Health Service Bodies ⁶ , and requires those bodies to act on the guidance. ⁷ England's first strategy was introduced in 2010 - <u>"Fulfilling and rewarding lives: the strategy for adults with autism in England"</u> . An update to the strategy, <u>"Think Autism"</u> , was introduced in 2014. There was a package of funding of £4.5 million which the Department of Health was to use to take forward themes in the strategy update. ⁸
The next five year review of England's autism strategy was underway in 2019, but as a result of the COVID- 19 pandemic its completion was put off. ⁹ The 2021 strategy, <u>"National strategy for autistic children, young</u> <u>people and adults: 2021 to 2026"</u> was released in mid-July 2021, and marks a widening of the strategy's scope to include autistic children.
 The 2021 Strategy is organized around the following priorities: improving understanding and acceptance of autism within society improving autistic children and young people's access to education, and supporting positive transitions into adulthood supporting more autistic people into employment tackling health and care inequalities for autistic people building the right support in the community and supporting people in inpatient care improving support within the criminal and youth justice systems It indicates the direction for each and lists 3-5 commitments per priority area that apply to the first year of the plan. An implementation plan has been published that includes these commitments and additional actions.
Autism-Europe found that England has the "most advanced legal regime in favour of autistic people" and that the Autism Act was the first autism-specific legislation in Europe. The National Health Service measures for the wait time for diagnosis. Thirteen weeks is their target timeframe for autism diagnoses. Recently figures indicate 40-50% of people going publicly were diagnosed within this timeframe. ¹⁰ A leading English autism advocate, summed up the situation ten years after the Act was introduced ¹¹ said:

⁶ <u>https://www.legislation.gov.uk/ukpga/2009/15/section/2</u>

⁷ https://www.legislation.gov.uk/ukpga/2009/15/section/3

^{8 &}lt;u>https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy</u>

⁹ https://www.autism.org.uk/what-we-do/news/2021-could-be-a-year-of-change

¹⁰ https://digital.nhs.uk/data-and-information/publications/statistical/autism-statistics

¹¹ <u>https://pearsfoundation.org.uk/wp-content/uploads/2019/09/APPGA-Autism-Act-Inquiry-Report.pdf</u>

	"There has been significant progress. Awareness of autism has increased hugely. Every council now has an adult autism diagnosis pathway, whereas fewer than half did before the Autism Act. Today, all but a very few councils have a lead commissioner for autism. Autism is also a cross- party priority and, significantly, was mentioned in the vast majority of parties' manifestos in the 2017 general election. However, every day [MPs] are contacted by autistic constituents who struggle to get a diagnosis, or have to wait several years for one. Too often, they cannot get support from social care or in school."
Lessons	 Reflections from an Australian autistic advocate who lived in England when the initial 2010 Strategy came into effect include: Lack of funding limited Strategy implementation. Report from those we interviewed were that funds that came with the 2014 strategy were not well managed and lacked clear criteria to deliver best value and sustainability. Aspects of autism services are provided by England's 300+ local authorities. Implementation, commitment, resourcing and quality were highly variable. For instance, the training expected and available to autism service providers varies between local authorities. Advocates have called for mandating of accredited, consistent, research-based training. Pre-assesment screening was also highly variable: in some authorities this was effective and helpful; in other places it was poorly done and detrimental. The Strategy and Act provided a solid foundation from which to promote and enforce rights to disability support – for example the interaction of England's human rights laws and the Autism Strategy meant people referred by GPs for autism assessments were able to access supports if encountering long waiting times for diagnosis. The process for strategy development was problematic. While some autistic people were involved in co-production, there was significant barriers to participation (e.g. no funding; short timeframes; information asymmetry). The needs of Autistic women were not given sufficient weight or commitment. More than two in three autistic adults in England don't get the support they need. Only 14% said that there were enough mental health services in their area. 50% of parents said their child had to wait more than a year for support at school. The Society are "calling for specialist autism support in every council in England, more mental health, education and care services in the community, and a national public understanding campaign, among many other things." <
Scotland	
Context	There is a <u>Scottish Strategy for Autism (2011-2021)</u> .
Elements	Scotland's Strategy lists 13 goals, 10 indicators and 26 recommendations that cover a wide range of issues. The recommendations are grouped under six summary statements (below with <i>emphasis</i> added):

¹² <u>https://www.autism.org.uk/what-we-do/news/coronavirus-report</u>

	 The Scottish Government will provide strategic leadership on improving the lives of people affected by autism. It will lead on creating a strategic vision for the development of services and support for people with autism, their families and carers. Achieving best value for services for people affected by autism will ensure that resources are effectively targeted and that the outcomes in improving people's lives are the best we can achieve. People with autism, and their families and carers, should be involved at all levels in decision making. The capacity for cross-agency working will be developed through stronger networks, best practice and training. This will help deliver cost-effective support and interventions. For adults, getting a good quality diagnosis is the key foundation that will lead them to understanding their condition and for the best support to be made available to them. There are many people with autism who would like to work but who face significant barriers to getting and sustaining a job. We will support them through training, creating opportunities and improving access to the workplace.
Impact	Scotland's Cross-Party Group on Autism, a large membership based body including several Scottish MPs, published their high profile non-government <u>evaluation</u> of the implementation of the Strategy in October 2020. They conclude that the Scottish strategy is essentially sound, but that only modest progress has been made towards most of its goals. The most significant progress during the strategy period has been "improvement in public awareness and understanding of autism in Scotland." The evaluation identified "a disconnect between what is expected to happen, as detailed in the Strategy, and what is actually happening in practice," and that some organisations/agencies had not sufficiently implemented the Strategy. The evaluation's community surveys showed that many autistic respondents or their carers believed that autism services and life in general had deteriorated for them during the period of the Strategy. The Scottish Government commissioned an evaluation of the Strategy in late 2020, which had not been released at the time of writing.
Lessons	A key recommendation of Scotland's Cross-Party Group on Autism to "seek to solve the accountability gap" is the establishment of Autism Commissioner to uphold autistic people's rights and ensure that effective policy and laws are implemented appropriately at a local level." This has broad community support, with a campaign to establish an Autism Commissioner "to improve access to support and champion the human rights of autistic people". ^{13,14} being led by ENABLE Scotland, National Autistic Society Scotland and Scottish Autism in the lead up to the 2021 election. We were advised that sustainability of funding was a problem, with some of the "one stop shops" having to close when the funding lapsed.
Wales	
Context	Wales was the first country in the UK to develop a national approach and publish a
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 ¹³ <u>https://www.autism.org.uk/what-we-do/news/2021-could-be-a-year-of-change</u>
 ¹⁴ <u>https://ourvoiceourrights.org/commissioner</u>

	strategic plan for people with autism. The Autistic Spectrum Disorder Strategic Action Plan for Wales (2008) was intended to run until 2018. It was 'refreshed' early, with a <u>new version</u> issued in early 2016, which is still current.
	A recent campaign for Wales to have its own Autism Act was unsuccessful (although the 2009 English Act appears to have had jurisdiction over Wales). However, the Wales Senedd did agree to develop the <u>Code of</u> <u>Practice on the Delivery of Autism Services</u> . The Code will come into force in September 2021.
Elements	The Autism Strategic Action Plan 2016 is organised around three key priority areas:
	 Awareness raising, information and training Assessment and diagnosis
	 Meeting support needs.
	A key initiative has been the creation of national Integrated Autism Services (IAS) which provide services to all regions of Wales and have a range of functions including diagnosis, advice and professional services, as
	well as sector capacity development. ¹⁵ Each IAS is a partnership between the local board of the National
	Health Service and the local government, and seeks to collaborate with the broader autism sector.
	The four main chapters in the Code of Practice on the Delivery of Autism Services are:
	 arrangements for autism assessment and diagnosis
	 arrangements for accessing health and social care services
	 arrangements for awareness raising and training on autism
	 arrangements for planning and monitoring services and stakeholder engagement.
Impact	A 2019 <u>independent evaluation</u> suggests that the Integrated Autism Service was reasonably well implemented, although there were significant delays in some regions.
	One of the key issues in Wales, like other UK jurisdictions, is that growth in demand for autism related services continues to outstrip the growth of supply, for both adults and children, resulting in long waiting times for some.
Norther	n Ireland
Context	Northern Ireland's Autism Act (2011) places "a statutory responsibility on the Department of Health to prepare an autism strategy in collaboration with all Northern Ireland Government Departments setting out how the needs of autistic people should be addressed throughout their lives." ¹⁶
	There is currently an <u>Autism Interim Strategy for 2021-22</u> in place because of pandemic interruptions, following on from their earlier Autism Strategy (2013-2020). Creation of the next longer term autism strategy is underway, with the interim strategy stating "the Department (of Health) is committed to the development of a <i>fully co-produced</i> autism strategy to refresh future strategic direction and actions and to build upon the progress already achieved".

 ¹⁵ <u>https://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
 ¹⁶ <u>https://www.health-ni.gov.uk/sites/default/files/publications/health/doh-autism-interim%20strategy.pdf</u>
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Elements	The 2013-2020 strategy was based upon 11 key themes that aimed to support people with autism to better exercise their rights, choices and life opportunities, have continuing development of an inclusive range of high-quality services and to develop clear, achievable actions which were capable of being monitored and evaluated." ¹⁷
	The 2020-21 interim strategy is arranged under the following three strategic outcomes areas:
	 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.
	 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 and as they transition throughout life stages.
	 An independent life supported by greater societal understanding and choices. We will provide opportunity 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.
Impact	 Northern Ireland's government reports achievements from the initial strategy include: Increased societal awareness which has led to many public facilities, such as shops, cinemas, museums, government services, airports and public transport providers making specific adjustments The establishment of regional multi-agency fora in Health and Social Care Trusts, comprised of autistic people, carers, clinicians, government departments and the community and voluntary sector, has fostered an ethos of partnership working and co-production to inform and develop services and support. The Additional Support Fund, administered by the Department for the Economy, has enabled further education colleges to provide additional support and advice for students who have autism. ¹⁸ They also note: "a greater prevalence of autism within our communities, the growing waiting lists of autism referrals for assessment and the rising demand for services show that there is still considerable progress to
	be made." ¹⁹
	Progress Reports were published in <u>2015</u> and <u>2019</u> .
Malta	
Context	Malta has the <u>"Persons within the Autism Spectrum (Empowerment) Act 2016"</u> . Malta's first <u>National</u> <u>Autism Strategy</u> has recently been released, following an extended period of development.
	The Chairperson of Malta's Autism Advisory Council describes its National Autism Strategy as "an all- encompassing, cradle-to-grave Strategy, making it one of the few such documents internationally."

 ¹⁷ <u>https://www.health-ni.gov.uk/sites/default/files/publications/health/doh-autism-interim%20strategy.pdf</u>
 ¹⁸ <u>https://www.health-ni.gov.uk/sites/default/files/publications/health/doh-autism-interim%20strategy.pdf</u>
 ¹⁹ <u>https://www.health-ni.gov.uk/sites/default/files/publications/health/doh-autism-interim%20strategy.pdf</u>

	Those we interviewed advised that the quality of Malta's approach to autism is high. In part, this reflects Malta's relatively inclusive and progressive political atmosphere, aided by its small population and geography.
Elements	 The Strategy includes extensive action lists grouped under the following topics: What is autism (including awareness and acceptance strategies) Early identification and autism interventions Education Employment Advocacy, Self-Advocacy and Outreach Autism and Adulthood The Autism Advisory Council (outlining the coordinating bodies for the strategy).
Impact	It is too early to see the impact of Malta's Strategy.
Spain	
Context	Spain's Congress rejected the call for a strategy as recently as 2010. Further advocacy led to unanimous support for a strategy in 2014. The <i>Spanish Strategy for ASD</i> 2015 was developed by the Ministry of Health, Social Services and Equality in collaboration with three national autism groups. ²⁰
Elements	 The strategy "is articulated around 15 thematic lines, addressing a wide range of key issues from access to diagnosis, to life-long support, independent living and health."²¹ Autism-Europe reports: "four of these lines have a cross-cutting character. They are devoted to: consciousness and awareness-raising, in order to boost the inclusion of people with autism and promote a positive image of their real capacities; accessibility, which aims to reduce difficulties in understanding the information; research, favouring the coordination of resources, development, innovation and transfer of knowledge; and training for professionals who work alongside people with autism throughout their lives. "The remaining eleven strategic lines deal with: health, with a number of proposals that favour the early detection of autism, access to diagnosis; education, with goals to promote school inclusion and academic success for pupils with autism. This will focus particularly on specialisation, innovation and an adaptation of schooling methods throughout their lives; employment, with measures for fostering orientation and services for employment facilitating employment in both the private and public sectors; and social inclusion, participation and independent life, favouring assistance integrated processes, specialised and multidisciplinary care, improving the associative network and autistic people's access to community resources.

 ²⁰ <u>http://www.autismo.org.es/quehacemos/incidencia-politica/estrategia-espanola-en-tea</u>
 ²¹ <u>https://www.autismeurope.org/wp-content/uploads/2018/03/LINK68.EN_.pdf</u>

	"In addition, other proposals are foreseen for promoting justice and furthering the rights of people with autism. What is intended is to promote the protection of their rights in legal proceedings and in cases of abuse and violence. Lastly, other measures foresee the consolidation of the quality, equity and sustainability of facilitated support."
Impact	The language barrier and lack of existing commentary in English makes it difficult to assess the achievements of the strategy.
France	
Context	France currently has its fourth autism plan, released in 2018, after a change of Government.
Elements	 The plan "revolves around five major commitments, as stated by the French government: 1. to put science back at the heart of public policy concerning autism by endowing France with research of excellence; 2. to intervene as early as possible with regards to young children. 3. catch up with other countries in the area of education; 4. support the full citizenship of adults; 5. support families and recognise their expertise."²²
Lessons	According to Autism-Europe, autism organisations generally gave mixed feedback to the strategy. <u>Autism</u> <u>France</u> made serious criticisms, noting that it lacked proposed timetables, indicators and measurement. It nominated several good elements of previous strategies which had been left out of the new strategy. It felt that the plan cast autism as a psychological problem without adequate attention to the social dimension. It highlights the needs for human rights focus and meaningful engagement with stakeholders.
United S	tates of America
Context	The USA passed the <u>Combating Autism Act</u> in 2006, which was reauthorised in 2011. In 2014 it was updated and renamed the Autism CARES Act (CARES stands for Collaboration, Accountability, Research, Education and Support). This was again updated and reauthorised in 2019. The Interagency Autism Coordinating Committee (IACC) stemming from the legislation has had a <u>Strategic</u>
	Plan for ASD since at least 2009, which was last updated this in 2018/19.23
Elements	 The USA's government efforts appear to lean towards the medical perspective on autism, with one summary noting these elements: Autism prevalence monitoring Training of medical professionals to detect and diagnose autism Development of treatments for medical conditions associated with autism The Interagency Autism Coordinating Committee (IACC) and its annual strategic plan Centers of Excellence in autism surveillance and epidemiology Countless programs and research grants to benefit individuals with autism.²⁴

 ²² <u>https://www.autismeurope.org/blog/2018/04/19/french-government-announces-its-new-autism-strategy/</u>
 ²³ <u>https://iacc.hhs.gov/publications/strategic-plan/2019/strategic_plan_2019.pdf?version=3</u>
 ²⁴ <u>https://www.autismspeaks.org/autism-cares-act</u>

Impact	Among other things the 2019 Act "expand[ed] the focus of government activities to include the entire lifespan of people on the autism spectrum" and reauthorises and expands the Interagency Autism Coordinating Committee (IACC), including requirements for additional community stakeholders to serve on the committee. Given the USA's federal structure, the outcomes and overall resourcing of autism measures are presumed to vary considerably in each of its 50 states.
New Zealand	New Zealand has an Autism Spectrum Disorder Guideline which was developed in 2008 following a review of autism services. A 'Living Guideline' process has been in place since 2009 to enable continuous updates, as needed. It covers: Part 1: Diagnosis and initial assessment of ASD Part 2: Support for individuals, families and carers Part 3: Education for learners with ASD Part 4: Treatment and management of ASD Part 5: Living in the community Part 6: Professional learning and development Part 7: Māori perspectives Part 8: Pacific peoples' perspectives.
Canada	Canadian advocates have long campaigned for a national strategy for autism. Funding has been allocated for strategy development recently and consultation will commence in April 2021. ²⁵ Concerningly, we are hearing that this work is not being well received by some parts of the Autistic community who believe the process has been captured by service providers.
Italy	Italy passed an autism specific law in 2015. ²⁶
Denmark	National Autism Plan, first version in 2006.
Hungary	National Autism Strategy of Hungary 2008.

²⁵ <u>https://www.canada.ca/en/public-health/services/diseases/autism-spectrum-disorder-asd/national-</u> strategy.html ²⁶ https://www.longdom.org/open-access/a-new-opportunity-for-autism-the-first-specific-italian-law-2165-7890-

¹⁰⁰⁰e135.pdf