

# Autism Strategy Consultation Review

To support the revised Autism Strategy and Action development a variety of engagement and consultation activities were undertaken.

A summary of this activity follows:

## Engagement Activity

A series of engagement and development activity with key groups and individuals took place to inform the draft Strategy and Action Plan for consultation.

- A Strategic Steering Group was established with membership initially from NHS Grampian, Aberdeen City Council and Aberdeen City Health & Social Care Partnership services. This group was expanded to include representatives from the Third Sector
- An Autism Forum, supported by ACVO, has nominated 3 representatives from Third Sector Organisations to join the Strategic Steering Group. The organisations within the forum aim to represent the views of Autistic People and their Families in both Aberdeen City and Aberdeenshire
- 4 initial engagement sessions were held with varied attendance, including Autistic People, Families/Carers, Professionals and Organisations. 1 of the sessions was solely for engagement with Autistic People
- In the region of 60 people attended these engagement sessions, with 3 of the sessions being supported by Autism Network Scotland (ANS is funded by Scottish Government to support the implementation of the national Autism Strategy)
- The engagement sessions focussed on the 4 outcomes identified in the refresh of the national Strategy outcome and priorities: A Healthy Life; Choice & Control; Independence; Active Citizenship. Feedback received identified that for our local Strategy refresh these outcomes although relevant were not the key aspects people would wish to be focussed on

- Following the engagement sessions feedback was collated and 13 key focus areas could be identified
- These were: Assessment and Diagnosis; Education; Transitions; Support for Carers; Housing; Training; Information; Criminal Justice; Health; Leisure and Activities; Services; Knowledge and Understanding; Employment
- A descriptor for each of these focus areas was created, through comments received at engagement and further developmental sessions were arranged
- 3 Development Sessions were conducted which focussed on the areas previously identified and sought to consider the actions needed to address any issues raised in relation to each specified area.
- 30 people attended these sessions, with mixed attendance including Autistic People, Families/Carers, Professionals and Organisation

## Consultation Process

A 6-week formal consultation period was initiated to capture views on the draft Strategy and Action Plan. The draft was produced primarily from feedback obtained within the engagement and development sessions, in addition to a review of the existing Strategy & Action Plan, and discussions within Strategic Steering Group.

- A consultation survey was created to capture views via the Aberdeen City Council's consultation platform 'Citizen Space'
- The survey could be completed anonymously and as either an individual or group response – enabling group discussion of the questions and then 1 entry of electronic feedback.
- Face to Face sessions for consultation feedback were considered but due to staff capacity were not viable on this occasion

- Information on the consultation was provided widely within the Steering Group, Services/Teams and across other organisations and partners to encourage dissemination of information and completion of the survey
- Where data sharing allowed, information on the strategy consultation was disseminated widely through a mailing list comprising of Public, Third Sector and Independent sector organisations as well as other interested parties
- Consultation information was placed on Aberdeen City Council, NHS Grampian and Aberdeen City Health & Social Care Partnership Websites. Third Sector Organisations were also encouraged to share this information
- Information on the consultation was made available through internal and external e-bulletins

## Consultation Overview

- 40 responses were received to the formal consultation
- Comprising of 28 individual and 12 group/collective responses. Group responses ranged from 2 people to upwards of 20 people's views being represented
- Respondents were asked to identify under which role they were completing the survey, with selection of more than 1 role possible. The highest response rates came from people identifying as a Professional or from an Organisation (20 responses), followed by Parent/Carer (16), Autistic Person (9) with the remaining classifying themselves as either Other Family Member (3) or Other (5)
- Respondents were asked whether they found the Strategy and Action Plan document easy to understand or had any views on the format. Around two thirds of respondents viewed it as being clear and understandable. The remaining third noted that some clarity was needed, and some responses indicated they did not like the format or did not find the structure easy to understand.

- We asked in what ways the format may be made more relevant to the audience, a range of comments were received with suggestions such as an easy read version, a video/audio version, summary document or leaflet, and a comic version.
- We specifically asked if people agreed with the vision identified, with 75% stating yes
- We also asked if people understood why the Strategy was being revised, with 90% stating yes
- We asked people for their views on which focus should be prioritised, and while some comments indicated that it was difficult to prioritise one area over another the survey results generally indicate some higher priority areas: Assessment & Diagnosis; Education; Training; Transitions: Support for Carers; Health; and Services

## Feedback

- Overall the feedback throughout the consultation could be related to the 13 key focus areas identified during the engagement and development activity
- Some increased clarity was requested in relation to concepts discussed in the document, this may be achieved via a glossary, further expansion of the concept or examples, a review of these aspects will be undertaken, and clarity provided
- The definition of Autism used whilst agreeable to many was not universally accepted, as such this will be reviewed and suggestions to provide an enhanced clinical view will be explored
- There were some comments on the language used within the document such as terminology and what was generally viewed as 'jargon', every attempt will be made to provide a Plain English approach to this Strategy, with the acknowledgement that some terminology may require to remain but will be further explained (e.g. in a glossary section)

- Some data referenced within the draft was noted to have been more recently updated, changes will therefore be made to ensure any data references are relevant and up to date
- There were mixed comments received on the format and style of the document, and whilst many people found the style clear, there were suggestions made which could offer improved readership. The draft document was provided in one format with the expectation that an approved Strategy and Action Plan will be available in a range of formats, such as Easy Read. We will use the suggestions highlighted earlier in this report to ensure any alternative versions are appropriate.
- The areas of Assessment & Diagnosis; Education; and Training were the most commented on. Overall people expressed dissatisfaction with these areas as they are currently delivered, this echoes the views within the engagement activities. Some suggestions for improvements in the draft were made in relation to these areas (amongst others) which will be reviewed and where appropriate will lead to changes in the Strategy. Many of the comments can be viewed as being in relation to the achievement of the actions outlined, such as clarifying the outcome, timeline and responsible person/organisation further
- The Action Plan section was viewed to be the most useful aspect of the document as respondents indicated that was where their main interest lay. Improvements were requested in relation to ensuring the actions were more specific (as detailed above). Additionally, some suggestions were received regarding formatting the Action Plan differently and even moving its location within the document. As the format of the document will more generally be reviewed and adjusted, these suggestions will be taken forward within that review

**The main challenges noted through engagement and consultation were in relation to:**

- Building trust and good relationships with stakeholders, many of whom feel they have been let down by either services or lack of progress under the current Strategy

- Ensuring the revised Strategy and Action Plan is deliverable, accountable and sustainable.
- Resource implications - with the acknowledgment that Autism does not attract specific funding and is not recognised as a service area, and that this must be rectified to ensure success
- How progress towards delivering on the outcomes will be measured and progress adequately reported on in a timely manner, and in a way which allows for public scrutiny

Overall the draft Strategy and Action Plan was welcomed, with some respondents recognising that although they had wished for the previous Strategy to have been more successfully implemented/progressed, that this revised version was a step in the right direction.

Many respondents echoed the view that we need to value Autism more, both in terms of Autistic people and their skills and abilities, but also in terms of the processes we have within organisations, such as ensuring good quality training is available and additional resources where appropriate.

There were mixed comments with reference to providing increased information and raising knowledge and understanding. Some responses favoured approaches which actively sought to raise the profile of Autism within Aberdeen, such as promotional campaigns but there were also responses which felt these approaches could be used as patronising and that being too focused on raising knowledge and understanding is still acting to promote segregation and distracts from the other more prominent issues that people felt should be addressed given the limited resources available.

Most responses acknowledged the complexities of Autism, particularly given its nature as a spectrum condition. With many respondents indicating a will to be more involved in the ongoing engagement around Autism and the implementation of the Strategy and Action Plan once approved.