Executive Summary

Consultation on the draft Autism strategy Jan 2013 – Feb 2013

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1 Executive summary

1.1 Purpose of the public engagement

Oxfordshire County Council (OCC) and Oxfordshire Clinical Commissioning Group (OCCG) carried out a period of engagement from 2 January 2013 to 17 February 2013.

Through the consultation we aimed to gather feedback from stakeholders on the draft Autism Joint Commissioning Strategy for Oxfordshire. This strategy has been developed with the help of members of the Oxfordshire Autism Partnership Board, (members include people with Autism, carers, commissioners, providers and partners), who have discussed unmet needs and desirable service improvements. The strategy addresses these issues and builds on some improvements which have been made in services and support for people with Autism in Oxfordshire in recent years.

1.2 Process & Methodology

A wide variety of engagement methods were used to support this consultation.

- Online engagement methods on the Public Involvement Network (PIN) website were used with an online survey;
- Online engagement methods on the OCCG Talking Health website were used;
- Direct feedback via email, phone, or freepost; and the opportunity to comment on an online embedded document;
- A workshop was held for people with Autism and Aspergers, carers and professionals across the county to find out more about draft strategy and give their feedback in person. Two hundred printed copies of the summary were also available and distributed in hard copy.
- Specific parent carer groups, including older carers were consulted to give their views.

1.3 Key Findings

Overall a good range of responses were received to the consultation. There were 143 who people took part in the online consultation, and responded to some degree to the survey, and 7 printed surveys were returned.

8 detailed email responses were also received, which included individual responses and those from Oxford Health Community Child and Mental Health

We held 4 engagement events which attracted over 130 people.

- The Big Plan in Kidlington, Over 80 people attended this event. The notes from the event are shown in appendix 2.
- Older Carers group in Abingdon, 15 people attended. The notes from this event are shown in appendix 1.
- Oasis event, 10 people attended. The notes from this event are shown in appendix 3.
- Parents Talking Aspergers, over 30 people attended. Feedback is shown in Appendix 4.

**Overall the survey responses were positive about the vision, what success will look like and how success will be measured along with the 5 Objectives.**

**Vision – What we are trying to achieve**
The draft Autism Strategy proposed that the vision should be:

- to support children and young people with Autism so that they can lead healthy and safe lives and have the opportunity to develop the skills and confidence they need to achieve their full potential.
- to support adults with Autism to be independent, to have choice and control so they can live ordinary lives as fully participating members of the wider community, including the opportunity to voice their opinions and experiences to ensure that services meet their individual needs.
- to support carers of people with Autism.
- to provide the best possible services, based on currently available evidence, at the earliest possible time in life, within the resources available, giving excellent value for money.

90% of registered respondents said they agreed the vision was right.

**What will success look like?**
86% of respondents were supportive of the success measures. They considered it right to set targets and goals at a high level but did question whether they were achievable. People felt that success should be measured on patient experience. People also wanted more detail on how success could be measured accurately, specifically where there is under diagnosis or poor management of adults.

Examples of comments received are:
‘Meaningful’ activity would need to be clearly and carefully defined to ensure it does not allow success to be counted as a ‘lowest common denominator’ activity but rather as one which maximises and reaches potential enabling life-long learning, progression, satisfaction and fulfillment’.

‘It depends how you measure success - if you are measuring it on how parents of autistic children find the experience or what the experience of adults with autism is then maybe’.

‘For Aspies and HFA, which is defined by inward thinking patterns, need Patient/Family Reported Outcomes to measure successful interventions between home&school’.

5 Objectives:
The draft Autism Strategy proposed that the objectives should include:

1. **Diagnosis and signposting**: achieve timely diagnosis and offer access to information, advice and a personalised approach to options for support for all those diagnosed, setting out clear pathways.

2. **Support for children and families**: ensure all children and young people with Autism and those who interact with them can benefit from expert advice and support whilst living in or near their family home.

3. **Fulfilling lives**: develop a range of local specialist support services to enable adults with Autism to live fulfilling lives, with a particular focus on supporting participation in meaningful activities including employment.

4. **Training and awareness**: promote greater awareness of Autism to encourage social acceptance and to enable staff that are likely to interact with people with Autism to operate more effectively.

5. **Sustainable approach**: ensure Oxfordshire County Council and Oxfordshire Clinical Commissioning Group can demonstrate delivery of these objectives and are managing effectively with the money available.
Key themes from the survey and stakeholder groups on these objectives were:

a) Is it achievable?
Whilst people thought the vision was commendable they were concerned that it may not be achievable for everyone on the Autism spectrum. They also wanted to ensure that it was deliverable across the whole of Oxfordshire, as it was felt that services currently were not equitable. There was also a view that the Strategy needs to be more inclusive with greater accountability.

b) Funding
There were points raised about the level of funding required both to achieve the priorities in the strategy and the need to re-distribute current funding.

‘The gaping hole in the consultation is being “joint” only between health and social services’.

‘what we would really care about is a joint strategy between all three services - Education, Health and Social Services’.

‘I would like to see clear references in the strategy to the EQUITABLE allocation of resources - not just efficient use.

‘This objectives seem very appropriate as long as they are clearly monitored e.g. what is considered to be “timely” diagnosis?

‘This sounds wonderful but there is no mention of how much this will cost and what other areas/services may have less funding and less tome devoted to it in order to do this. Each area will be important so your public consultation should be about all your plans, their necessary funding, who is going to do what and what else they are going to have to stop doing in order to do this’
c) Diagnosis
People wanted a clear understanding around the diagnostic pathways for children and adults supported by clear information explaining the condition.

Currently it is unclear how many prisoners have a diagnosis or suspected diagnosis of Autistic Spectrum Disorder as far as I know, so some kind of screening/access to

‘Early diagnosis is key in families obtaining the right support and advice’

d) Information, advice and support
People felt there was a lack of accessible information about where and who to go to for support. It was felt that there is a need for greater public awareness of Autism and its associated symptoms. People wanted greater support for working adults (especially dads). Social inclusion came out as a strong theme for all people on the Autism spectrum. People want greater support to ensure that people are more socially included whether that be through social clubs, in school or in the workplace.

‘There is a critical need for additional, specialised, sustained, intensive support for young people and adults to make the transition into the workplace either through voluntary or paid opportunities.’

‘Follow up support & practical advice is near none existant. Very specific, personal structured advice & support is paramount for happy family life’
e) Education/Schools
Education and Schools were a key theme than ran through all areas of the strategy. The majority of respondents were parents of school age children. In view of this several themes emerged relating to education.

People shared their negative experiences of mainstream schools and the lack of understanding of Autism from some professionals. People raised concerns that the Special Educational Needs system (SEN) is not sufficiently supporting children and young adults with Autism in school and that existing resources available to schools are overstretched and under resourced. People wanted reassurance that there will be greater partnership working with schools. Concerns were raised about the way some schools are formally or informally excluding children due to behaviour associated with autism. It was recognised that there is a need for residential placements in county.

f) Training
People want health and social care staff to be routinely trained in Autism. People felt that there needs to be greater awareness training amongst Schools (SENCo's, teachers and teaching assistants) GPs (and GP receptionists), Police and Mental Health professionals. People raised concerns that training for parents (The Early Bird Course) is not practical for working parents, and that training should be offered in the evenings and weekends for working parents.

'Greater awareness with GPs and Health Professionals (Health visitor's, Dentists, Opticians etc) so that they are aware of how best to treat both children and adults and...'

'Working in partnership with schools in order that they understand the individual and particular needs of children with Autism, having the appropriate staff within schools.

'Better communication between home/school regarding strategies in place - these maybe followed through at home to ensure...

'To whom can we turn to when teaching staff ostensibly responsible for our children in school fail us so blatantly?'

'A lot of young people with autism (or who are likely to be diagnosed with autism) are struggling in mainstream education'.

'General understanding & awareness that people with ASD are a gifted part of society.
g) Gaps
There were a few gaps highlighted that people felt were not covered by the strategy these included:

- People with Autism that are within the criminal justice system – lack of diagnostic pathway, support, or awareness amongst professionals
- Sensory Needs provision, lack of training or support to manage individual needs
- Transition – transition was identified as moving between services and key milestones in education, however, it was also identified that transition is also about human development, including developing relationships, sexual awareness and biological changes during the teenage and adult years.

1.4 Next Steps

This report and its findings will be tabled at the Autism Partnership Board, and the key themes will be taken into consideration in the writing of the final version of the Oxfordshire Autism Joint Commissioning Strategy. Detailed action plans will be drawn up to implement the priorities and these will be overseen by a newly formed Autism Partnership Board.