

National Autistic Society initial engagement with people with autism and their families in North Yorkshire

Headline report of findings

Background

North Yorkshire County Council and North Yorkshire and York PCT commissioned the National Autistic Society (NAS) to carry out four initial engagement events and an online survey in November 2012. The aim was to seek the views and opinions of people in North Yorkshire who are affected in some way by autism about their experiences, their needs and their wishes for the development of future services.

This report is a summary of the key messages from the events and survey. A copy of the full report produced in March 2013 by NAS can be found alongside this headline report on this website.

Results

NAS organised their report according to the five key outcomes of “Fulfilling and Rewarding Lives”, The Government’s strategy for adults with autism, which are listed below:

1. Increasing awareness and understanding of autism among frontline professionals
2. Developing a clear, consistent pathway for diagnosis in every area
3. Improving access for adults with autism to the services and support they need
4. Enabling local partners to plan and develop appropriate services for adults with autism
5. Helping adults with autism into work

(Please note, that NAS grouped outcomes 3 and 4 together for the purposes of their report).

The picture in North Yorkshire that was identified for each of these themes is described below:

1. Increasing awareness and understanding of autism among frontline professionals

People who attended the events and completed the online survey varied quite considerably in their opinions of the levels of understanding of autism amongst professionals with whom they have come into contact. People felt that some positive

steps had already been taken. These included the publication of the national autism strategy which had raised awareness. They also felt that there was evidence of training taking place and that this training was being standardised and accredited.

The following areas were identified for improvement:

- Awareness of autism amongst professionals working with people with autism, such as GPs or social care assessment staff, needs to be improved.
- There needs to be recognition that every person with autism is different and their needs and wishes will differ accordingly. It will be important for professionals working with people with autism to have a person-led approach.
- Professionals working with people with suspected autism should have adequate training and knowledge to recognise the signs of autism as early as possible.
- People with autism could, and should, be involved in delivering training to professionals. It would be beneficial to discuss real life stories as a training tool so that professionals can get an insight into what life is like for a person with autism.
- Autism training should be mandatory for all front line staff in social care and health.
- Autism training should be extended to other public services used by people with autism e.g.: job centres, travel companies, libraries, leisure centres, district councils, housing workers and police.
- Autism training should be provided to staff in mainstream schools and colleges, including teaching assistants
- Training should help agencies to recognise autism in girls and women.

2. Developing a clear, consistent pathway for diagnosis in every area

There was a high degree of consistency within the experiences described at the engagement events with the responses to the online survey. Some positive experiences were highlighted, particularly with regard to the diagnosis experience for children. A variety of professionals were commended despite there being no clear pathway to diagnosis.

The following areas were identified for improvement:

- There should be North Yorkshire-provided service/s where people can receive a clinical diagnosis.
- Professionals working with people with suspected autism should be knowledgeable about how the diagnostic process works and be able to direct people to their nearest diagnostic service.
- People should be able to receive their diagnosis quickly.
- As soon as a person has been given a clinical diagnosis of autism there should be training and support available for them and their family/carer on issues such as condition management, the types of advice, information and support available, such as advocacy and counselling services and, if appropriate, employment training.

- People with a clinical diagnosis of autism have a statutory right to have a social care assessment. This should be publicised via networks for people with autism.

3. Improving access to the services and support which adults with autism need to live independently within the community AND:

4. Enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities

At the engagement events people said that supported housing and community living were working well. They were positive about support that was personalised to them and there was evidence that creative and personalised support exists. START was identified as a good way to help transition to independent living. The future likelihood of personal health budgets was raised as a positive development.

The following areas were identified for improvement:

- Appropriate and person-led universal services should be available to people with autism. “Universal” means the services people receive from healthcare, social care and any other organisations. People should not be “falling into a gap” between mental health and learning disability services.
- Services need to be preventative and not crisis-led.
- Support needs to take into account planning for people living with ageing parents/carers.
- Transition arrangements for young people with autism in mainstream schools need to be planned early, with the person with autism, their carer/family and professionals from both children’s and adults’ services.
- There should be a clear housing strategy for people with autism. A range of living options should be available.
- Advice and information could be provided in a “One stop shop” arrangement for people with autism and carers - all North Yorkshire’s information and resources about autism should be available by calling one phone number, or visiting one venue.
- As well as developing appropriate services for people with autism there should be robust support available for carers and families of people with autism, including the opportunity to access respite services.
- Transport could be provided for people to access social groups.
- Respite should be made available to people with autism and their carers/families.

5. Helping adults with autism into work

The events and survey produced some exciting ideas around employment and self-employment. People have, however, experienced difficulties when trying to access work, and with welfare reforms on the horizon there was great concern in this area.

North Yorkshire County Council's Supported Employment service was praised. The following areas were identified for improvement:

- Creative and innovative planning needs to be available so that people with autism can take up employment, for example supporting people with application forms, interview techniques and on-going job coaching in the workplace to enable people to retain their jobs.
- Support needs to be in place to encourage and help people to take up opportunities for self-employment.

Summary

Although the people attending the engagement events and completing the online survey presented a mixed picture about the services and support available to people with autism in North Yorkshire, it was acknowledged there is already a lot of work taking place which will make a real difference to the lives of people with autism and their families.

Senior managers were present at the events. This was well received by attendees. Managers made commitments to work together, really listen to people's views and to engage further as developments happen.

Next steps

The detailed comments and data received from the engagement events and online survey has fed into the development of North Yorkshire's own strategy for adults with autism and helped determine the priorities for action. A draft strategy up to March 2015 will be available in early autumn, and we will be asking people affected in some way by autism what they think about it before it is finalised.

Once agreement has been reached on the priorities North Yorkshire will be working on, this will be published on our website. During this time we will also be working with Children's services to develop a joint autism strategy from April 2015 onwards.

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