Appendix 3

# All Ages Autism Strategy

## Consultation Report

March-May 2013



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## **Introduction**

The Customer Engagement Team were asked to support the development of Warwickshire County Councils All Age Autism strategy by supporting and delivering a comprehensive three month public consultation.

It was important to ensure that it was as wide ranging as possible with multiple accessible consultation methodologies that would include children and young people and adults with autism, family carers, professionals and providers.

Autism is a spectrum condition and whilst this means that peoples experiences are very different, for some people it can create barriers to participation and engagement, especially around verbal and written communication. It was vital to ensure as part of this process that those who face those communication barriers, and are thus often 'unheard' within language driven consultation approaches were included meaningfully to ensure that their voices and aspirations were reflected within the strategy development.

The consultation period ran from March to May 2013

### **Process**

In order to capture as many views as possible we utilised a variety of consultation methods.

#### Questionnaires

To ensure we had as wide as reach as possible we developed two separate questionnaires. Both versions were co-produced by people with autism and family carers under the overarching theme of 'What's important to me'

Children and Young People Under 16- This was a shortened version exploring areas important to children and young people including:

- What is autism?
- Finding out about my autism
- Moving on in my life
- Schools and Colleges
- Activities outside my home
- Anything else you want to tell us?

This was illustrated with animation style characters to make it more appealing to children and young people completing it. We received 75 completed responses.

Generic version for anyone aged 16 and over - This was a comprehensive questionnaire that looked at the following areas:

- An autism definition
- Diagnosis and support after diagnosis
- Education

- Transitions
- Awareness and Understanding
- Access to Services and Support
- Social Inclusion
- Access to work
- Housing and Keeping Safe
- Carers and Family Support
- Anything Else you would like to tell us?

We received 268 completed responses.

The questionnaires were available online via Survey Monkey and hosted on the Consultation Hub on the WCC website. Hard printed copies were also available and distributed on request.

Both questionnaires contained a section for respondents to express an interest in being further involved in co-producing and monitoring delivery of the Strategy and we received 121 responses.

## Social Media



We set up a specific Twitter account to spread the word about the consultation process and allow people to interact with us and give their views. This was particularly important as we are aware of the high usage of social media amongst young people. At the time of preparing this report we have sent 42 tweets and have 120 followers. This was a useful medium as people tweeted and shared the consultation links, thus helping us reach more people.

#### Focus Groups

Ensuring that family carers were able to input into the consultation process was an important aspect so we attended meetings at four parent /carer groups across the County

- Stratford ASA Group
- Nuneaton Parents group
- Coleshill ASD Group
- North Warwickshire Asperger's United

A Customer Engagement Officer and Service Re-design Officer attended all the meetings jointly and introduced the consultation, aims of developing the All Ages strategy and the timeline for consultation, writing the strategy and signing off the final document. The main themes and headings of the questionnaire were then discussed and captured by Officers.

At the Stratford ASA Group this session also included a group of young people with autism. This group meets with parent carers using a part of the space and young people with autism using another. So for this meeting Officers separated and sat in each group, again using the questionnaire headings to capture views and experiences.

#### Creative Consultation



We recognised that for some people with autism, especially children and young people, completing questionnaires or taking part in groups would be a barrier to participation in the consultation process, so we explored a less language based approach. We commissioned an artist, after a rigorous application and selection process, to deliver 11 workshops in the County's none mainstream schools and colleges. Again, working under the overarching theme of 'What's important to me' and focussing on the questionnaire headings, using a mannequin and a variety of arts materials, she worked with participants to create a visual story or image that was photographed and then used as a tool to explore experiences and aspirations.

147 children and young people participated over the 11 sites, with a gender split of 114 male and 33 female.

### **Themes**

Responses from the questionnaires were analysed by the Observatory, with the free text and qualitative data themed by the Customer Engagement and Service Re-Design Officers.

From the generic questionnaire responses highlighted:

- Diagnosis should be accessible and a smooth process, with the right support throughout and after diagnosis. Also highlighted was the need for improved training and awareness of autism.
- Educational opportunities should include social skills training and be
  flexible and adaptable to the needs of students with autism, and again
  have a smooth process for moving between schools and colleges, with
  improved staff training again highlighted
- The transitions process, moving from children's to adult services should be smoother, with clear assessments and plans with the involvement of family and support networks, with Organisations working in partnership
- There should be increased awareness and understanding of autism in the community and within organisations/professionals. Awareness training in schools was highlighted as way of improving this
- There should be opportunities for people with autism and their carers to be involved in developing services and support, be able to access services effectively and have increased independence. Well trained staff was suggested as an important element to allow this to happen alongside good timely access to information and advice
- Social and Support networks, like peer and mentoring schemes should be developed and that people with autism should not face barriers to social inclusion, with training in life and social skills and increased awareness and understanding should be implemented
- There should be increased opportunities and support for people with autism to enter and remain in the workplace with training and awareness

- raising for employers being strongly noted, alongside a buddy or mentoring scheme.
- Housing and accommodation should be flexible and people offered support and advice to ensure they are able to choose the right options for them, with respondents noting that increased support for families to continue to support people within the family home, and having more accessible information available was required
- People with autism should be safe from abuse and be aware of and able to use local resources and projects to keep safe, with again increased awareness and understanding being highlighted as a need, especially within Emergency services

The final section of the questionnaire looked at peoples experiences of being Carers and Cared for and this produced more mixed responses, but with a strong theme of needing support and information to be individualised, and highlighting the pressures of the caring role including being unable to work and being unclear about processes for accessing carers assessments, in order to get more support.

Responses from the Children and Young People Under 16 questionnaire highlighted:

- A need for access to good information and to understand autism, and for families to understand autism
- Having good support to move through significant events, like changing schools, transitions and ensuring there are clear care plans in place
- An increased need for better awareness and understanding of autism to stop bullying in schools and colleges, this was a strong theme.
- Having autism means for many children and young people that they don't go out socially with anyone other than close family

Alongside these, the main themes from the Creative consultation with children and young people were:

- Bullying and lack of awareness of autism in main stream schools
- The importance and advantages of specialist schools and colleges
- The benefits of early diagnosis
- Treating people with autism with respect and greater awareness of abilities and potential
- Importance of suitable work experience, creative opportunities and independence
- Greater understanding of the complexities of autism.
- Availability of emotional and practical support

## **Conclusions**

Using a variety of methods to conduct this consultation has enabled us to involve a wide range of people in shaping and influencing the development of the Strategy. Many of the themes are overarching and similar, especially around advice, a smooth process of transitions, experiences of bullying and a lack of understanding in education, and within wider society about autism.

These findings will inform the draft All Ages Autism Strategy, which will then be taken back to people to comment on and will then influence the direction and implementation of the final Strategy in 2014.