



Isle of Man
Government

Reiltys Ellan Vannin



Consultation on developing a National Autism Strategy

Department of Health and Social Care

April 2022

Introduction

The Department of Health and Social Care (DHSC) is writing a National Autism Strategy. This strategy will help us to improve the way we support our autistic population and their families, by making sure services are provided fairly, effectively, and where they will do the most good.

Please note: We are interested in all Autism Spectrum Conditions (ASC), including Asperger's Syndrome. We use the words 'autism' and 'autistic' to mean anyone with any ASC, including Asperger's – this is done to make the questions easier to read. We understand that not everyone on the spectrum feels the same or has the same needs, and we have no intention of stigmatising or overlooking any part of the community.

Why are we consulting?

We are asking these questions because we want to hear about the experiences, needs and values of autistic people of all ages (adults and children), so that we can better understand how to support you across the course of your life. If you are on the autism spectrum (or think you may be but haven't been diagnosed), we want to hear from you. We also want to hear from carers, family and friends of autistic people.

By answering these questions, you will help us understand more about the needs of our autistic population, and how those needs can best be met. It is important that you tell us what you need and value most, so that we can write a National Autism Strategy that works.

How to respond

You can respond online on the Isle of Man Government Consultation Hub, by email to DHSCEngagement@gov.im, or in writing to Amy Monroe, Department of Health and Social Care, First Floor, Belgravia House, Circular Road, Douglas, IM1 1AE. Telephone Number: 01624 685816.

If you would prefer to answer these questions in person, we will be holding drop-in sessions at the places listed below, where you will be able to get a paper copy of the questions and go through them with someone face-to-face.

- Tuesday 3rd May, 10am to 12pm - Autism Initiatives, Nunnery Howe, Old Castletown Road, Douglas
- Monday 9th May, 10.30am to 12.30pm - Autism Initiatives, The Oaks, May Hill, Ramsey
- Thursday 12th May, 5.30pm to 7.30pm - Autism Initiatives, Nunnery Howe, Old Castletown Road, Douglas
- Tuesday 17th May, 4pm to 6pm – University College Isle of Man, Homefield Road, Douglas
- Thursday 19th May, 1pm to 3pm - Centre 21, Greenfield Road, Douglas

- Friday 20th May, 10am to 12pm – University College Isle of Man, Homefield Road, Douglas
- Friday 27th May, 12pm to 2pm - Crossroads, Units B5 & B6 Eden Business Park, Cooil Road, Braddan

You can book a specific time-slot at any of these drop-in sessions by visiting <http://dhscengagement.eventbrite.com>. We will do our best to accommodate any special requirements – please contact DHSCEngagement@gov.im for more information.

The deadline for responses is **00.00 Friday 10 June 2022**.

Q1. (Tick one) Are you:

- a) Autistic, or think you might be autistic
- b) A professional carer for someone who is autistic (answering on behalf of a specific individual)
- c) A parent, relative, spouse, partner or friend of someone who is autistic
- d) A young carer for someone who is autistic
- e) A health or social care professional (e.g. GP, social worker, health visitor)
 - o Please specify:
- f) An education professional (e.g. teacher, SEN coordinator, Ed. Psych.)
 - o Please specify:
- g) A criminal justice professional (e.g. police, prison, courts)
 - o Please specify:
- h) A business professional (e.g. employer, human resources, recruitment)
 - o Please specify:
- i) Answering on behalf of an organisation
 - o Please specify:
- j) None of the above
- k) Other:

[If you answered options e – k, please skip to Part 2]

Part 1

We are asking these questions because we want to know more about what life is like for you on the Isle of Man. We want to get a better idea of what support you receive, and where more support might be needed. Knowing more about these things will help us to improve the way we support you, and become a truly autism friendly island.

You can skip any of the questions if you would rather not answer them or if you're not sure how to answer them. You can skip as many questions as you like – any answers you do give will still be important to us.

Each question has a space after it for any other comments – please feel free to use this space to qualify or expand on your answers, or to tell us if any questions are difficult to answer.

Please note: If you are answering these questions as a carer, parent, relative, spouse, partner or friend of someone who is autistic, answer them **as they relate to that person**.

Section 1: Background

Q2. How old are you?

Any other comments:

Q3. Do you have a learning disability (a significant impairment in intellectual or cognitive functioning)?

- Yes
- No
- Don't know / Not sure

Any other comments:

Q4. Do you have any additional learning needs (e.g. dyslexia, dyspraxia, ADHD)?

- Yes
- No
- Don't know / Not sure

Any other comments:

Q5. What is your gender identity?

- Woman
- Man
- Non-binary
- Intersex
- Prefer to self-describe:
- Prefer not to say
- Don't know / Not sure

Any other comments:

Q6. Who do you live with?

- I live on my own
- I live with my family
- I live with my friends
- I live in supported accommodation
- I live in residential care
- Other:

Any other comments:

Q7. Are you employed?

- Yes, I work full-time
 - Paid
 - Voluntary
- Yes, I work part-time
 - Paid
 - Voluntary
- No, but I am seeking employment
- No

Any other comments:

Q8. Are you in education?

- Yes
 - Full-time
 - Part-time
- No

Any other comments:

Section 2: Referral and diagnosis

Q9. Do you:

- a) Have a formal diagnosis of autism or Asperger's Syndrome
- b) Suspect you are autistic, and are waiting for referral or diagnosis
- c) Suspect you are autistic, but haven't asked for a referral or diagnosis
- d) Don't know / Not sure

Any other comments:

[If you answered options b – d, please skip to Q15]

Q10. Who referred you for diagnosis?

- GP
- Pre-school / Nursery
- School / Educational Psychologist
- Mental health service
- Don't know / Not sure
- Other:

Any other comments:

Q11. At what age were you diagnosed?

Any other comments:

Q12. How easy or difficult was it to get a referral?

- Very easy
- Quite easy
- Not easy, but not difficult
- Quite difficult
- Very difficult

Any other comments:

Q13. How supported did you feel when you received your diagnosis?

- Very supported
 - Quite supported
 - Not supported, but not unsupported
 - Quite unsupported
 - Very unsupported
- | |
|--|
| |
| |
| |
| |
| |

Any other comments:

Q14. What would have made it a better experience? (Tick all that apply)

- Shorter waiting lists
 - More information (e.g. being told what happens next, or what support is available)
 - Better communication (e.g. information being provided in different ways)
 - Having more time to ask questions
 - Nothing, it was very easy
 - Other:
- | |
|--|
| |
| |
| |
| |
| |
| |

Any other comments:

Section 3: Support

Q15. Do you receive any support services?

- a) Yes
- b) No, I used to receive services but I don't any more
- c) No, I have never received any services
- d) Don't know / Not sure

Any other comments:

[If you answered options b – d, please skip to Q21]

Q16. Please tell us which services you receive, and who provides them. If you receive a service, but you're not sure who provides it, please tick 'Don't know'. (Tick all that apply)

	Manx Care	Charity	Private	Don't know
Day services				
Education – e.g. pre-school, nursery, school, college				
Speech and language therapy				
Mental health support				
Occupational therapy				
Respite care				
Residential care				
Supported living				
Social activities				
Peer support / support groups				
Day-to-day living – e.g. cooking, cleaning, shopping				
Paperwork and forms – e.g. benefits, tax, phone contracts				
Organising medical care – e.g. making and attending appointments				
Employment				
Sports and leisure activities				

Other services:

Any other comments:

Q17. How satisfied are you with the support you receive? (Rate all that apply)

	Very satisfied	Quite satisfied	Neither satisfied nor unsatisfied	Quite unsatisfied	Very unsatisfied
Day services					
Education					
Speech and language therapy					
Mental health support					
Occupational therapy					
Respite care					
Residential care					
Supported living					
Social activities					
Peer support / support groups					
Day-to-day living					
Paperwork and forms					
Organising medical care					
Employment					
Sports and leisure activities					

Any other comments:

Q18. Do you think anything could be improved in the support you receive? (Tick all that apply)

- Nothing could be improved
- How often you receive support, or how long you receive it for
- Range of activities available
- Better communication (e.g. information being provided in different ways)
- More information (e.g. being told who to talk to about specific problems)
- Continuity of staff
- Having long-term arrangements for support
- Other:

Any other comments:

Q19. If you get support from more than one team or organisation, do they work together well?

- Yes
- No
- Don't know / Not sure
- Does not apply (I don't get support from more than one place)

Any other comments:

Q20. Are there any things you feel you need more support with? (Tick all that apply)

- Day services
- Education – e.g. pre-school, nursery, school, college
- Speech and language therapy
- Mental health support
- Occupational therapy
- Respite care
- Residential care
- Supported living
- Social activities
- Peer support / support groups
- Day-to-day living – e.g. cooking, cleaning, shopping
- Paperwork and forms – e.g. benefits, housing, tax, phone contracts
- Organising medical care – e.g. making and attending appointments
- Employment
- Sports and leisure activities
- Other:
- Don't know / Not sure

Any other comments:

Section 4: Reasonable adjustments

Reasonable adjustments are things that can be changed to make sure that people with disabilities or differences have equal access to things like education, employment, housing, healthcare, shops, banks, cinemas, restaurants, or clubs.

Q21. Are there things that could be changed to make it easier for you to access services in general (e.g. going to the bank, seeing the dentist, sitting exams, buying a car)? (Tick all that apply)

- The way information is provided
- Opportunities to ask questions
- Having more time to think
- Not being kept waiting
- Being told more about what will happen and when
- Noise levels (e.g. school bells, radios in shops)
- Lighting conditions
- Being well prepared before anything changes
- Other:
- No, I do not need any adjustments

Any other comments:

Q22. Have any organisations ever made helpful adjustments to make things easier for you? (Tick all that apply)

- Shops
- Bank
- Hospitality (e.g. restaurants, hotels, bars, cafes)
- Nursery / pre-school
- School / college / university
- Workplace
- Businesses (e.g. lawyers, accountants, mechanics)
- Healthcare (e.g. hospital, GP, dentist)
- Government department (e.g. tax office, social security)
- Police / courts / prison
- Other:

Any other comments:

Q23. What is the most helpful change any organisation has ever made to make things easier for you?

Any other comments:

Q24. Have any organisations ever failed to make helpful adjustments to make things easier for you? (Tick all that apply)

- Shops
- Bank
- Hospitality (e.g. restaurants, hotels, bars, cafes)
- Nursery / pre-school
- School / college / university
- Workplace
- Businesses (e.g. lawyers, accountants, mechanics)
- Healthcare (e.g. hospital, GP, dentist)
- Government department (e.g. tax office, social security)
- Police / courts / prison
- Other:

Any other comments:

Section 5: Acceptance and inclusion

Q25. On the whole, do you think of your autism as a positive thing?

- Yes, it's a positive thing
- No, it's a negative thing
- Neither – it can be positive, but can be negative
- Don't know / Not sure

Any other comments:

Q26. In your experience of living in the Isle of Man, how much do you feel the general population accept and include autistic people?

- A great deal
- Moderately
- Somewhat
- Not much
- Very little
- Don't know / Not sure

Any other comments:

Q27. In your experience, do you think people treat autistic women differently to autistic men?

- Yes
- No
- Don't know / Not sure

Any other comments:

Q28. In which situations do you feel accepted and included? (Tick all that apply)

- At home
- In education (e.g. at school, college, university, pre-school, or nurse)
- In the workplace
- In public spaces (e.g. cafes, shops, bars, restaurants, public transport)
- In healthcare settings (e.g. GP, dentist, optician, hospital)
- In social groups, clubs, or teams
- When I'm with a carer, parent, or other support
- Other:

Any other comments:

Q29. In which situations do you not feel accepted and included? (Tick all that apply)

- At home
- In education (e.g. at school, college, university, pre-school, or nurse)
- In the workplace
- In public spaces (e.g. cafes, shops, bars, restaurants, public transport)
- In healthcare settings (e.g. GP, dentist, optician, hospital)
- In social groups, clubs, or teams
- When I'm with a carer, parent, or other support
- Other:

Any other comments:

Q30. In general, do you feel valued by other people?

- Yes, I generally feel valued
- I sometimes feel valued, but sometimes I don't
- No, I generally don't feel valued
- Don't know / Not sure

Any other comments:

Q31. Is there anything you would like more people to understand about you?

Q32. What would make the Isle of Man more autism friendly?

Q33. How would you like to get in touch with us if there's anything you'd like to ask or tell us? (Tick all that apply)

- Email
- Phone
- Face-to-face
- Letter
- Social media
- Through support worker / carer
- Other:

Any other comments:

Part 2

We are asking these questions because we want to know more about how well support services for autistic people on island are currently working and where improvements are most needed. We also want to know more about general public perceptions of autism on the Isle of Man.

You can skip any or all of these questions if you would rather not answer them or if you're not sure how to answer them.

Each question has a free-text response option called 'any other comments' – please feel free to use this option to qualify or expand on your answers, or to tell us if any questions are difficult to answer.

Q34. What do you think are the biggest barriers to accessing services or support for autistic people? (Tick up to four)

- Lack of funding
- Eligibility criteria
- Long waiting lists
- Accessing a social worker
- Access to information
- Information sharing between organisations
- Lack of public understanding
- Lack of understanding among professionals
- Staff, or staff retention
- Lack of long-term care planning
- Other:

Any other comments:

**Q35. What would you like to see prioritised in the National Autism Strategy?
(Tick up to four)**

- Advocacy services
- Early diagnosis
- Early intervention
- Professional specialists
- Safeguarding (e.g. protection from criminal exploitation or self-neglect)
- Training and education for professionals
- Employment support
- Education
- Support and advice for families
- Other:

Any other comments:

Q36. Tell us where you have seen good practice in supporting autistic people on the Isle of Man

Q37. What stood out about it / why was it good practice?

Q38. Tell us where you have seen difficulties or room for improvement in supporting autistic people on the Isle of Man

Q39. What stood out about it / what improvements were needed?

Q40. Is there anything else you would like to tell us or say about how to make the Isle of Man more autism friendly?

What happens next?

Thank you for taking the time to complete this survey. Your responses will help us to understand how we can create a truly autism friendly island.

We will combine all of the responses we get so that we can build a picture of what matters most to our autistic community as a whole. We will use this information as a guide while we write our National Autism Strategy, so that we can make sure it produces the biggest improvements for the greatest number of people possible.

We will publish the results of this consultation as a 'You Said, We Did' report no later than 29th August 2022.



This document can be provided in large print or in audio format on request

Department of Health and Social Care
First Floor, Belgravia House, Circular Road, Douglas, IM1 1AE
Telephone: (01624) 685816
Email: DHSCEngagement@gov.im

Ref: