

## Appendix 4: Our Engagement Plan: Summary of responses

- **Background**

We created an Autism Planning Group which coordinated the development of the Aberdeenshire Autism Strategy, including work around engagement and communication.

The Planning Group is accountable to Aberdeenshire Council's GIRFEC Children and Young People with a Disability Group and Aberdeenshire Health and Social Care Partnership's Autism Strategic Development Group.

### **Autism Strategy Planning Group**

**Aim:** to co-ordinate the development of Aberdeenshire's Autism Strategy, including engagement and communications.

**Membership:** two co-chairs

Various professionals from Aberdeenshire Council, from Aberdeenshire Health and Social Care Partnership, from NHS Grampian, autistic adults, parents of autistic children, people with lived experience, representation from the third sector and an Independent Neurodivergent consultant.

- **Our Engagement Phase**

To help us develop our Strategy, we coordinated and delivered an **Engagement Phase** to seek the views from people of Aberdeenshire. Fundamentally, we wanted to know – *What should be in the next Aberdeenshire Autism Strategy?*

The Engagement Phase of our Strategy began in April 2022 and ended in September 2023. During this period, we carried out various engagement work with members of the public, professionals and other organisations. We reached out and engaged in discussions with children, young people and adults. We also engaged with parents, carers of autistic individuals and representatives from partners, such as the NHS and from third sector organisations.

We welcomed especially autistic individuals and individuals who self-identify as autistic to take part in our discussions.

- **Our set up**

We held a series of online-based sessions via MS Teams, created surveys and placed messages on social media. Such messages included asking people to contact us directly.

We hosted four online-based Joint Working Groups, and each group met on five occasions between the months of April until June 2022. Following on from the four key themes identified from within the Scottish Strategy for Autism<sup>1</sup>, we named the four Joint Working groups as the following:

1. A Healthy Life – this group discussed topics including autism assessment, post diagnostic support, mental health support and access to healthcare
2. Choice & Control - this group discussed topics including autism training and support for parents/carers
3. Independence - this group discussed topics including autism acceptance, autism friendly environments, strengths-based approaches to support, access to community facilities, peer support, independent-living and housing
4. Active Citizenship - this group discussed topics including transitions in key life stages, supported employment, social security, social isolation and digital inclusion

These groups were jointly facilitated and attended by professionals (i.e., teachers, social workers and speech and language therapists), as well as autistic individuals, parents/carers and representatives from voluntary organisations. Each session lasted approximately 2 hours. There were a total of 74 group participants from all four groups. Attendance varied from week to week.

We held an online-based group session, namely **Autistic-Led Group**. This group particularly welcomed autistic individuals and individuals who self-identify as autistic, as no formal diagnosis was necessary. This group session was facilitated by an autistic

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<sup>1</sup> Scottish Strategy for Autism: [The Scottish Strategy for Autism \(www.gov.scot\)](http://www.gov.scot)

adult/parent from the charity Autism Understanding Scotland and assisted by a consultant from a Neurodivergent consultancy company. A total of 10 participants, including two external facilitators, attended this 2-hour group session.

Additionally, we also hosted four online-based **Evening Group Sessions**. Each group was facilitated by two professionals who were either from Aberdeenshire Health and Social Care Partnership or Aberdeenshire Council. A total of 56 individuals had signed up to attend, however only 9 individuals attended that evening, for reasons unknown to us.

During each online group session, we also gave people the option to use the online application, Google Jamboard. This allowed people to place any additional thoughts onto virtual sticky notes.

All sessions were recorded for note taking purposes.

### What did we ask:

Overall, the following questions were used as a basis for the group conversations:

- Where are we right now?
- What have been our key achievements? What have we achieved so far?
- What has/is working well?
- What do we need to improve on? And how?

- What can we do better?
- What have been the key challenges? The barriers and the gaps?
- What does it look and feel like?
- Future Planning/Key Priorities: what is important to us all?
- Other themes and comments – shared experiences and shared knowledge

Some of these questions were altered to suit the session and the respondent's needs.

In light of covid related restrictions and challenges, no face-to-face contacts were organised. Nevertheless, we consistently shared the message that we were open to conversing with people via alternative methods, such as emails and phone calls.

## Surveys

During the months of June and July 2022, we launched **two online surveys**.

We gave people the choice to choose which survey they preferred to complete:

1. Comprehensive/detailed survey – this was a lengthier survey which focussed on four key themes: A Healthy Life, Choice & Control, Independence, and Active Citizenship.
2. Brief version – this survey contained fewer and more generalised questions.

In total, 25 surveys were completed.

An easy-read format was also issued.

### **Area Committees – Councillors**

During the Engagement Phase, the Project co-leads and the Strategic Development Officer briefed Aberdeenshire's 6 Area Committees (Banff, Banff and Buchan, Kincardine and Mearns, Marr, Formartine, Garioch). These area committees consist of elected Councillors who represented the local community.

### **Schools**

We invited schools to support the consultation with children and young people. Following discussion and consultation with the Pupil Participation Forum, GIRFEC, Children with a Disability Group and school staff, a survey was created and shared with Principal Teachers of Additional Support for Learning for further consultation. The survey was trialled in one of the schools before being shared more widely.

In August 2022, we approached all Aberdeenshire Council schools. Through the teachers and with their support, we asked the school aged children and young persons to complete an online survey and the following 9 questions were asked:

- Who supports you in school?
- How do you they support you?
- Is there someone in school you can speak to if you are worried or need help?
- Is there anything else that could be done to help you or make things easier in school?
- Who supports when you are not at school?
- How do they support you?
- Is there someone you can speak to if you are worried or need help outside of school?
- Is there anything else that could be done to help you or make things easier when you are not at school?
- Any other comments

In total, 33 surveys were completed.

### **Home-educated**

We wanted to capture the views of children and families of home-educated status. From having had conversations with members of the autistic community, we gained some insight into (diagnosed/undiagnosed/self-identify) autistic children and their families from within the home-educated setting. We also learned that there are families who refer to themselves as ‘hidden home-ed’ families, in addition to the children and families who are known and registered with the local authorities. In view of concerns around data protection, we were not allowed to contact the families who are registered with the Council and taking into consideration that they may not wish to be contacted; therefore we chose to attempt to reach out to the ‘home-educated’ children and families via social media. The message shared requested the views of home-educated children and families to help us develop the Strategy. In the

message posted on social media, we asked for volunteers to come forward and make direct contact with us. As a result of this callout for volunteers, three persons contacted us via email to share their views.

### Social Media and Webpage

To help keep in touch with others and shared updates, we created a webportal and platform tool webpage on the online platform, Engagement Aberdeenshire:

[A New Aberdeenshire Autism Strategy for Children, Young People and Adults | Engage Aberdeenshire](#). This allowed updates and interactions to be possible.

- **What people told us and our summary of findings**

Responses were analysed from the joint working groups, autist-led group, evening groups, surveys and 1:1 feedback and the following themes were identified:

Early recognition and clear diagnostic pathways	
Summary of comments:	<ul style="list-style-type: none"><li>• Education staff trained in early recognition and what to do</li><li>• Transparent pathways for children, young people and adults</li></ul>



	<ul style="list-style-type: none"><li>• Clear timescales</li><li>• Need to move away from medical model for diagnosis</li><li>• Need recognition for self-identification</li><li>• Still a postcode lottery</li><li>• Early intervention is needed</li><li>• Long waiting lists with no support while waiting</li><li>• Need pre diagnostic support as well</li></ul>
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<b>Post Diagnostic Support</b>	
<b>Summary of comments:</b>	<ul style="list-style-type: none"><li>• People feel left out after diagnosis often leading to crisis</li><li>• Support for young people post diagnosis</li><li>• Support for adults – what to do next, where to go for support, what this means</li><li>• Support for parents</li><li>• Consider those with English as a 2<sup>nd</sup> language</li></ul>

<b>Access to services</b>	
<b>Summary of comments:</b>	<ul style="list-style-type: none"><li>• Should be coordinated across Aberdeenshire</li><li>• Need services people to want - not make - people fit the services</li><li>• Services that are flexible, long term and adaptable to need</li><li>• Need clear routes into support for those who don't meet eligibility criteria</li><li>• Services should be free</li><li>• Social work assessment process needs overhauled to be much more inclusive and understanding of autistic people's needs</li></ul>

<b>Lifespan strategy</b>	
<b>Summary of comments:</b>	<ul style="list-style-type: none"><li>• Coordinated across lifespan</li><li>• Independent living skills should be more available</li><li>• Travel support (not just training but travel buddies)</li><li>• Support for teenagers</li><li>• Social support for older adults</li><li>• Need more joined up approach across the lifespan</li><li>• Transitions happen all through life</li></ul>

Training	
<b>Summary of comments:</b>	<ul style="list-style-type: none"><li>• Funded and sustainable</li><li>• Autistic led and up to date</li><li>• Training needs analysis</li><li>• All staff including school staff, MH and hospital staff, public services</li><li>• Available to everyone</li></ul>

Transitions	
<b>Summary of comments:</b>	<ul style="list-style-type: none"><li>• Lifespan transitions – not just school focused</li><li>• Need support across Aberdeenshire</li><li>• Long term planning is lacking</li><li>• 65yr+ transitions (e.g., into care, supported living)</li></ul>

Remote and Rural	
<b>Summary of comments:</b>	<ul style="list-style-type: none"><li>• People can become very lonely</li><li>• Cost of living is going to have a very big impact on autistic people in rural locations</li><li>• Digital inclusion is important but should not be the only option – not everyone is online or has good access to good service</li><li>• Travel – lack of public transport, lack of support for travel, no funds for taxis – big barrier to accessing things</li><li>• Access to support is often not available rurally which leaves people isolated</li></ul>

Information	
<b>Summary of comments:</b>	<ul style="list-style-type: none"><li>• Need one point of information where everything is held</li><li>• Need to map out exactly what is available locally, how to access it, referral process, route in etc.</li><li>• Co-ordinated services and information</li><li>• Services directory</li><li>• Services do not know what else is available and don't know what each other provides</li><li>• Not knowing what entitled to</li></ul>

<b>Understanding and Acceptance</b>	
<b>Summary of comments:</b>	<ul style="list-style-type: none"><li>• Community and societal understanding and acceptance would help with a lot of the other points</li><li>• Need to raise awareness that autism is not a mental health condition or learning disability!</li><li>• Local awareness campaign to run alongside the national one</li><li>• Autistic champions</li></ul>

<b>Accessibility</b>	
<b>Summary of comments:</b>	<ul style="list-style-type: none"><li>• Services (all services) should offer alternative communication options</li><li>• Public services should provide reasonable adjustments including consideration of sensory needs</li><li>• Trauma informed practice in all public services</li><li>• Housing – needs understanding and support to make accessible</li><li>• Digital inclusion – not the answer to everything but a good option along with others</li></ul>

Employment	
<b>Summary of comments:</b>	<ul style="list-style-type: none"><li>• Better training and understanding within employers</li><li>• Autistic people should be made aware of their employment rights</li><li>• Benefits of having neurodiverse workforce</li><li>• Businesses should be offered accredited courses (e.g. through Business Gateway)</li></ul>

Education	
<b>Summary of comments:</b>	<ul style="list-style-type: none"><li>• All staff should be trained – up to date, social model, autistic-ed.</li><li>• Fellow pupils should have opportunity to learn about neurodiversity</li><li>• Some staff have very negative attitudes which have big impacts</li><li>• Range of education options when mainstream doesn't work</li><li>• Reasonable adjustments</li></ul>

Human Rights	
<b>Summary of comments:</b>	<ul style="list-style-type: none"><li>• Right to be supported</li></ul>

Following on from analysing all the feedback and the information summarised above, we identified the following **7 Key Themes** which the Strategy and Action will prioritise:

**Key Theme 1: Whole Lifespan**

**Key Theme 2: Diagnostic Pathways (Children, Young Persons, Adults and Older Adults)**

**Key Theme 3: Training**

**Key Theme 4: Lifelong Learning**

**Key Theme 5: Employment**

**Key Theme 6: Connecting**

**Key Theme 7: Community**

Please see main Autism Strategy Report and Action Plan for detailed information on the 7 Key Themes – Aims, Outcomes and Actions.