

pre-school based ASD specific intervention programmes. Any other problems identified should be addressed. This may involve liaison with specialist services such as child and adolescent mental health (CAMH) services and learning disability services.

For pre-school and primary school aged children the Family Care Plan (FCP) and Individual Education Plans (IEP) must include clear ASD management strategies for all staff and parents to use, and access to ASD specific individual or small group therapeutic educational opportunities as guided by clinical and developmental needs. It is recommended that every local area should have an ASD trained teacher with resource backing who can visit any school and advise and set up as needed an appropriate IEP.

ASD are developmental disorders and the child's and family's needs will change with age. Professionals need to maintain family contact over time through a suitable team member. More intensive work using a variety of professionals may be needed at different stages in the child's development.

#### Intervention recommendations *(Grade C unless otherwise specified)*

- A co-ordinated care plan should be produced within 6 weeks of the MAA.\*
- A trained professional in ASD in each local area should be available. He or she must be capable of setting up a comprehensive home and pre-school based ASD specific intervention program within 6 weeks of diagnosis.\*
- The recommendation is for access to 15 hours per week for each pre-school child (Grade B).\*
- Every local area should have an ASD trained teacher with resource backing who can visit any school and advise and set up as needed an appropriate ASD specific IEP for a pupil with ASD within 6 weeks.\*
- The key service must be identified for follow up and rapid referral to the full range of appropriate services recognising that needs change over time.\*
- A care manager should be identified for longer term co-ordination of the Care Plan for all complex situations.

4

#### Resources *(Grade C)*

Services for children and young people with ASD require a core investment. For example, for a multi-ethnic inner city local area population, diagnostic assessments by the MAA team for sixty children per year have been costed at £210,000 annually as for June 2002. Ongoing review, support and intervention, including mental health and learning disability services, have substantial additional resource consequences. These services should be funded using joint budgets to ensure good quality co-ordinated services. In particular the funding of key workers, care manager and professionals for family and home based support and help is needed. Jointly commissioned and funded children's services should be guided by strategic planning.

#### Strategic planning *(Grade C)*

A local area ASD co-ordinating group should be established. Its responsibilities should include strategic planning and the facilitation of informed developments; audit and evaluation; local area training for parents, carers and professionals; academic and training links to inform local practice.

Grade A requires at least one randomised trial; Grade B requires well conducted clinical trials but no randomised clinical trials; Grade C is an expert NIASA Working Group recommendation; an asterisk (\*) indicates key points for clinical audit, which should be the responsibility of the local ASD co-ordinating group.

Tertiary services should maintain links with referring local area services and agree two-way referral procedures. The tertiary services should be capable of providing specialist multi-disciplinary diagnostic assessments and interventions.

Regional and national priorities should ensure equitable access to transparent ASD care pathways and service provision. New information about evidence based clinical practice should be disseminated and further research should be promoted. National networks are proposed in clinical, research and academic fields.

5

#### Training *(Grade C)* *(See 4.6 for further details)*

Joint multi-agency programmes of ASD awareness training on a continuous basis are necessary for all professionals working with children in the community and for parents/carers. All those providing assessment and diagnosis should undergo regular ASD specific training.

Training should be provided for all staff delivering both specific ASD interventions and other interventions for children with ASD. Training should include issues related to understanding ASD and not be limited to single intervention training.

All these three levels of ASD training should be evaluated and audited by the local area ASD co-ordinating group.\*

The NIASA working group recommends that a national ASD training committee and network be set up to agree and monitor standards for multi-agency programmes for all these levels of training.

#### Key actions

- 1 Easy and transparent access to assessment within a specified time frame.
- 2 Discussion of the diagnosis, taking into account a sensitive framework for sharing information.
- 3 Easy access for families to information and support in relating it to their needs.
- 4 Multi-agency, multi-disciplinary assessment and working.
- 5 Appropriate intervention.
- 6 Immediate appointment of a key worker for the family.
- 7 Care plan developed with and for the family.
- 8 Care management for complex situations and ongoing needs.
- 9 Regular ASD specific training of all professionals working in assessment and provision of services.
- 10 Strategic planning and co-ordination of ASD services for local populations must be undertaken.

Grade A requires at least one randomised trial; Grade B requires well conducted clinical trials but no randomised clinical trials; Grade C is an expert NIASA Working Group recommendation; an asterisk (\*) indicates key points for clinical audit, which should be the responsibility of the local ASD co-ordinating group.

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Ann Le Couteur, Chair, Core Working Group, March 2003.

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# National Autism Plan for Children (NAPC)

## Executive summary

These guidelines address identification, assessment, diagnosis and access to early interventions for pre-school and primary school age children with autism spectrum disorders (ASD). It is hoped that they will encourage transparent, efficient diagnostic processes able to meet the needs of these children and families that are not prescriptive but demonstrate good practice.

The guidelines have been published under the banner of The National Autistic Society (NAS) in collaboration with the Royal College of Paediatrics and Child Health and the Royal College of Psychiatrists. The guidelines are for parents and for all who work with children. They were developed by a multi-disciplinary core group of professionals from Health, Education, Social Services, parent representatives and representatives from the voluntary sector.

**In the executive summary (and in line with the Royal College of Paediatrics and Child Health summary guidelines for accepted Grades of Evidence) all recommendations are graded as follows:**

#### Evidence

**Grade A requires at least one randomised trial**

**Grade B requires well conducted clinical trials but no randomised clinical trials**

**Grade C is an expert NIASA Working Group recommendation**

**An asterisk (\*) indicates key points for clinical audit, which should be the responsibility of the local ASD co-ordinating group.**

1

#### Identification *(See Recommendation 4.1 for justification of all proposed timeframes and details)*

Autism spectrum disorder (ASD) affects at least 60 per 10,000 children under 8 years, of whom 10 to 30 have narrowly-defined autism. In a typical local population unit of 55,000 children under sixteen with 4,000 births per year, the number on which resource need has been based in this report, an annual incidence of 24 new cases is implied though presentation may be at varying ages. This in turn suggests that there would be considerably more than 250 children (under 16 years) with ASD at any one time in every such local health area.

Close to 4 per 1,000 children have severe learning disability, i.e. approximately 200 in a typical local area at any one time. Many of these children will have autism or an ASD. Approximately 25 per 1,000 additional children have moderate learning difficulty and many of these will also have ASD. The numbers of children with ASD who do not have a learning difficulty may have been previously underestimated. There is evidence that higher functioning ASD is increasingly recognised (Chakrabarti and Fombonne, 2001).

The benefits of the early identification of ASD are recognised by parents and professionals alike. While there is as yet no suitable test for the universal screening of pre-school children for ASD, the identification of ASD can nevertheless be improved by the increased recognition of alerting signals to identify those children for whom further assessment is needed. There should also be a positive response to parental concerns at all times. Opportunities for identification are available in the home, in early educational settings, in schools and during health care provision.

As ASD is a developmental disorder the presentation will vary with age and, in any one individual, vary over time. The characteristics of ASD may be more prominent at some ages than others. Thus a clear understanding of normal social, behavioural and language development is required among parents, carers and professionals. Existing child developmental surveillance programmes undertaken by primary care teams including health visitors offer a context within which better detection can occur. It is important to remember that ASD may occur in other developmental syndromes including developmental co-ordination disorders and specific developmental disorders and medical conditions such as early epilepsy and tuberous sclerosis. Learning and psychiatric co-morbidities are common.

### Identification recommendations

- No whole population screening test for autism (Grade B).
- Training of all involved professionals in ‘alerting’ signals of possible ASD both at pre-school and school age (Grade C).\*
- Regular opportunities (at least at 8-12 months, 2-3 years and 4-5 years) to discuss a child’s development with parents as part of ‘surveillance’ to detect and respond rapidly to any developmental concerns (Grade C).\*
- Age of detection/diagnosis of all developmental problems including autism/ASD as a specified disorder to be audited in each local area (Grade C).\*

2

**Assessment** (See Recommendation 4.2. for justification of all proposed timeframes and details). Currently, access to assessment is not consistent in local areas or nationally. Parental concern about any developmental problem should trigger referral for a general developmental assessment (GDA) and not be deferred until the next routine surveillance check.

Assessment should be available locally, or at least within the geographical area equivalent to the local ‘population unit’. It should be timely and delay should be audited (Grade C).\* While many local areas have a child development service (CDS), models vary considerably. Service configuration will be locally appropriate, but for children with a possible ASD, it should offer all the components of the recommended standardised ASD services.

After the identification of concern a three stage assessment framework is recommended, (with Stages 1 and 2 at local level). In some cases stages 1 and 2 may coincide.

**Stage 1** - is a general multi-disciplinary developmental assessment (GDA) as for any child with a possible developmental problem. It should comprise the clear identification of concerns, a developmental history, a full examination and appropriate further tests. When considering the possibility of an ASD, no evidence exists to recommend routine use of particular autism specific screening tests although some tests may help identify children who need a further multi-agency assessment (MAA). The outcomes of a GDA should include immediate feedback to the family, even where the diagnosis remains unclear. The family should have adequate opportunity to discuss the outcome of the GDA. Plans for appropriate provision should commence at this stage where possible. The Local Education Authority should be notified at this stage if special educational needs are suspected. Both the components and outcomes of the general developmental assessment should be standardised nationally (Grade C).

Grade A requires at least one randomised trial; Grade B requires well conducted clinical trials but no randomised clinical trials; Grade C is an expert NIASA Working Group recommendation; an asterisk (\*) indicates key points for clinical audit, which should be the responsibility of the local ASD co-ordinating group.

**Stage 2** - of the assessment process is a multi-agency assessment (MAA). A similar approach will often be applicable to other developmental problems. All the components of a MAA should be applied to all children in whom ASD are suspected since a full picture of the needs of the child and family requires the contribution of all members of the multi-disciplinary, multi-agency assessment team. A named key worker should be appointed at the beginning of the MAA process.

The central feature of the MAA is that it is undertaken by a multi-agency, multi-disciplinary team. The team’s core members should be available within a local area, including an educational specialist and an ASD family support worker. The assessment should be completed and feedback given to the family within 17 weeks from referral to the MAA team (Grade C).\* Assessment is ongoing. In some children a final diagnosis may not be possible at this stage, but the child’s needs should have been identified.

The multi-agency assessment should be capable of assessing the differential diagnosis of possible ASD and providing a baseline assessment of skills and difficulties for both the child and the family.

### Essential components for a complete multi-agency assessment (MAA)

- 1 Existing information from all settings should be gathered.
- 2 A specific ASD developmental and family history should be taken. No evidence exists on which to recommend any particular framework, but this history should be taken by an experienced team member with recognised ASD training. In some cases it may be useful to use a semi-structured interview such as the *Autism Diagnostic Interview (ADI-R)* or the *Diagnostic Interview for Social and Communication Disorders (DISCO)*. If the person taking the developmental history is not medically trained, then the medical history and examination should be completed separately.
- 3 Focused observations should be taken across more than one setting. This could include tools such as the *Autism Diagnostic Observation Schedule (ADOS)*. The focus of the assessment of primary school aged children should include their functioning in an educational setting.
- 4 A cognitive assessment should be performed in an appropriate setting by either a clinical or an educational psychologist with ASD training.
- 5 A communication assessment should be made and speech and language competences assessed where needed by a speech and language therapist with ASD training.
- 6 An assessment should be made of mental health and behaviour. Co-morbid mental health and behaviour problems are common.
- 7 An assessment of the needs and strengths of all family members should be undertaken.
- 8 A full physical examination should be performed including appropriate medical tests.
- 9 Choice of tests will depend on each child’s clinical presentation but chromosome karyotype and fragile X DNA analysis are the only current routine recommendations (Grade B). Clinical evidence of co-morbid medical conditions such as epilepsy should be sought but tests such as EEG not undertaken unless clinically appropriate. The evidence base for all investigations should be fully explained to parents.
- 10 Other assessments may be required to investigate unusual sensory responses, motor planning and co-ordination difficulties and self-care problems.

Grade A requires at least one randomised trial; Grade B requires well conducted clinical trials but no randomised clinical trials; Grade C is an expert NIASA Working Group recommendation; an asterisk (\*) indicates key points for clinical audit, which should be the responsibility of the local ASD co-ordinating group.

All professionals involved in an MAA should be experienced and knowledgeable about ASD and it should lead to specific recommendations. A written report should be produced and discussed with the parents and the key worker should be appropriately involved in these discussions. This should include a needs based Family Care Plan (FCP). At this stage genetic implications should be considered.

**Stage 3** - is the possible need for referral to a tertiary ASD assessment. The local area team may need this referral for several reasons, including a second opinion, diagnostic doubt, complexity, and specific advice about treatments or key transition stages. Either Stage 2 assessment or tertiary service should include access to paediatric neurology, gastroenterology, metabolic medicine, neuropsychiatry with competences in psychological and pharmacological treatments and other specialist therapy services.

### Assessment recommendations (Grade C)

In every local area there should be:

- An agreed written referral pathway for children with suspected ASD, both pre-school and school age, accessible to all professionals and parents: this may be the same as for all developmental problems.\*
- A local ASD co-ordinating group for strategic planning of training and service needs/development in each local area with representation from all statutory and voluntary services together with users of the service.\*
- A multi-agency assessment in all local areas to be available to families and to include medical, physical, psychometric, educational, communication, language and motor competency, behaviour and mental health assessments of the child.\*
- At least one lead clinician in every local area to be trained in ASD and in one of the current diagnostic interviews (ADI-R or DISCO) within three years.\*
- One person from each discipline/agency to have expertise in ASD.\*
- A clear timescale of response: response to referral within 6 weeks; Stage I (GDA) to plan of action – 13 weeks, and from referral for Stage 2 MAA to completion with Family Care Plan (FCP) after a further 17 weeks.
- A key worker or care manager (as appropriate) allocated for each family with diagnosed ASD.\*
- Access to a tertiary assessment available for tertiary opinion work. The tertiary team should be resourced for detailed discussion about specific children, professional consultation and training, and provide a lead in local research, data organisation and analysis.

3

**Interventions** (See Recommendation 4.3 for justification of all proposed timeframes and details).

The co-ordinated programme of early intervention should be discussed with the family, with support from a key worker, within 6 weeks of the end of the MAA and at regular review appointments. The family should receive information about local parent groups, education and training and information about support services from the family support worker. The child should receive interventions informed by specific ASD expertise. Pre-school children should have access to 15 hours per week of appropriate ASD specific programmes. ASD specific intervention does not necessarily imply segregated ASD provision nor 1:1 working (Grade B). It is recommended that there is a trained professional in ASD in each local area who is capable of setting up comprehensive home and

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