

## NICE Clinical Guideline

### Autism Spectrum Conditions in Adults Scoping Workshop Notes

31 March 2010

#### Group A

**1. Suggested guideline development group composition – Are all the suggested members (and the numbers of each type of member) appropriate and important? Should we be including any other types of members for this guideline? Could there be a role for expert advisers in this guideline?**

*The group suggested the following roles should be included in the GDG constituency:*

- *further education specialist*
- *housing/supported living/local authority specialist*
- *occupational therapist*
- *a greater number of SUC members are needed to fully reflect the range of ASC*
- *GDG members with ASC will need greater support, such as having a good and clear structure for the meetings, No jargon should be used. Also the project manager should meet with the service user prior to the GDG meetings to discuss what will be covered.*

**2. Scope - Are we on the right track? Have we struck an appropriate balance between the need to keep the scope manageable and covering the most important clinical issues?**

*The group agreed that the balance is right. They suggested looking at: DISCO, ADI 3DI, ADOS, full metabolic screening post diagnosis and neuroimaging.*

**3. Do the topics listed in the scope (section 4.3.1) cover the most important areas? Are there any omissions or any topics on the list that should be deleted?**

- *Need to consider how policy drivers can be used to help – payment by results, SARN tools etc.*
- *The transition into older age and the interaction with dementia should be considered. There has been some work done on this transition in Wales.*
- *Should look at how we can better use existing services in primary care, IAPT etc.*
- *The link between getting a diagnosis and then a community care assessment for people with ASC and their carers needs to be strengthened, as advised in the DH Autism Strategy.*
- *Need to be aware that ASC can change the effects of medication.*
- *Expertise of ASC needs to be imbedded into main stream services by raising awareness and providing training.*

**4. Suggested clinical questions – ask the group the following general questions in order to agree/prioritise their selection.**

**a) There is a particular emphasis on diagnosis and assessment is this the right place to start? Should we be covering the whole autistic spectrum?**

- *The group agreed that it is right for the scope to focus on diagnosis.*
- *There needs to be a clarification of terms. The terms 'high and low functioning' are not always helpful.*

- *Common coexisting conditions are: dyslexia, dyspraxia, tourettes, anxiety, sensory issues, ADHD, bowel disorders, epilepsy.*
- *Tests for physical conditions should be performed post ASC diagnosis.*

**b) How available/accessible are these services (diagnosis and assessment) and should we set out appropriate care pathways?**

- *There is a significant difference between children and young people and adult services. There is often quite a high level of support offered for children, usually through education, which just stops when people with ASC turn 18.*
- *Services available to adults are rarely fit for purpose and often a centre specialising in learning difficulties.*
- *There is a lot of confusion in diagnosis and it is sometimes assumed that someone with 'low-functioning' ASC has learning disabilities, which may not be the case.*
- *There is an urgent need for ASC specific services.*
- *The National Autistic Society offer good support but is not consistent through out the country.*

**c) How many adults with /families will be affected and what might be the implications for social and educational provision beyond health care systems**

- *Education services often offer the best support for ASC. There is some support in further education but this is not consistent.*
- *There are some adult services that help people with ASC apply for jobs, support them in the workplace and give ongoing support, but is not consistent.*
- *More case managers/advocates are needed to support people with ASC.*
- *There can be problems accessing the right support if ASC is not the primary diagnosis. If ASC is recorded as the secondary diagnosis less support is offered to the individual, and it is not picked up by the national statistics, and therefore the need for service provision is under estimated.*

**d) What are the group's views about the available evidence base and how we might recommend changes in clinical practice?**

- *There has been some research conducted in Sheffield showing 1 on 1 support can be effective.*
- *There is some limited evidence around the effectiveness of social groups.*
- *Should look at ABA and intensive interaction.*
- *The Autism Education Trust has a lot of evidence listed on website.*

**e) What are the key outcomes to be considered (see also section 4.4 of the draft scope)?**

- *The phrase 'clinical outcomes' is not helpful.*
- *Clear pathways are needed for coexisting conditions, particularly for mental health issues as symptoms can often be confused for ASC and vice versa.*
- *The DH document 'our health, our care, our say' will be helpful when thinking about these groups.*

**5. Equalities – how do inequalities impact on the provision of care for adults with autism? Should any particular subgroups of the population be considered within the guideline?**

- *There are often access issues for BME groups.*
- *Inequalities in gender – not recognised as well in women.*

## Group B

### **1. Suggested guideline development group composition – Are all the suggested members (and the numbers of each type of member) appropriate and important? Should we be including any other types of members for this guideline? Could there be a role for expert advisers in this guideline?**

*The group suggested the following roles should be included in the GDG constituency:*

- *A member from special care in dentistry*
- *Prison mental health*
- *More than one psychiatrist (one of which covers learning disabilities)*
- *Occupational therapist*
- *Representative from Wales*
- *A neurologist*
- *Keep a balance between groups and equal representatives within group categories*
- *Ensure you include people who have a genuine knowledge of autism*

### **2. Scope - Are we on the right track? Have we struck an appropriate balance between the need to keep the scope manageable and covering the most important clinical issues?**

- *Look at how certain interventions fit into the broad spectrum?*
- *Should focus on early interventions?*
- *Awareness in non health professionals?*
- *Can we include assessment and management of physical health such as preventing oral disease and cover dental treatment?*
- *The scope should include standardised sensory assessment (Dunn Sensory Profile) and sensory treatment.*

### **3. Do the topics listed in the scope (section 4.3.1) cover the most important areas? Are there any omissions or any topics on the list that should be deleted?**

- *Subgroups: What about people who do not have a diagnosis? The term PDD NOS is problematic. Suggest: People with ASC such as Asperger Syndrome (AS)...etc.*
- *Mention people from specific areas of risk or disposition.*
- *How do coexisting conditions relate to clinical treatment?*
- *Scope section 4.2 a) Include forensic settings (high and medium secure units).*
- *Scope section 4.3 a) Replace 'signs and symptoms' with 'features'*
- *Scope section 4.3 b) Include early developmental history in method of assessment*
- *What about involuntary assessments? E.g. people who do not present themselves for assessments. Also note that some people want to be undiagnosed (for reasons of returning to employment).*
- *Assessment is important to an individual's needs rather than the condition (needs assessment).*
- *Scope section 4.3 a) Include communication based interventions, biomedical interventions such as diet.*

### **4. Suggested clinical questions – ask the group the following general questions in order to agree/prioritise their selection.**

- a) **There is a particular emphasis on diagnosis and assessment is this the right place to start? Should we be covering the whole autistic spectrum?**

- *The group agreed this is right.*
- b) How available/accessible are these services (diagnosis and assessment) and should we set out appropriate care pathways?**
- *Access and management is more problematic.*
  - *The group raised concerns about age range and transition between childhood to adulthood.*
- c) How many adults with /families will be affected and what might be the implications for social and educational provision beyond health care systems**
- *Many adults will be affected.*
- d) What are the group's views about the available evidence base and how we might recommend changes in clinical practice?**
- *NAPC, National audit office report.*
- e) What are the key outcomes to be considered (see also section 4.4 of the draft scope)?**
- *The outcomes should be more person focussed (e.g. employment, education, establishing a family etc)*
  - *Social and health related quality of life. (Should be more broad)*
  - *How does the scope go from a diagnosis to impact and then needs*
- 5. Equalities – how do inequalities impact on the provision of care for adults with autism? Should any particular subgroups of the population be considered within the guideline?**
- *No areas of inequality were discussed.*

### Group C

- 1. Suggested guideline development group composition – Are all the suggested members (and the numbers of each type of member) appropriate and important? Should we be including any other types of members for this guideline? Could there be a role for expert advisers in this guideline?**
- *Members of the group queried what is meant by statutory: seek clarification and be explicit.*
  - *Also necessary to target those in higher education e.g. University*
  - *Members of the group raised concerns about only two people representing service users. In particular they felt that no number of people could represent the diversity of the disorder and all it means and this should be made explicit. The group agreed that it will be difficult to gain a 'representative view' of the disorder due to the diversity of views from people with very different manifestations of the disorder.*
  - *The importance of taking into account gender differences when dealing with service user representation was discussed. In particular, the group felt that there are large differences in experience between genders and this must be reflected in service user representation.*
  - *Moreover, the group felt that older adults (particularly those from age 50 onwards) are particularly neglected and this needs to be remediated.*
  - *The group also felt a need for there to be a representative from the sector of forensic services as this area is in particular need of change.*
  - *The group also felt that GDG members should have the required knowledge of the spectrum of disorders and that there should be cooperation between professionals.*

*Furthermore, autism is a broad spectrum and this should be reflected in the knowledge of the group as a whole.*

- *The group also highlighted the need for those with severe learning disabilities to have a voice even if it is not possible for them to advocate their needs via a service representative role.*
- *Members of the group also felt there was a need for a dietician in the group to represent the possible link between coeliac disease and autism spectrum disorder.*
- *The group also highlighted the need for the expertise of a behavioural nurse therapist on the GDG panel.*

**2. Scope - Are we on the right track? Have we struck an appropriate balance between the need to keep the scope manageable and covering the most important clinical issues?**

- *It was felt that the boundaries of the guideline should be clarified i.e. what it does refer to and what it does not refer to should be made explicit especially with regard to assessment of co-existing physical and mental conditions.*
- *It should be made more explicit in the scope that the guideline will cover the long term management of the condition and will involve continuous care that is proactive and amendable. Moreover, the importance of ongoing support (i.e. follow up) should be highlighted especially for education.*
- *The group mentioned that training for professionals should be comprehensive and should not be a tick box scenario but rather it should be more person centred.*
- *A member of the group mentioned that with regard to misdiagnosis, this section of the scope failed to mention psychosis/schizophrenia.*
- *The group queried the classification of anorexia (page 4) as a disability.*
- *The group suggested that the coexisting disabilities (e.g. developmental and physical) should be categorized into sub-groups and should be explicitly described. For example, it should be made clear what is meant by dysexecutive disabilities and what this condition entails.*
- *The group agreed that the term 'disadvantaged' was more appropriate than the term 'excluded' (page 3 of the scope)*
- *It should be made clear that any support provided should be systemic (i.e. including family, partners, carers etc.) and not just individually based in order to achieve the best results.*

**3. Do the topics listed in the scope (section 4.3.1) cover the most important areas? Are there any omissions or any topics on the list that should be deleted?**

- *The group felt a need for other physical disabilities to be highlighted and made more explicit and the importance of assessing physical health alongside mental capacity to be highlighted.*
- *Risk assessment (for example, harm to self) is a core aspect and should be acknowledged in the scope.*
- *Moreover, the issue of identifying depression within this population should be highlighted and addressed adequately.*
- *Some members of the group felt that the scope failed to mention the importance of diet maintenance*

**4. Suggested clinical questions – ask the group the following general questions in order to agree/prioritise their selection.**

- a) **There is a particular emphasis on diagnosis and assessment is this the right place to start? Should we be covering the whole autistic spectrum?**

- *The group highlighted the importance of certain psychosocial interventions such as applied behaviour analysis, anxiety management training, counselling, anger management training and relaxation training.*

**b) How available/accessible are these services (diagnosis and assessment) and should we set out appropriate care pathways?**

- *The group suggested that the guideline should focus on two main groups; those in psychiatric settings and those in non-psychiatric or non medical settings.*
- *It should be clarified whether acute liaison services include both non-learning disabled and learning disabled populations.*
- *Available services for those with severe learning disabilities should be dealt with also.*

**c) How many adults with /families will be affected and what might be the implications for social and educational provision beyond health care systems**

- *Educational programmes should also be incorporated into the scope.*

**d) What are the group's views about the available evidence base and how we might recommend changes in clinical practice?**

- *The group suggesting looking at the 'Research autism' website in order to obtain key marker papers.*
- *The group thought that there may be a gap in the evidence with regard to sensory interventions, self-injurious behaviour, dietetic interventions and a lack of evidence for those who are non-learning disabled.*
- *Suggested looking at the Royal College of Psychiatrists research recommendations with regard to psychiatric services.*
- *Training programmes such as TEACH, SPELL & NASF should be looked at in detail.*
- *Group also queried the evidence available for substance abuse and autism in scope.*

**e) What are the key outcomes to be considered (see also section 4.4 of the draft scope)?**

- *Group suggested a need to clarify what 'diagnostic accuracy' is.*
- *The level of autism or where it appears on a continuum is a possible useful outcome post-assessment.*
- *Historical outcomes such as ADIS-R*
- *Moreover, the group agreed that assessment of outcomes should be comprehensive and it should be made explicit that these assessment scales are limited.*
- *If available, a measure of training and skills of professionals would be useful.*
- *Other important outcomes noted were; employment levels drop out from medication, success rates from medication, access and integration into community services, social inclusion (i.e. self-esteem and empowerment).*

**5. Equalities – how do inequalities impact on the provision of care for adults with autism? Should any particular subgroups of the population be considered within the guideline?**

- *No areas of inequality were discussed.*

Group D

**1. Suggested guideline development group composition – Are all the suggested members (and the numbers of each type of member) appropriate and important? Should we be including any other types of members for this guideline? Could there be a role for expert advisers in this guideline?**

*The following contributors should be considered for inclusion in the group:*

- Occupational therapist specialising in sensory integration.
- Arts (music) therapist.
- Someone from the 'adapted experts patient' programme
- Need to think about how we can involve people on the autism spectrum with complex needs. This will include thinking about communication style and load.

**2. Scope - Are we on the right track? Have we struck an appropriate balance between the need to keep the scope manageable and covering the most important clinical issues?**

- Need to consider the use of terminology (e.g. terminology proposed by the neurodiversity movement)

**3. Do the topics listed in the scope (section 4.3.1) cover the most important areas? Are there any omissions or any topics on the list that should be deleted?**

- Co-occurring conditions (this term is preferred to co morbid conditions) – there are a range of conditions that commonly occur amongst people who have a diagnosis of autism. It would be helpful to identify these and signpost further support but the group recognised that the guideline could not cover the identification and management of these conditions. These included the management of anxiety, dyspraxia, dyslexia, ADHD.
- People on the autistic spectrum sometimes have atypical responses to drugs. This can have both positive and negative consequences and can result in some people benefiting from the use of drugs prescribed outside of their licensed indications.
- Adults on the autism spectrum can have a useful role as advocates, information givers and in raising awareness of important issues relating to the experience of autism that are often overlooked.
- Need to consider the management within institutions of individuals with challenging behaviour who are 'nursed' in isolation.
- Need to consider the problems associated with hyposensitivity as well as hypersensitivity.

**4. Suggested clinical questions – ask the group the following general questions in order to agree/prioritise their selection.**

**a) There is a particular emphasis on diagnosis and assessment is this the right place to start? Should we be covering the whole autistic spectrum?**

- There are a number of ways in which a person on the autism spectrum can be identified and subsequently diagnosed. Consideration needs to be given to the integration of these care pathways and in particular the role of generic versus specialist clinicians.
- Who defines diagnosis; should the model underpinning diagnostic criteria be social or medical? People on the autistic spectrum have developed 'discovery criteria' that emphasise the positive aspects of the condition. There is concern that the medical model places too much emphasis on negative issues suggesting that people on the autistic spectrum are 'broken and need to be fixed'.
- Differential diagnosis - consideration of alternative diagnosis would be helpful.

**b) How available/accessible are these services (diagnosis and assessment) and should we set out appropriate care pathways?**

- A social model would also consider much broader 'access issues' than a medical model, including, for example, access to work and consideration of how to manage both the physical (sensory issues) and social (relationship issues) environment.

*There is also value in considering the education/training that people working alongside someone on the autism spectrum may need to help them to better understand what support they could provide.*

- *The setting for the diagnosis needs to be considered – should people be offered alternative settings? Consideration should also be given to issues around diagnosis e.g. potential for parental resistance. Some people may be survivors of childhood abuse. The group agreed that cost issues would need to be taken into account*

**c) How many adults with /families will be affected and what might be the implications for social and educational provision beyond health care systems**

- *This was not discussed*

**d) What are the group's views about the available evidence base and how we might recommend changes in clinical practice?**

- *This was not discussed*

**e) What are the key outcomes to be considered (see also section 4.4 of the draft scope)?**

- *This was not discussed.*

**5. Equalities – how do inequalities impact on the provision of care for adults with autism? Should any particular subgroups of the population be considered within the guideline?**

- *Need to consider gender, including intersex and sexuality.*