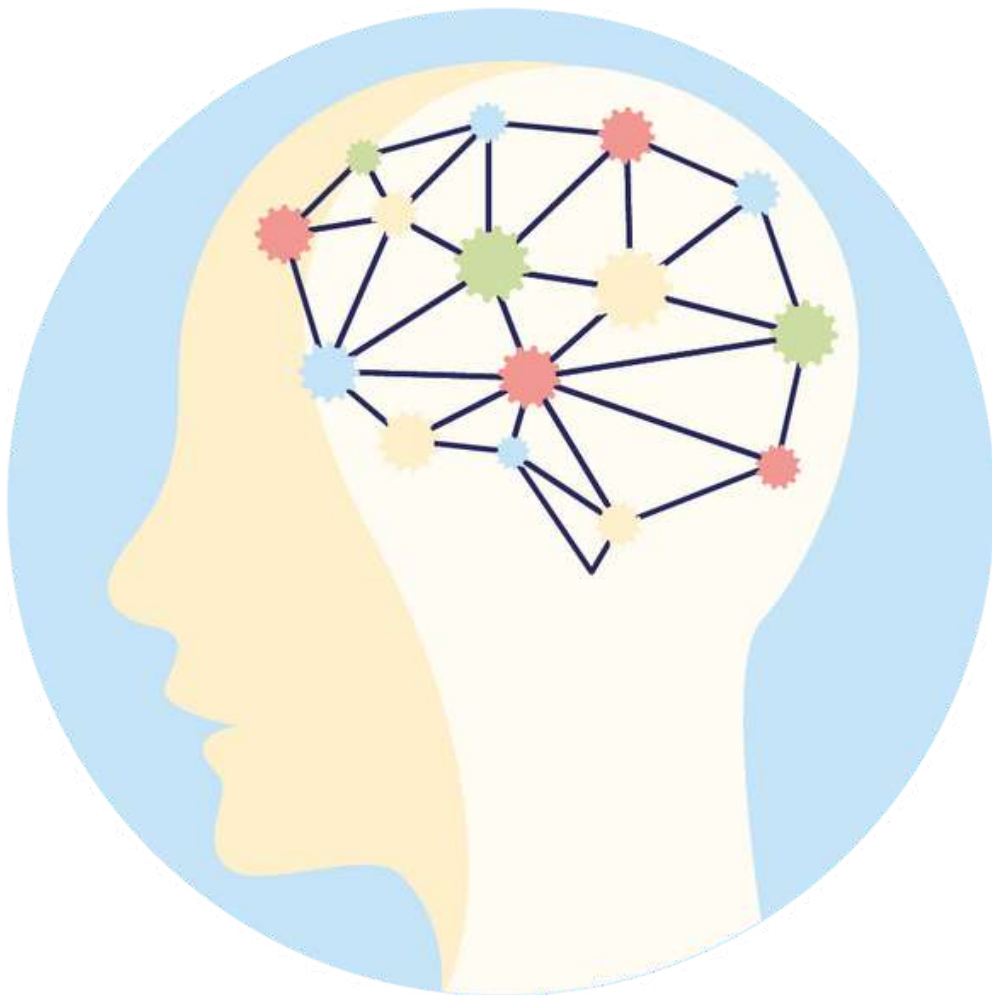


An ASC-Friendly Island

A national strategy for Autism Spectrum
Condition 2024 to 2034



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Health, Learning and Social Policy Board

Foreword

It is with great pride and a sense of collective responsibility that I introduce this national strategy for Autism Spectrum Condition (ASC) on behalf of the Health, Learning and Social Policy Board (HLSPB).

The HLSPB includes members of the Department of Health and Social Care, Department of Education, Sport and Culture, Treasury and the Department of Home Affairs. We understand that supporting those with ASC is a social policy matter, rather than just a health and social care issue.

As well as this, Tynwald has shown its commitment to developing this strategy through its inclusion in the Island Plan.

For this strategy to succeed, we believe that everyone must play their part. Responsibility cannot rest solely on government or any one sector or organisation; it requires the joint effort of public and private sectors, third sector organisations and the wider community. Together, we can create an environment that fosters understanding, support and inclusivity for those with ASC.

We are all aware that we live in a challenging economic climate and recognise the need to be smart with our funding choices. By making well-informed decisions, particularly about where we provide support, staff and funding, we can have the greatest effect. This strategy aims to improve the wellbeing, opportunities and overall quality of life for those within the ASC community.

Importantly, this national strategy is not about providing a 'gold standard', it is about ensuring equality of opportunity in all parts of life. Our aim is to create an inclusive society where barriers are dismantled and differences are accepted as just being a part of life. Only then can we truly embrace the richness of perspectives and talents that those with ASC contribute to our community.

It is also important that the contributions made so far by our ASC community are acknowledged. We would like to say that we have met you, heard you and understood that our services and society have not provided you with the understanding and support that you need and deserve. You have been generous enough to share your most difficult experiences with us in the hope that we will use them to make things better for the next person in your position. We thank you for this.

Hon. Lawrie Hooper MHK
Minister, Department of Health and Social Care

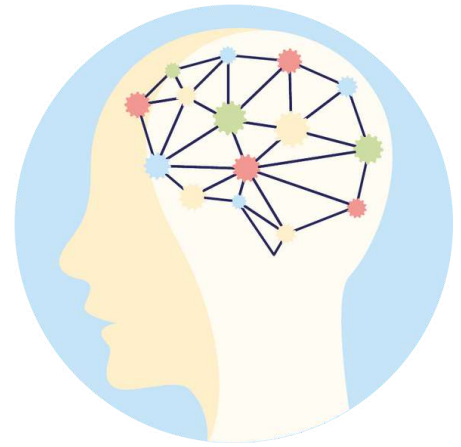


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The information in this strategy can be provided in other accessible formats, such as audio or braille, on request.

About autism and ASC

What are they?

Autism and Autism Spectrum Condition (ASC) are not medical illnesses with treatments or cures. The brains of those who are autistic, or who have ASC, simply work in a different way to other people. This means they experience the world and how people communicate in different ways to others.

Language

People use different language to talk about ASC - some people prefer the term 'autistic person', other people prefer different terms like 'person with Asperger's syndrome' or 'high-functioning autism' or being 'on the spectrum'. People now also talk about ASC using terms like 'neurodiversity' or 'neurodivergence' - these terms are intended to reflect that brain differences are natural variations instead of there being something 'wrong' with a person with this type of diagnosis.

In this document we will use words such as 'those with ASC' or 'people who have ASC' to be as inclusive as possible.

Strengths and talents

Some of the many diverse strengths and talents those with ASC can have include exceptional abilities in areas such as visual thinking, pattern recognition or focused attention to detail. For those with Asperger's (or who would have been considered Asperger's using the previous diagnosis criteria) in particular it is quite common to have 'special abilities' which can include exceptional memory, number skills or spatial awareness.

Recognising, harnessing and supporting these strengths is crucial in empowering those with ASC to reach their full potential.

Challenges

People with ASC may experience difficulties in understanding typical social communication and interaction, just as others experience difficulties in understanding how they communicate and interact. This can lead to feelings of isolation and frustration for a person with ASC.

Over or under-sensitivity to sounds, touch, tastes, smells, light, colours, temperatures or pain are also common. These can cause anxiety or even physical pain. They can have a huge effect on everyday experiences and may need additional, often simple, support to be given; this is what the Equality Act 2017 describes as 'reasonable adjustments'.

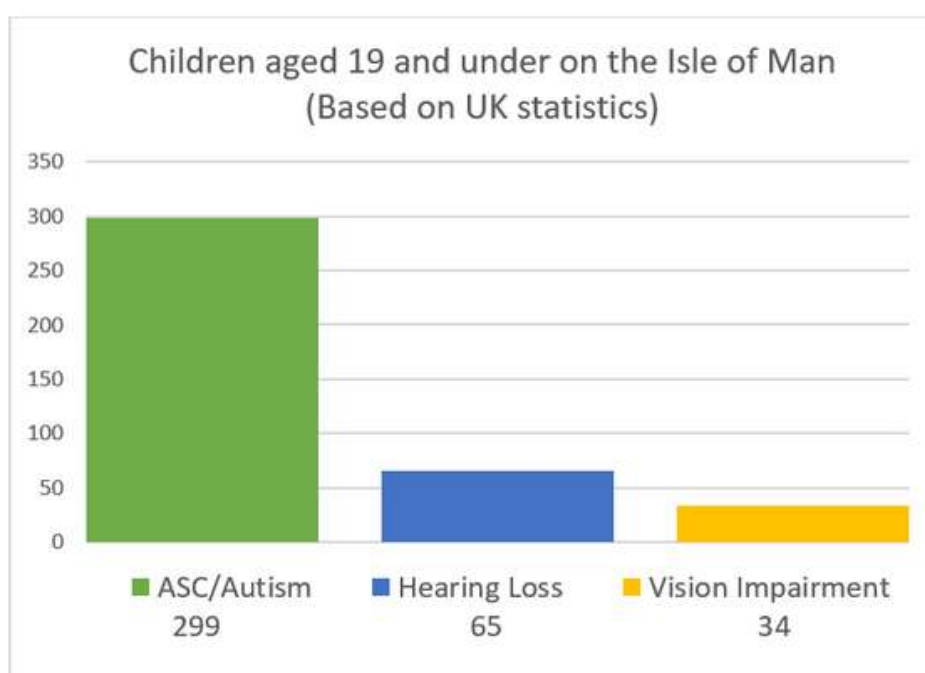
Those with ASC have a higher chance of being diagnosed with other conditions such as epilepsy, depression or anxiety. About a third of those with an ASC diagnosis also have a learning disability. This means that different people may have very different support needs, which makes it very important to treat every person as an individual.

Facts and Figures

How many people have ASC on the Isle of Man?

We currently don't have easy access to this type of information and we also do not have a central place where this information is stored. Gathering this information will be an important part of our early work. To give us an idea of the number of people affected we have used UK figures. For children the figure is 1.76% of the population, which for our island is 299 children aged 19 and under. This makes having ASC as common as having red hair.

To give an idea of how these figures compare to the number of children with other lifelong conditions we have shown them with the figures for children with hearing loss and also children with a visual impairment (both using UK statistics).



This means that, on average:

- Every high school has 23 pupils with ASC.
- Every primary school has 3 pupils with ASC.

When we look across all age ranges it becomes harder to predict exact numbers because professional knowledge and understanding, along with the availability of a diagnosis, have only really developed fully in the United Kingdom in the last 20 years. This means the older someone with ASC is the less likely they are to have a diagnosis. This is particularly true on our island as there is currently no way for an adult to receive an ASC diagnosis through our NHS.

If we use the percentage for those aged 19 and under for our adult population we would predict that we have about 1180 adults with ASC on our island. In total this gives us about 1479 members of our island community with ASC. This means that, on average, each of our GP surgeries will be supporting 105 patients with ASC.

Why we are creating this strategy

Early work was done to find out if there was a need for greater support for the ASC community. Meetings were held with members of the public and those who work in supporting them, both in the public and third sector. The outcome was that there was a great deal of work to be done in this area so, in 2022, we ran a public consultation (See Appendix 2) to ask our Island's ASC community what they needed us to include in our first national strategy for ASC.

Our approach

You gave us 10 main areas of issue and these have been our guide to making sure this strategy addresses the things you care about most.

The 10 most common issues were:

1. Lack of support resources, particularly for adults and those without a learning disability.
2. Need for more mental health support.
3. Lack of public awareness, and absence of reasonable adjustments in place across a wide range of settings.
4. Lack of training and awareness among professionals, particularly relating to 'high-functioning' autism and ASC in women and girls.
5. Lack of social support, including worries about bullying and safeguarding.
6. Difficulties accessing education, particularly higher or continuing education.
7. Difficulties finding enough or the right kinds of information, particularly about what kinds of support may be available.
8. Lack of support for finding or maintaining employment.
9. Lack of support for wider family networks.
10. Over-reliance on medication in comparison to other forms of support.

With a focus on these issues, we looked at research and services in countries around the world. This helped us to understand which things have worked elsewhere, and what may be useful here.

We also looked at the community support we have on our island and recognised that some great work is being done by our third sector. We aim to work with these groups in providing better support and services for our ASC community.

You also told us that supporting those with ASC extends beyond just health and social care.

The strategy is set out with the following sections:

Ambition: What the future looks like if we achieve our goals. This is linked to the Isle of Man Government's Our Island Plan.

Principles: The rules or guidelines for making decisions while we work to deliver the strategy.

Goals: The long-term areas of focus, or themes, that guide the actions we take.

Actions: The specific tasks we want to complete to make progress with our strategy.

Our ambition

Our ambition is to become an ASC-friendly island. We have defined this as: a place that is open to making changes and empowering those with ASC to participate fully in society.

In other words, a place where people accept your differences and make reasonable adjustments as standard practice. Where everyone's needs are considered before a new service is planned. A place where the healthcare and education you receive are of an equal standard to everyone else's. Where a prospective employer focusses on what you can do for their company not the perceived difficulties your ASC may bring. We want to be an island where you can just be you.

We intend to focus on both the things we can do quite quickly to make a noticeable difference and also longer term improvements. Some of these longer term plans will, amongst other things, require a greater level of funding than we currently have. We will work towards gaining broad political support so that Isle of Man Government provides the necessary financial support for this important work.

Working together

Across government different strategies are being developed that include areas of work that cross over with ours. That work is being carried out not just in the health and social care sector but covers all areas of life from the criminal justice system through to education, sports and much more. We will work with these teams to ensure the ASC community is represented and, where possible, we will have matching actions to allow us to work together and also more efficiently.

We will also be working with local industries, communities and various third sector organisations as part of this project. We have already received a great deal of support and encouragement from the public and by involving our whole community in this work we hope that making the necessary changes will become the social norm and everyone's responsibility.

What will happen in 2034 when the strategy ends?

In 2034, at the end of this strategy, the ASC Strategy Steering Group will submit a detailed end of strategy report to Tynwald. The report will explain how we have become a more ASC-friendly island. It will include an overview of the work carried out and how the lives of the ASC community have been improved over the previous 10 years.

The report will also provide evidence, using the information and figures gathered over the 10 year period, to show these improvements in a measurable way.

A follow-up strategy document containing a timetable for any future actions that may be necessary, along with details of who will be responsible for them being carried out, will also be included.

Our starting point

In the last 18 months we have:

- Completed a consultation with the ASC community.
- Completed our first annual awareness and acceptance campaign in April during Autism Acceptance Month.
- Interviewed people with ASC and shared their views and experiences with the public.
- Made a series of social media posts to promote awareness, acceptance and how to provide support.
- Worked to increase knowledge and understanding of the Sunflower scheme.
- Worked with other areas of government including Bus Vannin and Isle of Man Airport to improve accessibility as well as acceptance of ASC.
- Held public feedback sessions at Autism in Mann and Keyll Darree.
- Started work on potential content for the ASC website.
- Presented the draft strategy document at an Autism in Mann meeting.
- Used the feedback from the Autism in Mann meeting to improve the strategy.

Our Principles

Principles are the basic guidelines or rules that help us make decisions and determine what is right and wrong in different situations.

To be an ASC-friendly Island, we will have to make decisions about what actions to take and when. The following principles will help us to make these decisions and achieve our ambition as quickly as possible.

Person Centred

This means focusing on an individual and their needs. It recognises each person as different and involves listening to their concerns, involving them in decision making and tailoring support or services to their specific requirements.

Equality of Opportunity

This means that everyone is treated fairly and has the same opportunities, rights and dignity. It is about ensuring everyone has protection from being discriminated against because of their ASC.

Early Intervention and Preventing Problems

This means taking actions to stop problems from happening or addressing them at an early stage before they become more serious.

Integration

This means bringing different things together to work more smoothly and easily. This can be support services, people (groups or individuals) or systems. When things are integrated you should not have to repeat your personal story unnecessarily.

Evidence-based

This means prioritising decisions based on locally gathered facts and industry best practice, where possible (for example NICE* guidance).

Partnerships

This means joining forces and combining resources, skills, or expertise to achieve a common goal.

*NICE = National Institute For Health and Care Excellence

Our Goals

The goals we have set are the different areas of long-term focus that are needed to be an ASC-friendly Island.

We used comparisons with other jurisdictions (such as England) and best practice guidelines (such as NICE) to ensure these goals focus on the right areas for the long-term.

Our goals are interlinked, which means the success of one goal helps with the success of another.

To achieve our goals, a number of actions will be created for the duration of the strategy. The actions in this document will not all have the same timescale with some actions being delivered quickly and others taking longer. As time goes on, and actions are completed, more actions will be added.

All goals and actions have been numbered. The number they have been given does not show how important they are or which order they will happen in. All goals and actions are of equal importance.

Goal 1 Increase community awareness and acceptance of ASC

Goal 2 Reduce health and social care inequalities for people with ASC

Goal 3 Provide high quality, safe and clear all-age pathways for diagnosis and support

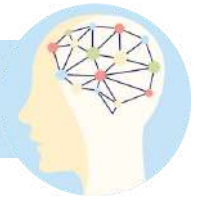
Goal 4 Improve professional awareness and capability across public service providers

Goal 5 Improve access, support and transitions to education at all levels

Goal 6 Improve everyday experiences of people with ASC, their carers and families

Goal 1

Increase community awareness and acceptance of ASC



Our aim is to promote positive opinions about ASC by highlighting the achievements, talents and contributions of this community. In other words, we aim to remove the negative feelings that can be associated with a diagnosis of ASC.

Through media campaigns, storytelling and public events, we will showcase the unique abilities and potential of people with ASC, encouraging acceptance, appreciation and inclusion in our communities.

We want this goal to include an understanding by the public of the distinction between awareness and acceptance. We will spread knowledge and encourage understanding about ASC, as well as the use of reasonable adjustments. We will then go beyond this to take us towards an island that automatically works towards making a positive difference for people with ASC.

We also aim to work closely with autism and ASC organisations, community groups, schools, Manx Care, businesses and government agencies to deliver joined-up initiatives that encourage awareness and acceptance.

Our actions

- a) Complete annual awareness and acceptance campaigns every April during Autism Acceptance Month.
- b) Carry out annual public awareness campaigns about reasonable adjustments. Both public and private sectors will provide reasonable adjustments in accordance with their obligations under the Equality Act 2017.
- c) Using feedback from the community, create an ASC website with details of the Island's diagnosis pathway and support services as well as information to help friends, family, carers and employers.
- d) Work to bring in the use of an ASC passport (or equivalent) across all public services to help staff be aware of any support that may be required.

Goal 2

Reduce health and social care inequalities for people with ASC



It is accepted that autistic people and those with ASC do not benefit from the healthcare system in the way that others do, this can be seen in the following statistics (1):

- higher rates of unmet healthcare needs compared with the general population.
- twice as likely to die of any given disease than the general population.
- a life expectancy 16–30 years shorter than the general population.

Figures (2) also show that:

- up to 35% of autistic adults had planned or attempted suicide.
- autistic children are 28 times more likely to think about or attempt suicide.
- autistic adults who do not have a learning disability are 9 times more likely to die from suicide.

Our goal is to reverse these inequalities.

Our aim is to understand the health needs of our ASC community and the range of services currently provided to support those needs. We will also provide easy access to information about complex care support, respite, day services and investigate the need for independent advocacy.

We then intend to deliver services to support these health needs. These services will be in line with our principles of person centred, problem prevention and early-intervention and integration. With that in mind, a person should not have to have a diagnosis before they receive the support that they need.

Our actions

- a) Review the mechanisms for collecting information and identify areas where information is not currently collected.
- b) Collect information about current services on the Island, both NHS and private, that support the needs of our ASC community.
- c) Create a future plan for support services using the information gathered.
- d) Bring in compulsory Oliver McGowan training(3) for all healthcare staff.
- e) Review the availability of information about complex care support, day centres and respite care.

(1) aph.gov.im, WHO.int

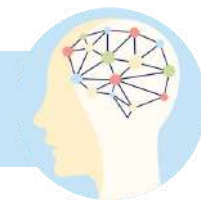
(2) autistica.org.uk, autism.org.uk

(3) Oliver McGowan Training on Learning Disability and Autism must be completed by all NHS England staff.

- f) Investigate the need for independent advocacy services.
- g) Ensure medical staff know that people should not have a 'Do not attempt cardiopulmonary resuscitation' (DNACPR) on their record just because they have an ASC diagnosis.
- h) Influence the development of the Island's Wellbeing and Mental Health Strategy to ensure the voices of the ASC community are represented.
- i) Produce a community suicide prevention awareness plan targeted to high risk groups. (This is part of the Suicide Prevention Strategy work).
- j) Ensure medications are not the only form of intervention or support offered following an ASC diagnosis.
- k) Add a section in the next census so that data can be collected on how many residents have an ASC diagnosis and also to list any co-morbidities e.g. ADHD, epilepsy, depression, anxiety, learning disability, advanced learning levels, being 'gifted' in a particular area.

Goal 3

Provide high quality, safe and clear all-age pathways for diagnosis and support



For many people having a formal diagnosis is very important. Getting a timely and thorough assessment and diagnosis can be helpful because:

- It can help you (and your family, partner, employer, colleagues and friends) to understand why you may experience certain difficulties and what you can do about them.
- It may correct a previous misdiagnosis (such as schizophrenia) and mean that any mental health problems can be better addressed.
- It should help you to get access to appropriate services and benefits.
- It should make it easier for others to understand why they need to make reasonable adjustments, including your employer, school or university.

Our aim is to improve access for everyone (regardless of age) to NHS provided ASC assessments when needed.

We want to have a clear pathway, supported by our principles, to help everyone understand the care and support that is available to them. This means everyone knowing what to expect, when and where.

Our actions

- a) Publish details of how a person (child or adult) can currently be assessed and get a diagnosis of ASC.
- b) Restart the Health and Care Transformation care and support pathway project for ASC, to include:
 - 1) Using England's national autism assessment pathway as a starting point
 - 2) Quality checking against NICE quality and safety guidelines
 - 3) Identifying a number of pathway options
- c) Establish how 'looked after children' (1) obtain a diagnosis and who is responsible for organising their ASC related care and support.
- d) Provide support to Manx Care in their work to significantly increase the capacity of the Child and Adolescent Mental Health Service (CAMHS). (This is also part of the Suicide Prevention Strategy work).
- e) Review clinical pathways for all major mental health conditions to make sure strong transition arrangements exist between services. (This is also part of the Suicide Prevention Strategy work.)

(1) Children who are in the care of the DHSC in accordance with the Children and Young Persons Act 2001. Also known as children in care.

Goal 4

Improve professional awareness and capability across public service providers



By improving the understanding and skills of professionals working within public services, we aim to create a more inclusive and supportive environment for people with ASC. This means improving professional awareness, acceptance and capability across multiple sectors from education, to health and social care, to infrastructure and so on.

We aim to develop compulsory professional training for all staff. We will include universal training (aimed at every professional) and targeted training (aimed at specialist roles).

We will aim to create a culture of ongoing, mandatory professional training based on our key principles of evidence based and person centred.

Our actions

- a) Develop a compulsory training program for public service staff so they can support, and provide better services to, those with ASC.
- b) Improve understanding of the Sunflower Scheme across the public service, providing specific information to staff who deal directly with the public.
- c) Encourage sport, heritage, entertainment and housing providers to review how ASC supportive their services are.
- d) Look into creating a government-wide Workforce Development Plan that includes ASC and other wellbeing topics. The level and type of training provided would depend on the job a person has. (This is an action that is also in the Suicide Prevention Strategy).
- e) Set up a resource centre for staff to share best practice and knowledge to make it easier to support people with ASC. Manx Care and DESC may find it more appropriate to have their own.

Goal 5

Improve access, support and transitions to education at all levels



Our aim is for all people seeking education to have the opportunity to succeed. We want to enable all children, young people, and adults on the Isle of Man to achieve their own personal goals by offering an accessible and high-quality education that meets their needs.

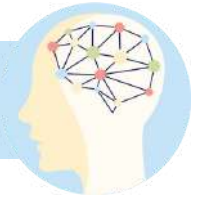
Our work will focus on providing support in school and childcare settings. This means creating an inclusive education approach, through access to a flexible curriculum and a suitable learning environment, where reasonably possible. If a child is still unable to attend school, after all reasonable adjustments have been made, then alternative ways of providing an education will be investigated.

Our actions

- a) Extend the school ASC advisory support service including a review of current staffing levels.
- b) Review the training available to schools to develop their understanding of ASC, including becoming a member of the Autism Education Trust to access their training and support materials. This will support schools and day care settings to look at how supportive physical school environments are, as well as at the flexibility of learning practices, curriculum and timetables, for those with ASC.
- c) Review the effectiveness and availability of the educational support currently provided to child day care providers and childminders in supporting the needs of children with ASC. The outcomes of this review will inform actions on the childcare strategy.
- d) Monitor the progress of the new Specialist Provision Centres (SPCs) and also of the increased capacity of some of the current SPCs to see if further increase in capacity is required.
- e) DESC will be developing an Inclusive Education Policy based on the principles of, and feedback about, the Additional Educational Needs (AEN) Code of Practice.
- f) Review and update the Continuum of Learning and Inclusion document (Social Communication and Interaction section) which provides advice and support to our schools, pre-schools, day care providers and childminders on how best to support children who have ASC.
- g) Investigate the need for, and feasibility of, introducing a digital AEN records and case management system.

Goal 6

Improve everyday experiences of people with ASC, their carers and families



Everyday experiences such as going to the shops, having a job, using public services and public transport, can be made more ASC-friendly. One of the challenges facing those with ASC is that they can feel that they don't fit into the world as it is, that society is not set up with them in mind. They can also feel misunderstood and socially isolated.

A lack of understanding from many employers also makes it particularly hard to get a job, which reduces social interaction and makes it harder to become financially independent. Statistics(1) show that, in the UK, only 29% of adults with ASC are in paid or voluntary work compared to 82.5% of those without ASC or a disability.

One thing we will focus on will be improving everyday experiences for those with ASC as customers on the Island, such as when they visit shops or use services. We also want to improve access to paid work and ensure we support carers and young carers affected by ASC.

We can also begin to explore the benefits of ASC legislation on the Island. This means we could have the ability, by law, to make sure that appropriate services and support are provided for the ASC community.

Our actions

- a) The Steering Group will set up a process to help small changes, that have a big impact, happen quickly and efficiently.
- b) Encourage more flexible working practices to support those with ASC and their carers or supporters to enter or remain in the workplace.
- c) Provide training for careers advisers in how to recognise positive skills and abilities in people with ASC, as well as training for Job Centre staff in how best to support people with ASC to apply for and keep a job.
- d) Create an annual ASC Acceptance Award for organisations who demonstrate acceptance, support and equality for staff and customers with ASC.
- e) Seek political support to develop ASC legislation based upon England's Autism Act 2009.
- f) Influence the development of the Island's Carers and Young Carers strategy to ensure the voices of the ASC community are represented.

- g) Influence the development of the Island's Workforce and Skills strategy to ensure those with ASC are supported to become and remain employed.
- h) Actions within the Childcare Strategy which relate to children with additional needs are implemented.
- i) Encourage the creation of ASC community led support groups for those without learning disabilities and their families. This could be groups for those with ASC and separate groups for families and carers. This can include groups within businesses or the public service.

Our Plan

We now have a plan for how we aim to become an ASC-friendly island but it is clear that we have a lot of work to do and that we will face challenges along the way.

We would not be being realistic if we didn't recognise that obtaining funding in the current financial climate will be one of the main challenges. It will also be difficult to find more staff with specialist knowledge and experience in supporting people with ASC.

This does not mean that our goals are not achievable, it just means that we will have to work smarter and harder to provide the support and services that are required.

Action Plan

We have created an Action Plan (see Appendix 1) that sets out what will happen and when it will happen. This plan also shows who is responsible for each action.

The actions in the plan have been chosen for a variety of reasons, these include:

- They are in the Top 10 issues mentioned by the ASC community.
- They can be achieved relatively quickly.
- They will help many people.
- They can be started without waiting for extra funding.
- They involve representing the ASC community in other government work.

To ensure the actions happen on time and make a real difference to the lives of people with ASC and their families, the Steering Group will monitor progress and report on this every year. If actions do not happen on time the Steering Group will be responsible for finding out why and working with the responsible department to make sure progress is made.

Some actions depend on other government strategies. This may mean that, if other work is delayed, some of the actions in this strategy may be delayed also. We will work with our colleagues across government to try and make sure that this does not happen.

Our first step will be to set up an ASC Strategy Steering Group (the Steering Group) who will be responsible for the strategy being carried out. They will also provide feedback to, and be the voice of, the ASC community. The Steering Group will include government, business, third sector groups and members of the ASC community and will report directly to the Health, Learning and Social Policy Board.

We can see that a one-off strategy document won't allow us to make all of the changes we need to make so we have chosen a more flexible process. We are starting off with a strategy document and will regularly review our progress; making changes and updating our plans when necessary.

A Terms of Reference document will be written, it will explain how the Steering Group will review and manage the progress of the actions in the strategy.

18 months after this strategy has been approved the Steering Group will produce their first report showing the progress we have made and the plans for the next year. After that an annual report and action plan will be produced every 12 months with these reports being made available online. The Steering Group will meet on a quarterly (3 monthly) basis and the minutes from these meetings will be made available online.

The Steering Group will also provide regular updates, at least once a year, to Tynwald.

In addition to this a 6 monthly update will be provided by the DHSC Engagement Team.

Funding

We have mentioned earlier about the need to be smart with our funding choices. This is important when limited amounts of funding exist to support the vast amount of services being provided across Government.

The actions in this strategy are listed in Appendix 1 with a column that confirms whether funding has been allocated to deliver the action. We are pleased to confirm that the Department of Health and Social Care has allocated funding to deliver the majority of the actions in Appendix 1. This funding will make it possible to deliver actions that could not be delivered using our existing budget.

Once the actions in Appendix 1 are complete, a new set of actions will be created and the steering group will work with members of the Health Learning and Social Policy Board to secure further funding in order to keep making the progress required to achieve our vision of an ASC-friendly Island.

Value for money

As can be seen in Appendix 1, the more we invest in this strategy the greater the positive impacts will be and the more lifelong changes we can create for our ASC community, their family, friends, employers, colleagues and carers. We believe, given the amount of positive change that can happen from a relatively small investment, this strategy provides great value for money for our island.

Note:

When working out funding costs we have used figures that were correct in November 2023 and that did not take into account future inflation and any other unknown price increase.

It is important to note that some of the actions in Appendix 1 are only the first step to further improvements. This means that we have been unable to accurately say the amount of funding we require for the whole of these actions. The lack of local facts and figures has also made it difficult to work out exact costs and further work will need to be carried out by the steering group on this.

Goal 1: Increase community awareness and acceptance of ASC					
Ref.	Action	Measure of success	Action owner (responsible for the action)	Date of completion	Funding confirmed (new or existing)
1A	Complete annual awareness and acceptance campaigns every April during Autism Acceptance Month.	Campaigns are carried out and public awareness and acceptance increases.	DHSC Engagement Team (moving on to Public Health)	Annual	Yes
1B	Carry out annual public awareness campaigns about reasonable adjustments. Both public and private sectors will provide reasonable adjustments in accordance with their obligations under the Equality Act 2017.	Campaigns are carried out and public awareness increases.	DHSC Engagement Team (moving on to Cabinet Office)	Annual	Yes

Appendix 1

Action Plan

Ref.	Action	Measure of success	Action owner (responsible for the action)	Date of completion	Funding confirmed (new or existing)
1C	Using feedback from the community, create an ASC website with details of the Island's diagnosis pathway and support services as well as information to help friends, family, carers and employers.	Initial ASC website is up and running and containing relevant information within 6 months. Feedback shows that it is easy to use and also easy to find the information that you need. Improved information included by 18 months.	DHSC Engagement Team (moving on to Manx Care Engagement Team)	6 months / 18 months	Yes
1D	Work to bring in the use of an ASC passport (or equivalent) across all public services to help staff be aware of any support that may be required.	Draft document is created by 12 months, finalised version decided upon and roll-out plan created by 18 months.	HLSPB (Steering Group)	12 months / 18 months	Yes

Goal 2: Reduce health and social care inequalities for people with ASC					
Ref.	Action	Measure of success	Action owner (responsible for the action)	Date of completion	Funding confirmed (new or existing)
2A	Review the mechanisms for collecting information and identify areas where information is not currently collected.	Areas identified where improvements can be made.	DHSC (Manx Care)	6 months	Yes
2B	Collect information about current services on the Island, both NHS and private, that support the needs of our ASC community.	The information has been gathered and a database of service providers has been created.	DHSC (Registration and Inspection)	9 months	Yes
2C	Create a future plan for support services using the information gathered.	Future plan is completed.	DHSC (Manx Care)	18 months	Yes

Ref.	Action	Measure of success	Action owner (responsible for the action)	Date of completion	Funding confirmed (new or existing)
2D	<p>Bring in compulsory Oliver McGowan* training for all healthcare staff.</p> <p>(*All NHS England staff must complete Oliver McGowan Training on Learning Disability and Autism.)</p>	<p>Step 1: Assess options for who will provide training and costs involved within 6 months. Investigate the possibility of joining the NHS England training program.</p> <p>Step 2: Training provider is selected and creates timetable for providing training within 9 months.</p> <p>Step 3: Training is provided and staff are using the skills and knowledge they have gained within 18 months. Training is provided for all new employees on an ongoing basis.</p>	<p>DHSC (Registration and Inspection & Manx Care), Cabinet Office (LEaD)</p>	<p>Step 1: 6 months Step 2: 9 months Step 3: 18 months</p>	<p>Step 1, Step 2 and Start of Step 3</p>
2E	<p>Review the availability of information about complex care support, day centres and respite care.</p>	<p>Availability is reviewed and, where necessary, improvements are made.</p>	<p>DHSC (Manx Care)</p>	<p>12 months</p>	<p>Yes</p>

Ref.	Action	Measure of success	Action owner (responsible for the action)	Date of completion	Funding confirmed (new or existing)
2F	Investigate the need for independent advocacy.	Review is carried out and paper submitted to DHSC Senior Leadership Team (SLT).	DHSC (SLT)	18 months	Yes
2G	Ensure medical staff know that people should not have a 'Do not attempt cardiopulmonary resuscitation' (DNACPR) on their record just because they have an ASC diagnosis.	<p>Step 1: All healthcare staff, including GPs, know that having an ASC diagnosis must not be used as a reason for putting a DNACPR on a person's medical record, particularly without their, or their carer's, knowledge, within 3 months.</p> <p>Step 2: The records of all patients with an ASC diagnosis are reviewed to see if a DNACPR has been added and appropriate action taken, within 9 months.</p>	DHSC (Manx Care)	<p>Step 1: 3 months</p> <p>Step 2: 9 months</p>	Yes
2H	Influence the development of the Island's Wellbeing and Mental Health Strategy to ensure the voices of the ASC community are represented.	Wellbeing and Mental Health Strategy reflects the needs of the ASC community.	HLSPB (Steering Group)	Unknown	Yes

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Action Plan

Ref.	Action	Measure of success	Action owner (responsible for the action)	Date of completion	Funding confirmed (new or existing)
2I	Produce a community suicide prevention awareness plan targeted to high risk groups. (This is part of the Suicide Prevention Strategy work).	The awareness strategy reflects the needs of the ASC community.	HLSPB	Unknown	Linked to another Government Strategy
2J	Ensure medications are not the only form of intervention or support offered following an ASC diagnosis.	Step 1: Appropriate alternative support options are investigated and made available. Step 2: All relevant staff are informed and, if necessary, have been offered appropriate training.	DHSC (Manx Care)	Step 1: 12 months Step 2: 18 months	No (funding to be determined)
2K	Add a section in the next census to collect data about how many residents have an ASC diagnosis and also to list any co-morbidities.	A new section is added into every census, and interim census, to allow data collection in relation to how many residents have an ASC diagnosis and also to list any co-morbidities e.g. ADHD, epilepsy, depression, anxiety, learning disability, advanced learning levels, being 'gifted' in a particular area.	Cabinet Office (Statistics Isle of Man) DHSC (incl. Manx Care)	3 months	Yes

Goal 3: Provide high quality, safe and clear all-age routes (pathways) for diagnosis and support

Ref.	Action	Measure of success	Action owner (responsible for the action)	Date of completion	Funding confirmed (new or existing)
3A	Publish details of how a person (child or adult) can currently be assessed and get a diagnosis of ASC.	Current information is published online.	DHSC (Manx Care)	6 months	Yes
3B	Restart the Health and Care Transformation care and support pathway project for ASC, to include: 1) Using England's national autism assessment pathway as a starting point 2) Quality checking against NICE quality and safety guidelines 3) Identifying a number of pathway options	Step 1: Make plans to restart the Pathway Project within 3 months. Step 2: Pathway Project is restarted within 6 months. Step 3: A number of pathways are identified and costed within 12 months.	DHSC (Health and Care Transformation Team)	Step 1: 3 months Step 2: 6 months Step 3: 12 months	Step 1 and Step 2

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Action Plan

Ref.	Action	Measure of success	Action owner (responsible for the action)	Date of completion	Funding confirmed (new or existing)
3C	Establish how 'looked after children' * obtain a diagnosis and who is responsible for organising their ASC related care and support. (* Children who are in the care of the DHSC in accordance with the Children and Young Persons Act 2001. Also known as children in care.)	Information is known and shared with necessary people.	DHSC (Manx Care - Children and Families Team)	3 months	Yes
3D	Provide support to Manx Care in their work to significantly increase the capacity of the Child and Adolescent Mental Health Service (CAMHS). (This is also part of the Suicide Prevention Strategy work).	The capacity of CAMHS is increased to appropriate levels within 18 months.	HLSPB and DHSC (Manx Care)	Ongoing	Linked to another Government Strategy
3E	Review clinical pathways for all major mental health conditions to make sure strong transition arrangements exist between services. (This is also part of the Suicide Prevention Strategy work.)	The pathways ensure robust transition arrangements.	DHSC (Manx Care), Cabinet Office (Public Health)	Ongoing	Linked to another Government Strategy

Goal 4: Improve professional awareness and capability across public service providers					
Ref.	Action	Measure of success	Action owner (responsible for the action)	Date of completion	Funding confirmed (new or existing)
4A	Develop a compulsory training program for public service staff so they can support, and provide better services to, those with ASC when they are using public services.	Step 1: Appropriate and free online training is identified and undertaken by all staff within 9 months. Step 2: Training to be given to all new staff and repeated by staff every 12 months. Healthcare and education staff will also receive more in-depth training as mentioned in other Actions.	Cabinet Office (LEaD)	Ongoing	Yes
4B	Improve understanding of the Sunflower Scheme across the public service, providing specific information to staff who deal directly with the public.	Staff working on public counters will understand how to support those using the Sunflower Scheme within 6 months. All other staff will have this understanding within 18 months.	Cabinet Office (Office of Human Resources)	Ongoing	Yes

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Action Plan

Ref.	Action	Measure of success	Action owner (responsible for the action)	Date of completion	Funding confirmed (new or existing)
4C	Encourage sport, heritage, entertainment and housing providers to review how ASC supportive their services are.	<p>Step 1: Sport, heritage, entertainment and housing providers have reviewed their service provision to assess if any changes need to be made to make them more 'ASC-friendly', within 18 months. The third sector could be asked to assist with this.</p> <p>Step 2: Services are updated based on findings of step 1, within 3 years.</p>	DESC, Manx National Heritage, Local Authorities, third sector	<p>Step 1: 18 months</p> <p>Step 2: 3 years</p>	Step 1 and Step 2
4D	Look into creating a government-wide 'Workforce Development Plan' that includes ASC and other wellbeing topics. The level and type of training provided would depend on the job a person has. (This is an action that is also in the Suicide Prevention Strategy.)	<p>Step 1: Group set up and timetable written, within 9 months.</p> <p>Step 2: 'Workforce Development Plan' has been designed, within 18 months.</p> <p>Step 3: Plan is being used by staff, 2 years.</p>	HLSPB (Steering Group - all members)	<p>Step 1: 9 months</p> <p>Step 2: 18 months</p> <p>Step 3: 2 years and ongoing</p>	Linked to another Government Strategy

Ref.	Action	Measure of success	Action owner (responsible for the action)	Date of completion	Funding confirmed (new or existing)
4E	Set up a resource centre for staff to share best practice and knowledge to make it easier to support people with ASC. Manx Care and DESC may find it more appropriate to have their own.	<p>Step 1: The Office of Human Resources creates a dedicated area on https://hr.gov.im/ where staff can find advice and information about supporting staff with ASC. To include an area where staff can upload lessons learned following workplace experiences.</p> <p>Step 2: All public service staff are made aware of the resource and encouraged to use it.</p>	Cabinet Office (LEaD) HLSPB (Steering Group - all members)	Step 1: 9 months Step 2: 18 months	Yes

Goal 5: Improve access, support and transitions to education at all levels

Ref.	Action	Measure of success	Action owner (responsible for the action)	Date of completion	Funding confirmed (new or existing)
5A	Extend the school ASC advisory support service including a review of current staffing levels.	The advisory support service has been extended and information is held as to how appropriate the current number of staff is.	DESC	12 months	Yes
5B	Review the training available for schools to develop their understanding of ASC, including becoming a member of the Autism Education Trust to access their training and support materials. This will support schools and day care settings to look at how supportive physical environments are, as well as at the flexibility of learning practices, curriculum and timetables, for those with ASC.	The review has been completed and a report written. This has been shared with senior leaders in educational settings and action plans formed as appropriate	DESC (Senior Leadership Team (SLT)/School Leaders)	12 months	Yes

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Ref.	Action	Measure of success	Action owner (responsible for the action)	Date of completion	Funding confirmed (new or existing)
5C	Review the effectiveness and availability of the educational support currently provided to child day care providers and childminders in supporting the needs of children with ASC. The outcomes of this review will inform actions on the childcare strategy.	Findings from the review have been used by those working on the childcare strategy to support their decision making.	DESC (Early Years and Key Stage 1 Lead)	12 months	Yes
5D	Monitor the progress of the new Specialist Provision Centres (SPCs) and also of the increased capacity of some of the current SPCs to see if further increase in capacity is required.	Review if the new and expanded services are working as planned and if there is a need for a further increase in services.	DESC (SEN Advisor and Disabilities Lead)	Ongoing annual review	Yes
5E	DESC will be developing an Inclusive Education Policy based on the principles of, and feedback about, the Additional Educational Need (AEN) Code of Practice.	An implementation plan has been developed, based on the policy, and this plan is being put into use in educational settings.	DESC SLT	12 months	Yes

Ref.	Action	Measure of success	Action owner (responsible for the action)	Date of completion	Funding confirmed (new or existing)
5F	Review and update the Continuum of Learning and Inclusion document (Social Communication and Interaction section) which provides advice and support to our schools, pre-schools, day care providers and childminders on how best to support children who have ASC.	The document has been reviewed, updated and circulated to appropriate staff.	DESC	12 months	Yes
5G	Investigate the need for, and feasibility of, introducing a digital AEN records and case management system.	Costings and options paper produced in order to support an informed decision.	DESC	12 months	Yes

Goal 6: Improve everyday experiences of people with ASC, their carers and families					
Ref.	Action	Measure of success	Action owner (responsible for the action)	Date of completion	Funding confirmed (new or existing)
6A	The Steering Group will set up a process to help small changes, that have a big impact, happen quickly and efficiently.	The process will be up and running and making positive changes for the ASC community within 3 months. The scheme will be reviewed after 3 years.	HLSPB (Steering Group)	3 months (scheme will continue for 5 years)	Yes
6B	Encourage more flexible working practices to support those with ASC and their carers or supporters to enter or remain in the workplace.	Public service demonstrates more flexibility when advertising/interviewing for jobs and employing new workers. Also demonstrates more flexibility when current employees request flexible working due to having ASC or being a carer for someone with ASC.	Cabinet Office (Office of Human Resources)	9 months	Yes

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Action Plan

Ref.	Action	Measure of success	Action owner (responsible for the action)	Date of completion	Funding confirmed (new or existing)
6C	Provide training for careers advisers in how to recognise positive skills and abilities in people with ASC, as well as training for Job Centre staff in how best to support people with ASC to apply for and keep a job.	<p>Step 1: Investigate appropriate training courses and training providers within 6 months. It is possible that this training may be available free and online.</p> <p>Step 2: Training is provided resulting in careers advisers and Job Centre staff being better equipped to advise and support those with ASC within 18 months. More people with ASC end up in paid work on the island.</p> <p>Step 3: Training provided for all new staff.</p>	The Treasury (Job Centre) DESC (Careers Advice and Guidance)	<p>Step 1: 6 months</p> <p>Step 2: 18 months</p> <p>Step 3: Ongoing</p>	Step 1 and Start of Step 2
6D	Create an annual ASC Acceptance Award for organisations who demonstrate acceptance, support and equality for staff and customers with ASC.	First annual award is presented within 18 months.	HLSPB (Steering Group)	18 months	Yes

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Action Plan

Ref.	Action	Measure of success	Action owner (responsible for the action)	Date of completion	Funding confirmed (new or existing)
6E	Seek political support to develop ASC legislation based upon England's Autism Act 2009.	Political support sought to help the ASC Strategy gain Tynwald approval and funding. Maintain contacts and approach them for further support for future legislation.	HLSPB (Steering Group) Isle of Man Children's Champion (Kerry Sharpe MLC)	2 years	Yes
6F	Influence the development of the Island's Carers and Young Carers strategy to ensure the voices of the ASC community are represented.	The needs of the ASC community are included in the Carers and Young Carers strategy.	HLSPB (Steering Group - DHSC members)	6 months	Linked to another Government Strategy
6G	Influence the development of the Island's Workforce and Skills strategy to ensure those with ASC are supported to become and remain employed.	The needs of the ASC community are included in the Workforce and Skills strategy.	HLSPB (Steering Group - DESC members)	12 months	Linked to another Government Strategy

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Action Plan

Ref.	Action	Measure of success	Action owner (responsible for the action)	Date of completion	Funding confirmed (new or existing)
6H	Actions within the Childcare Strategy which relate to children with additional needs are implemented.	Actions have been carried out or plans are in place to carry them out.	HLSPB	Ongoing	Linked to another Government Strategy
6I	Encourage the creation of ASC community led support groups for those without learning disabilities and their families. This could be groups for those with ASC and separate groups for families and carers. This can include groups within businesses or the public service.	<p>Step 1: Members of the ASC community have been asked if they wish to set up these types of support groups. When possible, assistance is provided through the provision of a room to meet in, publicising the groups etc.</p> <p>Step 2: Those within the ASC community feel more supported.</p>	HLSPB (Steering Group)	<p>Step 1: 9 months</p> <p>Step 2: Ongoing</p>	Yes

Appendix 2

Consultation outcome

We asked

Between 29 April and 10 June 2022, we ran a public consultation to ask our Island's ASC community what they needed us to include in our first national ASC Strategy. We wanted to find out about any current gaps in services or support, and what the community's priorities for improvement were.

We asked a range of questions about the experiences of those with ASC, as well as their needs, and values, to give us a better understanding of how we can help our ASC community to flourish.

In total, 392 people responded to our consultation. Of these:

- 120 people had ASC, or thought they might have ASC,
- 188 were parents, relatives, partners or friends of people with ASC,
- 6 were carers answering on behalf of a person with ASC,
- 41 were education professionals,
- 27 were health or social care professionals,
- 2 were criminal justice professionals,
- 3 were answering on behalf of an organisation, and
- 5 were none of the above.

The consultation was split into two parts.

In Part 1, we wanted to hear about what life is like for someone with ASC on the Isle of Man – this part of the consultation was only for those with ASC and their family, friends and carers.

In Part 2, we asked everyone (including professionals and other interested parties) what they thought would improve support for our Island's ASC community.

You said

Part 1 – Listening to our ASC community

In Part 1, we asked people with ASC to tell us about their own experiences, and we asked family, friends and carers to tell us about the experiences of those with ASC that they support. We asked a mix of closed questions (ones with a list of answers to pick from) and open questions (ones which let people write in their own answers).

In total, answers to the open questions amounted to 195 pages of text. We analysed this text to pick out recurring themes in people's answers, and then we counted the total number of comments relating to each theme. This let us see which issues are causing the greatest concern for our ASC community.

The 10 most common issues were:

1. Lack of support resources, particularly for adults and those without a learning disability.
2. Need for more mental health support.
3. Lack of public awareness, and absence of reasonable adjustments in place across a wide range of settings.
4. Lack of training and awareness among professionals, particularly relating to 'high-functioning' autism and ASC in women and girls.
5. Lack of social support, including worries about bullying and safeguarding.
6. Difficulties accessing education, particularly higher or continuing education.
7. Difficulties finding enough or the right kinds of information, particularly about what kinds of support may be available.
8. Lack of support for finding or maintaining employment.
9. Lack of support for wider family networks.
10. Over-reliance on medication in comparison to other forms of support.

Part 2 – Listening to everyone

Part 2 of the consultation was open to everyone who wanted to be involved in the conversation about improving support for those with ASC on the Isle of Man.

We asked what people saw as the biggest barriers to accessing ASC support on the Isle of Man. All groups identified long waiting lists as one of the biggest hurdles. Our ASC community also identified a lack of professional expertise, lack of public understanding and a lack of funding as major issues. Professionals told us difficulties with staffing or staff retention were a significant barrier.

We asked what people would like us to prioritise in the first national ASC Strategy. The top 3 priorities for the ASC community are training for professionals, early diagnosis and more support for families. Professionals also said they would like to see more support for families, early intervention and the employment of ASC specialists as priorities.

Finally, we asked everyone what would make the Isle of Man more ASC-friendly. The overwhelming majority of people said that more public education is needed to increase awareness, acceptance, understanding and inclusion.

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<https://www.england.nhs.uk/coronavirus/documents/c1146-do-not-attempt-cardiopulmonary-resuscitation-dnacpr-and-people-with-a-learning-disability-and-or-autism/#:~:text=This%20is%20particularly%20important%20in,learning%20disability%2C%20autism%20or%20both.>

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Glossary

- ASC:** Autism Spectrum Condition. The umbrella term for all types of autism, with the most common being Autism, Asperger's Syndrome, High-functioning Autism and Kanner's Syndrome.
- ASC community:** People with an ASC diagnosis or who think they may have ASC. Also their families, carers and support network including their friends.
- ASC passport:** A document that provides others with the information they need so that they can provide appropriate support and reasonable adjustments. These documents come in a variety of forms but all contain personal information about a person's support needs.
- ASC Strategy Steering Group (the Steering Group):** The group that will be responsible for the strategy being carried out. They will also provide feedback to, and be the voice of, the ASC community. The Steering Group will include government, business, third sector groups and members of the ASC community and will report directly to the Health, Learning and Social Policy Board.
- DESC:** Department of Education, Sport and Culture
- DHA:** Department of Home Affairs
- DHSC:** Department of Health and Social Care
- Health and Care Transformation Team:** Following on from the independent health review, carried out by Sir Jonathan Michael, Isle of Man Government set up the transformation team to ensure the recommendations of the review's report were carried out.
- HLSPB:** Health, Learning and Social Policy Board. The Board includes members of the Department of Health and Social Care, Department of Education, Sport and Culture, Treasury and the Department of Home Affairs amongst others.
- Learning disability:** "Someone with a learning disability has a reduced intellectual ability and has difficulty with everyday activities - for example household tasks, socialising or managing money - which affects someone for their whole life." (Mencap.org.uk)
- Looked after children:** Children who are in the care of the DHSC in accordance with the Children and Young Persons Act 2001. Also known as children in care.

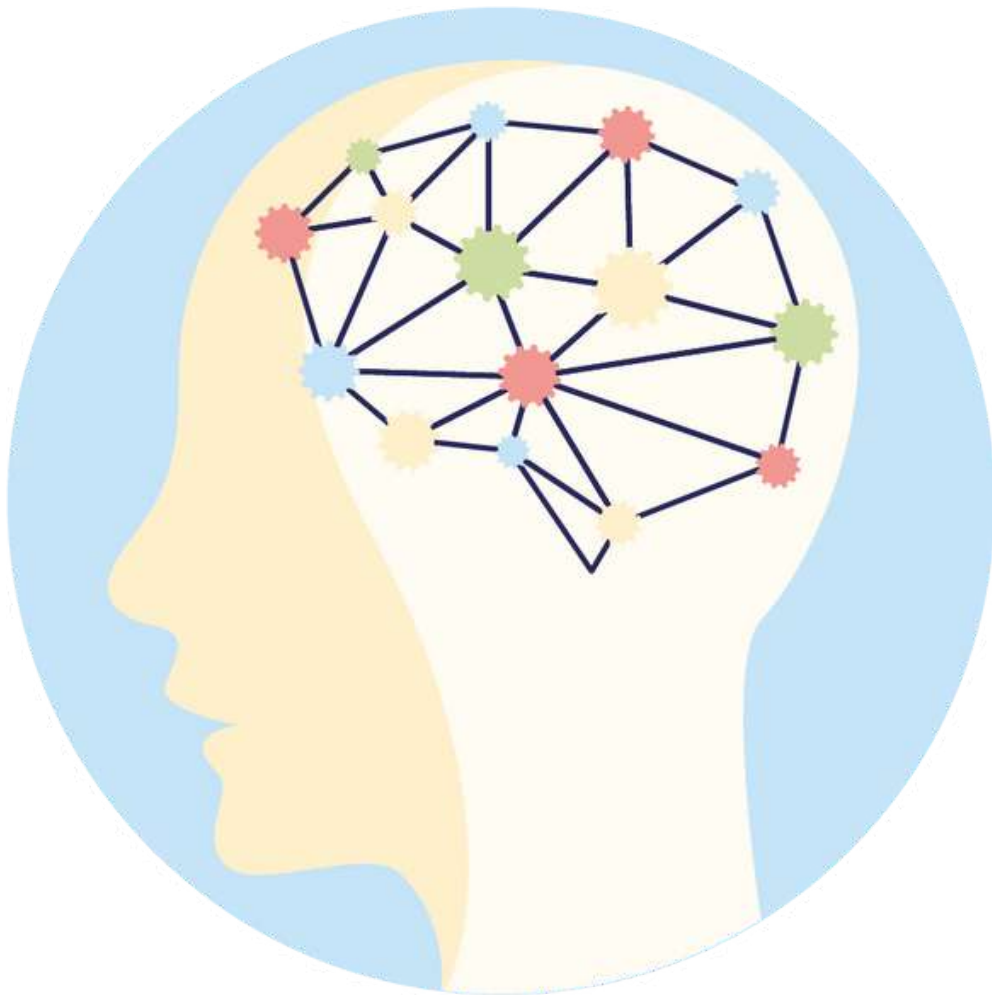
Oliver McGowan Training: Learning Disability and Autism training that must be completed by all NHS England staff.

Public Consultation: A survey to ask the public their views on a particular topic. Usually carried out online but, for our consultation, we also went out and met people and held discussions with local support groups.

Reasonable adjustments: Changes that organisations and people providing services or public functions have to make for you if your ASC puts you at a disadvantage compared with others without ASC. Other groups of people should also receive reasonable adjustments. Details of everyone covered can be found in the Equality Act 2017.

Safeguarding: Protecting a person's health, wellbeing and rights to allow them to live free from harm, abuse and neglect.

Specialist Provision Centres (SPC): SPCs provide specialist support within schools for children with highly personalised learning and care needs. The support provided by each SPC may be different as it will be based on the individual learning and care needs of pupils. It can include support as part of a separate class, with the other pupils in their school year or as a mix of both if appropriate.



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