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Appendix A

Detailed recommendations
The following materials have all been informed by research and expert advice.

i. Tables and Figures

Table 1  Diagnostic criteria for childhood autism (WHO 1993)
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Figure 1  Flowchart for the identification, assessment and diagnostic process
Table 1

Diagnostic criteria for childhood autism (WHO 1993)

<table>
<thead>
<tr>
<th>International Classification of Diseases (ICD-10) issued by WHO 1993</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A</strong> Abnormal or impaired development is evident before the age of 3 years in at least one of the following areas.</td>
</tr>
<tr>
<td>(1) receptive or expressive language as used in social communication;</td>
</tr>
<tr>
<td>(2) the development of selective social attachments or of reciprocal social interaction;</td>
</tr>
<tr>
<td>(3) functional or symbolic play.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>B</th>
<th>A total of at least six symptoms from (1), (2) and (3) must be present, with at least two from (1) and at least one from each of (2) and (3):</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1)</td>
<td>Qualitative abnormalities in reciprocal social interaction are manifest in at least two of the following areas:</td>
</tr>
<tr>
<td>(a)</td>
<td>failure adequately to use eye-to-eye gaze, facial expression, body posture, and gesture to regulate social interaction;</td>
</tr>
<tr>
<td>(b)</td>
<td>failure to develop (in a manner appropriate to mental age, and despite ample opportunities) peer relationships that involve a mutual sharing of interests, activities and emotions;</td>
</tr>
<tr>
<td>(c)</td>
<td>lack of socio-emotional reciprocity as shown by an impaired or deviant response to other people’s emotions; or lack of modulation of behaviour according to social context; or a weak integration of social, emotional, and communicative behaviours;</td>
</tr>
<tr>
<td>(d)</td>
<td>lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. a lack of showing, bringing, or pointing out to other people objects of interest to the individual).</td>
</tr>
</tbody>
</table>

| (2) | Qualitative abnormalities in communication are manifest in at least one of the following areas: |
| (a) | a delay in, or total lack of, development of spoken language that is not accompanied by an attempt to compensate through the use of gesture or mime as an alternative mode of communication (often preceded by a lack of communicative babbling); |
| (b) | relative failure to initiate or sustain conversational interchange (at whatever level of language skills is present), in which there is reciprocal responsiveness to the communications of the other person; |
| (c) | stereotyped and repetitive use of language or idiosyncratic use of words or phrases; |
| (d) | lack of varied spontaneous make-believe or (when young) social imitative play. |

| (3) | Restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities are manifest in at least one of the following areas: |
| (a) | an encompassing preoccupation with one or more stereotyped and restricted patterns of interest that are abnormal in content or focus: or one or more interests that are abnormal in their intensity and circumscribed nature though not in their content or focus; |
| (b) | apparently compulsive adherence to specific, non-functional routines or rituals; |
| (c) | stereotyped and repetitive motor mannerisms that involve either hand or finger flapping or twisting, or complex whole body movements; |
| (d) | preoccupations with part-objects or non-functional elements of play materials (such as their odour, the feel of their surface, or the noise or vibration that they generate). |

| C | The clinical picture is not attributable to the other varieties of pervasive developmental disorder |
Table 2

Suggested time frame for assessment: minimum time frame standards

<table>
<thead>
<tr>
<th>STAGE of PROCESS</th>
<th>Response time at each step</th>
<th>Cumulative Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referral for general developmental assessment (GDA) (Stage 1 assessment)</td>
<td>6 weeks</td>
<td></td>
</tr>
<tr>
<td>Developmental assessment</td>
<td>7 weeks</td>
<td></td>
</tr>
<tr>
<td>Completion of Stage 1 assessment and report:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage 1 (GDA) Total</td>
<td></td>
<td>13 weeks</td>
</tr>
</tbody>
</table>

If multi-agency assessment (MAA) referral made

| Appointment of key worker within 4 weeks             |                            |                 |
| Referral to MAA made (Stage 2)                       |                            |                 |
| Acknowledgment of referral (2 weeks)                 |                            |                 |
| Personal contact by MAA team member with family and key worker | 6 weeks                    |                 |
| Assessment including diagnostic interview            | 7 Weeks                    |                 |
| Feedback to family                                  | 4 weeks                    |                 |
| Stage 2 (MAA) Total                                 |                            | 17 Weeks        |
| Stage 1 and Stage 2 Total                           |                            | 30 Weeks        |

- The initial assessment at Stage 1 may involve seeing the child over time and at more than one appointment. It may also involve other members of the multi-disciplinary team seeing the child before ASD becomes part of the differential diagnosis. In these circumstances the time scale before referral to Stage 2 may take longer (this is common with higher functioning children and with children under two with severe learning difficulties as well as ASD).

- However if Stage 1 and Stage 2 follow on directly together the process should take about 6-7 months (i.e. 30 weeks)

- Adequate opportunity must be given within the course of GDA and MAA to discuss the assessment findings with the family

- Some district services have established specific nursery placements (NIASA 2002) to assist assessment/observation of children and promote parent training and support examples of good practice.
Table 3 (see over)

Community Health South London NHS Trust
Services for children with social communication disorders
In Lambeth, Southwark and Lewisham

Resources needed to provide the specialist assessment service: Stage 2 MAA (June 2002)

Resource requirements

Funding for specialist services for children with social communication disorder has varied significantly across Lambeth, Southwark and Lewisham. This has led to the differential development of such services across the three Boroughs. We compared working practices in the three boroughs and estimated the current resource allocation. We gathered the best practice together, and estimated the resource consequence. In order to deliver services as set out in this proposal and minimum possible waiting times for specialist assessment the investment required is outlined below.

This proposal includes:

- costings for the full assessment of 60 children per year (more referrals requiring multi-agency assessment would require pro rata increase in resources)
- provision of a limited package of support for families of children newly diagnosed and specialist early intervention for children under 5 (i.e. EarlyBird or equivalent).

This proposal does not include:

- routine follow up of children with ASD (whether by school doctor or psychologist)
- general support and interventions for children with social communication disorders across all the age range from the period post-diagnosis to leaving school and the transition to adult services (including family support worker)
- specialist support and interventions (e.g. behavioural management, psychiatric intervention and psychopharmacology)
- education resources.

The estimate is based on one new child per diagnostic session plus all the work in preparation and after the diagnostic assessment. 60 children per year require approximately 1.5 diagnostic assessments per week (or three new referrals seen every two weeks) to allow for annual leave, study leave, teaching and training commitments.

Tony O’Sullivan, Core Member
### Table 3

**Example of resource costings for assessment:**
**Multi-ethnic population in inner city location (June 2002)**

<table>
<thead>
<tr>
<th>Estimated cost of diagnostic and early intervention service for children with ASD and their families (60 referrals per year)(a)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ASD assessment team</strong>(b)</td>
</tr>
<tr>
<td>---------------------------------</td>
</tr>
<tr>
<td>Consultant (paediatrician)</td>
</tr>
<tr>
<td>Speech and language therapist (SLT)(c)</td>
</tr>
<tr>
<td>Psychologist</td>
</tr>
<tr>
<td>Support worker</td>
</tr>
<tr>
<td>Administrative support</td>
</tr>
<tr>
<td>Education: specialist ASD teacher(e)</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
</tr>
</tbody>
</table>

(a) Education input is included here. In Lewisham the contribution from the Early Years Service (part of Education) to the EarlyBird course is 2 sessions per week. The course was initiated by committed, EarlyBird-accredited individuals. There are no ring-fenced resources allocated by Education at present.

(b) Mid-points on salary scales are used and employers on-costs are included.

(c) ASD specialist spine points 36-38 £39,565-42,652, including London weighting and on-costs: includes EarlyBird course running twice yearly.

(d) Clinical psychology spine point Sp39 (range 37-39).

(e) Specialist ASD teacher with a managerial role in MAA team.

*Figures include London Weighting and employers on-costs e.g. for whole time equivalent (WTE) SLT inner London +£2,592, outer London +£1,542*
### Table 4

**Proforma for possible checklist for multi-agency assessment (MAA) and intervention planning**

**Management plan for children with autism spectrum disorder**

Please check periodically if these actions or services have been discussed or arranged.

<table>
<thead>
<tr>
<th>Action or referral</th>
<th>Comment</th>
<th>Yes/No</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diagnosis of ASD:</strong> has this been discussed with both parents</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Investigations:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) Have these been discussed?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Have investigations been carried out?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Has <strong>hearing</strong> been satisfactorily assessed?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) Has <strong>vision</strong> been satisfactorily assessed?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e) <strong>Psychometric measurement:</strong> is this required? (referral to clinical psychology)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f) Is referral to <strong>occupational therapist</strong> required for <strong>fine motor/ADL</strong> concerns</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Research:</strong> consider possible involvement in research (EEG, twin/sibling etc)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Education:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) <strong>Notification</strong> to Education (LEA) (under 5s) (1996 Education Act), <strong>cc educ psychology</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Liaison with <strong>educational psychology</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) <strong>Pre-school place:</strong> referral to early years service</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) Referral to special needs adviser, Early Years Service/pre-school specialist resource</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e) Referral to <strong>district portage service</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Parent training</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Parent course – EarlyBird</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Support:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) <strong>Special needs health visitor</strong> and/or liaison with the family HV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Referral to <strong>disability social worker</strong> (assessment: benefits, respite, support etc.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Behavioural support or counselling: referral to <strong>clinical psychology</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Information:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) NAS information pack</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Local parent group-leaflet/access info</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Contact a Family leaflet</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Tertiary referral</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Genetic advice:</strong> has this been discussed?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Key worker identified?</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Lewisham and Southwark checklist (01/11/01)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 5

Example of proforma for ASD developmental history

Autism spectrum disorders – an aide-memoire for interviewing parents/carers of young children

This is an aide-memoire-not a formal interview schedule nor a diagnostic tool. The structure and headings are based on the ICD-10 research diagnostic criteria for pervasive developmental disorders. The content draws from the Autism Diagnostic Interview-Revised (Le Couteur, Rutter and Lord, 1994)

Detailed descriptions of behaviours should be elicited through asking open questions. The descriptions will form the basis for judgements to be made by the interviewer. Behaviours need to be judged against the child’s developmental level. It is important to clarify the chronology and pattern of development of behaviours.

(Revised by Helen McConachie and Ann Le Couteur, December, 2001 from version created by Paul Bernard, July, 2000)

1 Qualitative abnormalities in reciprocal social interaction

(a) Failure adequately to use eye-to-eye gaze, facial expression, body posture, and gesture to regulate social interaction

Eye-contact
Quantity and quality during communication

Does X look you directly in the face when doing things with you?
Frequency and duration of eye contact?
With a range of people?
Unusual quality?

Facial expression
Range and use of; subtle as well as extreme

Uses normal range of facial expressions? e.g. happy, sad, afraid, embarrassed, surprised, disgusted
Facial expression sometimes inappropriate to the situation?

Social smiling
Spontaneity, range of contexts and people

Smiles as a greeting?
Smiles in response to a smile/a compliment?
Smiles at a variety of people (i.e. not simply parent)?
Appendix A

Gesture

Range and quality

Range? e.g. head shaking, nodding, waving, beckoning, putting out hand to ask for something, shushing
Variety of contexts?

(b) Failure to develop (in a manner appropriate to mental age, and despite ample opportunities) peer relationships that involve a mutual sharing of interests, activities, and emotions.

Interest in other children

Unfamiliar children of same age – interest and interaction with them

What does X think about other children of roughly her/his age whom she/he doesn’t know? Is she/he interested? Does she/he try to approach them/interact with them?

Prefers adult company?

Response to other children’s approaches

Unfamiliar children of same age – look for efforts to keep interaction going

How does X behave if another child approaches her/him?

Group play with peers

Participation in spontaneous games with other children; attending to peers and modifying behaviour accordingly; flexible and interactive play

How does X play with groups of children (i.e. more than 2 others)? Can X co-operate in games like hide and seek/ball games?

Peer groups (for older children)

(c) Lack of socio-emotional reciprocity as shown by an impaired or deviant response to other people’s emotions; or lack of modulation of behaviour according to social context, or a weak integration of social, emotional and communicative behaviours

Response to other people’s emotions

Does X try to comfort you when you are sad/hurt/unwell?
Spontaneity, range of people, quality

Seeks comfort when sad/hurt/unwell?
Unprompted comfort-seeking

Shares in other people’s pleasure or excitement? e.g. someone else’s birthday

Inappropriate response to another’s emotional state? e.g. laughs at another’s distress

Greeting behaviour
Response to re-union following everyday separation; look for verbal and non-verbal expression of pleasure
Lack of modulation of behaviour according to social context

Lacks social inhibition because unaware of social cues/social rules

Varies behaviour according to where he is?/who he is with? e.g. in library vs park, with family vs with strangers
Socially inappropriate and embarrassing behaviour?
Over-personal with unfamiliar people?
Socially embarrassing questions/statements? e.g. why are you so fat?

Response to approach by unfamiliar adults

In everyday but non-routine situations

How does she/he respond if talked to by an adult she/he doesn’t know? e.g. a friendly lady in a shop

Integration of social and communicative behaviours

E.g. co-ordination of gaze, facial expression, gesture and speech when making social overture

when she/he wants something or wants help, how does she/he try to get your attention?

(d) Lack of spontaneous seeking to share enjoyment, interests or achievements with other people

When pleased/happy – tries to share these feelings?
When interested in something – tries to share the interest with others? When has created something (e.g. drawing etc.) – important to him that others see it? Shares things with others? – unprompted: e.g. food, toys, space on sofa

Qualitative abnormalities in communication

(a) A delay in, or total lack of development of spoken language that is not accompanied by an attempt to compensate through the use of gesture or mime as an alternative mode of communication (often preceded by a lack of communicative babbling).

Age when first used single meaningful words (other than mama and dada)? Delayed = after 2nd birthday

Age when first used phrases (2 words, one of which a noun)? Delayed = after 33 months

Pointing to express interest (NB not simply to request)

Does she/he ever spontaneously point at things around her/him? (e.g. helicopter, bus, in distance)

Did she/he ever show you what she/he wanted by taking your hand or wrist? (i.e. use your hand as if it were a tool)
(b) Relative failure to initiate or sustain conversation interchange (at whatever level of language skills is present), in which there is reciprocal responsiveness to the communications of the other person.

**Reciprocal conversation (at whatever verbal level possible)**
*Offering of information and building on other person’s response – not limited to conversations about ‘special interests’*

Can people have conversations with X?
Only about certain topics?
Does she/he add something to what has been said so that the conversation will continue?

**Social chat**
*Just to be friendly – rather than to express needs or give information*

‘Small talk’?
How often?
With whom?
Asks questions about you (e.g. what you like, think, how you feel)?

(c) Stereotyped and repetitive use of language or idiosyncratic use of words or phrases.

**Idiosyncratic use of language**
*Speech patterns that are clearly odd in content or context; includes self-commentary on own actions. Explore how much it dominates her/his speech*

Uses odd phrases?
Speaks in a very formal or precise way – e.g. saying mother instead of mum?
Says the same thing over and over again?
Gives a running commentary on what she/he’s doing?

**Neologisms**
*New and obviously peculiar words; not imitated; not metaphors; not part of a game or shared joke*

Uses words that she/he seems to have made up her/himself?
Uses words to mean things they don’t usually mean?

**Delayed echolalia**
*Repetitive re-runs of things that have been said; out of context; not as part of play or when ‘practising’ or for re-assurance*

Repeats phrases that she/he’s heard others say?
Out of appropriate context?

**Prosody**
*Unusual accent, intonation, pitch, volume, rhythm, rate*

Anything unusual about the way she/he speaks (e.g. how loud, her/his accent, intonation, speed etc.)?
(d) Lack of varied spontaneous make-believe or social imitative play

**Imaginative play**
*Formation of mental images of things not really present; look for creative and varied use of actions or objects in play to represent child’s own ideas; variety, spontaneity and complexity; doll (etc.) as subject as well as object*

Plays pretend games? e.g. with cuddly toys, tea sets, action man, cars?
Doll (etc.) as agent of action, as well as actions done to?
Makes up stories within the play? e.g. doll walks to car, gets in, drives to visit someone etc.
Varies from day to day?

**Imaginative play with peers**
*Look for spontaneity, variety, reciprocity, taking lead as well as following*

Plays pretend games with others?
What do they do?
Can she/he understand when other children are pretending?

**Imitative social play**
*Look for reciprocal participation as both leader and follower in social games that require imitation and co-ordination of simple actions, e.g. peek a boo, pat a cake, Simon says; also teasing games (*I’m coming to get you*) initiating as well as responding*

Does she/he play.....?
Does she/he enter into the spirit?
Does she/he spontaneously try to join in?
Just with you or in other contexts too?

**Spontaneous imitation of actions**
*Look for spontaneous imitation of a range of non-taught actions or characteristics; not vocal imitation; not tv/film characters*

Imitates people in the family? e.g. pretending to mow the lawn/do the ironing/fix the car

### 3 Restricted, repetitive and stereotyped patterns of behaviour, interests and activities

(a) An encompassing preoccupation with one or more stereotyped and restricted patterns of interest that are abnormal in content or focus; or one or more interests that are abnormal in their intensity and circumscribed nature though not in their content or focus.

**Abnormal content or focus**
*An interest that is odd or peculiar in itself. Explore how much it interferes with child’s/family’s life and how much it limits other interests/activities and how much distress if interrupted*

Unusual interests? e.g. traffic lights, street signs
Does it interfere with her/his/your life?
How much time does it take up?
For how long has it been an interest?

**Abnormal in intensity and circumscribed nature (children aged 3 years and over)**

*Differs from ordinary hobbies in intensity; usually very circumscribed; non-social; relative non-progression over time; explore how much it interferes with child’s/family’s life and how much it limits other interests/activities*

Any special hobbies or interests?
How long has it been an interest?
Does it interfere with her/his/your life?
For how long has it been an interest?
Has she/he ever had any objects (other than a soft toy or blanket) that she/he had to carry around?

**Rituals**

*Fixed sequences that are performed as if child feels pressured to complete them in a certain way; includes verbal rituals*

Has X any rituals (i.e. things she/he seems compelled to do in a certain way)? e.g. touching a certain spot on the wall before going out of the front door? Sequence of words she/he and you have to say?

**Difficulties with minor changes in routines**

*Look for extreme reactions to minor changes in routines of daily life*

Upset by minor changes to routines? e.g. having a bath at an earlier time; getting dressed before breakfast rather than after

**Difficulties with minor changes in environment**

*Look for extreme reactions to trivial changes in environment – and efforts made to prevent such changes*

Upset by minor changes to surroundings? e.g. how the furniture is arranged, change of car

**(c) Stereotyped and repetitive motor mannerisms that involve either hand or finger flapping or twisting, or complex whole body movements**

**Hand and finger mannerisms**

*Typically – rapid, voluntary within child’s line of vision; not nail biting, hair twisting, nor ‘overflow’ movements seen in toddlers when excited; distress when interrupted*

Any odd ways of moving hands or fingers? What happens if you try and stop her/him?
Complex whole body movements
*Stereotypic, voluntary whole body movements – e.g. spinning; arm waving while on tip-toes; not simple rocking*

Any unusual movements of whole body?

(d) Preoccupations with part-objects or non-functional elements of play materials (such as odour, the feel of their surface, or the noise or vibration they generate)

Part-objects
*E.g. when playing with car – spins wheels/opens and shuts door*

Lines objects up?
Plays with parts of toys rather than the whole toy itself?
Constrains ‘normal play’?

Non-functional elements of play materials
*Unusually strong interest in sight, smell, taste, texture etc., or strong reactions to sensory experiences*

Particularly interested in sight, feel, sound of things?
Strength of interest?
Particularly disturbed by feel, smell, taste?
Are there any sensory experiences (e.g. pain) that she/he seems not to notice?

Undue sensitivity to noise
Is X over-sensitive or show unusual response to everyday noises (e.g. traffic, hoover, hair dryer, toilet flushing)

Age of onset

(a) How old was X when you first wondered if there might be something not quite right with her/his development?

Below 36 months = significant

(b) Regression
Were you ever concerned that X might have lost skills?
E.g. language? How much language before loss?
E.g. other skills?
Appendix A

Additional behaviours

(a) Toilet training
Have you started toilet training? Any particular problems? e.g. reluctance to bowel movement.

(b) Eating
Is X a picky eater? Are you concerned about her/his diet?

(c) Sleeping
Do you find it difficult to settle X to sleep? Is this a problem? Does X wake often in the night? Is this a problem?

(d) Aggression
Have there been times when X has been aggressive to other people?
In the family?
Outside the family?

(e) Self injury
Does X ever injure her/himself deliberately? e.g. bites arm, bangs head

(f) Fits/faints
Has X ever fainted or had a fit/seizure/convulsion?

(g) Special skills
Does X have any unusually marked special skills? e.g. shapes, memory, music, drawing
Figure 1: NIASA flowchart of the Identification, Assessment and Diagnostic Process

Identification of concerns → Referral to professional/s for GDA → Developmental history + Full examination + Appropriate further tests

Immediate feedback to family → Appointment for family to discuss GDA → ASD suspected

Named key worker appointed → Multi-agency assessment (MAA)

LEA notified if SEN suspected → Plans for appropriate provision to begin → Other assessments

Within 6 Weeks

Within 13 Weeks

4 Weeks

Stage 1 GDA

Observations → Assessment → Full physical
Appendix A

Existing information gathered
ASD specific developmental history taken
Observations across more than one setting
Cognitive assessment
Communication assessment
Assessment of mental health and behaviour
Full physical examination and investigations

Differential diagnosis baseline of skills and difficulties

Co-ordinated programme of intervention/care plan + written report discussed with parents

Professional knowledgeable re ASD to visit home/pre-school/school placement

Second opinion, diagnostic doubt, complex case and/or specific advice required

Referral for Stage 3, tertiary ASD assessment

Stage 3, tertiary ASD assessment

Diagnostic formulation report

Within 17 Weeks
Within 6 Weeks
Within 3-6 Months
Within 6-8 Weeks
ii. **Identification** *(see 4.1)*

Listed below is a selection of the screening tools mentioned in the report.

*Parents Evaluation of Developmental Status (PEDS)*

*CHecklist for Autism in Toddlers (CHAT)*


*Social Communication Questionnaire (SCQ)*
Previously known as the *Autism Screening Questionnaire (ASQ)*

*Childhood Asperger’s Syndrome Test (CAST)*

*Pervasive Developmental Disorder Screening Test (PDDST)*

iii. **Assessment and diagnosis** *(see 4.2)*

*Conceptualisation of autism spectrum disorders (see 2.2)*
As Frith (1991) has pointed out, the determiners of any ‘syndrome’ are twofold: firstly, that those with the syndrome should have symptoms in common and secondly, that these symptoms should differentiate them from others. These are the fundamental characteristics of a categorical system of classification on which medical diagnostic systems depend. ‘Autism spectrum disorder’ (ASD) is not in itself a category within this system, although it broadly coincides with the category of ‘pervasive developmental disorder’ and includes both ‘autism’ and ‘Asperger syndrome’.

It is a pragmatic category, reflecting the level of knowledge and degree of certainty by which we are currently able to categorise different ‘syndromes’. Thus, while it is generally accepted that there are sub-groups within the spectrum, our current divisions are neither scientifically valid nor of practical benefit. It may be the case, however, that there are good social and/or political reasons for some subdivisions and in the UK at least ‘Asperger syndrome’ has come to be a shorthand for those within the autism spectrum who have good structural language skills and no general intellectual impairment.
The identification of an ASD is through behavioural ‘symptoms’, although its biological base is undisputed. The diagnostic systems (DSM IV, APA, 1994; ICD-10, WHO, 1993) currently in use give exemplar behaviours on which a diagnosis may be based. Yet behaviour by itself is a poor guide to diagnosis and certainly there is no single behaviour or even set of behaviours that unequivocally denote autism, although missing behaviours may be a better guide. Making a diagnosis is, therefore, a clinical judgement, with behavioural ‘symptoms’ as a guide to that judgement. This task is made more problematic by the fact that most behaviours that are seen as ‘characteristic’ of an ASD can be seen in other (including normally developing) populations, albeit at times of particular stress or in isolation.

A further difficulty for the categorical model of ASD is that the three behavioural domains (communication, social understanding and skill, flexibility in thinking and behaviour) vary dimensionally across both the normally developing and the ASD populations. There is no point (other than an arbitrary one) at which behaviour along any one of these three dimensions can be divided into ‘autistic’ versus ‘non-autistic’. That is why it is always most difficult to make a diagnosis at the extremes of these dimensions where the behaviours merge into mere ‘eccentricities’ at one end or into severe and profound learning difficulties at the other. It is also the case that many people with ASD view themselves as part of normal human variation, rather than as having a pathology.

The paradox is, that in spite of this failure to differentiate adequately along any one of the dimensions, there are qualitative differences between those who differ on all three dimensions and those who do not, regardless of general ability levels (Wing and Gould, 1979). The two views of ASD can be reconciled by viewing ASD as a broad category sharing certain developmental characteristics within the three dimensions within which there is normal variation, but it is only when someone is situated beyond a certain (necessarily arbitrary) ‘cut off’ point along all three of these dimensions that they would be categorised as having a disorder. The decision on the ‘cut off’ point would be a judgement on the extent to which adaptive functioning was affected.

**Diagnosis and special needs**

The conceptualisation of ASD outlined above sits between a classical medical model of categorisation and an educational model of special needs. There is a consensus that a diagnosis is essential for providing a ‘signpost’ to needs (Jordan, 1999; Wing, 1996) but there are also dangers in this reliance on diagnosis. Volkmar (1998), for example, has been among those who have pointed out how the use of diagnosis as a gateway to services has distorted the diagnostic process in the US, and the same process can be seen in the UK and elsewhere. A diagnosis can lead to a more valid interpretation of behaviour and identification of needs, but special needs are far from synonymous with a diagnostic category.

The notion of ‘special needs’ is a relative one, being dependent on both ‘within-child’ and ‘beyond-child’ factors. Knowing a child has an ASD directs one to particular hypotheses about the behaviour seen, but that behaviour will also depend on how that child’s ASD is affecting the way the child thinks, learns, experiences, and perceives the world and how that interacts with the child’s interests, motivation, abilities, memories, experiences, habits and mood. Nor are the influences on the behaviour limited to child factors; behaviour is also affected by the way others are behaving, the way the physical environment is structured, the level of stimulation and so on.
In other words, no matter how pervasive an effect it has on the child’s development, the ASD is just one aspect that needs to be considered when determining needs, and the child must be considered as an individual, not as a category. Special needs are not static; they diminish in situations where they are well met and they vary with the child’s strengths as well as reflecting impairments.

Rita Jordan, Core Group Member

2*

ASD specific developmental history

Autistic Diagnostic Interview – Revised ADI-R (WPS)


Diagnostic Interview for Social and Communication Disorders (DISCO)


A number of districts have developed proformas for the developmental history based on ICD-10, DSM-IV Criteria (one example is provided table 5, p64).

3*

Observational assessment

Assessments which inform needs
The processes of assessment and identification of needs, and diagnosis should be cyclical with each process informing the other. Assessment of needs and diagnosis should be used to develop a profile of the child/young person’s strengths and difficulties and inform future planning. Many children with an ASD will require an Individual Education Plan (IEP) which should emphasise teaching learning and thinking skills as well as the social skills that are necessary to function within school and home settings. Education personnel can play a key role in any assessments which inform need. Teachers, specialist support teachers, educational psychologist (EPs) and specialist EPs, learning support assistants, lunch-time supervisors, parents/carers and speech and language therapists can all play a vital role in observing and assessing the child across a range of settings.

Focused observations taken across more than one setting
Observations can provide diagnostic information and help to inform any assessment of needs. Detailed observations and/or video record of the child can be made in their home and in a peer setting (in both unstructured and structured settings). Observations under the headings from the triad will inform both identification and the plan of action.

*Numbers correlate to sequence in 4.2.4.3
Appendix A

- communication
- reciprocal social interaction
- repetitive behaviours.

Other skills it is important to observe are:
- the ability to attend
- to imitate others
- to comprehend and use language
- to play appropriately with toys
- to interact socially with others.

Assessment through teaching
Valuable information about a child’s strengths and difficulties and ability to function within pre-school/school/social settings can be gained by assessment through teaching. There are a variety of curriculum-based assessments which can be used together with assessments of the child’s learning style. Scaffolding tasks can be used to measure and observe:
- how much input it takes to maintain pupil’s attention
- co-operation
- behaviour
- memory
- style of response to task
- response to praise
- situations/activities that appear to generate anxiety
- how much support is needed to communicate response (from assessor and augmentative systems such as PECS or Makaton).

Use of standardised tests
Before any standardised tests are used with children with ASD it should be clear that the information gained will inform future planning. Standardised assessments/tests can, however, be useful as structured observations of learning and response style. As with all children, if standardised tests are used it is important to show the profile of skills; IQ scores can give misleading pictures of a child’s abilities. This is especially important when assessing children/young people with an ASD as their profiles are often ‘spiky’, showing marked strengths and difficulties.

Observation of the environment
It is also important to observe the environment that the child/young person is to operate in. Different settings will require different skills. We need to know what skills the child/young person requires to function in different settings. Does the child have these skills? Are there particular issues regarding the difficulties associated with the triad of impairments?

Dawson and Osterling (1997) identified five important skills that children need to function in the classroom or early years settings:
- the ability to attend
- to imitate others
- to comprehend and use language
- to play appropriately with toys
- to interact socially with others.
It is also important that the child is helped to become as independent as possible in many different settings. Critical elements for independence in the classroom are described by Powers (1992):

- compliance with requests
- turn-taking
- listening to directions from any source
- sitting quietly during activities
- volunteering
- raising a hand to gain attention
- picking up toys/equipment after use
- communicating basic needs
- toileting.

**Observational profile for primary school aged children**

There are many commercial checklist and observation schedules that can be used for observing children/young people with an ASD. For example:


Other examples include in-house observation schedules such as Birmingham’s SENCO Questionnaire and Blackpool Learning Support Service’s ‘Iconic Communication and Interview Observations’.

*Annette English, Core Group Member*

Checklists are available that provide a framework for characterising behaviours associated with ASD, for example:

**Childhood Autism Rating Scale (CARS)**

This was initially intended as a screening assessment but is widely used and well known.


**Vineland Adaptive Behaviour Scales (VABS)**

This interview is given to the main caregiver and provides important structured information about developmental level by focusing on everyday skills such as dressing and independent travel.


**Direct observational assessments**

**Autism Diagnostic Observation Schedule (ADOS)**

Cognitive assessment (pre-school and primary school aged children)

Tests used in the cognitive assessment of children with autism
Where they are well standardised, IQ tests are generally considered to be reliable measures of functioning. However there are a number of problems related to the use and scoring IQ tests with young children with autism:
• Very different skills may be assessed by different tests and comparative data are few. Generally the choice of test is determined by tester’s familiarity/bias or time/financial costs
• The age range of many IQ tests is limited, so that, especially for longer-term follow-ups, different IQ tests need to be used at different times.
• Scoring protocols for typically developing children may not be appropriate for children with abnormal development, and may result in inaccurate estimates of their level of functioning. Unusual profiles of ability/difficulties, also give rise to problems in establishing basal and ceiling levels.
• Variability in the IQ tests used in different research studies/clinical centres, and lack of consensus on scoring standards can have a considerable impact on how results should be interpreted.

In order to avoid misinterpretation of findings from cognitive tests it is recommended that:
• Rules for scoring of tests when used with children with autism should be made explicit. In particular, decisions on how verbal IQ items are treated (as failures/refusals etc.) in non-verbal children should be made clear. Decisions about reaching basal and ceiling should be clarified.
• Full details of the tests used over time should be presented. Ideally when assessing change over time the same tests should be used. If the original test is not age-appropriate then an additional test should be used as well.
• There should be sharing of information on the relationship between different cognitive tests (i.e. those that tend to give higher or lower cognitive scores).
• Core measures to be used in all outcome studies/comparisons between clinical centres should be agreed.

The following scales/tests are among the most commonly used for the assessment of general cognitive ability (age ranges are given in parenthesis). (See reference list for details of publishers/dates etc.)
• Bayley : 0-42 months
• Mullen : 0-68 months
• WPPSI : 3 years - 7 years 3 months
• WISC : 6-16 years
• Merrill Palmer : 18-78 months
• Ravens CPM 5 to adult
• Leiter 2-18 years
• Vineland 0-adult
• Griffiths 0-5 years
• British Ability Scales (3 levels: 2-3; 3-6; 7-17 years)
• Kaufman-ABC 2-12 years
• McCarthy Scales 2.5 - 8.5 years (also screening test 4-6.5 years)
• Stanford-Binet 2+ years

*Numbers correlate to sequence in 4.2.4.3
No test is without problems and each has various advantages/disadvantages e.g.:

- **Wechsler tests:** WPPSI: Relatively few autistic children within the specified age range are able to complete even the non-verbal items. As they grow older, however, more children seem able to score on the WISC subtests. Both tests provide verbal and non-verbal IQ but scoring leads to problems when children with an IQ below 40 are involved.

- **Merrill-Palmer:** The norms are very elderly (though extended version, 1978 now available). The materials are attractive to children with autism and a test score is often possible to obtain on this when other tests are not successful.

- **Bayley:** Assesses verbal and non-verbal skills but it can make a significant difference to scoring if verbal items are coded as omissions or failures (this also applies, but to a lesser extent to the Merrill Palmer). Again, the materials are attractive and work well with children with autism.

- **Ravens CPM:** This assesses a restricted range of skills but the book version can be useful for children of lower IQ.

- **Leiter:** Also assesses restricted range of skills; the nature of the sequencing tasks involved may present specific problems for children with autism; however, the age range is wide age range wide.

- **Kaufman:** Has wide age range; reduced verbal content; attractive materials, and offers analysis of learning styles (e.g., face recognition).

- **Vineland and Griffiths Scales:** Both depend on parental reports; may overestimate observed skills. However, this makes it possible to obtain a score for almost all children.

- **Stanford-Binet/ McCarthy Scales:** American only norms; former also has very high verbal content.

- **BAS II/ Mullen Scales:** These are relatively new instruments on which more information with regard to use with children with autism is required.

Pat Howlin, Core Group Member

Psychoeducational Profile Revised (PEP-R)


This is a semi-structured observational assessment which can be useful especially for non-verbal children. Skills are assessed in 3 different ways: passing, emerging, and failing - useful for developing intervention programmes. A long test with 174 items. Poorly standardised. Recommended for use in children age 6-7 years with developmental levels between 2 and 5 years.

Jennifer Ravenhill, Educational Psychologist, NAS
Appendix A

5

**Communication, speech and language assessment (pre-school and primary school aged)**

The choice of language assessments will depend on individual factors within the child. Listed below is a range to aid the selection process.


**Derbyshire Language Scheme**
1980 Knowles and Masidlover Derbyshire County Council.


**Test of Reception of Grammar** (TROG 4 - 12 years) 1983 Bishop University of Manchester

**Symbolic Play Test** (1 - 3 years) 1988 Windsor: NFER-Nelson.

**Test of Pretend Play** (ToPP 1 - 6 years) 1997 The Psychological Corporation.

**The Pragmatics Profile of Early Communication Skills in Children** (9 months - 10 years) 1995 Windsor: NFER-Nelson


**Understanding Ambiguity** (8 - 13 years) 1996 Windsor NFER-Nelson

**Theory of Mind Stories**

* Numbers correlate to sequence in 4.2.4.3

*Maureen Aarons and Tessa Gittens, Core Group Members*

### Behavioural and mental health assessment

A specific, systematic assessment of behaviour, temperamental characteristics and current mental state is essential. In some services self report scales, mental health checklists and semi-structured interviews are considered as part of the assessment protocol. There is no evidence base for using currently available mental health diagnostic assessment tools with children with ASD. Indeed caution must be used when considering the reliability of such assessment tools and in the interpretation of clinical meaning for children with ASD.

The assessment must include the diagnosis of ASD, co-morbid developmental disorders and psychiatric disorders. Recent surveys of children and young people with ASD have reported increased rates of psychiatric co-morbidity. Co-morbid mental health problems, such as anxiety, depression, OCD, ADHD/hyperactivity should be identified and treated (Ghaziuddin and Greden, 1998; Gordon et al, 1993)

Most studies have considered older children and adolescents (Green et al, 2001; Gilchrist et al, 2001; Tantum et al, 2001; Howlin, 2000; Hutton et al, in preparation). Recent reports of the use of newer antipsychotic medication and SSRIs; need replication but emphasise the importance of a multi-agency approach to assessment and intervention.

Bromley et al, (2002) conducted a recent postal questionnaire with parents/carers. They reported high rates of emotional disturbance in children aged 3-18 years (caseness criteria was met in 91% of the sample). The behaviours and symptoms identified by parents/carers included disruptive behaviours (52%); anxiety (56%); self absorbed (43%); communication disturbance (40%); anti-social behaviour (48%).

*Ann Le Couteur, Core Group Member*

### Family assessment

The family is the child’s best resource. Indeed parents of young children with ASD have been described as their child’s co-therapist since 1970s (Schopler and Reichler, 1971). The *Framework for the Assessment of Children in Need and their Families* (2000) may provide a useful framework for the systematic evaluation of family strengths, parenting styles, capacity and wider family issues.


In April 2000 the DoH issued a national framework for assessing children in need and their families, under Section 7 of the *Local Authority Social Services Act 1970*, which means that it must be followed by Social Services Departments unless there are exceptional reasons not to do so. However, it is also intended to provide a foundation for policy and practice for all professionals and agencies who are responsible for providing services to children in need and their families. Social Services Departments are already working together locally with other agencies, to implement the Assessment Framework model across the agencies.

*Numbers correlate to sequence in 4.2.4.3*
The model is based on three domains: The Child’s Developmental Needs, Parenting Capacity, and Family and Environmental Factors. Within each domain there are a number of Dimensions, as set out below. The assessment is undertaken in partnership with the child and family, and the analysis of information gained through the assessment process, provides the basis for an interagency plan to help the child and his or her family.

The assessment framework provides a relevant and useful tool for assessing the needs of the children and young people with learning disabilities and mental health problems, giving equal weight to parenting capacity and family and environmental factors, as to the developmental needs of the child.

Many of the stresses experienced by families with a child with ASD are common to families with a child who has a disability but the literature suggests that parents of children with ASD have significant unmet needs. Bromley et al (2002) reported that 93% of parents did not receive help during holidays; 87% requested a break from caring; 81% needed advice on education and 80% identified a need for advice on behaviour. 40% of those parents interviewed described their housing as unsuitable.

Overall 59% of the mothers had significant psychological distress. This level of distress was associated with low levels of support and high levels of challenging behaviour from their child with ASD.

A number of studies have now confirmed an increased risk for both autistic spectrum disorder and a broader range of cognitive and social difficulties in relatives of probands with autism (Bailey et al, 1995; Bolton et al, 1994). Only a small proportion of relatives will show clear cut autism, whilst the majority of affected individuals will have a range of related social difficulties and personality traits that appear to co-occur (Bailey et al, 1998; Szatmari et al, 1998). The broad range of difficulties seem to map onto the domains of impairment in autism in ICD-10 and DSM-IV (namely social interaction, communication and restricted, repetitive behaviour). The third domain (restricted, repetitive behaviours) has received much less investigation when compared with studies of social and/or communication impairment. Repetitive behaviours are certainly more difficult to define and
study. In contrast with findings in individuals with autism, recent studies of relatives have shown no clear association with either mental handicap nor a consistent pattern of cognitive discrepancies (Fombonne et al, 1997; Folstein et al, 1999).

Whether for relatives of an affected individual with autism, in addition to the increased genetic susceptibility to ASD and the broader phenotype, there is also a pre-disposition to other psychiatric disorders, is at present unclear. Some family studies of autism and ASD have reported increased rates of psychiatric disorder especially affective disorders (particularly major and recurrent depressive illness) amongst relatives (Bolton et al, 1998). These disorders do not seem to overlap with the autistic-related social or language deficits, either at the individual (Piven and Palmer, 1997) or familial level (Bolton et al, 1998). Further, there are reports that adult relatives also have increased rates of anxiety-related personality traits (Murphy et al, 2000) and anxiety disorders (Smalley et al, 1995; Bolton et al, 1998). There is no consensus about whether the risk is for generalized anxiety disorders or social phobia. Despite the need for further studies to replicate this work, these findings need to be taken into account when undertaking an assessment of family strengths and needs and how best to support families with a child with possible ASD.

Christine Lenehan, Council for Disabled Children
Ann Le Couteur, Core Group Member

8* Physical examination


9* Medical investigations

- Frequency of known medical conditions associated with autism.
  Gillberg and Coleman (1996): Review of 7 studies investigating children with autism (1979-91). Found 11-37% had known medical conditions, commenting that the positive rate increased with severity of learning disability and extent of investigations.

  Fombonne et al (1997): In a population-based study of medical disorders excluding epilepsy reported that medical conditions were recognised in 10% (similar in narrowly defined autism and Pervasive Developmental Disorder (PDD)). Tuberous sclerosis was the only condition more strongly associated with autism than with other developmental disorders. The extent to which the children in this study were investigated was not clear. Fombonne’s (1999) review of 23 epidemiological surveys (a total of 4 million subjects, 1500 cases) noted associated medical conditions in 6%.

  Barton & Volkmar (1998): Investigating 3 groups (autism, PDD and other developmental disorders) reported that 9.8% of the autism group had strictly defined medical conditions (versus 22% of the other 2 groups). Positive findings were correlated with low IQ and broader spectrum PDD (as defined using DSM-IIIR).

  Skjeldal et al (1998): Extensively investigated 25 children with autism and age matched IQ controls. 8% of children with autism versus 36% of the controls had associated medical conditions.

*Numbers correlate to sequence in 4.2.4.3
**Practice point:** A minority of children with ASD (approximately 10-15%) have known medical conditions and the rate is likely to vary depending upon how extensively the children are investigated (Rutter et al., 1994), and on the severity of their learning disability. However, extensive investigation for conditions that do not have implications for management of the child or genetic counselling are not recommended.

- **Basis of specific medical investigations**
  - **Genetic investigation:** Autism is positively associated with certain genetic conditions; for example, 40-60% of children with tuberous sclerosis are reported to also have autism (Hunt & Shepherd, 1993; Gillberg et al., 1994), and 15-30% of those with Fragile X (Bailey et al., 1998; Hagerman et al., 1986). Conversely a much smaller percentage of children with autism will have a specific genetic basis for their condition. For example in a study of tests in children looking for undiagnosed aetiology for autism, 3% had abnormal karyotype including 4 out of 11 with Fragile X (Lewis et al., 1995).

  **Practice point:** Genetic investigation is likely to have higher pick-up if targeted to individual conditions on the basis of a raised index of clinical suspicion.

  - **Imaging studies:** Abnormalities have been reported both in the cerebellum and also cortical migration anomalies in some individuals. There are no consistent diagnostic findings in autism.

  **Practice point:** Routine imaging in ASD is not indicated. Imaging in tuberous sclerosis is indicated, because of association of the triad of autism, epilepsy and severe learning disability.

  **Epilepsy, epileptiform EEGs and autism:** Epilepsy is common in autism. Current estimates of the lifetime incidence of epilepsy in autism is 17% (Fombonne, 2001). Epilepsy may arise at any age but two peaks are recognised, in early childhood and adolescence. The probability of epilepsy increases with the severity of the underlying brain dysfunction as shown by the presence motor deficits and mental retardation (Tuchman, 1991). Thus within the population of children diagnosed with ASD there will be many who require the investigation and management of epilepsy.

  Regression occurs in a variable number of children with autism, around a mean of 21 months (Tuchman, 1996), but the prevalence of epilepsy is not greater in those who show early regression compared with those who do not. In a group of 585 children with autism, 11% of those without regression had epilepsy compared to 12% of those with regression (Tuchman, 1991). Epileptiform EEG’s are common in autism and are marginally more prevalent if there is a history of regression. Prolonged sleep EEG monitoring increases the sensitivity of detection of an epileptiform EEG. No child in the Tuchman study had electrical status epilepticus during slow wave sleep (ESES) as would be found in Landau-Kleffner syndrome. Thus the significance of an epileptiform EEG in autism with or without regression remains unclear and the results of treatments are inconclusive. Treatment with anti-epileptic drugs for epileptiform discharges is not without risk, and there is a lack of evidence of effectiveness (Ronen, 2000).

  **Practice point:** Routine EEGs in ASD are not indicated; rather investigation should be based on clinical grounds. Some children who have a fluctuant course of behaviour or other unusual features will need the opinion of a paediatric neurologist but the place of routine EEG monitoring in characteristic autism with a history of loss of use of words within the first 10 word stage, is not recommended. Much later developmental regression with onset of autism following normal development to 24 months or beyond (childhood disintegrative disorder) is rare (7-8%) and is
associated with greater regression of all functions. (Volkmar 1994). More extensive neurological investigation may be warranted in this subgroup.

The corollary is that among services for children with epilepsy a significant number of children will need assessment and comprehensive services for ASD. In early onset (under 2 years of age) severe epilepsy, ASD is particularly common, usually combined with severe cognitive impairment, and often attention and hyperactive symptoms and co-ordination impairments. Services for epilepsy and ASD need integration at training and service levels. Children with ASD who have epilepsy should be investigated and managed according to the usual protocols for epilepsy. Children who have epilepsy and associated developmental disorders need the same general and specific assessments recommended in this report for suggested ASD.

Inborn errors of metabolism: In the Fombonne (1999) review phenylketonuria (PKU) and other inborn errors of metabolism were causes in less than 1% of cases of autism. Conditions considered to be associated with autism are

1. Phenylketonuria currently screened for at birth
2. Tyrosine hydroxylase deficiency which is accompanied by gross neurology
3. Methylmalonic aciduria in which there is acute decompensation
4. Ornithine transcarbamylase, purine and pyrimidine disorders which are non-specific
5. The mucopolysaccharidoses in which there are dysmorphic features
6. Mitochondrial cytopathies with very wide spectrum of presentation
7. Smith’s Lemli-Opitz in which there is dysmorphology.

Practice point: The indications generally for looking for inborn errors of metabolism are mental retardation, encephalopathy, recurrent vomiting and dysmorphic features. Screening for inborn errors in the absence of clinical features which suggest further investigations, cannot be routinely recommended.

Other abnormalities for which there are some available studies:

1. Evidence has been presented for abnormalities of bowel function including increased bowel permeability, antibodies to gluten or the presence or absence of gut permeability in autism. The latter has been found in one study only; antibodies to gluten are not noted to be raised in autism. Evidence for inflammatory bowel disorders (IBD) in autism is still at the investigation/research phase but constipation and variable bowel symptoms are common and one group of researchers have found possible auto-immune complexes (Murch, 2002).
2. Vitamin deficiencies e.g. B12 and yeast overgrowth: evidence for latter is insecure.
4. Excess Indolylacryloylglycine (IAG) in the urine: discussed by Shattock (2001) IAG is said to be increased in the urine of those with autism but it is not clear what the meaning of this is and whether it is specific to autism: further studies needed (Waring, 1993).
5. Research studies of anti neuronal antibodies (for example, antimyelin basic protein) to date have all involved small numbers. The relevance of these findings are difficult to comment on, further research is needed.
6. Lead levels – no new evidence was considered during the NIASA review.

Gillian Baird, Core Group Member
Hilary Cass, Neurodisability Consultant, Great Ormond Street Hospital
**Other assessments**

Suggested occupational therapy assessments suitable for Stage 2/Stage 3 assessments

**Screen with:**
*Movement ABC Checklist* (Henderson and Sugden, 1992), and/or *Developmental Co-ordination Disorders Questionnaire* (Wilson et al, 2000)
*The Sensory Profile* (Ermer and Dunn, 1998; Watling et al, 2000)

Assessment instruments:
*Movement ABC Test* (Henderson and Sugden, 1992)


*A Visual Perceptual/Spatial Assessment* (VM1 and supplementary tests or MAT) (Gardner 1988; Naglieri, 1986; Colorusso and Hammill, 1996; Hammill, Pearson and Voress, 1998)

*Play Assessment and/or School Function Assessment or School Based Assessment of Motor and Process Skills* (Bundy, 1997; Knox, 1997; Ziviani et al, 2001; Filipek et al, 1999; Coster et al, 1999; Fisher, 1995).

* Dido Green, Guy’s Hospital

**Interventions** *(See 4.3)*

**Early interventions for children with ASD** *(See 4.3)*

**Summary**

A detailed literature review was conducted of a range of different treatments for young children with autism. The focus was on therapeutic interventions of a non-medical kind, although reviews of pharmacological, dietary and other physical treatments were also briefly considered.

The findings generally support the view that early educational/behavioural programmes are a good option for young children with ASD but there is little evidence in support of any one specific methodology, or intensity of treatment. Certain pharmacological treatments also seem to be effective, but further research is required to pinpoint which particular medicines work for which particular children, and for which particular types of problem. There was little or no scientific evidence in support of dietary or vitamin treatments, or the use of secretin. Experimental data in support of a variety of other treatments, such as Facilitated Communication, auditory or sensory integration programmes, psychoanalytically based interventions or teaching methods such as the Son Rise programme (Option), Walden or Daily Life Therapy (Higashi) did not exist. Thus, whilst some of these approaches may be helpful for individual children with ASD and their families, there is no evidence to support their wider use. Moreover, in the case of Facilitated Communication there was some evidence to suggest that it should not be used at all.

In the UK, however, approaches to education at all levels are largely eclectic and case study evidence was provided of centre-based education focusing on communication and social interaction skills as

* Numbers correlate to sequence in 4.2.4.3
well as direct skills teaching. There were also home-based programmes, some of which also had a communication focus or behavioural skills based approach. Good models were presented of early intervention based on parent training either following directly on diagnosis (EarlyBird: Shields, 2000; Nottingham Early Years centre: Christie et al, in press) or from the first confirmation of suspicion (Sowter et al, 2001; Sussman, 1999).

Whilst no one approach to treatment can be recommended for all children with autism, evidence from psychological and educational research more generally can be used to indicate the types of strategies that are most likely to be helpful for this group of children. These are summarised below. Recommendations for evaluating new or existing therapies are also presented.

**Current findings**

In the field of autism very many different treatments have been suggested as being able to bring about remarkable improvements, or even cures for children suffering from this condition. Therapies as diverse as swimming with dolphins, being swung around in nets, dosing with evening primrose oil or listening to tapes of filtered sound have all been suggested as effective. However, recent reviews have generally indicated that many of these claims are made in the absence of any scientific data (Howlin, 1997; Rogers, 1996; 1998, New York State Department of Health, 2000). ‘Evidence’ for many of these treatments is based simply on anecdotal reports of successful cases, with little information either on the exact nature of the treatment, or the types of child involved. Rarely is any information presented on the types of children who did not respond.

In the few cases where highly popular interventions have been subject to experimental research, the results have often been far from positive. In the case of Facilitated Communication, for example, extensive experimental studies demonstrate conclusively that this did not result in enhanced independent communication by the children involved (Bebko, Perry and Bryson, 1996). Moreover, because its use has led to unsubstantiated claims of physical or sexual abuse, it is now strongly discouraged (New York State Department of Health, 2000: American Psychological Association, 1994). Auditory integration therapy has also recently been subject to careful analysis, and again the results indicate that the effects are no greater than for placebo conditions (Mudford et al, 2000; Dawson and Watling, 2000).

Whilst dietary and vitamin treatment have their advocates, both amongst professionals (Knivsberg et al, 1995; Reichelt et al, 1991; Shattock et al, 1998) and parents, scientific evidence in support of such interventions is lacking. Anecdotal reports suggest that while these treatments may offer benefits for some children, they are entirely unhelpful for others, and there is no clear criteria for determining which children are likely to show negative or positive effects. It is important to be aware that substantial modifications to a child’s dietary or vitamin intake, without appropriate monitoring can have serious physical consequences. In addition, restricting the diet of a child who already has rigid eating habits can lead to an exacerbation of feeding problems.

Pharmacological treatments are used much more widely in the US than in the UK (Gringras, 2000), and although the quality pharmacological research is generally higher than for many other types of interventions (New York State Health Department Review, 2000) large scale randomised control studies of children with autism are still rare. Gringras (2000), reviewing the use of pharmacological treatments for children with ASD in the UK, concludes that much of the early research in this field has generated false hopes. Fenfluramine, for example, previously widely used in the US, has been virtually withdrawn because of adverse side effects; whilst initial control trials of secretin (Sandler et al, 1999; Chez et al, 2000) indicate no advantages over placebo.
One of the most recent, detailed reviews of therapies currently used for children with autism is that of the New York State Health Department (2000). In a systematic review of interventions currently in use in the US, they concluded that the majority of studies did not even meet the basic requirements of describing the treatments or children involved adequately to allow for replication. Of those that did, fewer still met basic criteria for experimental research. For inclusion in the review single case studies could be included if they involved more than three individuals with ASD, and used a standard single subject research design (multiple baseline, ABA etc.). Group studies were included if they compared a treatment vs a no treatment/different treatment group, if subjects were assigned to treatment in ways that did not lead to bias, and if equivalent methods were used for measuring baseline and outcome in both treatment and controls.

Although this review focused almost exclusively on US based treatments, the overall conclusions reflect the findings of other reviews in this area (e.g. Howlin 1998; Rogers 1996). Thus, in the majority of studies the standard of experimental research was poor and evidence for the effectiveness of any one specific treatment was limited. The programmes that seem to be most widely effective are those involving early behavioural interventions (Lord, 2000; Schreibman, 2000). These may follow strict behavioural lines (e.g. the ABA programmes of Lovaas and colleagues: McEachin, Smith and Lovaas, 1993; Smith, Groen and Wynn, 2000) or they may also incorporate broader developmental and educational strategies (e.g. Harris et al, 1991; Rogers 1998). A number of comparative and review studies now indicate clearly that behavioural approaches generally, particularly those that begin in early childhood, do lead to positive improvements in children with autism, both with regard to behavioural problems, the acquisition of new skills and greater social integration.

Nevertheless, there is no evidence in support of one specific approach, degree of intensity, length of intervention, or home vs school based programmes. There is some indication, however, to suggest that very brief treatments are ineffective, and that programmes involving 20 or so hours per week are likely to result in more enduring gains (Rogers, 1998). The involvement of families in therapy also seems to be crucial for generalisation and maintenance (Howlin and Rutter, 1987). For this reason current intervention programmes have begun to focus specifically on helping parents to foster communicative interactions with their child in the months following diagnosis (Shields, 2000; Sowter et al, 2000; Sussman, 1999).

The way forward

Although few of the more sensational claims for treatment have been substantiated by hard evidence, and there are still no good data to indicate that any one particular treatment is the gold standard for all children with autism, more general findings from psychological and educational research are important in indicating what components of a treatment package are likely to be most effective.

Very early studies of educational programmes for children with ASD (Rutter and Bartak, 1973; Lansing and Schopler, 1976) indicated that structured teaching programmes, focusing on the learning of specific skills, resulted in greater progress, both academically, socially, and behaviourally. The term ‘structure’ refers to the degree to which ambiguity and confusion is removed from the teaching/learning situation. This is done through modifying (often, but not exclusively, through visual means) the physical environment, the instructional medium, time, space and the learning task so that answers to ‘what?’ ‘where?’ ‘when?’ ‘for how long?’ ‘how?’ ‘what next?’ ‘who with?’ questions are all immediately apparent to the child, or can be taught to be so. TEACCH (cf Schopler, 1997) is a prime example of this kind of cued learning, although the principles of TEACCH include other aspects such as individualisation and functionalism.
Many other interventions rely on structured teaching although this may involve various different forms eg discrete trial, one to one teaching; interactive interventions based on music and play methods (e.g Christie et al, 1992; Nind and Hewett, 1994), and, more recently cognitive methods, sometimes involving computer assisted learning, designed to teach specific cognitive skills in an attempt to replace external with internal structures. Although there are no evaluations of such programmes in natural settings over the medium to long term, immediate gains are often apparent.

There is a large body of research on the importance of helping children with autism develop more effective communication skills (both verbal and non-verbal). Supplying children with more efficient ways of communicating their needs can result in a significant decline in behaviour problems, as well as a marked increase in communication more generally (Durand and Carr, 1991). The value of non-verbal strategies for increasing communication skills in more severely impaired children is also well documented (Durand, 1990; Koegel 2000; Prizant et al, 1997).

The importance of a functional approach to problem behaviours, and understanding the role that a fundamental deficits in autism (communication, social understanding, and ritualistic and stereotyped behaviours) may play in causing or maintaining behavioural problems has had a major impact on educational and therapeutic strategies (Dawson and Osterling, 1997).

For nursery and pre-school children, in particular, the value of involving peers as therapist has been demonstrated in a number of studies (Lord, 1995; Wolfberg and Schuler, 1993).

Basic behavioural strategies such as prompting and shaping techniques, backward and forward chaining to develop more complex skills and the systematic breakdown of complex tasks into their component tasks have all been demonstrated to enhance learning (Prizant and Rubin, 1997; Koegel and Koegel, 1995; Anderson and Romanczyk, 1999). Whilst the importance or reinforcement has been demonstrated in numerous studies, it now also appears that naturally occurring reinforces (resulting from successful completion of the tasks itself) are likely to be more effective, and result in greater generalisation than extrinsic reinforcers such as sweets.

Predictability and routine, and consistency of management strategies have also been found to be important elements, both in teaching new skills, and reducing problem behaviours (Koegel and Koegel, 1997).

Finally, whilst there have been no studies directly comparing children who receive very early interventions with those for whom intervention begins later, a number of studies have suggested that if appropriate management strategies are developed early on in the children’s life, this may well prevent the development of secondary behavioural problems subsequently (e.g. Howlin and Rutter 1978; Institute of Medicine, 2001; Stone et al, 2000; Harris and Handleman, 2000). Programmes involving parents of very young children, in which they are helped to understand and communicate more effectively with their child, also suggest that parental self esteem and ability to cope is enhanced by support in these earliest years (Shields, 2000).
Appendix A

General interventions: (see 4.3.1)

Key worker
Person who:
• has specialist knowledge of autistic spectrum disorders
• has dedicated time
• relates to the child and family
• offers liaison
• is able to take an overview
• has the ability to recognise need
• is able to work collaboratively
• is skilled in team working
• recognises that the child is the focus
• is an advocate for the child.

The key worker will be part of the team that is involved with the child and family to:
• ensure follow up support, especially in relation to post-diagnosis issues and behaviour management
• ensure guidelines are in place to enable all people involved with the child to work consistently
• recognise when short breaks are necessary and, if necessary, negotiate this
• help parents prepare for children’s long term needs
• co-ordinate the transition from children’s services to adult services
• co-ordinate service provision and ensure that management plans are followed. (This should include all the child’s needs and interventions.)

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Specific interventions (see 4.3.2)

Family support, therapeutic interventions and information (see 4.3.2.1)

Examples of group training approaches
• EarlyBird
• More than Words
• help!
  A six session information and support programme for parents/care of school age child, young people and adults with ASD. Email: help!@nas.org.uk

Child focused interventions (See 4.3.2.2)

Educational interventions for primary school aged children
Features that are associated with identified good practice in ASD provision are:
• staff knowledgeable about ASD and able to observe and interpret behaviour in the light of that understanding and resources to liaise with specialist advisors (educational psychologists or advisory teachers) as necessary
• flexibility in school arrangements that permit adaptations to meet needs (e.g. individual working space arrangements, time for transitions, management of participation in assemblies, playtimes etc.)

• commitment to the child and recognition that problems are transactional failures from which all must learn and adapt

• explicit and clear rules with flexibility in imposition of sanctions

• recognition of need to ‘escape’ and provision of ‘escape routes’ for child

• a whole school approach involving all staff in contact with the child and a programme of active peer support (‘buddy’ systems, ‘circles of friends’)

• a programme to develop communication regardless of language level and resources to liaise with speech and language therapists to develop a context-based communication programme across the curriculum

• resources to liaise with occupational therapists or physiotherapists as appropriate for advice on the physical management of the learning environment and (where necessary) to provide programmes of posture control and physical development

• commitment to close home/school liaison with regular communication to ensure sharing of information, transfer of skills and consistency of programmes

• structuring of the environment and learning task to enable independent and group learning, using visual forms of instructions in preference to verbal instructions, as needed

• a programme to develop social and emotional understanding, utilising reflection, ‘philosophy for children programmes and social stories and cartoons

• arrangements for asocial learning (e.g. computer assisted learning) to enable access to academic achievement without waiting for the development of the social skills necessary for group learning and social mediation

• specific teaching to control impulses and self-manage behaviour and an approach to difficult behaviour that concentrates on teaching more appropriate behaviour to serve the same function

• emphasis on building on strengths rather than teaching to deficits

• behaviour management systems that do not rely on physical manipulation or restraint.

Recommendation
1 All schools should have whole school ASD awareness training as part of regular supported INSET provision at least once every three years.
2 All specialist provision should have staff with a recognised qualification in autistic spectrum disorders or social and communication disorders (not just short term attendance at courses).
3 All schools should have access to specialist ASD staff (educational psychologist, advisory teachers, speech and language therapists and occupational therapists, as needed) and should be resourced for appropriate liaison with such staff.
4 Specialist schools should have mandatory arrangements for managed integration opportunities with mainstream pupils and all staff in mainstream schools should be resourced to gain from local specialist provision to develop skills and understanding and establish partnerships for shared expertise across settings, especially in relation to shared placement arrangements, integration and inclusion opportunities.

Statements (England and Wales) and Records (Scotland) of special educational needs
A diagnosis of ASD is important in directing a more accurate interpretation of the behaviour of the child and in opening up avenues of appropriate support and education. However, each child remains an individual and careful assessment of needs and strengths (including interests and learning style) is needed to inform individual educational plans. That much is generally accepted and reinforced by this report.
The question remains whether this assessment of needs should be formally identified and legally protected in a statement or record of needs. Paradoxically, this protection is most needed where it is least likely to occur. Thus, in a situation where local professionals are well aware of the needs arising from autistic conditions and services are well adapted to meet this range of needs, the child is most likely to have needs met without a statement or record. It is only where the needs of the child are not recognised by local professionals and services are unable or unwilling to adapt to those needs, that a legal protection may be needed to ensure the child and family gain access to what is required.

Yet even a legal statement or record of ‘entitlement’ cannot in reality always ensure the suitability of local services, change entrenched attitudes or inform and qualify professionals. In the long term, therefore, this report looks forward to a more inclusive system where a full range of local services are ‘autism friendly’ and there is minimal need for such legal protection. In the short and even medium term, however, some legally enforceable record or statement of a child’s needs may well be needed and useful in alerting uninformed professionals of the nature of those needs if the needs are not being appropriately met at School Action or School Action Plus under the SEN Code of Practice.

The NIASA working group does not support the policy of limiting statements or records to a group arbitrarily defined in terms of academic ability as this is likely to discriminate against children with Asperger’s syndrome or ASD without learning difficulties. It is also unacceptable to delay appropriate placement pending the production of a statement or record of needs. Just as appropriate provision and support should not wait for a formal diagnosis, nor should it wait for a formal description of needs. Placement or support may alter as needs are assessed and defined, but the process of identifying needs should occur as part of the educational process, not as an entry requirement.

**Inclusion versus specialist educational provision**

Knowing a child has an autistic spectrum disorder can never give the total picture and does not, of itself, determine the child’s placement. There will always be a range of issues to consider when deciding on the best placement for a particular child and Jordan and Powell (1995) explore some of these in their advice to parents on choosing a school. There has been some research evidence that children with autistic spectrum disorders benefit from contact with normally developing peers and that this contact also benefits their classmates (Strain and Hoyson, 2000).

However, success is only documented in relation to well supported situations, where professionals are trained and mere placement (even with 1 to 1 support of an untrained teaching assistant) does not guarantee true inclusion or the meeting of needs (Jordan and Powell, 1994). There are some good examples of making non-specialist schools of all kinds autism-friendly and there are many initiatives for training support assistants, but the situation is very variable. It is important that local professionals (especially educational psychologists and LEA officers) understand the school and child variables that need to be considered in making a decision on placement. They must also be in a position to inform and support parents in making an informed choice.

There is no guarantee that labelling a provision as ‘autism-specific’ necessarily makes it so or that a local mainstream or general special needs school might not have as much expertise and understanding of ASD (or at least have sufficient, with other significant advantages). Jordan et al (2001) provide a rough guide for professionals on the different factors that might partly determine the degree of specialism versus inclusion best suited to the child at any one time. What is important is that decisions are not irrevocable and there should be greater flexibility in arrangements between
specialist and other schools (whether or not either is independent or maintained) that facilitate (rather than just allow) a range of opportunities for integrated experiences and sharing of staff expertise across settings. The guiding principle of ‘the least restrictive environment’ is a sound one, providing that meeting the individual’s needs (including the basic right to freedom from persecution, stress and distress) is a paramount consideration.

‘ASD-friendly school provision’
As with pre-school provision, there are no single approaches that have been demonstrated to be better than other approaches (Jordan, Jones, and Murray, 1998). Most of the evaluative research on interventions in autism have concentrated on the goal of reducing the child’s autism and on gross measures of development such as IQ (although the latter is as likely to reflect changes in the child’s compliance rather than real IQ change). However, children with ASD also have the same rights and entitlements as other children to a broad and relevant curriculum experience to meet their needs and help them develop their potential. A good school for a child with autism, then, should enable the child to gain access to their entitlement and also enable the child to manage and live with their own autistic ‘symptoms’ to prevent emotional distress and behavioural disturbance. For the young child, or those with additional learning difficulties, the provision will need to be specially adapted to meet the child’s needs.

As the child develops, however, it is the role of education to help the child develop his/her own strategies to manage their ASD and to learn to cope with a world which will not have such specialist adaptations. The art of teaching is to take the child along this route by steps that present challenges just sufficient to facilitate development and learning but not so great that the child is discouraged and frustrated. Some children may never reach a state of full independence, and most, no matter how great their academic skills and achievements, remain vulnerable and in need of some support throughout life. However, to paraphrase a young woman with autism – (Ros Blackburn, personal communication) it is important to have high expectations, as long as they are backed up with appropriate levels of support.

There are no curriculum subjects that of themselves are unsuitable for children with ASD, although there are aspects of many subjects where specific difficulties may arise. For example, teaching reading should not await a child’s ability to relate a story or sequence pictures but should utilise many children with ASD capacity to be hyperlexic to build understanding of language, story structure and even aid speech development. Team games may be particularly problematic but should not automatically be ignored. It may be worth teaching the child systematically on a one to one basis to a level that allows participation so that the child eventually learns through practice, rather than becoming increasingly disabled in this activity through non participation. Children with ASD can be helped to participate in group activities by specific teaching of group cues and by managing the physical environment (i.e. allowing clearly marked personal space, placing the child so that no-one passes behind them) and introducing it by a process of gradual desensitisation.

Rita Jordan and Ann Le Couteur, Core Group Members
Special medical interventions – (see 4.3.2.3)

It is important to distinguish treatments for ASD from treatments aimed at the many associated co-morbid disorders. The latter include disorders that can amplify the ASD, such as epilepsy and depression, as well as numerous symptoms (as varied as sleep disturbance, obsessions and compulsions, attentional disturbance, bowel problems and aggression). However, the distinction is arbitrary and it is a matter of judgement, for example, at which point repetitive self-stimulation becomes self-injury. These symptoms can reflect a variety of problems ranging from communication problems through to physical discomfort and emotional malaise. While a treatment may have the intended, direct effect on the individual, the programme is also likely to affect the person’s environment, their pattern of living and their relationships with other people, any of which may have a much more profound effect on their symptomatology.

There have been a large number of reports suggesting one treatment or another to be very effective only for further and more rigorous studies to have shown the effectiveness of a placebo to be as great - examples are the use of fenfluramine (du-Verglas, Banks, and Guyer, 1988) and secretin (Chez et al, 2000). These forays have taught us the hazards of evaluating a treatment. They have confirmed the extent to which ASD symptomatology changes over time. Not only does it vary from day to day but, as a developmental disorder, it alters with age; change occurring unevenly in a series of spurts, particularly in early childhood, early adolescence and as the person moves into adulthood. A third factor is the ability of an individual to adapt to change, whether shown by the loss of effectiveness of a reward programme or tolerance to a drug.

Some treatments hold some popular favour, such as naltrexone (Campbell, 1996) or an exclusion diet (Knivsberg et al, 1998). At present the level of evidence is such that it is not possible for the NIASA working group to make any definite recommendations either for or against specific therapies. Therefore, should a family determine to try an exclusion diet, this should proceed with appropriate medical and dietician/nutritional support.

ASD is a heterogeneous disorder and it is likely that should a treatment be effective, it would work only for a subset of people and then only for some of their symptoms. Consequently, it is to be expected that the profile of response (including both adverse and desired effects) for a given treatment will vary from person to person: every programme of treatment becoming a therapeutic trial for that individual.

Haloperidol has been the most thoroughly investigated of the neuroleptics and it has been shown to be effective in improving both the core and the associated symptoms of autism. Currently, however, haloperidol is no longer recommended as it has also been shown to be very likely to produce significant adverse effects. This now should seriously restrict its use (Campbell, 1999). Recent reports of newer, atypical neuroleptics, for example risperidone, appear encouraging. Serotonergic drugs, such as fluoxetine, are also being used to treat symptoms such as anxiety. Low dose melatonin has also been used with individuals with significant sleep difficulties.

It usually takes a long time and widespread usage to establish the relative safety and benefits of a drug, particularly in childhood where its effect on maturation must be taken into account. Access to expert advice in paediatric psychopharmacology should be available to the local multi-disciplinary multi-agency team. Unfortunately, at present this is an unusual and specialist area for which the evidential base is limited. There are relatively few psychiatrists or paediatricians with experience in this field.
Practice point
In conclusion there is a place for the use of medication in the management of co-morbidity whether it is epilepsy, depression, behavioural or sleep disturbance and there are a number of reviews of this field (Gringras, 2000; Santosh, 1999).

Tom Berney and Ann Le Couteur, Core Group Members

v. Professional groups: summary of existing ‘minimum standards’ for ASD training (see 4.6.3)

It was recognised by the NIASA Working Group that:
• The existing and planned roles of professional groups may vary in different local population units and regions across the United Kingdom.
• It is the expert skills and clinical judgement of the individuals within the GDA and MAA teams that are important, not necessarily their professional background.
• Core Group members were asked to provide a brief summary of minimum standards for ASD training for their professional group.
• This section is not exhaustive. For example Community and Inpatient Child and Adolescent Mental Health services and other Community Children’s services consist of multi-disciplinary teams that can include clinical nurse specialists, learning disabilities nurses, child psychotherapists, and other therapy specialists. These professional groups were not separately represented on the Core Working Group but the Core Working Group acknowledges the importance of the three levels of specific ASD training for all professionals working directly with children and young people. These three levels of specific ASD training are:
  1. Training in increasing awareness of ASD is needed for all community based staff.
  2. Specific skills in the diagnostic assessment of ASD and related disorders is required for all professionals involved in Stage 2 Multi-Agency Diagnostic Assessment.
  3. Specific skills and enhanced understanding for all professionals involved in the delivery of intervention, education and support services for children with suspected ASD and their families.

Recommendations
The NIASA working group recommend that within a local population area ongoing joint multi-disciplinary/multi-agency training with parents/carers should be encouraged.

Reviews are undertaken by Core Group members unless otherwise stated.

General practitioner training
All undergraduate medical training must include autism spectrum disorders awareness, assessment and diagnosis. Training in the developmental needs of children and autism spectrum disorders experience should be included in the core child health curriculum during GP vocational training. Experience in the use of Parent Evaluation of Developmental Status (PEDS) and an awareness of the principles behind the Checklist for Autism in Toddlers (CHAT) should be considered. At postgraduate level teaching in child health as part of the postgraduate training programme should regularly include autism spectrum disorders. Training materials such as awareness raising videotapes and other training aides can also be included in continuing professional development (CPD) initiatives. Child health surveillance courses should include aspects of social communication.
Appendix A

development including joint attention and early play skills to update and enhance ASD awareness. There is also the need to consider co-morbidity in the field of developmental disorders. General practitioners who provide child health surveillance (CHS) services must attend a CHS course or show appropriate experience (such as the Diploma in Child Health). They should attend regular refresher courses, although this obligation is rarely enforced.

The ASD co-ordinating group, in collaboration with the Primary Care Trust (PCT) and GP tutors should encourage GPs in this obligation. The PCT will also have to ensure that those GPs not providing child health surveillance are sufficiently aware of ASD and the referral pathway.

Jamie Nicholls, Core Group Member

Health visitors and all community nursing staff working with children

For both these groups professional training in normal child development should include training to observe behaviours such as aspects of early social communication, joint attention and early interactive play skills. Graduate training should enhance these observational skills with further specific training in the use of particular behavioural assessment checklists such as the CHAT and PEDS. ASD awareness materials including the use of videotapes can also enhance training opportunities and the dissemination of knowledge.

Jenny Hugman, Core Group Member

Local education funded staff (working directly with children) including pre-school support staff, early educators, SENCOs, teachers, and classroom support staff

All staff should receive ASD awareness training. However, awareness training is not enough for those working specifically with children with an ASD. There is a need to accredit practical experience as part of a modularised training programme. The ability to make detailed informed observations about aspects of a child’s behaviour and functioning is essential to enable education staff to consider each child’s unique mixture of skills and deficits. Acknowledgement of the types of social communication skills children need to access learning should be included in core professional training. There are increasing LEA and Higher Institutions (HI) initiatives for Level 1 training of early educators, teachers and support staff.

The Teacher Training Agency standards – the National Special Educational Needs Specialist Standards (1999) – describe the ‘extension standards’ necessary to work within pupils on the autistic spectrum.

Training enhances the knowledge about specific disorders including autistic spectrum disorders. A number of training courses and programmes provide information about successful educational intervention strategies and approaches for teaching children with autistic spectrum disorders. Details of accredited programmes in ASD available at UK HE institutes are available from the NAS and the Good Autism Practice Journal. These programmes may be accessed by teachers, teaching support assistants and school based care workers as well as other local authority and health care and CAMHS staff, as appropriate for their CPD training needs and qualifications. Many LEAs also provide training programmes for staff, some of which are accredited through HE institutes.

Rita Jordan, Core Group Member
**Speech and language therapists (SLTs)**
Undergraduate training must include awareness of the early diagnostic pointers in relation to social communication, in order to differentiate between ASD and developmental language delay and disorder. Early diagnosis and intervention should be highlighted and students should be given opportunities to support their academic training with placements in a variety of settings including clinics and schools. SLTs are often among the first professionals to encounter young children with ASD because it is their difficulties with language and communication that alert parents to the fact that something may be wrong. It is therefore essential that SLTs working in the community have specific training skills for appropriate assessments and management of children with ASD.

At post graduate level SLTs must access accredited training courses if they want to be considered for specialist autistic spectrum disorders posts. Such courses need to be developed and expanded. Generalist SLTs should make use of the Regional Advisory Network which is provided by specialist SLTs who offer practical information and guidance over a wide range of topics in the field of autism. SLTs working in this field should be affiliated to an ASD special interest group.

It is also recommended that a further level of expertise should be acknowledged by the establishment of Consultant posts within the speech and language therapy profession. These will be for individuals with known expertise in the field of ASD which may include clinical practice, research, writing, teaching and training.

*Maureen Aarons and Tessa Gittens, Core Group Members*

**Chartered clinical psychologists**
In the UK all chartered clinical psychologists must have completed a training course accredited by the British Psychological Society. In addition, in order to work effectively with children with autism and their families, clinical psychologists should have:

- experience of working (under supervision) with children with a range of different disorders. This is necessary in order to experience the breadth of strategies that can be employed with children with very different disorders/developmental levels. Experience of other disorders is also important for developing better awareness of the very specific problems associated with autism
- undergone formal training and supervision in the administration, scoring and interpretation of standardised instruments designed to assess basic cognitive, language, play and self help skills. (See lists)
- experience of different methods for conducting observational assessments of children in home and school settings
- practical training in the use of behaviourial approaches to intervention
- training in and experience of family based approaches
- familiarity with formal diagnostic criteria for childhood disorders generally and Autism Spectrum Disorders in particular
- training in the use of basic screening instruments (e.g. CHAT; ASQ)
- opportunities to observe and take part in multi-disciplinary diagnostic and assessment sessions

*In addition*, for psychologists working in specialised settings for children with developmental disorders, formal training in diagnostic and assessment techniques should be provided (e.g. ADOS and ADI-R training).

*Pat Howlin, Core Group Member*
Educational psychologists

- All educational psychologists (EPs) in England are trained and experienced teachers and will therefore have learnt how to make detailed informal observations of a child’s behaviour and functioning in order to create a profile of a child’s strengths and difficulties. Basic ASD awareness raising should also have been covered in initial teacher training but if it is not, it should be covered in all postgraduate Educational Psychology professional training courses. EP training should include a working knowledge of the ‘alerting signals’ for ASD and specific methods of observation, assessment and intervention to meet the needs of children with an ASD.
- Practising EPs need to ensure they are kept abreast of current thinking and research either by attending continuing professional development (CPD) courses on ASD or through in-house training delivered by specialist colleagues.
- EPs wishing to specialise in ASD should consider further modular courses in ASD.

They should know how to:

- identify the main characteristics of ASD and understand the factors contributing to varied expression in individuals
- assess the value of a range of diagnostic tools and be able to present information to contribute to multi-disciplinary diagnosis and assessment
- understand the barriers to learning and teaching in ASD and have strategies for working with schools and pre-school services in overcoming these
- understand the ontology of behavioural disturbance in ASD and be able to support schools and families in analysing behaviour and developing plans to prevent and manage challenging behaviour
- recognise stress-related behaviours in individuals with ASD and help schools, families and individuals implement strategies to reduce that stress
- understand the effects of ASD on all family members and have ways of helping families deal with and reduce their own stress
- work collaboratively with professionals across the health/social services interface with schools and families in meeting the needs of children with ASD
- evaluate interventions on an authority-wide basis and train staff and parents to make evaluations of their own practice.

Annette English, Core Group Member; Glenys Jones, University of Birmingham, and Jane Leadbetter, West Midlands SEN Regional Partnership

Social workers

Social workers working within child development centres, area offices, CAMHS or children’s disability services should have core training in autism spectrum disorders as part of their career development. No social worker should be allocated to a child with an ASD without having undergone specific autism training and each district should have at least one member of staff for whom autism is a specific interest. Ongoing training in autism spectrum disorders should be an integral part of performance planning.

Christine Lenehan, Council for Disabled Children

Paediatricians and child health doctors

Undergraduates

The curriculum should include specific teaching about autism spectrum disorders, including aetiology as currently understood, diagnostic criteria, functional impact and co-morbidities.
All undergraduates should develop sufficient understanding of ASD that they recognise indicators of undiagnosed ASD, know where to refer for detailed assessment and are sympathetic to the functional challenges which the condition might present.

Knowledge and competence should be assessed as part of the assessment and examination process for medical students.

Paediatric trainees (and therefore consultant paediatricians of all specialties)
All trainees intending to pursue a career in Paediatrics should develop the competence to recognise children with potential ASD and to know how to achieve timely detailed assessment towards appropriate management. ASD is an important part of disability training and developmental paediatrics.

All trainees should develop a sufficient knowledge base about ASD to understand and be sympathetic to the functional consequences and to give basic advice and make appropriate on-referrals.

These competencies should be assessed as part of the Membership of the Royal College of Paediatrics and Child Health (MRCPCH) examination.

Consultants with special responsibility for paediatric neurodisability
The education and training subgroup of the RCPCH Standing Committee on Disability has produced a training pack which defines the competencies expected by the time of Consultant Certificate Specialist Training (CCST) for a paediatrician applying for a consultant post which requires special responsibility for paediatric neurodisability.

It is expected that these clinicians will recognise and be able to contribute to the multi-disciplinary/multi-agency assessments that leads to a possible diagnosis of ASD and a needs based family care plan (FCP), and know how and where to refer those children who present special diagnostic challenges. Competencies will be assessed using tools defined in the training pack.

Each district should have one disability specialist who has the competences for diagnosis of autism trained in using the specially developed frameworks for interview and observation. Such a person would have the competences for diagnosis and management of ASD and co-morbid disorders across their range of learning difficulties, be experienced in assessments, investigations and treatment options.

Gillian Baird, Core Group Member, Karen Whiting, Sunderland Royal Hospital and Dianne Smyth, St Mary’s Hospital

Child and adolescent mental health team members and other staff including clinical nurse specialist and inpatient unit staff, nursery staff, learning disability nurses, psychotherapists and other therapists will require ASD specific training (see comments as part of introductory section in (v) Professional groups – training on p96).

Psychiatrists
Child and adolescent psychiatry and child and adolescent learning disability psychiatry

Level 1 – Basic experience – the knowledge/skills required at MRCPsych level

Level 2 – Basic competence (the level that might be expected from any psychiatrist on appointment as a consultant). The psychiatrist as a member of an MAA team should be:
1 Able to contribute to the diagnosis or exclude the diagnosis of ASD in straightforward cases using standard diagnostic criteria.
2 Also able to recognise and/or diagnose those conditions that are often co-morbid or part of the differential diagnosis (learning disability, ADHD, Tourette syndrome, epilepsy, dyspraxia, mental illness).
3 Able to contribute to the development of a multi-agency intervention plan that includes psychological, educational and social contributions.
4 Know the indications, contraindications and limitations of the use of medication and other interventions. Recommending medication if necessary for co-morbid psychiatric conditions.
5 Able to work psychotherapeutically with the family and to help them to understand and come to terms with their child’s disability.
6 Have an involvement with local support groups.

Level 3 – Specialist competence (the level that might be aimed for within a few years of consultant appointment and those with special responsibility for ASD. The psychiatrists should be:

1 Able to carry out a very full and comprehensive assessment of an individual with ASD (usually as a member of a team) including the more borderline and complex presentations. Training and/or experience of a standardised approach to taking a developmental history and observational assessment (e.g. ADI-R/ADOS, DISCO). A similar level of competence in the diagnosis of those conditions that are often co-morbid or part of the differential diagnosis.
2 Have experience and skills in initiating and leading the use of medication, psychotherapeutic and other interventions in the management of ASD as part of a multi-disciplinary intervention strategy.
3 Show experience and skills in working psychotherapeutically with those families who have found it very difficult to understand or come to terms with their child’s disability.
4 Liaise with and consult providers of services for people with autism spectrum disorders.
5 Be involved in early intervention programmes, parent support groups and other activities supporting and informing families.
6 Have knowledge and ability to advise the Courts concerning the nature of a child’s condition, its relevance to behaviour and the best ways of treating/managing the condition and fostering the child’s development.
7 Able to play a lead role in the development of services – in conjunction with representatives of all relevant professional groups with ASD expertise.
8 Contribute to teaching and research on this topic and in related areas.
9 Have an awareness of other agencies providing ASD services.

Tom Berney and Ann Le Couteur, Core Group Members

vi. Regional and national ASD academic and training networks (June 2002)

Regional and national ASD network

1 Historically there have been very few clinical academic sites in the UK providing clinical and multi-agency training in the diagnosis of ASD. The existing sites provide training in the use of particular semi-structured instruments (namely the DISCO; ADI-R and ADOS); each requires specific training to administer the instrument reliably. The training courses have significant waiting lists (up to 2 years) and provide training for some research and some clinical staff. There has been no national training strategy to support local clinical local area developments.
2 For educational training and interventions, the Special Educational Needs Training Consortium in conjunction with the Autism Monitoring Group (a consortium of Higher Education educational trainers in ASD) has established standards of training and practice, which have been incorporated into the DfES and Teacher Training Agency approved standards for Specialist Training. The Confederation of Service Providers for People with Autism (COSPPA) has developed an induction pack for minimum standards for staff working with individuals with ASD.

3 The Autism Working Group of the DfES and DoH has issued *Good Practice Guidance* for ASD in the form of:

- 01 Guidance on autistic spectrum disorders and
- 02 Pointers to good practice.

These documents are intended to give practical help to those ‘who make provision for children with ASD’. An expanded version is available on-line at www.dfes.gov.uk/sen with examples of good practice from around the UK and from wide consultation.

4 A number of academic and independent institutions provide ASD specific training for parents/carers and professionals in different parts of the UK.

5 Much of the existing successful training in the UK has been developed in non clinical training institutes with a particular emphasis on learning and educational interventions. Distance learning courses provide ASD training for a range of professionals (including clinical and non clinical individuals) working with children with ASD. Call the NAS Information Centre 020 7903 3599 (open 10.00am-2.00pm weekdays) for details of appropriate training courses and programmes, or consult *Good Autism Practice Journal* (contact Publications Secretary, Autism West Midlands, 18 Highfield Road, Birmingham B15 3DU).

6 There is a need to develop a national training strategy and agree appropriate training courses and programmes for the different groups of professionals who need training in ASD awareness, diagnosis and appropriate interventions. There are significant resource and training implications that arise directly as a consequence of the recommendations outlined in this report.

7 The UK training capacity will need to expand to include the development of some new training sites, to fund the infrastructure support necessary to develop training programmes, to coordinate the training and to monitor the quality of the training initiatives.

8 Funding will be required to meet this considerable training agenda. Consideration should be given to joint collaborative funding initiatives involving the statutory authorities and voluntary charitable institutions and organisations.

9 The dangers of failure to ensure high quality for early identification, assessment, diagnosis and intervention, education and support services for children with ASD and their families is both the inevitable distress of unmet need and the inability for affected individuals to achieve their full potential.
Appendix A

One suggested model of UK training

- **A national network** of training centres could provide a co-ordinated response to the growing UK demand for high quality multi-agency training in early identification, accurate case ascertainment and diagnosis in ASD in close collaboration with existing education and training organisations and initiatives.

- The UK clinical and non-clinical training needs and responsibilities should be overseen by a **UK ASD training committee**, with representation from the regional academic clinical centres, existing ASD training institutes, local area ASD co-ordinating groups, and relevant statutory and independent agencies (health, education, social services, voluntary parent and young people organisations).

- Such a training committee should audit current UK ASD training and develop a **UK wide training strategy** to meet the current clinical and non-clinical training needs.

- The resulting training strategy should develop a **network of regional training partnerships** involving existing academic regional clinical centres engaged in ASD collaborative research and training initiatives (using the currently recognised diagnostic assessment tools employed in most multi site research collaborations).

- The next step should be to increase collaboration and cooperation between smaller specialist clinical sites with existing clinical and non-clinical training centres. Some of these specialist clinical sites may be providing diagnostic and intervention services but not have the capacity to provide ASD specific training. Collaboration between existing academic clinical training sites, other clinical and non clinical training sites using innovative training methods for multi-agency training with ASD families (such as distance education, and/or web training) would also increase training capacity.

- A network of mobile training teams supervised by each regional training partnership could provide individualised programmes of multi-agency and multi-disciplinary training appropriate for the differing training needs of local area services.

- Once a national training strategy has been established, the success of local training initiatives should be audited for each regional network and new initiatives evaluated against national examples of best practice.

- Further, as academic progress is made in ASD research, new diagnostic assessment instruments will be required for both clinical and research work. The UK ASD Training committee should co-ordinate both the development of new diagnostic and outcome measures and the dissemination of best practice throughout the UK.

- The UK ASD training committee should oversee training programmes for:

  **Level 1**
  Joint local multi-disciplinary and multi-agency programmes of ASD awareness training on a continuous basis for all professionals working with children in the community and for parents/carers.
Level 2
(a) ASD specific training for all those providing assessment and diagnosis of ASD.
(b) Training for all staff delivering both specific ASD interventions and other interventions for children with ASD (not limited to a single intervention approach).

Level 3
Training in use of ASD specific research diagnostic tools and specific research assessments to evaluate outcome and the changing characteristics of this group of children with long developmental disorders.

Ann Le Couteur, Core Group Chair

vii. Research and evaluation

Much progress has been made over the last forty or so years in the recognition and understanding of autism (Rutter, 2001). In more recent years there has been a greater awareness of the broader spectrum of autism disorders and an increasing interest in early detection and access to early interventions for these disorders.

It is now generally recognised that autism is an organic, neurodevelopmental disorder and that genetic factors play an important role in the aetiology of both autism and the broader autism spectrum. Progress has been made in our understanding of some of the underlying neuropsychological deficits, the biological underpinnings and the genetic findings. A number of recent reviews have focused on particular aspects of research in ASD (MRC, 2001; New York State Department of Health, 1999; Lord et al, 2001). All these reviews have highlighted the importance of high quality research and emphasise the need to build on research strengths; to identify opportunities for multidisciplinary collaborative research; to develop methodologies that answer professionals’ and carers’ concerns and build on existing knowledge.

The MRC Review of Autism Research 2001 was a joint professional/scientific and lay group collaboration undertaken by the Medical Research Council at the request of the UK Department of Health, to review research on the causes and epidemiology of autism. The report concluded with a proposed set of strategic themes to take forward research on ASD. The New York State Review 1999 provided a systematic review of interventions currently in use in the United States and concluded that the standard of experimental research was poor and that further research was required to answer specific questions relevant to the assessment and management of individuals with suspected ASD. In Educating Children with Autism, Lord et al (2001) focused on educational interventions but again concluded that there was a lack of rigorous scientific evaluation studies.

High quality research is essential to the development of evidence based practice that can in turn be incorporated in family care plans. There is evidence of the effectiveness of a range of intervention approaches (in particular behavioural and educational approaches). However, many unanswered questions remain.

The National Autism Plan for Children and the MRC Review have identified a number of UK strengths, which offer opportunities to enhance research capacity and research requirements. There is a need to develop across the UK:
Appendix A

(i) A network of research centres that facilitate lay and service provider participation within researcher-funder partnerships. These partnerships should then develop agreed research priorities. Increased lay participation will inform research priorities and reduce the apparent gulf between scientific research and the unanswered questions that are often the subject of anxiety and speculation amongst the general public.

(ii) A national strategy that strengthens the interface between service delivery and the research groups undertaking high quality ASD research. This would have a number of benefits including the dissemination of research findings to enable the promotion of evidence based practice, the building of closer relationships between relevant research outcomes and the intended beneficiaries; enhance relevant intervention evaluation and effectiveness studies and promote training in appropriately informed assessment and intervention techniques.

Research priorities

I Identification of ASD
Taking into account the complex ethical considerations, there is still a need for further research on early screening for ASD. This should involve the refinement of potential screening tools and investigation of the impact of screening on families and service providers.

II What is autism/ASD?
The definition of ASD is fundamental to all research questions. The development of specific assessment tools for core autism and the broader spectrum of ASD has been a UK strength. In the light of new findings on the prevalence of ASD and the broadening of the diagnostic spectrum, there is a need to re-evaluate and revise existing diagnostic tools and develop new reliable and valid instruments for diagnostic assessment and outcome evaluation studies. Once such diagnostic assessment tools have been developed and appropriately tested there will be an ongoing need to train sufficient numbers of individuals in the reliable use of these tools to meet the manpower requirements for both high quality research and appropriate levels of service delivery. What are the assessment tools required to make a reliable and accurate diagnosis of individuals with differing levels of ability at different stages of development across the life-span?

Further studies are needed to investigate and describe specific phenotypic characteristics of ASD, to ascertain the longer term consequences of particular behavioural characteristics, the diagnostic validity of potential sub-groups and the overlap with other developmental disorders. ASD research registers and specifically targeted cohort studies would allow the formal testing of causal hypotheses and the investigation of possible genetic and environmental influences. Further research is also needed to investigate the impact of diagnosis/diagnoses on carers and the longitudinal significance of early pre-school diagnosis when compared with those individuals who receive a diagnosis at a later age. Population based studies within an epidemiological framework enable the testing of the prevalence of specific symptoms, case definition, natural history, co-morbidity and outcome studies.

III Investigations of related developmental skills and needs
Alongside the diagnosis of ASD, there is the need for specific assessment tools to investigate related skills and needs (e.g. cognition, communication and language, mental health and behaviour, etc.). There is no database to govern decisions about which tests are most suitable for which children of a particular age or level of development. Research is needed to identify the most valid and reliable tests for use with children with ASD of different ages/ability levels, both for the assessment of
general and specific skills. There is also a need for research into the relationship between specific tests and the stability of scores from different tests over time.

**IV How common is ASD?**

A number of recent epidemiological studies have now confirmed that autism spectrum disorders are among the most common developmental disorders of childhood. The UK has strengths in its population-based studies, especially in the use of regional databases. Such databases, when maintained over time, enable longitudinal studies to track any changes in prevalence. Population-based studies within an epidemiological framework enable the testing of the natural history of symptoms of ASD, co-morbidity and outcome studies.

Specifically targeted cohort studies would allow the formal testing of causal hypotheses and the investigation of possible genetic and environmental influences. New epidemiological studies that incorporate genetic data will allow for the fairly rapid further investigation of gene-environment interaction. Such studies will pose challenges not least the need for national/international scientific collaboration.

**V What are the causes of ASD and what investigations should be undertaken?**

In common with most medical conditions, ASD is likely to be a multi-factorial condition or group of conditions. Much scientific progress has been made investigating the genetic susceptibility. The current consensus is that several genes may interact to create the susceptibility to ASD. Genetic studies may identify ASD sub-groups. Further genetically sensitive research designs will inform our understanding of the role of possible environmental risk factors. As yet there are few replicated findings and many unanswered questions in relation to possible physiological and physical abnormalities in individuals with ASD.

*Co-morbid medical conditions, behaviour abnormalities and mental health disorders*

These have increasingly been recognised in association with cases of ASD. The *MRC Review* (2001) has outlined potential research strategies to investigate these associations further. The population-based study of the range of co-morbid disorders in ASD linked to the longitudinal study over time will identify populations at risk for co-morbid psychiatric disorder and the impact on outcome. The identification of predictive factors will inform appropriate levels of assessment and in turn evidence-based clinical practice.

*Medical investigations*

The report of small scale studies on abnormalities of gut function, gut permeability and related abnormal findings such as plasma sulphate, needs to be repeated in large epidemiological based samples with appropriate controls. Is there an increased rate of bowel disorders in children with ASD? What investigations should be undertaken and how should this influence treatment strategies? These and related questions are frequently presented by individual families and their representatives.

The relevance and significance of epileptiform EEG abnormalities in children with ASD at varying developmental ages and at developmental levels also needs further investigation.
Appendix A

Genetic and family studies

Further hypothesis driven studies to investigate rates of disorder amongst relatives of those with ASD, language disorders, developmental co-ordination disorders and related developmental difficulties will inform understanding of the wider ASD phenotype and the development of appropriately targeted specific interventions.

Significant progress has been made in the development of several psychological theories that may help to explain the nature of specific symptoms in ASD. A full psychological understanding of ASD should inform both studies of the neurobiological basis and appropriate intervention approaches for ASD.

Underlying brain behaviour relationships

Further research is needed to explore the links between underlying neurobiological structure and the behavioural consequences of such abnormalities. The understanding of normal and abnormal development of psychological functions will in turn inform intervention strategies i.e. moving from theoretical underpinning to effective evidence based practice. It will also be essential to elucidate brain behaviour mechanisms from molecular genetic findings through to the study of physiological and neuropathological consequences of particular genetic constitutions. It is hoped that this in turn will lead to the development of new informed interventions. Inevitably as described by Rutter (2001) there is a long way from the identification of genes to therapy.

VI What are the most effective interventions in ASD?

There is no good evidence for the use of one particular intervention or therapy over another. The National Autism Plan for Children report provides a guide to current best practice. In determining the agenda for intervention research there should be a focus on approaches that are relevant and appropriate in the UK. The research agenda should not be driven by educational ‘fashions/whims’; legal rulings or topics that are the focus of attention in other countries. Appropriate research strategies can take a variety of different forms from single case designs, multiple baseline case series, case-control studies or randomised controlled trials. In the initial stages of evaluating the potential value of any approach to intervention, single case or small group designs will be required.

However, no design other than a randomised controlled trial can avoid bias resulting from unmeasured confounding factors. It is necessary to develop a framework within which randomised trials can be successfully conducted across several sites/centres in order to develop sufficient power to determine whether any specific approach is superior to others. These studies must include access to educational interventions and all strategies that appear to offer something of potential value to parents.

Other intervention studies that need to be undertaken across research centres to ensure a sufficiently large cohort of affected children include:

(i) The investigation of potentially modifiable environmental risk factors.

(ii) The identification of which components of behavioural and educational intervention programmes are most effective.
(iii) Intervention research also needs to focus on the issue of which treatments work best for which particular children at which stages of development and within which family and social context. It is unrealistic to assume that any one approach will be appropriate for all children regardless of age, ability and family background. Are there individual characteristics that impact on outcome? These questions apply to general and specific interventions for both children, parents and other family members. It is also important to identify appropriate measurable outcome features. Although there has been successful focus on the importance of developing effective social communication skills in children with ASD and on the specific focus of helping parents foster communicative interactions in early development, there is very little information on the views of young people themselves through childhood, adolescence and into early adult life.

(iv) Appropriate strategies to evaluate interventions are needed. These should include medical intervention studies (including psychopharmacological medication), the use of dietary additives as well as the treatment of co-morbid disorders, especially mental health and behavioural disorders.

(v) Evaluation of service provision for families is also required, eg. respite care, behavioural support and joint funding between agencies for children with challenging behaviour who may need more specialist facilities.

VII ASD training and evaluation

The National Autism Plan for Children has highlighted current UK training needs for carers and for professionals across disciplines. This applies both to clinical practice and the training of research teams in the use of appropriate diagnostic assessment tools and to all those staff supporting individuals with ASD and their families in a wide variety of intervention opportunities.

VIII Audit timeframes and targets

The National Autism Plan for Children has identified achievable timeframe and service specification targets. These can be used to audit existing multi-agency services against the templates outlined in the report. Further, the recommendations of this report based on existing research findings and examples of best practice, provide a framework to inform the development of local practice, regional and national networks.

The core group strongly endorses the concluding comments of the MRC Review on Autism research. There is an urgent need to develop national strategies to nurture the research-service interface. This report provides a template for the co-ordination of a number of UK centres working in collaboration to provide professional training for the assessment and diagnosis of ASD for both researchers and clinicians. The funding and resource implications make it imperative that there is a national strategy to establish further partnerships of researchers, funders, service users and their representatives and direct service providers. Such partnerships will enhance scientific understanding, research capacity and the dissemination of new evidence based findings.

The National Service Framework for Children in collaboration with other national initiatives endorse the training and research recommendations outlined in this report.

Ann Le Couteur
Core Group Chair
Appendix B

In Appendix B details of evidence used to inform the recommendations are presented.

i. Presentations on a series of key topics were made to the NIASA working group from a wide range of experts in the field of autistic spectrum disorders. Listed below are the titles of the presentations. Lists of speakers and further details are available on the NAS website www.nas.org.uk

Presentation topics

• Identification: screening and surveillance for autistic spectrum disorders for pre-school and school age children – (9 May 2001)

• Investigations: investigations for children diagnosed with ASD – (5 July 2001)

• Assessment: diagnosis and assessment of ASD at ‘district’ level in the UK – (16 August 2001)

• Interventions: Evaluation of Early Educational Intervention, Continuity of Education and Care provision – (12 October 2001)

• Development of NIASA guidelines: Districts – (31 October 2001)

• Preliminary presentation on the guidelines and their implications (29 January 2002) to invited audience

ii. NIASA survey results

Survey of current practice in Child Health Services 2001

As part of a mapping exercise of existing services, the Working Group wrote to the 313 child development services (286 teams/centres) on the BACCH (British Association of Community Child Health) data base. The 286 child development teams or centres come from 127 different Health Authorities, Health Boards and Health Commissions in England, Scotland Wales and Northern Ireland. Since this survey was undertaken, District and Health Authorities have disappeared in the Health Service reorganisation.

Respondents (individuals, often but not exclusively doctors, are identified on the BACCH database) were asked whether their district had a screening program for ASD, if so which test was used; whether there was a written protocol for referral of suspected ASD; whether there was a multi-disciplinary assessment team for ASD separate from the general developmental assessment, and whether specific diagnostic instruments were used and if so, what they were. Respondents were also asked if CAMH services were an integral part of the child development service, if so, which
professionals were involved; also if regular joint assessments were conducted and if so, for what age groups of children. Many indicated that their services were in active discussion about autism services.

Replies were received from 114/127 Health Authorities, Boards or Commissions, 240/286 teams/centres. (Some respondents described a service covering several districts.) Those who had written protocols sent them.

Results are expressed as a percentage of 240 replies.

1 9% had a primary (total population) screening program for autism, most using the CHAT.
2 40% of services had a multi-disciplinary assessment that was autism specific and separate from their usual CDS assessment (Stage 1).
3 31% had a written protocol for referral of suspected ASD from primary to secondary services and a further 5% had one in preparation. Many district services for ASD organised themselves on an age basis, e.g. concerns in a pre-school child were referred to the CDS/T and school age concerns to CAMHS.
4 14% used ADI or DISCO. The same numbers used ADI as DISCO.
5 38% (91) teams said that CAMHS were integral in the child development service. This was usually through a psychologist, employed by mental health but working in child development. (This does not necessarily represent the number of child development services who have a psychologist as some are employed directly by child health rather than through a mental health trust, however several respondents indicated that although there was establishment for psychology, there were frequently vacant posts and many comments were made about the absence of crucial personnel for comprehensive assessment especially a psychologist.) 6 services only (2.5%) had an educational psychologist working as part of the MD team. In 20% (48 teams) a psychiatrist was regularly involved in the child development service (in 3% a Learning Disability psychiatrist). 35 (14.6%) child health services held joint assessments with CAMHS for children/young people with suspected ASD. 3 services (1%) had a psychotherapist/parent counsellor or nurse therapist. 4 replies commented on the excellence of their liaison although there was no CAMH service incorporated in the child development service.

Gillian Baird, Core Group Member
Appendix B

iii. Background papers and literature review


National Autism Plan for Children


Psychopharmacology Bulletin, 26, pp. 260-266.


Appendix C

Glossary of Terms (in alphabetical order)

**ADHD**  Attention Deficit Hyperactivity Disorder  
**ADL**  Adaptive living skills  
**ADI-R**  Autistic Diagnostic Interview - Revised  
**ADOS**  Autistic Diagnostic Observational Schedule  
**AED**  Anti epileptic drugs  
**APA**  American Psychiatric Association  
**APPGA**  All Party Parliamentary Group  
  Chair: Dr Stephen Ladyman, MP  
**ASD**  Autistic Spectrum Disorder  
**BACCH**  British Association of Community Child Health  
**BCS**  Base Clinical Services  
**BPS**  British Psychological Society  
**CAMHS**  Child and Adolescent Mental Health Service  
**Care manager**  (See 4.3.2.1) A care manager is envisaged as being actively involved in the assessment for provision of services and advocacy for the family (Disability EWG for National Service Framework for children)  
**CARS**  Childhood Autism Rating Scale  
**CAST**  Childhood Asperger’s Syndrome Test  
**CCST**  Consultant Certificate for Specialist Training  
**CDS**  Child Development Service(s)  
**CHAT**  CHecklist for Autism in Toddlers  
**CHS**  Child Health Surveillance  
**CTLD/CLDT**  Community Team for Learning Disabilities  
**CLDS**  Community Learning Disability Services  
**COSPPA**  The Confederation of Service Providers for People with Autism  
**CPD**  Continuing Professional Development  
**CPK**  Creatinine Phosphokinase  
**CT**  Computerised Tomography  
**DISCO**  Diagnostic Interview for Social and Communication Disorders  
**DFES**  Department for Education and Skills  
**DoH**  Department of Health  
**DNA**  Deoxyribonucleic Acid  
**DSM-IV**  Diagnostic and Statistical Manual IV 4th Edition  
  (American Psychiatric Association)  
**EEG**  Electroencephalogram  
**ESES**  Electrical Status Epilepticus during Slow Wave Sleep
Appendix C

<table>
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<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>FCP</td>
<td>Family Care Plan</td>
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<tr>
<td>Fragile X</td>
<td>Fragile X Chromosomal Anomaly</td>
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<tr>
<td>GDA</td>
<td>General developmental assessment</td>
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<tr>
<td>HEI</td>
<td>Higher Education Institute</td>
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<tr>
<td>IAG</td>
<td>Indolylacryloylglycine</td>
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<tr>
<td>IBD</td>
<td>Intestinal Bowel Disorder/Inflammatory Bowel Disease</td>
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<tr>
<td>ICD-10</td>
<td>The ICD-10 Classification of Mental and Behavioural Disorders (See end of glossary) for F84 Pervasive Developments Disorders</td>
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<tr>
<td>IEP</td>
<td>Individual Education Plan</td>
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<tr>
<td>IQ</td>
<td>Intelligence Quotient</td>
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**Key worker** (See 4.3.1)

Person who:
- has specialist knowledge of autistic spectrum disorders
- has dedicated time
- relates to the child and family
- offers liaison
- is able to take an overview
- has the ability to recognise need
- is able to work collaboratively
- is skilled in team working
- recognises that the child is the focus
- is an advocate for the child.

The key worker will be part of the team that is involved with the child and family to:
- ensure follow up support, especially in relation to post-diagnosis issues and behaviour management
- ensure guidelines are in place to enable all people involved with the child to work consistently
- recognise when short breaks are necessary and, if necessary, negotiate this
- help parents prepare for children’s long term needs
- co-ordinate the transition from children’s services to adult services
- co-ordinate service provision and ensure that management plans are followed. (This should include all the child’s needs and interventions.)

*By permission of the Warwickshire Social Development Team (English, 2002)*

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>LAS</td>
<td>Local Autistic Society</td>
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<tr>
<td>LEA</td>
<td>Local Education Authority</td>
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<tr>
<td>LPU</td>
<td>Local Population Unit (or Local Area)</td>
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Refers to the geographical area usually referred to for Health Services provision. The area may or may not be coterminous with Social Services or Education areas. Such Units typically comprise a local population of approximately 55,000 children under sixteen with 4000 births per year. This definition of a local population unit/local area is comparable to the previous health terminology of ‘district’ It is helpful for service
delivery for Health, Education and Social Services to have coterminous boundaries. However, it is often the case that Health Trusts and Primary Care Trusts may work across geographical areas served by more than one local authority.

<table>
<thead>
<tr>
<th>MAA</th>
<th>Multi-Agency Assessment</th>
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<tr>
<td>MD</td>
<td>Multi-Disciplinary</td>
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<tr>
<td>MMR</td>
<td>Measles, Mumps and Rubella Immunisation</td>
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<td>MRC</td>
<td>Medical Research Council</td>
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<tr>
<td>MRI</td>
<td>Magnetic Resonance Imaging</td>
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<td>NAS</td>
<td>National Autistic Society</td>
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<tr>
<td>NSF</td>
<td>National Service Framework</td>
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<td>OCD</td>
<td>Obsessive Compulsive Disorder</td>
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<td>PBS</td>
<td>Positive Behaviour Support Systems</td>
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<td>PCT</td>
<td>Primary Care Trust</td>
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<td>PDD</td>
<td>Pervasive Developmental Disorders</td>
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<td>PDDST</td>
<td>Pervasive Developmental Disorders Screening Test</td>
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<tr>
<td>PECS</td>
<td>Picture Exchange Communication System</td>
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<td>PEDS</td>
<td>Parent Evaluation of Developmental Status</td>
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<td>PEP-R</td>
<td>Psychoeducational Profile Revised</td>
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<td>PKU</td>
<td>Phenylketonuria</td>
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<tr>
<td>RCPCH</td>
<td>Royal College of Paediatrics and Child Health</td>
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<tr>
<td>RCPsych</td>
<td>Royal College of Psychiatrists</td>
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<tr>
<td>SCQ</td>
<td>Social Communication Questionnaire</td>
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<tr>
<td>SEN</td>
<td>Special Educational Needs</td>
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<td>SENCO</td>
<td>Special Educational Needs Co-ordinator</td>
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<tr>
<td>SLT</td>
<td>Speech and Language Therapists</td>
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<tr>
<td>SSRI</td>
<td>Selective Serotonin Reuptake Inhibitors</td>
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<tr>
<td>TEACCH</td>
<td>Treatment and Education of Autistic and Communication Handicapped Children</td>
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<tr>
<td>TS</td>
<td>Tuberous Sclerosis</td>
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<tr>
<td>TTA</td>
<td>Teachers Training Agency</td>
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<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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<tr>
<td>WTE</td>
<td>whole time equivalent</td>
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### ICD-10 DEFINITION (1993)

**F 84 Pervasive developmental disorders**

This group of disorders is characterised by qualitative abnormalities in reciprocal social interactions and in patterns of communication, and by restricted, stereotyped, repetitive repertoire of interests and activities. These qualitative abnormalities are a pervasive feature of the individual’s functioning in all situations, although they may vary in degree. In most cases, development is abnormal from infancy and, with only a few exceptions, the conditions become manifest during the first 5 years of life. It is
usual, but not invariable, for there to be some degree of general cognitive impairment but the disorders are defined in terms of behaviour that is deviant in relation to mental age (whether the individual is retarded or not). There is some disagreement on the subdivision of this overall group of pervasive development disorders.

In some cases the disorders are associated with, and presumably due to, some medical condition, of which infantile spasms, congenital rubella, tuberous sclerosis, cerebral lipidosis, and the fragile X chromosome anomaly are among the most common. However, the disorder should be diagnosed on the basis of the behavioural features, irrespective of the presence or absence of any associated medical conditions; any such associated condition must, nevertheless be separately coded. If mental retardation is present, it is important that it too should be separately coded, under F70 - F79, because it is not a universal feature of the pervasive developmental disorders.

**F84.0 Childhood autism**

A pervasive developmental disorder defined by the presence of abnormal and/or impaired development that is manifest before the age of 3 years, and by the characteristic type of abnormal functioning in all three areas of social interaction, communication, and restricted, repetitive behaviour. The disorder occurs in boys three to four times more often than in girls.

**Diagnostic guidelines**

Usually there is no prior period of unequivocally normal development but, if there is, abnormalities become apparent before the age of 3 years. There are always qualitative impairments in reciprocal social interaction. These take the form of an inadequate appreciation of socio-emotional cues, as shown by a lack of responses to other people’s emotions and/or a lack of modulation of behaviour according to social context; poor use of social signals and a weak integration of social, emotional, and communicative behaviours; and, especially, a lack of socio-emotional reciprocity. Similarly, qualitative impairments in communications are universal. These take the form of a lack of social usage of whatever language skills are present; impairment in make-believe and social imitative play; poor synchrony and lack of reciprocity in conversational interchange; poor flexibility in language expression and a relative lack of creativity and fantasy in thought processes; lack of emotional response to other people’s verbal and nonverbal overtures; impaired use of variations in cadence or emphasis to reflect communicative modulation; and a similar lack of accompanying gesture to provide emphasis or aid meaning in spoken communication.

The condition is also characterised by restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities. These take the form of a tendency to impose rigidity and routine on a wide range of aspects of day-to-day functioning; this usually applies to novel activities as well as to familiar habits and play patterns. In early childhood particularly, there may be specific attachment to unusual, typically non-soft objects. The children may insist on the performance of particular routines in rituals of a non-functional character; there may be stereotyped preoccupations with interests such as dates, routes or timetables; often there are motor stereotypes; a specific interest in non functional elements of objects (such as their smell or feel) is common; and there may be a resistance to changes in routine or in details of the personal environment (such as the movement of ornaments or furniture in the family home).

In addition to these specific diagnostic features, it is frequent for children with autism to show a range of other non specific problems such as fear/phobias, sleeping and eating disturbances, temper tantrums, and aggression. Self-injury (e.g. by wrist-biting) is fairly common, especially when there is
associated severe mental retardation. Most individuals with autism lack spontaneity, initiative, and creativity in the organization of their leisure time and have difficulty applying conceptualisations in decision-making in work (even when the tasks themselves are well within their capacity). The specific manifestation of deficits characteristic of autism change as the children grow older, but the deficits continue into and through adult life with a broadly similar pattern of problems in socialization, communication, and interest patterns. Developmental abnormalities must have been present in the first 3 years for the diagnosis to be made, but the syndrome can be diagnosed in all age groups.

All levels of IQ can occur in association with autism, but there is significant mental retardation in some three-quarters of cases.

Includes: autistic disorder infantile autism infantile psychosis Kanner’s syndrome

**Differential diagnosis.** Apart from the other varieties of pervasive developmental disorder it is important to consider: specific developmental disorder of receptive language (F80.2) with secondary socio-emotional problems; reactive attachment disorder (F94. 1) or disinhibited attachment disorder (F94.2); mental retardation (F70-F79) with some associated emotional/behavioural disorder; schizophrenia (F20.) of unusually early onset; and Rett’s syndrome (F84.2).

**F84.1 Atypical autism**
A pervasive developmental disorder that differs from autism in terms either of age of onset or of failure to fulfil all three sets of diagnostic criteria. Thus, abnormal and/or impaired development becomes manifest for the first time only after age 3 years; and/or there are insufficient demonstrable abnormalities in one or two of the three areas of psychopathology required for the diagnosis of autism (namely, reciprocal social interactions, communication, and restrictive, stereotyped, repetitive behaviour) in spite of characteristic abnormalities in the other area(s). Atypical autism arises most often in profoundly retarded individuals whose very low level of functioning provides little scope for exhibition of the specific deviant behaviours required for the diagnosis of autism; it also occurs in individuals with a severe specific developmental disorder of receptive language. Atypical autism thus constitutes a meaningfully separate condition from autism.

Includes: atypical childhood psychosis mental retardation with autistic features

**F84.2 Rett’s syndrome**
A condition of unknown cause, so far reported only in girls, which has been differentiated on the basis of a characteristic onset, course, and pattern of symptomatology. Typically, apparently normal or near-normal early development is followed by partial or complete loss of acquired hand skills and of speech, together with deceleration in head growth, usually with an onset between 7 and 24 months of age. Hand-wrinking stereotypes, hyperventilation and loss of purposive hand movements are particularly characteristic. Social and play development are arrested in the first 2 or 3 years, but social interest tends to be maintained. During middle childhood, trunk ataxia and apraxia, associated with scoliosis or kyphoscoliosis tend to develop and sometimes there are choreoathetoid movements. Severe mental handicap invariably results. Fits frequently develop during early or middle childhood.
Appendix C

Diagnostic guidelines
In most cases onset is between 7 and 24 months of age. The most characteristic feature is a loss of purposive hand movements and acquired fine motor manipulative skills. This is accompanied by loss, partial loss or lack of development of language; distinctive stereotyped tortuous wringing or ‘hand-washing’ movements, with the arms flexed in front of the chest or chin; stereotypic wetting of the hands with saliva; lack of proper chewing of food; often episodes of hyperventilation; almost always a failure to gain bowel and bladder control; often excessive drooling and protrusion of the tongue; and a loss of social engagement. Typically, the children retain a kind of ‘social smile’, looking at or ‘through’ people but not interact socially with them in early childhood (although social interaction often develops later). The stance and gait tend to become broad-based, the muscles are hypotonic, trunk movements usually become poorly coordinated, and scoliosis or kyphoscoliosis usually develops. Spinal atrophies, with severe motor disability, develop in adolescence or adulthood in about half the cases. Later, rigid spasticity may become manifest, and is usually more pronounced in the lower than in the upper limbs. Epileptic fits, usually involving some type of minor attack, and with an onset generally before the age of 8 years, occur in the majority of cases. In contrast to autism, both deliberate self-injury and complex stereotyped preoccupations or routines are rare.

Differential diagnosis. Initially, Rett’s syndrome is differentiated primarily on the basis of the lack of purposive hand movements, deceleration of head growth, ataxia stereotypic ‘hand-washing’ movements, and lack of proper chewing. The course of the disorder, in terms of progressive motor deterioration, confirms the diagnosis.

F84.3 Other childhood disintegrative disorder
A pervasive developmental disorder (other than Rett’s syndrome) that is defined by a period of normal development before onset, and by a definite loss, over the course of a few months, of previously acquired skills in at least several areas of development, together with the onset of characteristic abnormalities of social, communicative, and behavioural functioning. Often there is a prodromic period of vague illness; the child becomes restive, irritable, anxious, and overactive. This is followed by impoverishment and then loss of speech and language, accompanied by behavioural disintegration. In some cases the loss of skills is persistently progressive (usually when the disorder is associated with a progressive diagnosable neurological condition), but more often the decline over a period of some months is followed by a plateau and then a limited improvement. The prognosis is usually very poor, and most individuals are left with severe mental retardation. There is uncertainty about the extent to which this condition differs from autism. In some cases the disorder can be shown to be due to some associated encephalopathy but the diagnosis should be made on the behavioural features. Any associated neurological condition should be separately coded.

Diagnostic guidelines
Diagnosis is based on an apparently normal development up to the age of at least 2 years followed by a definite loss of previously acquired skills this is accompanied by qualitatively abnormal social functioning. It is usual for there to be a profound regression in, or loss of, language, a regression in the level of play, social skills, and adaptive behaviour, and often a loss of bowel or bladder control, sometimes with a deteriorating motor control. Typically, this is accompanied by a general loss of interest in the environment, by stereotyped, repetitive motor mannerism and by an autistic-like impairment of social interaction and communication. In some respects, the syndrome resembles dementia in adult life, but it differs in three key respects there is usually no evidence of any identifiable organic disease or damage (although organic brain dysfunction of some type is usually inferred); the loss of skills may be followed by a degree of recovery and the impairment in
socialization and communication has deviant qualities typical of autism rather than of intellectual decline. For all these reasons the syndrome is included here rather than under F00-F09.

Includes:  
dementia infantilis  
disintegrative psychosis  
Heller’s syndrome  
sybiotic psychosis

Excludes:  
acquired aphasia with epilepsy (F80.3)  
elective mutism (F94.0)  
Rett’s syndrome (F84.2)  
schizophrenia (F20.-)

F84.4 Overactive disorder associated with mental retardation and stereotyped movements
This is an ill-defined disorder of uncertain nosological validity. The category is included here because of the evidence that children with moderate to severe mental retardation (IQ below 50) who exhibit major problems in hyperactivity and inattention frequently show stereotyped behaviours; such children tend not to benefit from stimulant drugs (unlike those with an IQ in the normal range) and may exhibit a severe dysphoric reaction (sometimes with psychomotor retardation) when given stimulants; in adolescence the over activity tends to be replaced by under activity (a pattern that is not usual in hyperkinetic children with normal intelligence). It is also common for the syndrome to be associated with a variety of developmental delays, either specific or global.

The extent to which the behavioural pattern is a function of low IQ or of organic brain damage is not known, neither is it clear whether the disorders in children with mild mental retardation who show the hyperkinetic syndrome would be better classified here or under F90.-; at present they are included in F90.

Diagnostic guidelines
Diagnosis depends on the combination of developmentally inappropriate severe over activity, motor stereotypes, and moderate to severe mental retardation; all three must be present for the diagnosis. If the diagnostic criteria for F84.0, F84.1 or F84.2 are met, that condition should be diagnosed instead.

F84.5 Asperger’s syndrome
A disorder of uncertain nosological validity, characterized by the same kind of qualitative abnormalities of reciprocal social interaction that typify autism, together with a restricted, stereotyped, repetitive repertoire of interests and activities. The disorder differs from autism primarily in that there is no general delay or retardation in language or in cognitive development. Most individuals are of normal general intelligence but it is common for them to be markedly clumsy; the condition occurs predominantly in boys (in a ratio of about eight boys to one girl). It seems highly likely that at least some cases represent mild varieties of autism, but it is uncertain whether or not that is so for all. There is a strong tendency for the abnormalities to persist into adolescence and adult life and it seems that they represent individual characteristics that are not greatly affected by environmental influences. Psychotic episodes occasionally occur in early adult life.

Diagnostic guidelines
Diagnosis is based on the combination of a lack of any clinically significant general delay in language or cognitive development plus, as with autism, the presence of qualitative deficiencies in
Appendix C

reciprocal social interaction and restricted, repetitive, stereotyped patterns of behaviour, interests, and activities. There may or may not be problems in communication similar to those associated with autism, but significant language retardation would rule out the diagnosis.

Includes: autistic psychopathy
          schizoid disorder of childhood
Excludes: anankastic personality disorder (F60.5)
          attachment disorders of childhood (F94.1, F94.2)
          obsessive compulsive disorder (F42.-)
          schizotypal disorder (F21.-)
          simple schizophrenia (F20.6)

F84.8 Other pervasive developmental disorders

F84.9 Pervasive developmental disorder, unspecified

This is a residual diagnostic category that should be used for disorders which fit the general description for pervasive developmental disorders but in which a lack of adequate information, or contradictory findings, means that the criteria for any of the other F84 codes cannot be met.
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National Autism Plan for Children

‘This report will focus attention on the need to raise standards in childhood disability services as a whole, in health, education and social services. It emphasises once again the enormous potential benefits that result from collaborations between parents and professionals. We hope too that it will stimulate interest in the importance of properly funded and expertly designed research, which will enable us to understand more clearly what can and cannot be achieved for children with disabilities.’

Dr Sue Bailey
Chair of Child and Adolescent Psychiatry Faculty, Royal College of Psychiatrists
Professor David Hall, FRCPCH
President, Royal College of Paediatrics and Child Health

‘On behalf of our faculty, I am pleased to say that we welcome this document…

In our view, the challenges of autism – one of the most socially excluding of all disorders – can hardly be overstated, especially when one considers its lifelong implications. As a specialty which deals with many adults with autism, we are only too aware of the enormous difficulty many individuals and their families experience in receiving help. For this reason, people affected by autism spectrum disorder merit the attention to assessment, diagnosis and intervention in early life that you recommend.’

Professor Gregory O’Brien
Chair, Faculty of Psychiatry of Learning Disability, Royal College of Psychiatrists

‘Having a diagnostic label has helped; without it our son would have been seen as a naughty or disturbed child.’ Parent

‘Although life has been hard for my son, I know that with a little bit of help and support he will make his way in the world. He has enriched my life in so many ways and deserves all the happiness he can get.’ Parent

National Autism Plan for Children

Plan for the identification, assessment, diagnosis and access to early interventions for pre-school and primary school aged children with autism spectrum disorders (ASD)

Produced by NIASA:
National Initiative for Autism: Screening and Assessment

Ann Le Couteur, Chair, Core Working Group
March 2003

Published by The National Autistic Society for NIASA in collaboration with The Royal College of Psychiatrists (RCPsych), The Royal College of Paediatrics and Child Health (RCPCH) and the All Party Parliamentary Group on Autism (APPGA)