Focus on Autism

You Said, We Did

NHS England Learning Disability and Autism Advisory Group-

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You Said We Did- Focus on Autism

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Prepared by: Learning Disability and Autism Engagement Team

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1 Focus on Autism

Advisory Group members met to discuss issues affecting people with autism. The meeting explored a wide range of issues around diagnosis and support after diagnosis. Specific points were drawn out about autistic children and young people, autistic women and older autistic people, and there was significant discussion of mental health.

2 Diagnosis

Speed up diagnosis

- Diagnosis can take a long time. Local authority reported waiting times for diagnosis were said to be unreliable.

Improve and standardise testing for autism

- There isn’t a ‘standard’ test that is used in diagnosis. NICE have no standard, and there are variations between the ICD-10 and DSM-5 definitions.
- There is reported lack of recognition that autism presents in very different ways and any diagnosis must use a test – or a combination of tests – that covers the full range of ‘autism’.

Recognise and research autism in of women and girls

- Under-diagnosis in women and girls is a major concern. Improved knowledge on the part of clinicians – particularly around the breadth of what ‘autism’ means – may help this. In Salford raising awareness with GPs and commissioners has closed this gap.
- Some research focuses entirely on autistic boys and men, and some [such as Extreme Male Brain Theory] is rooted in ‘male’ presentations of autism: changing the direction of research, or widening its scope, would benefit diagnosis rates in autistic women.
- There must be increased awareness of the support required for autistic women and girls. One member of the Advisory Group knows other autistic mothers online who love their children dearly but were in agony throughout most of their pregnancy because they were hypersensitive to the changes in their body, and were terrified by the baby's movements and wanted to get rid of it purely to escape the terror.
- Cervical smear tests can be unbearable for people who do not like to be touched anyway – hypersensitivity can be a major barrier to physical health interventions. Changes such as starting periods, pregnancy, gynaecological problems, menopausal symptoms, etc are potentially far more confusing and scary to autistic women, and often the woman or girl concerned has few if any confidantes for support.

Offer support during diagnosis process

- Support is offered only at the end of the assessment process, with a diagnosis. Providing support to people seeking a diagnosis would help people during the process. Support is unlikely to be harmful – and as people who have autistic traits but will not receive a diagnosis may benefit from support. There should be an assumption that seeking a diagnosis indicates a potential benefit of such interventions. Withholding support while waiting for a long diagnostic process means people are denied support that will benefit them. Particularly in the case of children and young people (who are more in the midst of development), this delays the point at which things can start to improve.

- Clinicians must recognise that a person's autism does not present in one uniform way at all times. Diagnosis needs to be grounded in the whole picture. For example, diagnosis shouldn't be only on the basis of how someone is at school [where the routine may be helpful], 'meltdowns' may happen at home. The observations of parents and others must be taken seriously. Examples:
- Parents have been accused of Munchausen's by proxy for reporting the difficulties their child was having when this was at odds with reports of the child's behaviour at school.
- Parents are often accused of being too anxious or that behaviour is compared to that of a 'naughty child'.

Support diagnosis of autism in people with a learning disability

- People with a learning disability also have the right to assessment for autism (one member of the group has been denied an assessment).
- Information about assessment for autism and what a diagnosis means should be available in accessible formats. Some people don't understand what it means for them.

Help people to challenge diagnoses

- Diagnoses (especially diagnoses of *not* being autistic) need to be easier to challenge. It needs to be easier to get a second opinion.
- [Successful] challenge of a diagnosis, complaint about practice, etc. should trigger further training for the clinician involved.
- Involving experts by experience in diagnosis may help counter very 'clinical' views.

Provide peer-support

- Both before and after diagnosis, there may be great value in having local autism champions. Champions are people who can help others find out what services are available, what support networks are available including for families and carers, how to access advocacy and how to challenge diagnostic decisions. This may be something that local Healthwatch could facilitate.

Improve autism awareness in the criminal justice system

- Training should be given to the police and Approved Mental Health Professionals about autism: a mental health crisis may be symptomatic of undiagnosed autism. The National Police Autism Association may be able to help.

Diagnose autism in prisons

- Diagnosis in prisons may help. One issue is that some autistic people may find the routine of prison helpful and have great difficulty adjusting once released.

3 After diagnosis

Improve clinicians understanding of autism

- There is lack of understanding on the part of clinicians.
- Clinicians need to understand that autism presents very differently from person to person.
- Clinical knowledge must be combined with understanding of who the individual is and how their autism affects them.
- Useful to explore the resources from the Royal College of GPs about autism.

Give people support with a new diagnosis

- People will need time to learn what the diagnosis means to them, and may need time to accept the diagnosis.
- Diagnosis should trigger an immediate offer of support (delivered as appropriate to the individual):
  - ➢ counselling or other mental health support
  - ➢ support around employment (people gave examples of people being fired due to their diagnosis – even when they had been performing well in the job up to that point).
- It should be made clear to people why particular support is prescribed. And why it is right for them as an individual.
- People should be able to contribute to the description of their own autism – how it presents, the specific challenges they face and the individual outcomes they want from support.
- Assessment and planning should be ‘holistic’, not just focused on health needs and formal social care needs1.
- The National Audit Office has reported on the effectiveness of the right interventions- this should be included in medical training.
- Diagnosis is rarely the only assessment people will receive. Benefits assessments for Personal Independence Payment, Employment Support Allowance and Education, Health and Care Plans (if a child is in education) must be just as well-informed – and ideally connected to the diagnosis assessment to reduce duplication.

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[1] noted reference points for this: Care & Treatment Reviews; person-centred planning.

Support families and carers

- Some parents and family carers feel that there is an expectation on them to have an understanding of autism and of local pathways to receiving support. Sometimes they are asked “what do you want me to do?” by GPs and others after a diagnosis.
- People should be linked with local Parent Carer Forums and the ‘local offer information’ from councils.
- Unless an individual wishes otherwise, families must be kept involved – and valued as vital parts of the person’s life and support network.
- As there can be a genetic link in autism, a diagnosis should trigger the offer of assessment to other family members. Clinicians should recognise that even if family members are not diagnosed, they may have autistic traits and *may* benefit from some form of support (e.g. parenting support).

Develop peer support in all areas

- Peer support would likely include help signposting, support through shared experience and understanding, etc. There should be representation in relevant patient participation groups for autistic people and their families and carers.

Provide specialist support, in advocacy and multidisciplinary teams

- Independent, specialist advocacy must be available.
- All staff in Multidisciplinary teams [MDTs][2] must have thorough understanding of autism. MDTs should be able to offer crisis interventions (see the community support aspects of Transforming Care) – with 24/7 availability.

Learning from different cultural attitudes

- Different communities have different attitudes to autism. Some parts can be beneficial, and other parts detrimental. The example was given of Jewish and Muslim communities who were known [at least in the commenter’s city] to have positive attitudes towards finding roles for autistic people that play to their strengths.
- A big difference could be made in communities which have a more hostile attitude to autism.

Consideration of rural difficulties in accessing services

- Rural communities are likely to have greater difficulty accessing services due to the services being further away.

Physical health needs addressing too

- Some physical health conditions are more prevalent in autistic people (although there is a relative lack of evidence for this). Diagnosis should trigger

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[2] Teams made up of a range of professionals such as nurses, Occupational Therapists, Speech & Language Therapists, etc.

investigation – and Annual Health Checks should be offered. Similarly, there should be automatic consideration of referral to occupational therapy, speech and language therapy, etc.

- Physical wellbeing needs to be addressed in inpatient settings, as well as in the community.
- Physical causes of complex and challenging behaviours are not always considered in assessment. Differing pain thresholds also need to be taken into account when assessing and treating people.
- 'Flagging' on health records (e.g. the use of the enhanced Summary Care Record) could be used to help advocate for people's needs and their right to reasonable adjustments. [There has been progress on this for people with a learning disability.]
- As well as clear information about support that is available, people must be given clear information about pseudo-'cures' and other ineffective or dangerous interventions. It was strongly noted that people turning to such 'underground' interventions is the result of a lack of information and support.

Developing NHS systems for autistic people similar to those for people with a learning disability

- Develop a system where diagnosis leads to a 'flag' on your medical record. This means that if someone in the NHS (paramedic/doctor/A+E) looks at your record then they know they should make adjustments. Useful for the police too.
- Further information could be put on people's Summary Care Records (links with work on the Learning Disability Programme)- to tell staff what adjustments would help.
- A register of people with autism at the GP (similar to the all age register for people with a learning disability) would:
    - remind the practice to make reasonable adjustments for people
    - support understanding in variation in diagnosis between practices/areas
    - help NHS to understand the physical and mental health of autistic people across the country
- The benefits of being on the register and having a 'flag' would have to be explained well, or could be seen as scary/stigmatising.
- Annual Health Checks would be useful to people with autism[3].

4 Mental health

Treat causes before symptoms

- There needs to be a shift towards treating causes rather than symptoms. For example supporting people to feel more in control of life may remove the need for antidepressants to treat anxiety.
- Poor mental health could show a lack of support – improved social support for people will reduce the need for mental health support.

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[3] See notes from Advisory Group meeting on 16 July 2017

- Low rates of employment amongst autistic people may be contributing to high rates of poor mental health.
- Loneliness and isolation are potential causes of poor mental health. Friendships and relationships can be both a source of support and a source of difficulty. Professionals must recognise that the stereotype of ‘autistic people have no empathy’ [which some read as “autistic people don’t make friends”] is false.

Understand the difference between mental health and autism

- Treatable mental health conditions may be misdiagnosed as being the presentation of someone’s autism. Useful to involve family and others as they will know what someone’s usual behaviour is.

Make adjustments to appointments

- A 10-minute GP appointment is not long enough for dealing with mental health difficulties. Longer appointments useful for all things (not just mental health).

Make adjustments to mental health treatment

- In some parts of the country cognitive behavioural therapy (CBT) is the only form of psychological therapy available[4]. CBT is not suitable for some autistic people.
- People report waiting ages to see someone through Improving Access to Psychological Therapies (IAPT) and then find they have been referred to someone who knows nothing about autism. A care pathway that meets the varied needs of autistic people should be developed.

Mental capacity assessments need adjustments

- Capacity assessments must recognise non-verbal communication. A key principle of the Mental Capacity Act is that any form of communication is valid, but this is not always followed in practice.
- Capacity should be assumed in the patient, unless it has been formally assessed otherwise.
- A report by the British Association of Social Workers found assessments finding someone to lack capacity are almost never challenged.
- IMCAs [Independent Mental Capacity Advocates] need suitable knowledge and skills.
- The quality of advocacy should be more closely measured – there is a high level of availability in long-stay hospitals, but it is unknown how good it is in practice.

Strategies should address high suicide rates

- Autism strategies should respond to high rates of suicide amongst autistic people.

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[4] It is heavily promoted through IAPT – Improving Access to Psychological Therapies.

5 Children, young people, transitions

- There must be a focus on strengths and skills, not just needs. Assessments must be skills-led; there should be careers advice [underpinned by an understanding of autism].
- Child and Adolescent Mental health Services (CAMHS) services were said to be widely varied in the quality of support they give to autistic children and young people.

6 Older autistic people

- Care homes and other providers of support to older people need greater understanding of autism.
- Autism may sometimes be misdiagnosed as dementia in older people, e.g. on admission to a care home where the person's behaviour is not already known.
- Solicitors need robust guidance on doing capacity assessments in autistic people – e.g. for Lasting Power of Attorney.

7 Further issues to explore

The NHS should be using empowering language around autism

'Cures' such as bleaching

- There needs to be more information about autism for people and their families and carers[5]. This should include the evidence that tells us that you cannot buy a cure for autism and many approaches are harmful. Lack of support leaves families feeling isolated and desperate. Such practices are child abuse and put their wellbeing at risk.
- It was suggested that there are similar issues raised by the claimed link between MMR vaccination and autism – there may be a lack of clear information about why the link is not recognised by the vast majority of medical professionals. This is a sensitive area as it relates to the fallibility of parental reporting. Elsewhere in the meeting it was underlined just how important parental reporting is in many children's diagnoses.

Research into things that can help physical health

- The impact of autism on physical health needs to be better understood, and therefore adjustments to healthcare. This includes chemical sensitivity, different reactions to medications and food sensitivity. Special diets such as gluten-free and casein-free are unsupported by clinical evidence but which one attendee at the meeting said around 80% of parents say are effective.

Better training for health professionals

Share information that is out there already

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[5] See notes from meeting that focused particularly on the problem of 'bleaching' - 2nd March 2017

- Information is out there but not used (e.g. RCGP's website). This area may benefit from linking with the Department of Health, and with Jean O'Hara's work on including learning disability in health professionals' training.
- Established health professionals may also benefit from training to update knowledge. One person noted that even a few short paragraphs has had an impact on clinicians' understanding in Greater Manchester [including removing the disparity in diagnosis rates in women and girls].

NHS 111needs to adapt to meet the needs of autistic people

- Currently NHS 111 doesn't meet the needs of autistic people who contact them. There needs to be an alternative to telephone-based support from 111, which is a problem for people whose sensory processing makes spoken communication difficult. Staff need to have good awareness of autism.

Support professionals to understand communication differences

- Work is needed to improve health professionals' understanding of communication differences. Some services tend to rely heavily on mail or telephone, both of which can be problematic. Even short, simple exercises to give people an insight into sensory processing disorders can have a significant impact on understanding. This fits into the wider topics of training and of reasonable adjustments.

8 Next steps

(1) Share these notes with

(a) Participants and the wider Advisory Group- anything else to add?
(b) Improving Health and Quality colleagues- ideas for how to address the different issues.
(c) Department of Health- see how to make links with Autism Strategy Board
(d) Senior Management Team of Learning Disability Programme for advice on how to address the issues.
(e) Colleagues on the Mental Health Programme- work out best how to use Advisory Group expertise to influence the programme
(f) Share thoughts about training with Jean O'Hara.
(g) The team who worked on making NHS111 more accessible for people with a learning disability.

(2) Share the resources mentioned in the meeting

(a) Royal College of GPs training and resources around autism
(b) National Audit Office report- Supporting People with Autism Through Adulthood
(c) Ambitious about Autism – Know Your Normal
(d) Westminster Autism Commission – A Spectrum of Obstacles
(e) Autistica- Mental health leaflet
(f) National Autistic Society resources for health professionals

(3) Prioritise actions which come from conversations- with Advisory Group

(4) Make offer of Advisory Group members/other NHS England Learning Disability and Autism Forum members working with clinicians/commissioners to develop work on autism.

If you would like this information in an alternative format, contact the Engagement Team on Engage@nhs.net