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14 December 2022 – 8 March 2023

Autism Strategy

2023-2028

Consultation Document

**Autism Strategy 2023-2028 Consultation**

**Introduction**

The Department of Health would welcome your views on how we develop the action plan for the next autism strategy.

**Background**

In March 2021 the Minister for Health, Robin Swann, published an Autism -Interim Strategy for the years 2021-2022 with the vision ‘*To respect, to listen, to involve’* and this has been central to the work that the Department of Health has been undertaking in relation to autism in recent years.

We recognise that autistic people, their families and carers can only be supported if they are involved and have opportunity to influence the work that we do.

The current autism strategy is drawing to an end and to prepare for a further autism strategy and action plan to commence in 2023, last year we launched a public questionnaire to provide opportunity for autistic people, their families and carers, and also the services and organisations who provide support, to tell us what the priorities for this strategy needed to be.

A summary of the responses to this questionnaire can be accessed here.

[Autism Strategy 2023-2028 | Department of Health (health-ni.gov.uk)](https://www.health-ni.gov.uk/publications/autism-strategy-2023-2028)

You may also be aware that legislation, the Autism (Amendment) Act (NI) 2022 will, provide further support to autistic people, their families and carers was enacted April 2022. A copy of this legislation is available at the link below.

[Autism (Amendment) Act (Northern Ireland) 2022 (legislation.gov.uk)](https://www.legislation.gov.uk/nia/2022/13/data.pdf)

Each of these documents are important in driving forward the work that must be achieved in the coming years.

However, it continues to be important that **all** people who have lived experience of autism, care for an autistic person or have an autistic relative remain central to informing what needs to change or improve, therefore we would invite you to complete this consultation to contribute and express your views.

**Please e-mail your response to** [**Autism.Strategy@health-ni.gov.uk**](mailto:Autism.Strategy@health-ni.gov.uk) **no later than**

**08 March 2023**

**AUTISM STRATEGY DELIVERY TEAM**

**DEPARTMENT OF HEALTH**

**Personal information**

**Whilst the Department looks forward to receiving your views we would ask that your response remains anonymous and that no personal data is disclosed in your response to this document.**

**Thank you.**

**BACKGROUND**

We are asking these questions because we want to know more about what life is like for you. We want to get a better idea of what support you receive, and how support could be improved.

If there are questions you would prefer not to answer, we understand that. The answers you provide will be helpful.

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

|  |  |  |
| --- | --- | --- |
| **Please tick one answer** | **Yes** | **No** |
| Do you have an autism diagnosis? |  |  |
| **Are you:** |  |  |
| Waiting for an autism assessment? |  |  |
| A parent, carer, relative or friend of someone who is autistic. |  |  |
| Answering on behalf of someone who is autistic. |  |  |
| A health or social care professional e.g. GP, Social Worker, Psychologist, Allied Health Professional.  Please specify: |  |  |
| An education professional e.g. School Principal, Teacher, SEN Co-ordinator, Educational Psychologist.  Please specify: |  |  |
| Answering on behalf of an organisation.  Please specify: |  |  |
| Other.  Please specify: |  |  |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Age group (please tick below)** | | | | |
| **Under 18** | **18-25** | **26-50** | **51-65** | **Over 65** |
|  |  |  |  |  |

|  |  |  |
| --- | --- | --- |
| **Gender (Please tick below)** | | |
| **Male** | **Female** | **Other** |
|  |  |  |

|  |  |  |
| --- | --- | --- |
| **Do you have any additional learning needs, for example ADHD, Dyslexia, a learning disability? (Please tick as relevant below)** | | |
| **Yes** | **No** | **Not sure** |
|  |  |  |
| **Additional comments if required.** | | |

|  |  |  |
| --- | --- | --- |
| **Who do you live with?** | | |
|  | **Yes** | **No** |
| I live on my own |  |  |
| I live with my family |  |  |
| I live with friends |  |  |
| I live in supported accommodation |  |  |
| I live in residential care |  |  |
| Other, please specify: |  | |

|  |  |  |
| --- | --- | --- |
| **Are you in education?** | | |
|  | **Yes** | **No** |
| I am in full time education |  |  |
| I am in part time education |  |  |
| Other, please specify: |  | |

|  |  |  |
| --- | --- | --- |
| **Are you in employment?** | | |
|  | **Yes** | **No** |
| I work full time |  |  |
| * Paid |  |  |
| * Voluntary |  |  |
| I work part time |  |  |
| * Paid |  |  |
| * Voluntary |  |  |
| I am seeking employment |  |  |
| Other:  Please specify. |  | |

**Consultation Questions**

1. **Waiting lists for autism assessment**

We acknowledge that waiting times for autism assessment and support need to be improved, this will be an important action in the Autism Strategy 2023-2028. We also want to find out what sort of support would be helpful for people, and their families, when they are referred for an autism assessment.

You have told us that early support and intervention, for example, occupational therapy, speech and language, social skills, adjustments for education or employment, signposting to help or counselling is helpful for individuals and their families and carers both pre and post diagnosis and we want this to be enhanced and accessible for everyone.

|  |  |  |
| --- | --- | --- |
| **Based upon how you were feeling, and your needs at the time, did you or have you received any other assessment or support prior to your referral for autism?** | **Yes** |  |
| **No** |  |
| **If yes, can you tell us more?** | | |
| **Do you have an autism diagnosis?** | **Yes** |  |
| **No** |  |
| **Have you been referred for an autism assessment?** | **Yes** |  |
| **No** |  |
| **Did you, or have you, had support or intervention offered to you before or whilst you were waiting for an autism assessment?** | **Yes** |  |
| **No** |  |
| **Yes, but didn’t accept** |  |
| **If yes, please tell us what type of support you received?** | | |
| **Did you find this helpful?** | **Yes** |  |
| **No** |  |
| **Please tell us what type of support you would find most helpful?** | | |
| **If you have received an autism diagnosis, has it helped you to understand how to adapt to your needs and manage how you feel?** | **Yes** |  |
| **No** |  |

1. **Adult Autism Services**

We want to improve access to adult autism services and support across our Health and Social Care Trusts to enable individuals who are referred for an autism assessment to obtain the support that they need on a consistent basis across the region.

|  |  |  |
| --- | --- | --- |
| **Have you been referred to Adult Autism Services within the Health and Social Care sector for an autism assessment?** | **Yes** |  |
| **No** |  |
| **Have you tried to obtain an assessment but been unsuccessful?** | **Yes** |  |
| **No** |  |
| **Have you sought a private diagnosis for autism?** | **Yes** |  |
| **No** |  |
| **Other, please specify:** | | |
| **If you have sought a private diagnosis for autism, would you be willing to tell us why?** | | |
|  | | |
| **Have you, or are you, receiving services provided by Adult Autism Services?** | **Yes** |  |
| **No** |  |
| **Have you been unable to access services** | **Yes** |  |
| **No** |  |
| **Other, please specify:** | | |
| **If you have accessed services, what type of support did you receive?** | | |
|  | | |
| **Did you find this helpful?** | **Yes** |  |
| **No** |  |
| **What type of support would you find most helpful?** | | |
|  | | |

1. **Emotional Wellbeing and Mental Health**

To help us feel fulfilled and content in our lives it is vital that our emotional health and wellbeing is supported and that people, whether child or adult, are equipped to feel strong and resilient. When help is required, we must provide the right support at the right time, this may be within the school environment, workplace or in your own life. We would welcome responses based on your experience.

|  |  |  |
| --- | --- | --- |
| **Have you ever needed help to support your emotional wellbeing and mental health?** | **Yes** |  |
| **No** |  |
| **Yes, but didn’t seek help** |  |
| **Other, please specify:** | | |
| **Were you able to access support?** | **Yes** |  |
| **No** |  |
| **Didn’t know how** |  |
| **Other, please specify:** | | |
| **How long did you wait to access support?** | **0-6 months** |  |
| **6-12 months** |  |
| **More than 12 months** |  |
| **Other, please specify:** | | |
| **Did you find the support provided helpful?** | **Yes** |  |
| **No** |  |
| **Are you aware of, or have you had access to, emotional wellbeing or mental health programmes or services, for example, within the health and social care sector, the education environment or the community?** | | |
| **Please tell us which service you have accessed:** | | |
| **What barriers have you experienced in accessing emotional wellbeing or mental health support?** | | |
|  | | |
| **Please tell us what additional support would be most helpful?** | | |
|  | | |

1. **Short breaks and Respite Services**

Short Breaks allow people to have enjoyable planned experiences away from their primary carers and also enable some personal space and time from caring responsibilities for families and carers.

Health and Social Care Trusts deliver short breaks (a series of short-term placements) in partnership with the community and voluntary sector. It is acknowledged that Covid-19 and the HSC response had a significant impact on day care and short breaks for vulnerable adults. In 2022, upon direction from the Minister of Health, Trusts have remobilised short breaks with services at pre-pandemic capacity in the majority of Trust areas.

Short Breaks remain significantly limited for children with disabilities due to increasing levels of complexity of need, resulting in the need to accommodate emergency placements. The Department is finalising a framework for children’s disability services that seeks to restore and further extend short breaks provision.

|  |  |  |
| --- | --- | --- |
| **Do you receive short break and respite services?** | **Yes** |  |
| **No** |  |
| **How often would it be helpful to have short break or respite support to be provided?** | **Weekly** |  |
| **Fortnightly** |  |
| **Monthly** |  |
| **Other, please specify:** | | |
| **What type of respite care would be most useful?** | **Overnight** |  |
| **Daytime** |  |
| **Regular activities e.g. groups, music, social activity** |  |
| **Other, please specify:** | | |
| **Do you get advanced notice of short breaks or are they provided on an ad hoc basis?** | **Yes** |  |
| **No** |  |
| **Are you permitted to leave the country while your loved one is accessing short breaks?** | **Yes** |  |
| **No** |  |

**5.**  **Transitions**

Change can be difficult to manage and adapt to, however for many autistic people, their families and carers these changes can extend beyond what many others will experience.

For children and young people, challenges will be experienced as they move through the education sector, adapt to adolescence and deal with the inevitable experiences that life will present.

For adults this may also be difficult, as everyday experiences such as the work environment, social interaction, changes in living arrangements, expectations from society to conform can make life particularly difficult to navigate and often impacts on emotional health and wellbeing.

We want to understand the experiences of the transition planning process and identify how this can be improved and support enhanced.

|  |  |  |
| --- | --- | --- |
| **Have you, or do you, find managing change difficult?** | **Yes** | **No** |
| **When moving from primary to post-primary school** |  |  |
| **When moving from school to college or university** |  |  |
| **When moving to a new or different place to live** |  |  |
| **Managing or adapting to change in employment or within the workplace** |  |  |
| **Within the health and social care sector** |  |  |
| **Adjusting within your community** |  |  |
| **How could this be improved in:** | | |
| **Education** | | |
| **Health and Social Care** | | |
| **Employment** | | |
| **Independent or supported living** | | |

**6. Educational Environment**

We recognise within the educational environment, in school, college or university, that an understanding of the needs of autistic people is important to enable support to be provided that meets the needs of pupils and students. This may be by increasing understanding within the education workforce or by making reasonable adjustment within the environment, for example, provision of a quiet space, calming techniques, ear defenders or support for sensory sensitivity or through a structured routine.

|  |  |  |
| --- | --- | --- |
| **Are you confident that schools have the skills and resources to provide support to autistic children and young people in the school environment?** | **Yes** |  |
| **No** |  |
| **Have you experienced any barriers accessing support in education which could be eased through reasonable adjustment or greater understanding?** | **Yes** |  |
| **No** |  |
| **If yes, please tell us what would be helpful?** | | |
| **Have you accessed additional technology or equipment to provide support in school?** | **Yes** |  |
| **No** |  |
| **Please tell us what it was used for:** | | |
| **Please tell us what additional technology or equipment would be helpful.** | | |
|  | | |
| **Are you aware of the new Special Educational Needs (SEN) Framework?** | **Yes** |  |
| **No** |  |
| **Are you aware of the changes the SEN Framework will introduce?** | **Yes** |  |
| **No** |  |
| **Middletown Centre for Autism was established in 2007 by the Department of Education and Skills Ireland and the Department of Education in Northern Ireland to provide cross border support for the promotion of excellence in the education of autistic children and young people.** | | |
| **Are you aware of the services provided by Middletown Centre for Autism?** | **Yes** |  |
| **No** |  |
| **Have you used the services provided by Middletown Autism Centre?** | **Yes** |  |
| **No** |  |

**Further or Higher Education**

|  |  |  |
| --- | --- | --- |
| **Do you, or have you, attended a further education college or university?** | **Further Education College** |  |
| **University** |  |
| **Are there barriers preventing you from accessing higher or further education?** | **Yes** |  |
| **No** |  |
| **If yes, please tell us:** | | |
| **Please tell us what support would be most helpful to enable you to access higher or further education?** | | |
|  | | |
| **Have you ever received support for autism at either a college or university?** | **Yes** |  |
| **No** |  |
| **Did the support meet your needs?** | **Yes** |  |
| **No** |  |
| **If you have answered yes, please tell us why?**  **If you have answered no, please tell us why not?** | | |
| **What support should be in place for autistic people in an educational setting?** | | |
|  | | |
| **Did you know that the Disabled Students Allowance (DSA) can help Higher Education students who are autistic with course related costs?** | **Yes** |  |
| **No** |  |
| **If yes, have you received DSA support for your course?** | **Yes** |  |
| **No** |  |
| **If you answered yes, did you find the DSA process straightforward?** | **Yes** |  |
| **No** |  |

**7. Careers**

Provision of advice is important when making career choices. For people who are autistic, provision of careers advice may be more helpful if delivered in alternative ways, therefore we want to know how this is working and what could be improved.

|  |  |  |
| --- | --- | --- |
| **Are you confident that the educational curriculum meets the needs of autistic children and young people in preparing them for future career opportunity?** | **Yes** |  |
| **No** |  |
| **If you have answered yes, please tell us why?**  **If you have answered no, please tell us why not?** | | |
| **Is the current mode of delivery for careers information and advice meeting the needs of autistic people?** | **Yes** |  |
| **No** |  |
| **If you have answered yes, please tell us why?**  **If you have answered no, please tell us why not?** | | |
| **Would the introduction of specific online support for autistic people be beneficial?** | **Yes** |  |
| **No** |  |
| **What sort of careers support would be most helpful? Please tell us:** | | |
|  | | |

**8. Employment**

We acknowledge that employment, and the work environment, can present challenges to autistic people and that understanding and acceptance of autism within the workplace must increase. For some autistic people accessing employment can prove difficult and for others the experience, expectations and challenges that the work environment can present may prove difficult to manage.

It is important that this can change and improve. That employers can understand the needs of autistic people and that, where possible, reasonable adjustments can be provided to make the work environment a more positive and comfortable experience for autistic people.

|  |  |  |
| --- | --- | --- |
| **Have you experienced any challenges or difficulty in gaining employment as a result of an autism diagnosis?** | **Yes** |  |
| **No** |  |
| **If yes, please tell us what challenges you have experienced:** | | |
| **What support would be most helpful to enable you to access employment?** | | |
| **Please tell us:** | | |
| **Have you experienced any challenges or difficulty in the workplace as a result of an autism diagnosis?** | **Yes** |  |
| **No** |  |
| **What support would be helpful to improve this?** | | |
|  | | |

**9. Housing**

We understand that access to housing choices can be challenging for autistic people and that we need a range of housing and independent living accommodation which is appropriate to specific needs.

|  |  |  |
| --- | --- | --- |
| **Do you know what the current range of housing and independent living accommodation available is?** | **Yes** |  |
| **No** |  |
| **Do you know where to access information in relation to housing and independent living accommodation?** | **Yes** |  |
| **No** |  |
| **What housing solutions do you consider could improve the current range of accommodation options?** | | |
| **Please specify:** | | |

**Supported Living**

|  |  |  |
| --- | --- | --- |
| **Do you understand what is meant by supported living?** | **Yes** |  |
| **No** |  |
| **Do you know which agencies are involved in supporting vulnerable adults with their housing/supported living choices?** | **Yes** |  |
| **No** |  |
| **What changes would you like to see in relation to supported living to improve the service user experience?** | | |
| **Please specify:** | | |

**10. Our community**

We want to address inequality and obstacles within our society so that everyone feels included and has a sense of belonging. We want autistic people to feel comfortable and confident about accessing and participating in the groups and activities which are available in our communities.

|  |  |  |
| --- | --- | --- |
| **Do you participate in arts or cultural activities?** | **Yes** |  |
| **No** |  |
| **No, but would be interested in participating if obstacles were removed.** |  |
| **What are the barriers to participation in activities you have experienced?** | | |
| **Please tell us:** | | |
| **What type of support or intervention would be most helpful in removing these barriers?** | | |
| **Please tell us:** | | |
| **Do you participate in sporting or physical activities?** | **Yes** |  |
| **No** |  |
| **No, but would be interested in participating if obstacles were removed** |  |
| **What are the barriers to participation in activities you have experienced?** | | |
| **Please tell us:** | | |
| **What type of support or intervention would be most helpful in removing these barriers?** | | |
| **Please tell us:** | | |

|  |  |  |
| --- | --- | --- |
| **Do you participate in activities or groups within your community?** | **Yes** |  |
| **No** |  |
| **No, but would be interested in participating if obstacles were removed** |  |
| **What are the barriers to participation in activities you have experienced?** | | |
| **Please tell us:** | | |
| **What type of support or intervention would be most helpful in removing these barriers?** | | |
| **Please tell us:** | | |

Thank you for taking time to complete this consultation. The response you provide will be very helpful for us to understand the improvements and progress that needs to be made, and also the things that you consider may be working well.

If you have any additional comments or suggestions that you would like to include, please provide these in the Additional Comments box below.

|  |
| --- |
| **Additional Comments** |
| Do you have any additional comments that you would like to make? |
|  |

**Please e-mail your response to** [**Autism.Strategy@health-ni.gov.uk**](mailto:Autism.Strategy@health-ni.gov.uk) **no later than**

**8 March 2023**

**Thank you for your comments.**