

# **Autism focus 2**

## **You Said, We Did**

**NHS England Learning  
Disability and Autism  
Advisory Group**



# Autism- You Said, We Did

Version number: 1

First published: December 2017

Prepared by: Learning Disability and Autism Engagement Team

Classification: OFFICIAL

This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request. Please contact the Learning Disability and Autism Engagement Team on [engage@nhs.net](mailto:engage@nhs.net).

## Contents

Contents .....	2
1 Autism in Transforming Care- David Gill .....	2
2 Department of Health Autism Strategy- Simon Dowlman .....	4
3 Language around autism - Piers Wright.....	4
4 What we will do next.....	6

## 1 Autism in Transforming Care- David Gill

### There needs to be more suitable mental health support for autistic people

- There needs to be more work on mental health for autistic people. Not just for children and young people ('CAMHS').
- Post-traumatic stress disorder (PTSD) is very common in autistic people, but not often diagnosed or support put in place.
- SSRIs (Selective Serotonin Reuptake Inhibitors – a commonly used class of antidepressant) may not be right for an autistic person.
- Some people are having medicines withdrawn too quickly.

## **Diagnosis and support prevents problems later on**

- There needs to be more focus on preventing mental ill health. The Fair Access to Care and Support criteria (FACS) do not help this. If people with 'mild' to 'medium support needs are given support, that would avoid many people ending up being sectioned or in jail.
- Some local authorities discourage labels and diagnoses. High IQ can hide a lot of problems in autistic people, it can mean that people mask the autism all their lives which prevents a diagnosis. This increases risk of mental health issues. 'High functioning' is not a useful label.
- Diagnosis should be a way to access services but must not be used to identify someone's needs – this should be done with the individual.

## **Don't confuse learning disability and autism**

- Work that affects autistic people as well as people with a learning disability does not always work as well for autistic people. STOMP (Stop Over Medication of People) was given as an example of this.
- There should be quality checkers for autism as well as quality checkers for learning disability.
- There should be annual health checks for autistic people, as well as for people with a learning disability.

## **Staff, especially clinicians, need to understand autism**

- Autism is often overlooked, especially in inpatient settings. People need to be understood.
- The training clinicians get about autism is inadequate or non-existent. It still tends to foster a paternalistic attitude, especially amongst consultant psychiatrists and psychologists and mental health clinicians.
- Meeting autistic people would be a good start – autistic people should deliver the training on autism to staff. There was a good example from London when a GP receptionist was trained in autism.

## **There needs to be better language on 'challenging behaviour'**

- 'Challenging behaviour' is not a useful term. We should not use euphemisms - which means, we should say what we mean. If you label someone 'challenging', that label stays with them forever. Some people preferred 'a risk

to self or others', but others didn't like it. Others suggested 'potentially violent behaviour' but not everyone liked this either. At the moment we encourage people to use 'behaviour that challenges services'.

### **Include more autistic experts by experience in Transforming Care**

- Autism is not a major part of all Transforming Care plans, for example North East or South East Transforming Care Plans. There's a gap in 'real voice' on Transforming Care Partnerships (TCPs), there needs to be more involvement of experts by experience, not just professionals from charities. There should be several people with autism involved in each TCP, not just one. There's some good practice in London.

### **There should be autistic experts by experience on care and treatment review panels**

- It is useful if the experience of experts by experience on Care and Treatment Review Panels is matched. So if the person in hospital is autistic, the expert by experience on the panel should be autistic.

## **2 Department of Health Autism Strategy- Simon Dowlman**

The Advisory Group responded to a presentation about an update on the Autism Strategy.

### **The Autism Strategy could become more effective if it was well linked up with the Autism Programme Boards. Autism Programme Boards need better involvement with the NHS**

- This ongoing work must be done through working with autistic people. Autism Programme Boards would be one resource for this (though they may need to have more weight than currently). Local autism programme boards could be strengthened to support the Autism Strategy. Involvement of the NHS in the boards could be improved.

### **Involve more experts by experience in the delivery of the Autism Strategy**

- It would be useful to have more experts by experience on different bits of the Autism strategy, like the health and wellbeing work stream. Don't just rely on the usual suspects (such as National Autistic Society) or people provided by services – also connect to people who are more independent. Sussex has 8 experts by experience on the board. The Advisory Group could support Department of Health to reach out to more experts.

### **Improve adult diagnosis**

- Really important to address the undiagnosed adult autism in the population. 3 children are diagnosed for every 1 adult, showing under-diagnosis in adults.

## **3 Language around autism - Piers Wright**

We discussed the Dos, Don'ts and Maybes of good language about autism. This was for two reasons-

## OFFICIAL

- (1) To support Piers' work supporting NHS England communication team talking positively about autism
- (2) To help the Engagement Team encourage Transforming Care and NHS England staff use person centred language about autism.

We started with the [National Autistic Society's research about language](#) from 2015.

### Do

#### When talking with people

- Talk about **autistic people** rather than people with autism
- Talk to people as humans- as you would talk to someone in your family
- Use clear, precise, concise, everyday language
- Consider alternative communication
- NHS communications need to be clear and concise for everyone
- Think of us as individuals, not as labels

#### In news or campaigns

- Communicate about positives of autism not just negatives
- Talk about **difference** not different
- Communicate about a wide range of people
- Promote communication by and from autistic people and parents.
- Explain autism with positives- make links with support – don't get people on a negative trajectory
- Talk about how to talk to people in a way that includes autistic people. Don't highlighting a massive difference
- Use **social model of disability** in language
- If you run a campaign, launch it positively and actively

### Don't

- Don't **use high or low functioning labels** as they can mask the need for support. Many people who are described as 'high functioning' can become suicidal.
- Don't confuse autism for a learning disability. 75% of autistic people don't have a learning disability.
- Don't be paternalistic- talk to people as equals
- Don't limit people, for example by talking about things like the kind of jobs autistic people would do (can do all sorts!)
- Don't talk in euphemisms- say what you mean
- Don't say '**challenging behaviour**' or 'behaviour that challenges'- could talk about 'potentially violent behaviour'
- There isn't a 'special autism communication approach'
- Don't use the **medical model of disability**
- Don't talk about how to talk *to* autistic people as this implies a huge difference

## OFFICIAL

- Don't talk about treatment. It's the National Health Service not the National Treatment Service
- Don't assume if someone doesn't talk that they can't understand or be involved.

### Maybe

- Take care with the term 'self-advocate' – we advocate for others too.
- Useful to have a diagnostic 'don't list'

### Other things to note

- Be careful with labels – they lead to assumptions and prejudice
- What might be okay for one person won't be okay for someone else – there isn't one right way that is always right
- Autistic people should do staff training
- Don't expect all journalists to change language just because the NHS does.
- There are some fantastic blogs from non-verbal autistic people, which can challenge assumptions.
- Be aware that people don't always communicate the right thing the first time, every time- be patient and check that you have understood.
- Professionals should be trained in alternative communication.
- Review the list of approved language, as acceptable words change over time.
- [Archie is a lovely cartoon that explains autism well](#)

## 4 What we will do next

- Share [webinar slides from David Gill on Transforming Care for children and young people](#)
- Share speakers' email addresses- so people can continue to send ideas
- Use these notes to tell people at NHS England and others working on Transforming Care what the Advisory Group recommends around autism
- Use advice on language and communications in Piers' and the Engagement Team's work
- Share the information on the NHS England website
- Ask the Advisory Group to share notes with their networks