

National Institute for Health and Clinical Excellence

**Autism spectrum disorders in children and young people  
Stakeholder Comments – Draft scope**

<p><b>Please enter the name of your registered stakeholder organisation below.</b></p> <p>NICE is unable to accept comments from non-registered organisation or individuals. If you wish your comments to be considered please register via the <a href="#">NICE website</a> or contact the <a href="#">stakeholder organisation</a> that most closely represents your interests and pass your comments to them.</p>		
<b>Stakeholder organisation:</b>		<p><b>Association of Child Psychotherapists</b> 120 West Heath Road, London NW3 7TU Tel: 020 8458 1609 Fax: 020 8458 1482 www.childpsychotherapy.org.uk</p>
<b>Name of commentator:</b>		<p><b>Beverley Tydeman, Chair, Association of Child Psychotherapists</b></p>
<b>Comment No.</b>	<b>Section number</b> <small>Indicate <b>number</b> or <b>'general'</b> if your comment relates to the whole document</small>	<b>Comments</b>  Please insert each new comment in a new row.  Please do not paste other tables into this table, as your comments could get lost – type directly into this table
1	3.1 b)	This section highlights the importance of the emotional repercussions of autism spectrum disorders (ASDs) for children and young people, hereafter referred to as children, which are important even in those whose cognitive function is good. This is supported by recent research with parents of children with disabilities, which found that many would like better access to Child and Adolescent Mental Health Services (CAMHS). Child and adolescent psychotherapists (CAPTs) offer specialist expertise as part of a multidisciplinary team in helping children to manage difficult feelings and supporting parents to do the same.
1	3.1 c)	Features commonly found also include high levels of anxiety.
1	3.1 d)	The presentation can be more complex at times, as there may be overlaps between developmental disorders and associated co-morbidity.
1	3.1g)	Families with a child or young person with ASD often take the full brunt of their child's difficulties; strain on the family often feeds back into the experience of the child/young person with autism, further complicating the presentation. The impact of a child or young person with ASD on all family members should be considered.

2	3.2 b)	The ACP agrees wholeheartedly with the need for good communication between healthcare, social care and education professionals and carers, as set out here. The specific need for ASD children and their families for a wide variety of professional input means that parents can feel overwhelmed in the absence of effective communication with them and between professionals.
3	3.2 e)	The emphasis here on the need to pick up on a variety of 'peripheral' symptoms is very welcome. We would also emphasise other possible precursors to an ASD diagnosis, which can include: strikingly quiet behaviour during infancy, lack of eye contact, extreme difficulties in self-regulation including eating and sleeping, lack of babbling, excessive muscular flaccidity or rigidity, and persistent sadness or withdrawal.
4	3.2 f)	We welcome the recognition that other conditions can mimic the behaviours that define ASD. Misdiagnosis of ASD can be traumatic for parents and carers and mean that the child does not receive the most appropriate services. It would be helpful to emphasise that ASD should not be diagnosed on the basis of instruments alone, however helpful and essential these may be, without a clinical opinion from a professional with specialist experience.
5	3.2 g)	It is important for families to be supported through the assessment process, which can be traumatic, by a professional who can explain the implications of what they are going through and help them to manage their reactions to it. This can result in stronger parental involvement in partnerships with professionals later on. See also our comments on 3.2 b), above.
6	4.2 b)	Since cooperation between different sectors is particularly important for children with ASD and their parents, it would be helpful for the guideline to include suggestions as to how this might best be implemented, even if these do not carry the authority of the main body of the guideline.
7	4.3.1 a)	It would be useful to specify whether this specialist assessment should be multidisciplinary or multi-agency at this stage, or whether there might be an intermediary stage e.g. a paediatric screening or speech and language therapist (SALT) assessment.
8	4.3.1 a)	There is a need for wider dissemination of knowledge concerning possible precursors. This is currently being researched in France by PREAUT, who have the cooperation of hundreds of GPs and are engaged in a ten-year study. See also our comments on section 3.2 e). The importance of early intervention in ASD cases is now widely recognised and further steps need to be taken to encourage this. Infants showing signs of possible precursors should be routinely monitored. In many cases, anxiety could be allayed at 18 months. Those children who did give cause for concern, for example levels 2 or 3 on the Checklist for Autism in Toddlers (CHAT), should receive input at 18 months rather than the present earliest age of at least two years. As things stand, health visitors no longer carry out an 18-month check unless requested to do so by the family. Understandably, parents with concerns are often too frightened to ask for this. Since professional concern would have had to be aroused by the presence of possible precursors, this should not be viewed as population surveillance, as mentioned at 4.3.2 a).

9	4.3.1 d)	We would argue for the inclusion in the guideline of the clinical and cost effectiveness of all the autism-specific investigations, not only the biomedical ones as set out here. Costings should be carried out of the entire assessment and its component parts, including the Autism Diagnosis Observation Schedule (ADOS), Autism Diagnostic Interview – Revised (ADI-R), SALT assessment, CAMHS assessment etc., so that commissioners can be made aware of how much a good assessment costs.
10	4.3.2 e)	Part of the ongoing information and support for families during the process of assessment of ASD may include reassessment and review of diagnoses, so we think reassessment and review of diagnoses does need to be covered by the guideline. In our experience, for example, many diagnoses of Asperger’s Syndrome are not borne out by the developmental history of the child.
11	4.4	The reliability of the standardised assessment tools, for example ADOS and ADI-R, should also be examined.
12	4.5	Any review of the economic evidence should be multi-agency. For example, if a child attends a special school for autistic children, there may well be savings for CAMHS. Costs to education and health need to be thought about together.
13	General	This submission draws on the research and clinical expertise of members of the Association of Child Psychotherapists with specialisms in working with children and young people with autistic spectrum disorders.

Please add extra rows as needed