NICE-SCIE Clinical Guideline

Autistic spectrum conditions in children and young people
Stakeholder consultation workshop

1. 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?

    Group 1
    The group thought that the scope was on the right track in general.

    The group thought that the scope could be broadened in a few ways, to expand the population and the settings looked at:
    -   4.1.1 (a): the guideline population should be changed to include 'children and young people *and their families*'
    -   4.2 (a): tertiary services should be included, or it should be made clear that services other than primary/secondary will be considered

    Group 2
    The group agreed the main issues were covered, with some amendments needed:
    *   The group discussed using the terms Autism Spectrum Conditions vs Autism Spectrum Disorders. The group agreed both terms were used in clinical practice, although policy seems to be moving towards 'conditions'.
    *   Physical health problems should include: gut problems, deafness and blindness. Also need to look at how the management of physical health problems needs to be amended. The group agreed it would be unmanageable to look at all coexisting conditions, but suggested how different settings could be adjusted (e.g. A&E, inpatients, GPs etc)

    *   4.1.1b) second bullet point doesn't make sense. Should read: *management and support of children and young people with autistic spectrum conditions with additional vulnerabilities/needs*
    *   The group raised the importance of children being able to access advocacy services and it should not always be assumed that the parent is the most appropriate person for this role.
    *   Recognise that not all aspects of ASC should be managed, and some can be damaging e.g. forced socialisation.

    Group 3
    Important clinical issue that needs to be covered – children who have not yet been given a conclusive diagnosis of autism but are nevertheless in need of support

    o   As soon as you have a clear ASC diagnosis, a clear care pathway opens – but what about those who are pending diagnosis? They would benefit from ASC management but don't have that label yet so don't receive management.
    o   Management should be needs-based not diagnosis-based (care pathway should start pre-diagnosis as there is a danger of missing opportunities for early intervention).
    *   START with the person – what the child and family/carers want from their management
        o   Positive behaviour management focused on specific outcomes
        o   Person-centred support tailored to the need of the individual

Group 4
The group felt we were on the right track also but that there were some areas that were not mentioned that they thought were necessary to cover such as

- Clarify to what extent 'treatment' is part of the guideline
- Highlighting the need for a holistic approach to assessment and treatment
- Different age groups should be illuminated and treatment and management should be appropriate to developmental age e.g. consent issues.
- Assessment and treatment should be interwoven and iterative. It should also be ongoing and developmentally appropriate to transition periods.
- Therapeutic interventions should be a rewarding experience for those involved and should build good relationships.

2. The scope covers a wide range of organisations and professions - balancing representation and comprehensiveness will be challenging. Do you think the current composition will enable us to achieve that?

Group 1
The group agreed on the importance of coordinated healthcare, social care and education in the effective management of ASC in children and young people, whilst acknowledging that the guideline will have limited power to influence care pathways in education. The group acknowledged the difficulty of framing recommendations so that they are applicable and useful for different professions, including education, and thought that a broadly constitutive GDG would be central to achieving this.

The group thought that the guideline could look at how services and care pathways could be coordinated, for example by looking at common assessment frameworks and geographical inconsistency (for example, in local planning groups).

Group 2
The group agreed that the professional members of the group should be focused specialists in ASC, with experience of working with people from across the spectrum.

Group 4
The group thought that there needed to be additional representation of professions that involve communication e.g. speech and language therapists, drama therapists etc and occupational along with educational backgrounds. The group agreed that a broad range of professions should be included in the GDG make up to help represent different social, educational, psychological and medical perspectives.

3. Regarding the 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?

Group 1
The group thought that having broadly representative GDG members would be very important. They suggested that the GDG could include:
- A headteacher, possibly from a mainstream school. The group thought that educational input would be vitally important for this guideline, even more so than for the diagnosis guideline.

- A speech and language therapist
- A clinical psychologist
- A behavioural psychologist or analyst, ideally with an interest in learning disabilities
- A CAMHS psychiatrist
- A paediatrician
- A specialist liaison officer, with experience of providing support to families post-diagnosis

Group 2
The group agreed that the following professions should be GDG members:
- education/schools
- parents
- speech and language therapists
- OTs
- Dieticians

The group also discussed the possibility of having focus group with parents, teachers and support assistants.

Group 3
- SENCo's (Special Education Needs Coordinators)
- Pharmacologists
- Teaching assistants
- Educational psychologists
- Occupational therapists
- Nurses
- Speech language therapists
- Dieticians
- Paediatricians

Group 4
The group thought that having broadly representative GDG members would be very important. They suggested that the GDG could include:

- Speech and language therapist
- Occupational therapist
- Drama therapist
- Nurses
- Dieticians

4.   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?

Group 1
The group thought that this section could be divided into issues relating to core symptoms (for example, interventions that target key symptoms), and other areas (for example, interventions for co-existing conditions, which might be modified for children and young people with ASC).

The group did not think that anything should be removed from this section, but suggested some additional areas that could be covered:

- safeguarding
- sensory issues (for example, effective therapy and training for staff)
- general best practice (for example, the importance of environmental factors in delivering interventions)
- parents' and carers' views, and how support can be led by the family's needs
- dealing with worries; psychological support for families post-diagnosis and during transition (to adult services and to secondary school)
- how complex problems (for example, co-existing conditions) leads to problem behaviour
- the group thought that 4.3.1 (f) should be modified to say that information should be provided throughout life
- toileting
- motor coordination
- recognition of epilepsy
- management of co-existing psychiatric conditions (for example, ADHD)
- attachment problems
- managing puberty (for example, dealing with sexualised behaviour/modification to sex education due to inappropriate behaviour)
- youth justice

Group 2
The group suggested the following amendments:
- 4.3.1- need to separate out some issues. There needs to be separate sections for:
    - Occupational therapy (to include sensory processing integration, auditory and visual issues)
    - Nutritional interventions (shouldn't be part of physical interventions) e.g. high vitamins, gut problems
    - Under pharmacology, melatones should be looked at as part of hormones
    - Language and communications (to include Picture Exchange Communications [PECs], signing, assisted communication, assisted technology)
    - Education (to include TEACH, visual timetables, structured teaching)

- 4.3.1a) add relationship development interaction, floor time, music interation therapy, somerise, CBT early start, Denver model.
- 4.3.1c) add acupuncture and chelation. Also look at bladder and bowel problems, allergies and skin problems
- 4.3.1e) add 'harm to self and others' including self injurious behaviour
- 4.3.1f) Should include ASCEND which are local parent training programmes, early bird, post diagnostic counselling, genetic counselling (if not included in other guideline), parent as therapist. Also, respite care.
- 4.3.1g) add the importance of access to physical healthcare

Group 3
- Point (a) – Psychosocial interventions
    - Creative therapies, speech language therapy, occupational therapy, and psychoeducational interventions need to be added to the list.
    - Need to be looking at interventions that are being used in practice around the UK – won't necessarily have RCTs of these but they are nevertheless being used in practice.

- Interventions in general – two points to focus on:
  o What adds value to people's lives?
  o What works?
- Point (f) – Information and support – should be prioritised/appear further up in the list. Information, understanding, and respect for treatment options and aspirations are important at all points in the care pathway.
- Point (g) – Organisation and delivery of care
  o The group felt this should be point (a) as they believed it to be the most important issue to focus on.
  o Pre-diagnosis management as mentioned in Q1.
  o Specifically they felt emphasis needed to be placed on the arrangements/key components of multi-agency management
    ▪ Is there a clear route for a multi-agency approach and understanding of what services are available to parents and families?
      • Are family being offered a chance to be a part of/make decisions regarding multi-agency management at critical points starting at the post-diagnosis state? (Not necessary to involve the child as this can be traumatic).
      • Is the family being run through the process by a professional with an unbiased approach – and is there a choice by the family of who the link person is between the different agencies/sectors?
  o Organisation and delivery of care across all schools and settings, teaching staff and educational psychologists, mentors, teaching assistants etc.
    ▪ Guideline also may wish to add training recommendations (for understanding/managing ASC in children) for these professionals.
  o Organisation of delivery of care in all transition periods including early years and post 16 yo

Group 4
The group did not think that anything should be removed from this section, but suggested some additional areas that could be covered or revised:

- Behavioural management sounds quite negative: should focus on strengths and needs more. It should be person centred including collaborative formulations
- Therapeutic interventions should be used instead of the term treatment.
- Area of communication not covered: communication therapy. Also, various other therapies that were not specified e.g. psychotherapy, drama therapy, occupational therapy, sensory processing.
- A holistic approach to care should be highlighted including person-centred care and a comprehensive needs assessment and individual packages of therapeutic interventions tailored to the individuals needs.
- The group thought that vitamins were not considered a physical intervention but rather a drug/herbal intervention.
- With regard to pharmacological interventions specific advice should be provided on how drugs should not be mis-used to manage behavioural problems.
- Other physical interventions that may be harmful are not listed e.g. restraint, isolation, holding therapy etc.
- The group felt that point (d) should be split into two parts. The first part should deal with sleep, eating and gastrointestinal problems and the second about

modification and adaptation of therapeutic interventions for children with autism spectrum conditions.
- The group felt that (g) was one of the key areas to prioritise
- For point (f) the group felt that the key worker should be named here

5. Suggested key areas (section 4.3.1) – ask the group the following general questions in order to agree/prioritise their selection.

a) How available/accessible are these services and should we set out appropriate care pathways?

<u>Group 1</u>
On the whole, the group thought that section 4.3.1 was appropriate and comprehensive. The group suggested some services which are not always available:
- speech and language therapy
- family training
- electronic resources
- post-diagnosis management plan – information (general and about specific interventions, which should be irrespective of age, so that YP with a late diagnosis are not disadvantaged) and support (for example, from specialist liaison helpers)
- cranial osteopathy

The group agreed that joined up services were very important and that this should be considered carefully. The group also suggested that timelines for care pathways should be considered.

The group also had some specific comments about transition to adult services:
- transition can be poorly coordinated
- there can be poor provision for CYP in mainstream settings and who have an IQ in the normal range
- CYP with learning disabilities are generally better provided for; however they usually have learning disabilities services to transit to which are generally based in social care settings – underlining the importance of designing care pathways that cross different areas
- it would be useful to consider when discussion about transition should start
- transition clinics can be very healthcare focussed
- multidisciplinary support networks would be valuable

<u>Group 2</u>
The group raised the importance of care pathways, and suggested there may be a need for more than one due to the different ages being looked at in the guideline.

<u>Group 4</u>
On the whole, the group thought that section 4.3.1 was appropriate and comprehensive. The group suggested some services which are not always available:

- Training and education for staff
- Alternative communication options
- Co-ordination and continuity of care and communication between services
- Advocacy assistance e.g. a key worker acting as an advocate
- Family support especially post-diagnostic support

b)   Does the scope capture the appropriate range and nature of social and educational services?

Group 1
The group thought that educational settings do not fit under the heading to 4.2 (b), 'health and social care settings', so it was suggested that the heading is changed to just 'settings'.

The group also thought that the heading of section 4.3 should be changed, to consider management beyond purely clinical management.

As noted in the answer to question 2, the group were concerned that care pathways took education into account, and were more concerned about this than particular services. The group's concerns were:
- as academies are being given more freedom and are forced to pay for services out of their core budgets, they are increasingly deciding not to retain SEN/psychological services
- children without SEN statements are less likely to have adequate support

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

Group 2
The group suggested the following evidence may be helpful to review:
- PACT trial
- Work done by Christopher Gilbert

Group 3
Important to also look at little-known interventions/management approaches that are being used throughout the UK (have not necessarily been researched but are being used nonetheless)

d)   To what extent should we consider early interventions in health, social care and education services (i.e. the evidence on effective interventions at those stages)?

Group 4
The group felt that the evidence needs to be looked at for early intervention and that early intervention services should not be age dependent but rather problem focused.

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

Group 1
The group agreed that the outcomes listed were very appropriate and suggested a some additional outcomes that could be considered:
- behaviour in all settings (that is, at home as well as school) and at multiple times
- mental well-being and self-esteem (a)
- personal independacne/the ability to make choices
- family/community
- parental stress and mental health, employment and well-being of siblings (d)

- reduction in challenging behaviour (d)
- fewer CYP being taken into care/excluded
- destinations
- scores on SDQ (which the group thought was not useful for CYP with learning difficulties) and other goal-based measures

Group 2
The group suggested the following outcomes:
- quality of life/wellbeing, not just health related.
- Impact on families.

Group 3
- Aspirations of family and young people – what is important for them in their lives.
- Impact on the person
- Safety and vulnerability factors
- Amendment to 4.4 (b) "Functioning to the best of their ability across their living environments"/ Leading Fulfilling and Rewarding Lives
- Amendment to 4.4 (e) "Effective transition throughout childhood to adult services"
- Amendment to 4.4 (f) "Experience of all care"
- (Positive) experiences of care
- (Positive) impact on families

Group 4
The group agreed that the outcomes listed were very appropriate and suggested a some additional outcomes that could be considered:

- Strengths and difficulties questionnaire
- HONOSCA
- Quality of life
- Ability for family to carry on employment and other financial impact outcomes
- Mental wellbeing of carers
- Quality of life of carers
- Experience of carer

6. Equalities – how do inequalities impact on the provision of care for children and young people with and ASC? Should any particular subgroups of the population be considered within the guideline?

   Group 1
   The group agreed that there should be special consideration given to looked after children and were happy that this was covered in section 4.1.1 (b).

   The group also thought that the guideline could look at the traveller community, and thought that there should be some consideration of the fact that there is sometimes better provision made for CYP with learning disabilities, with those in mainstream education and other service settings sometimes being disadvantaged.

   The group agreed that the exclusions listed in section 4.3.2 were appropriate.

Group 2
Extra consideration should be given to children whose parents also have ASC.

Group 3
How does NICE guidance join up with other jurisdictions in the UK e.g. Northern Ireland? Will this be explained/accounted for in the guideline?