PROPOSED GUIDELINES

For Identification; Assessment; Diagnosis and Access to Early Interventions for Pre-School and Primary School Aged Children* with ASDs (ASD)

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

CONTENTS:

5   **Appendices**

*The initiative will not consider the needs of adolescents and the transition to young adult services (see 2.6.5)

1.1   Core Working Group

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1.2 Executive Summary

The production of these guidelines was agreed by the executive committees of the Royal College of Paediatrics and Child Health and the Royal College of Psychiatry. The guidelines are for parents and for all who work with children and were developed by a multi-disciplinary core group of professionals from Health, Education, Social Services and representatives from the voluntary sector and parents.

The guidelines address identification, assessment, diagnosis and access to early interventions for pre-school and school age children with ASDs. It is hoped that they will encourage transparent, efficient diagnostic processes able to meet the needs of children and families that are not prescriptive but demonstrate good practice.

(*indicates key points for clinical audit)

Identification

Autism Spectrum Disorder (ASD) affects at least, 60 per 10,000 children under 8 years, of which 10 to 30 have narrowly-defined autism. In a typical population unit of 55,000 children under sixteen with 4000 births per year, (and this is the number on which resource need has been based in this report) this implies an annual incidence of 24 new cases, though presentation may be at varying ages. This in turn suggests that there would be considerably more than 250 children (under 16 years) with ASD in every such health local area.

Close to 4 per 1000 children have severe learning disability (approximately 200 in a typical local area). Some of these children will have autism or ASD. Approximately an additional 25 per 1000 have moderate learning difficulty and many of these will also have ASD. The numbers of children with ASD who do not have a learning difficulty are harder to estimate. The figure of 20% of children with ASD but without learning difficulty may be an underestimate as higher functioning ASD is increasingly recognised. Learning and psychiatric comorbidities are common. As ASD is a developmental disorder the presentation will vary with age and, in any one individual, vary over time. The characteristics of ASD may be more prominent at some ages than others.

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

A clearer understanding of normal social, behavioural and language development is required among parents, carers and professionals. Existing child developmental surveillance programmes undertaken by primary care teams including health visitors, offer a context within which better detection can occur. It is important to remember that ASD may occur in those with medical conditions such as early epilepsy.

Recommendations evidence graded as (A)-at least one randomised trial;(B)-well conducted but no randomised trial;(C)-expert committee recommendation)

No whole population screening test for autism. (Grade B)

*Training of all involved professionals in 'alerting' signals of possible ASD both pre-school and school age.(Grade C)

*Regular opportunities (at least at 8-12 months, 2 years and 3.5 years) to discuss a child's development with parents as part of 'surveillance' to detect and respond rapidly to any developmental concerns.(Grade C)
*Age of detection/diagnosis of all developmental problems including autism/ASD as a specified disorder to be audited in each population unit.

Assessment (See Recommendation 4.2.1.5 for justification of all proposed timeframes and details)
Currently, access to assessment is not consistent locally or nationally. Parental concern of any developmental problem should trigger referral for assessment and not be put off until the next routine surveillance check.

Assessment should be available locally, or at least within the geographical area equivalent to the local "population unit". It should be timely and delay should be audited (Grade C). While many areas have a Child Development Centre, models vary considerably. Service configuration will be locally appropriate, but should offer all the components of standardised ASDs services. In some it will be the same professionals carrying out Stage 1 and Stage 2. In this situation, and where the diagnosis is clear at Stage1, all the elements of Stage 2 assessment should nevertheless be initiated, since a full picture of the needs of the child and family requires the contribution of all members of the multi-disciplinary multi-agency assessment team.

A three stage assessment framework is recommended, Stages 1 and 2 at local level. Stage 1 is a General Developmental Assessment (GDA) as for any child with a possible developmental problem. It should comprise of the clear identification of concerns; a developmental history; a full examination; and appropriate further tests No evidence exists to recommend routine use of particular autism specific screening tests although some tests may help identify children who need a further Multi-Agency Assessment (MAA). The outcomes of a GDA should include immediate feedback to the family, even where the diagnosis remains unclear. The family should have adequate opportunity to discuss the outcome of the GDA. Plans for appropriate provision should commence at this stage where possible. The Local Education Authority should be notified at this stage if special educational needs are suspected. Both the components and outcomes of the general developmental assessment should be standardised nationally. (Grade C)

Stage 2 of the assessment process is a Multi-Agency Assessment. All children in whom ASDs are suspected should have all the components of a MAA and a named key worker appointed. The central feature of the MAA is that it is undertaken by a multi-agency multi-disciplinary team. The teams' core members should be available within a local area, including an educational specialist and an ASDs family support worker. The assessment should be completed and feedback given to the family within 17 weeks from referral to the MAA team. (Grade C)

The multi-agency assessment should be capable of assessing the differential diagnosis of possible ASDs and providing a baseline assessment of skills and difficulties for both the child and the family. We have identified seven components of a complete MAA.
- First, existing information from all settings should be gathered.
- Second, a specific ASDs developmental and family history should be taken. No evidence exists on which to recommend any particular framework, but this history should be taken by an experienced team member with recognised ASDs training. In

some cases it may be useful to use a semi-structured interview such as the Autism Diagnostic Interview (ADI-R) or the Diagnostic Interview for Social and Communication Disorders (DISCO). If the person taking the developmental history is not medically trained, then the medical history and examination should be completed separately.

- Third, focused observations should be taken across more than one setting. This could include tools such as the Autism Diagnostic Observation Schedule. The focus of the assessment of school aged children should include their functioning in an educational setting.
- Fourth, a cognitive assessment should be performed in an appropriate setting by a psychologist (either clinical or educational).
- Fifth, a communication assessment should be made and speech and language competences assessed where needed by a speech and language therapist with ASD training..
- Sixth, an assessment should be made of mental health and behaviour. Comorbid mental health and behaviour problems are common.
- Seventh, a full physical examination should be performed including appropriate medical tests. Choice of tests will depend on each child's clinical presentation but chromosome karyotype and fragile X as only current routine recommendation (Grade B, co-morbid medical conditions such as epilepsy should be sought)

All professional involved in an MAA should be experienced and knowledgeable about ASDs The MAA should lead to specific recommendations. . The process of assessment is ongoing, but this should not prevent the production of a needs based Care Plan. A written report should be produced and discussed with the parents. The key worker should be appropriately involved in these discussions. This should include the Care Plan. Genetic implications should be discussed.

The local area team may need to refer to a Stage 3, tertiary ASDs assessment for several reasons, including a second opinion, diagnostic doubt, complexity and specific advice about treatments or key transition stages. The tertiary service should include access to paediatric neurology. gastroenterology, metabolic medicine and neuro psychiatry with competences in psychological and pharmacological treatments.

Recommendations.(Grade C)

*Agreed written referral pathway for children with suspected ASD both preschool and school age accessible to all professionals and parents. (this may be the same as for all developmental problems)
***ASD coordinating group** for strategic planning of training and service needs/development in all local area representation from all statutory and voluntary services plus users.
*Multi-Agency assessment in all local areas available to families to include psychometric, learning, communication, language and motor competency, behaviour and mental state assessment of the child.
*At least one lead clinician trained in ASD in every local area and the current diagnostic interviews of ADI or DISCO and *one person from each discipline/agency to have expertise in ASD*Timescale of response to referral of 6 weeks, stage I general assessment to plan of action-13 weeks , and completion of Stage 2 MAA with Care Plan after a further 17 weeks. To be audited.
*Key worker for each family with diagnosed ASD.

*Tertiary Assessment available, resourced for second opinion which should include resources for children to be discussed/ professional consultation and training as well as second opinions for parental request , lead in research/ data organisation and analysis.

Interventions (See Recommendation 4.3 for justification and details)
The co-ordinated programme of early intervention should be discussed with the family (with support from key worker) within 6 weeks of the end of the MAA and at regular review appointments. The family should receive information about local parent groups, education and training and information about support services from the family support worker. The child should receive specific ASDs interventions. Pre-school children should have 15 hours per week of appropriate ASDs specific programmes although this does not necessarily imply segregated ASDs provision nor 1:1 working (Grade B). It is recommended that there is a trained professional in ASD in each local area who is capable of setting up a comprehensive home and pre-school based ASD specific intervention program.   Any other conditions identified should be addressed, including liaison with specialist services such as CAMH services and learning disability services.

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

ASDs are developmental, the child's and family's needs will change over time. Professionals need to maintain family contact over time through a suitable team member. More intensive work using a variety of professionals may be needed at different moments in time.
Recommendations (Grade C unless otherwise specified)
*Coordinated care plan within 6 weeks of MAA
*A trained professional in ASD in each local area who is capable of setting up a comprehensive home and pre-school based ASD specific intervention program within 6 weeks of diagnosis.
*The recommendation is for 15 hours per week for each pre-school child.(Grade B)
*Every local area should have an ASD trained teacher with backing resource who can visit any school and advise and set up as needed an appropriate IEP for a pupil with ASD Within 6 weeks.
*Key service identified for follow up and rapid referral to the range of services recognising that needs change over time.
Care Manager recommended for longer term coordination of care plan for all complex situations

Resources (Grade C)
Services for children and young people with ASD require a core investment. For example, in multi-ethnic inner city local area population, diagnostic assessments by the MAA team for sixty children per year might cost approximately £169,0000 annually. Ongoing review, support and intervention, including mental health and learning diasability services, have substantial additional resource consequences. These services should be funded using *joint budgets to ensure good quality coordinated services. In particular the funding of key workers, care managers and professionals for family based behaviour managment help is needed.

A Local Area ASD Co-ordinating Group should be established. Its responsibilities should include strategic planning and producing informed developments; audit and evaluation; local area training, including for carers; academic and training links to inform local practice.

Tertiary services should maintain links with referring services and agree referral procedures. They should be capable of providing specialist diagnostic assessments and interventions.

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

Training (Grade B and C)
Joint multi-agency programmes of ASD continuous awareness training are necessary for all professionals working with children in the community and for parents/carers.

All those providing assessment and diagnosis should undergo regular ASDs specific training.

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

All these 3 levels of ASD training should be developed, evaluated and audited by the Local Area ASD Co-ordinating Group.

2.   Introduction & Context

2.1 History

The NIASA work was commissioned by the Executive committees of the Royal College of Paediatrics and Child Health (RCPCH) and Royal College of Psychiatrists (Faculty of Child and Adolescent Psychiatry).

A framework of approximately 12 months was agreed for the bulk of the work of the core group to be completed prior to the drafting of the report.

The report will initially be presented to the Executive committees of the Royal College of Paediatrics and Child Health (RCPCH) and Royal College of Psychiatrists (Faculty of Child & Adolescent Psychiatry), the National Autistic Society and the All Party Parliamentary Group on Autism.

Once the report is ratified by the two Royal College Executive Committees, each core group member will submit it to their professional organisation with the strong endorsement of the jointly commissioning Royal Colleges.

In response to increased public and professional awareness of ASDs (Howlin & Moore 1997; APPGA 2000; Filipek et al 1999; 2000; NAS 2000; McConachie et al 1998), concern about rates of diagnosis, and increasing demand for specific investigations and service provision (Charman & Baird 2002), the Child Development and Disability Group committee of the Community Paediatrics Group (BACCH) of the Royal College of Paediatrics & Child Health (RCPCH) (with the agreement of the president David Hall) proposed a joint initiative with the support of the National Autistic Society (NAS), All Party Parliamentary Group on Autism (APPGA) and the Royal College of Psychiatrists (Faculty of Child & Adolescent Psychiatry) to convene a representative multidisciplinary, multi agency core group to investigate the current UK perspective. The NAS survey confirmed that many local areas across the UK are reviewing current workloads through audit, needs assessments and multi agency strategic planning. Most initiatives have been conducted within existing resources (NAS 2000).
The NAS and other 'interested parties' were also concerned about the inequalities of so-called 'post code' driven clinical practice (Howlin & Moore,1997; NAS 2000; McConachie et al 1998); that families receive very different services depending on their locality and the knowledge and skills of the professionals involved in any assessments; about length of waiting lists; cost of additional demands on existing services rather than an emphasis on cost effective best practice; clinical governance and other quality initiatives.

The resultant collaborative initiative was charged with the task of recommending proposals for a way forward i.e. transparent, efficient, diagnostic processes able to meet local area needs, that are not prescriptive but demonstrate good practice.

2. 2 Terminology

The term Autism Spectrum Disorders **(ASD)** will be used throughout this report to mean the group of Pervasive Developmental Disorders (PDD) (WHO, 1993; APA 1994) characterised by qualitative abnormalities in reciprocal social interactions and in patterns of communication, and by a 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.

It is now generally recognised that there is a **spectrum of autistic disorders** that includes individuals across the range of severity and intellectual ability- from severely impaired to "high functioning". This latter term may be misleading in that levels of functioning (for example daily living skills) may not be determined by intellectual functioning. For many in this latter group clinical diagnosis may only be made at a much later age.

ASDs are unique in their pattern of deficits and areas of relative strengths. It is not a category within the ICD-10 or DSM-IV classification systems but will be used as a pragmatic 'umbrella term' to reflect the current level of knowledge and degree of certainty of the different syndromes. **Autism** is defined as the prototypical disorder of the group (see Figure 1). Despite the reliance (for diagnostic purposes) on developmental history and direct observation of the qualitative impairments in behaviour, the validity of core autism has been relatively well established and a reliable diagnosis can be made by experienced clinical practitioners at 2 or 3 years of age. However the broadening of inclusion to ASD has resulted inevitably in diagnostic debate about children who appear to show differing degrees of impairment at differing ages (Bishop, in press) and those children who have some impairment in the core features of autism but functional impairments due to another disorder such as Attention Deficit Hyperactivity Disorder (ADHD).

Issues of syndrome boundaries remain the topic of some debate and the nosological validity of the sub categories (such as atypical autism, Asperger's syndrome, Pervasive Developmental Disorder Unspecified etc.) within ICD-10 and DSM-IV remains uncertain (see Appendix for detailed discussion on the Conceptualisation of ASDs and the importance of considering both diagnosis and the identification of special needs when developing guidelines for this client group). Special needs are of course not static. They can vary with a child's strengths, reflect underlying vulnerabilities and diminish in situations where they are well met. Individuals who meet the current diagnostic criteria for the category ASDs/PDD are probably much more common than individuals with a diagnosis of autism. Co-morbid developmental behavioural and medical problems are common and frequently the most important management issue.

The term ASD provides a clearer representation of the continuity between autism and related disorders within the spectrum (Lord et al, 2000) thus acknowledging the importance of the varied manifestation of these core deficits and the need to plan for the assessment, diagnosis and provision of intervention and support services for the much larger number of individuals and their families than might have been previously considered.

DIAGNOSTIC CRITERIA FOR CHILDHOOD AUTISM

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

(1)   Qualitative abnormalities in reciprocal social interaction are manifest in at least two of the following areas:

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

(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;

(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;

(d)   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).

(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

2.3 Prevalence

Prevalence estimates will depend on the age of the children involved and the assessment tools, and ascertainment methods used, and variations across studies will reflect methodological differences. However, according to recent reviews, there appears fairly good agreement that the ASDs affect approximately 60 per 10,000, of which 10-30 per 10,000 children under 8 have narrowly-defined autism (Baird et al 2000; Scott et al 2001; Bertrand et al 2001; Chakrabarti and Fombonne 2001). These estimates confirm that ASDs are far more common than was previously generally recognised (MRC 2001). All local area services will need to plan for these increased levels of demand on already over stretched existing services and consider the impact on current practice of separate service delivery.

2.4 Current UK initiatives

The work of NIASA has been closely linked with other UK initiatives. A number of the core group members are directly involved in these initiatives.

- National Service Framework for Children
- National Screening Committee
- Health for all Children
- Valuing People- DoH white paper on Learning Disabilities
- Autistic Spectrum Disorders: Needs Assessment Report (2001): Public Health Institute of Scotland
- DfES' Special Educational Needs (SEN) Regional Partnerships Report on Autistic Spectrum Disorders - West Midlands SEN Regional Partnership
- DfES Autism Working Group-(Good Practice Guidance to be published shortly)
- British Psychological Services (BPS) Guidelines
- DfES Multi-agency Working Party for children with special needs from birth to Two (2002) Guidance to be issued in Summer 2002 as "Together from the start"
- DfES SEN Programme of Action (1998- 2001) including the SEN and Disability Rights Act (2001) and the revised SEN Code of Practice (2001)
- Standards document Child Development Services, British Association of Community Child Health
- Disability Discrimination Act 1995, as amended by Special Educational Needs and Disability Act 2001
- Human Rights Act 2000
- NHS Clinical Governance framework
- Quality Protects programme
- Assessment Framework for Children in Need
- Best Value initiative
- MRC Review of Autism Research (2001)
- National Screening Programmes and new developments such as the introduction of Universal Newborn Hearing Screening (UNHS)
- Right from the start
- Northern Ireland task force
- Carers and Disabled Children Act 2000
- Royal College of Speech and Language Therapists clinical guidelines
- Excellence for all children (DfEE, 1997)

2.5 Duties and Powers of Statutory Bodies

This guidance reflects the principles contained within the United Nations Convention on the Rights of the Child, ratified by the UK Government in 1991 and the Human Rights Act, 1998. Many agencies have contact with and responsibility for children and young people under a range of legislation:

- **Duties of Local Authorities**
  The Children Act 1989, section 17, sets out the responsibilities of councils to provide services to children in need and their families to safeguard and promote their welfare. Where there is a disabled child the local council has an obligation to assist the family if they need help in bringing up the child. It is the duty of local councils to work in partnership with families to provide those services that will best meet the needs of the children. Schedule Two, Section Two of the Act also imposes duties on local authorities to set up and maintain a register of disabled children and publish service information.

- **The Special Education Needs (SEN) Code of Practice (2001) and the Education Act 1996 (the Act)** apply in general to any "child". The Act and the SEN Code set out local education authorities', schools' and early education settings' duties as regards the special educational needs of pre- school children, including children below the age of two, those of compulsory school age and young people aged 16 – 19 who are registered at a school

- **Duties of Health Authorities and Primary Care Trusts**

- **Carers and Disabled Children's Act** enables parents of disabled children to receive, following assessments, direct payments to purchase care packages.

- **The Government's Policy Agenda**
  Promoting the well being of children to ensure optimal outcomes requires integration at national, regional and local levels. The Government is committed to ending child poverty, tackling social exclusion and promoting the welfare of all children, so that they can thrive and have the opportunity to fulfil their potential as citizens throughout their lives. A number of initiatives and programmes has been introduced to support families and young children and to raise the profile and importance of **early years in child development.** Of particular importance for this age group are initiatives such as Sure Start, Children's Fund, Neighbourhood Nurseries and the Early Excellence Programme.

2.6 Terms of Reference

2.6.1   To review current UK practice on Screening, Identification, Assessment and Interventions of Children with ASDs using:
- existing evidence based practice
- examples of best clinical practice in the UK(see Appendix)
- the advice and experience of the core working group including
- findings from other UK and international reports (available up until December 2001) and a
- literature review

2.6.2   To take note of the National Service Framework and its aims of:
- improving quality
- reducing variation
- setting a plan of a service model that can be delivered locally, underpinned by clinical governance
- establishing performance indicators by which the process can be measured
- supporting partnerships for service implementation addressing those services that 'allow children to start their lives well and grow into healthy adults, ready and able to play a full part in society' and particularly pertain to the 'cross cutting themes' of ' tackling inequalities and access problems;
- supporting children with disabilities and special needs; involving parents and children in choices about care' and 'integration and partnership, including breaking down professional boundaries' (Dept of Health 2001)

2.6.3   To develop a template that will constitute agreed guidelines for the process of identification, assessment and access to appropriate interventions for Pre-school and School-aged children with ASDs in the UK. This will allow families and professionals to know what is agreed as current (2002) best clinical practice irrespective of location across the UK. The intention is to provide potential models of 'good practice' that will encourage the development of multi agency identification, assessment and diagnostic teams' (English 2001)

2.6.4   To acknowledge the needs of a wide variety of different family groupings from diverse cultural and ethic backgrounds

2.6.5   To review and make recommendations for Specialist Tertiary ASDs services and the links that should support locally accessible community local area services

2.6.6   To propose a realistic framework to meet the training needs for professionals   (clinical and research) to implement the recommended guidelines

This work has been commissioned to concentrate on childhood. ASDs are lifespan developmental disorders. However this Initiative will <u>not</u> consider the needs of adolescents, the transition to adult services nor the acknowledged demand for services for young adults.

2.6.7   To propose time frames within which professionals should respond to concerns and complete their assessments. NIASA proposes that all local areas should have developed a local co-ordinating group and set up an MAA by summer 2003 for each stage of Assessment, Development and Implementation of Care Plan

2.7 Who are the guidelines for?

- Parents and parent groups
- Commissioners / purchasers and providers of children's services Education; Health; Social Services; Independent sector
- Local multi agency and multidisciplinary services: Education; Health; Social Services; Independent and voluntary sectors
- Legal and advocacy services
- Charities supporting parents and children
- Paediatricians
- Primary Care Team Members
- Psychiatrists
- Psychologists
- Health Visitors
- Speech and Language Therapists
- Professionals Allied to Medicine (PAMS)
- Social Services staff
- Early years workers
- Teachers
- Special Educational Needs Officers
- School and early education setting Special Educational Needs Co-ordinators (SENCO'S)

3. Key underlying principles for a service for <u>ASDs</u>
(Adapted English 2002)

3.1 General principles

- The implementation of any proposed code of good practice/protocol needs **an environment that accepts and understands autism**. The proposed protocol requires that the awareness of autistic spectrum disorders continues to increase across everyone professionally involved with children/young people with autistic spectrum disorders

- Early response to concerns should facilitate **early identification** of need and **early intervention**

- There should be a **consensus regarding the terminology** used to describe these needs.

- There should be an **ownership of the diagnosis and procedures** by all concerned

- A commitment to multi-agency working **should be acknowledged by budget holders so that there is a commitment to provide the necessary resources. This could be facilitated by joint agency funding**

- ASDs are complex and it should be recognised that there can be an **overlap of developmental disorders and associated co-morbidity**

3.2 Working with families

- **Active family involvement** is essential – there needs to be **high-quality, accurate information for the families** which begins as soon as difficulties are recognised. Provision of information should be seen as a two-way process. It is important that **families are listened to** and their views and the information they provide, are seen as central to the identification/diagnostic process. Support should begin, and should continue throughout the assessment process

- The **identification/diagnosis process needs to be transparent** and written information provided where appropriate

- **Cultural differences should be recognised and acknowledged.** There should be a commitment to meeting the needs of families from all cultural backgrounds, recognising the profound impact that cultural differences may exert for families with a child with an autistic spectrum disorder

- There should be **training for carers (parents and others) following identification** of the child's needs- access to shared training with professionals in the field should lead to a shared understanding of needs and interventions
- The **views of the child should be incorporated where appropriate**. An advocate should be used where necessary

3.3 Service provision

- There should be an **identified multi-disciplinary/multi-agency team** of professionals with **specialist skills** to whom open referral is possible. Teams should be available to assess individuals across the age range. More than one team may operate in the same area depending on the age of the individual being assessed

- Communication between of all services is vital. Ideally there should be a **single referral point** to identification and assessment services. All parties involved should know who the key personnel are and the pathways to referral

- **Service co-ordination** is essential. Children with complex needs usually require child health, mental health and learning disability services. Professional practice and service delivery eligibility criteria should not exclude children from appropriate interventions and resources

- **Ongoing specialist support** is vital for the child and family, teachers, carers and residential workers. This will include any further diagnosis and management of co-morbid learning or behaviour problems which may change over time

- Assessments should always lead to a Care Plan/ Plan of Action. Care pathways should be agreed by all

- Social Services should have a central role in the Care Plan and planning social support for the child and family. If Social Services know the family then they should be involved from the start of the assessment and diagnostic process. If they are not known to Social Services a referral should be made at any point where the need for extra family support is recognised

- Resources should not be contingent on diagnosis but on an identification of need. NIASA is aware of concerns over 'labelling for resources'

- A key person (a key worker) should co-ordinate management of post diagnostic support, across all agencies including the management of transitions. The key worker may come from any professional background depending on family preference and the defined needs of the child

- Managers should ensure that there are adequate resources to ensure high quality services. The identification process should be continually monitored with **clear guidelines** for **quality standards and evaluation**

- Local areas should have a minimum of **one nominated individual** from each discipline involved in child health and development, who is appropriately skilled and experienced, to lead on ASD across **all statutory services**

3.4 Training

- **Specialist professional training** in ASDs for staff involved in the identification of ASDs should take place both **during qualification and post qualification**. In particular an acknowledgement and understanding of the breadth of the spectrum needs to be achieved

- Nominated individuals should have developed their practice, knowledge and awareness of ASDs to such a level that they can appropriately **provide training and consultancy** to colleagues during training and post qualification

- All parents and professionals involved in child health and development should understand how to access training and consultancy within their locality

4. Recommendations

4.1 Identification

> **"**The identification of ASDs requires expertise, experience and time. If the procedure is rushed and the right questions are not asked, the diagnosis can be missed"
>
> Wing (1996)

4.1.1 Early Identification: Whether to Screen for autism spectrum disorders

- Although many parents are aware by 18 months that there is a problem, formal diagnosis of autism has been delayed in the past (Howlin & Moore, 1997). Retrospective surveys have indicated that 60% of parents report that they were the first to suspect a problem, compared with 10% who remembered that it was the Health Visitor and in 7% it was school staff who first acknowledged concern (English & Essex, 2001). Although skilled community staff (such as a knowledgeable health visitor, general practitioner, speech and language therapist, playgroup leader, Special Educational Needs Co-ordinator (SENCO) etc.) can assist parents to the recognition of a problem, many parents comment that the response of professionals to their expressed concerns, can also be inappropriate reassurance or give the impression that the parents' were being ' over anxious'

- Recent studies (Lord et al 1995; Cox et al 1999; Stone et al 1999) show that a valid clinical diagnosis can be made at aged 2-3 years. This is more difficult in both the more able young children and those with significant general developmental delay (e.g. a mental age below one year)

- Awareness of autism is and has been rising (at least in some part thanks to recent wide media coverage) and referrals of children aged 2 years are now common place creating a need for knowledge and training in professionals

- There have been a number of barriers to early diagnosis. These have included failure to recognise symptoms/denial of problem/failure to get referral/waiting time for appointment/inadequately trained staff for diagnosis/ further waiting lists

- Most parents and professionals recognise the benefits of early identification and that effective interventions are those that start early and are properly focused for both child and family (Rogers 1996; Dawson and Osterling 1997; Lord 2000)

- There is also an acknowledged need for genetic counselling in ASDs

- Parents express greater satisfaction when they are offered services as 'early' as possible once concerns have been recognised

- In the UK, the term "screening" is defined as the identification of a previously unrecognised disease or defect by the application of tests, examinations or other procedures that can be applied to a whole population. This process results in the identification, with high sensitivity and specificity, of an 'at risk' group. The National Screening Committee examines whether certain diseases or tests meet the criteria of Wilson and Jungner (1968), Cochrane and Holland (1969). In other countries the term 'screening' can also be the application of a test or other procedure to an 'at risk' population for the purpose of further refining ' risk'. In this report, the latter process will be referred to as **secondary screening**

- Screening tests for developmental problems applied by professionals have limited sensitivity and specificity. It is now accepted that parents are able to recognise developmental problems/delay in their children. Parental questionnaires such as PEDS (Parent Evaluation of

Developmental Status) can be a valuable adjunct to detection of problems and identification of those who have no problems (Glascoe et al 1991)

- Many children with autism may show qualitative impairments and delays in development from birth but this may not necessarily be recognised by either parents or professionals within the first year. Possibly 1/3 will show a regressive pattern often around 21 months (varying from 13-23 months) in which word use is lost, and eye contact and social awareness diminish. (A very few show normal development to 24 months and beyond and then regress,- Volkmar 1999).

- Screening tests developed for total population use for autism are few. One such test is the CHAT (Checklist for Autism in Toddlers) (Baron-Cohen et al, 1992). This was administered by primary care professionals –mainly Health Visitors- at 18-20 months, to 16,000 children. Although there was high specificity, (99%) sensitivity was low (38%). Both high and low functioning children with autism were not detected by this screening test alone.(Baird et al 2000).

- Autism/ASDs is a group of behaviours with qualitative impairments and delays in achieving certain skills. Screening tests that focus on acquisition of developmental skills will be 'developmental age' dependant. Scambler et al (2001) have shown that the CHAT distinguishes autism from developmental delay in referred children aged 29-37 months (mean 33 months) with a non verbal mental age of 17-29 months (mean 23 months).

- On the basis of current evidence, **primary screening** for autism and ASDs by the use of tests applied to the whole population at specific ages **cannot be recommended**. However, qualitative abnormalities suggestive of the core behaviours of ASDs can be detected in preschool and school age children, by parents or trained professionals using an awareness of normal development and the specific developmental impairments noted in research studies in autism and incorporated into checklists such as CHAT.

- The concept of child health surveillance as practised in primary care/child health services in the UK is a process of continuous dialogue between parents and health professionals (initially in the early pre-school period) that mutually informs about the development of a particular child . The aim is early and prompt identification of **any developmental problem.** Currently (Health for All Children,4th Edition in press) no routine **tests** of development are recommended in the preschool years.

- The working party endorses the recommendation that at specific times in each of the preschool years there is a focus on development by a professional (usually a health visitor) with parents/carers i.e. during the first year 8-12 months, 2-3 years and 3-5 years in all children and more frequently if there are concerns.(Health for all children 4th Edition* in press). In particular, attention is drawn to the use of recommended "Alerting signals" (see 4.1.2.9 below).

- ASD may be an important developmental disorder associated with other medical conditions such as early assessment severe epilepsy yet management of the latter may obscure the ASD. Where one

medical/developmental problem exists, especially if the brain is involved, the possibility of another developmental problem needs to be remembered or other behavioural diagnoses

4.1.2   Training Implications

4.1.2.1   **Programmes of continuous awareness training of ASD** should extend from health visitors and primary care doctors to all day care/early years staff/the early education practitioner and school/education related services. The training should include joint multi-agency and carer training and should be co-ordinated and audited by **The Local Area ASD Coordinating Group** (see Recommendation 4.4). Concerns about social communication skills, development, and the behavioural features of ASD and parents' concerns should be recognised as relevant and important aspects of all reviews of a child's developmental progress throughout childhood

4.1.2.2   Each local areas needs to organise and audit, as part of Continuous Professional Development (CPD), programmes to promote increased and continuous awareness of the "alerting signals" for ASDs for community based staff, including all support staff working with children and their families. (see Recommendation 4.6:Training)

4.1.2.3   **The Local Area ASDs Coordinating Group** (see Recommendation 4.4) should review working practice and local area training initiatives with the Regional ASDs Network (see   Recommendation 4.6: Training) and obtain an update each year on information about screening tools, assessment instruments and diagnostic developments. This information should be used to inform local clinical practice

4.1.2.4   Information from studies of the early signs of developmental impairments in autism and ASDs can be used in the training of professionals. Instruments developed for screening such as CHAT are recognised by NIASA (English et al, 2001) as useful training instruments and can help to clarify concerns at the age of 20-24 months (or equivalent mental age)

4.1.2.5   Primary care staff may wish to use a structured form of enquiry (eg. the PEDS (Glascoe et al, 1991) about a child's development with parents. The use of such schemes needs to be audited.

4.1.2.7   For school aged children, when concerns are expressed by parents, primary care staff, school SENCO or other trained members of the school support staff or the educational psychologist, the Social Communication Questionnaire (SCQ) (Rutter et al, 2002), the Childhood Asperger's Syndrome Test (CAST) (Scott et al, 2002), or the Attwood questionnaire (Attwood, 1998) may be useful in identifying the need for a more detailed assessment (see appendix)

4.1.2.8   Although these and other instruments can be used as **secondary screeners** for the purpose of further refining 'at risk' of ASD in children with **any** developmental problem there is limited evidence for the

recommendation of their use at primary care level (Baird et al, 2000, Charman and Baird, 2002)

4.1.2.9. **Alerting signals** of ASDs should be widely appreciated and are also useful for training .purposes.

- In the **first year** of age there are usually no clear discriminating features but parental concerns should be elicited.
- Between **2 and 3 years of age** concerns in the following areas should prompt referral for a **General Development Assessment (GDA) (**Modified from Stone, 1994)
- Communication/delays in language development especially comprehension/unusual use of language/poor response to name, deficient non-verbal communication e.g. lack of pointing and difficulty following a point, failure to smile socially to share enjoyment and respond to the smiling of others
- Social impairments: limitation in, or lack of imitation of, actions e.g. clapping, toys or other objects; showing; limitation in or lack of interest in other children or odd approaches to other children. Minimal recognition or responsiveness to other peoples happiness or distress; limited variety of imaginative play/pretence especially social imagination and play i.e. not joining with others in shared imaginary games, 'in his own world', failure to initiate simple play with others or participate in early social games-preference for solitary play activities; odd relationships with adults (too friendly or ignores)
- Other behaviours: over sensitivity to sound/touch; motor mannerisms; biting/hitting/aggression to peers; oppositional to adults; over liking for sameness/inability to cope with change especially in unstructured setting; repetitive play with toys e.g. lining up objects; turning lights switches on and off regardless of scolding
- The **"absolute indicators for referral"(for a General Developmental Assessment)**
  - ▪ *No babble, pointing or other gesture by 12 months*
  - ▪ *No single words by 18 months (*Rescorla et at, *??) JCPP reference*
  - ▪ *No 2-word spontaneous (non-echoed) phrases by 24 months*
  - ▪ *[1]ANY loss of any language or social skills at ANY age*

  (Modified from Filipek et al 1999; 2000**)**

- **Alerting features in school age children**
  Professional concerns about more able children, or those with Asperger's syndrome/so called "high functioning" ASD individuals, may not develop until they are exposed to the greater social demands of the primary school environment. Indeed, prior to school entry some may have been thought to be well advanced in their development, because of their special interests and precocious vocabulary.
  The following features should alert teachers and others to the possibility of:.
  ASDs
  1. Abnormalities in language development including muteness, odd or inappropriate intonation patterns, persistent echolalia,

reference to self as 'you' or 'she/he' beyond 3 years, unusual vocabulary for child's age/social group

2. Limited use of language for communication and/ or tendency to talk freely only about specific topics
3. Inability to join in with the play of other children or inappropriate attempts at joint play (may manifest as aggressive or disruptive behaviour)
4. Lack of awareness of classroom "norms" (criticising teachers; overt unwillingness to cooperate in classroom activities; inability to appreciate/follow current trends e.g. with regard to other children's dress, style of speech, interests etc.)
5. Easily overwhelmed by social and other stimulation
6. Lack of flexible, cooperative imaginative play/ creativity, although certain imaginary scenarios (e.g. copied from videos or cartoons) may be frequently re-enacted alone
7. Difficulty in organising self in relation to unstructured space (e.g. hugging the perimeter of playgrounds, halls)
8. Inability to cope with change or unstructured situations, even ones that other children enjoy (such as school trips, teachers being away etc)
9. Failure to relate normally to adults (too intense/ no relationship)
10. Showing extreme reactions to invasion of personal space and extreme resistance to being 'hurried'
11. Unusual profile of skills/ deficits (e.g. social and motor skills very poorly developed, whilst general knowledge, reading or vocabulary skills are well above chronological/ mental age)
12. Loss of skills or evidence of odd behaviours

4.2 Assessment

4.2.1   Accessing the local referral pathway

4.2.1.1   **Parental   or   professional   concerns** of   an   ASDs /social/communication/behavioural problem at any age should lead to the implementation of the local referral pathway usually via a member of the primary health care team. School age children may be referred via the primary care team or the school nurse/doctor, or alternatively by the SENCO or educational psychologist as a negotiated direct referral from the school or an early education setting

4.2.1.2   **Access**
Parents should be able to access information easily about whom they can contact with a concern. The advice to wait for a routine check or 'wait and see' should be resisted. Professionals health visitor, early years worker (e.g. in nurseries, family centres toddler groups etc), play group leader, school teacher, SENCO, Educational Psychologist, doctor who have concerns in the absence of parental worries should have the skills and confidence to negotiate sensitively with parents so that concerns can be discussed and action agreed before referral onwards.

4.2.1.3   **Process and location**
In the first instance, referrals for developmental assessment are usually, but not invariably, to the community paediatrician in the child development service. Depending on the size of the local area and service structure, the referral route may be to a locality base or the area-wide Child Development Service or Centre (CDC).

Each area throughout the UK has a child development service, though models of service organisation vary greatly. Some are sited with hospital trusts and most are based in primary care trusts or community health trusts. Child and Adolescent Health Services (CAMHS) also vary greatly in how they are resourced and whether their remit covers learning disability and autism. Many areas of the country now have a child development centre (CDC) serving a child and adolescent population of 50-60,000 under 16 years.

For children over 5 years without a learning disability referral may be co-ordinated through the local CAMH service in some local areas. For children over 5 years with a learning disability, the initial referral may be made to the child learning disability service where there is a defined service, or to the child development service, or the CAMH service depending on local arrangements. At the moment such arrangments lead to a diversity of care pathways for families who receive a different type of service depending on whom they see rather than the problem that is presented. All parents comment on the need for a clear accessible service which assessesses their concerns and diversifies at treatnet not assessment stage.

The local referral pathway for all children should be discussed and agreed by all professionals, written down and reviewed. A leaflet outlining the **local referral pathway** should be available.

4.2.1.4   **What is assessment?**
Assessment is a process usually undertaken by gathering information about the health, education and care needs of a child and family. This results in a diagnosis, an assessment of needs and a plan for action to meet the identified needs. It is a process that should meet the needs of both child and family. It should address three specific aims:

- identify the health needs of the child, based on diagnosis, including consideration of differential diagnosis, establishing aetiology, and provision of genetic advice
- promote understanding and agreement about the potential developmental implications of the condition so that effective educational, behavioural, physical, emotional, social and communication strategies can be put in place to promote development.
- address the needs of the child in the family context such that the family is given confidence to provide for the learning and care needs of their child, whilst feeling that their own needs are being addressed.

For some children, an initial assessment of need may not include a final diagnosis of the cause of disability. Diagnosis usually brings with it information about the reasons for the disability, the possible outcomes and prognosis. It is not always appropriate to offer an immediate diagnosis, either it may not be clear, sometimes parents vary in their stage of recognition of a problem. The diagnosis may also be delayed. Where this occurs, it is important that the uncertainty should be acknowledged and that this should not be a barrier to service provision. Children and families should not have to wait upon definitive diagnosis before getting the support they need. The value of assessment should be gauged by the timeliness and appropriateness of the framework for action that is put in place. This framework should be regularly reviewed.

4.2.1.5 Timeframe for Assessment (Grade C)
Throughout this document, the recommended timeframes have been agreed by the Core Working Group after wide consultation with UK colleagues and close reference to the existing literature.

The **recommendation** is that the first professional personal contact with the parents is **within 6 weeks of the date of referral** and that the time period for the assessment process to action plan (Stage 1) should be completed within **13 weeks**. The **Local ASD Co-ordinating Group** should audit the timeframe and access to the General Development Assessment to avoid delays in families' receiving an initial appointment.

Table 1 (Appendix: Timeframe for Assessment)

? *Where should this be* (The local Population Unit is a geographically defined area usually for Health Services which may or may not be co-terminus with Social Services or Education areas. There is usually a local population of approximately 55,000 children under sixteen with 4000 births per year) This definition of a local population unit is comparable to the preivious health terminology of "district".

(Figure 1 Appendix) Pathways for Referral

4.2.2 Stage 1: General Developmental Assessment (GDA)
This part of the document describes (Good Practice for any emerging developmental concern in any location regardless of the service involved)

4.2.2.1 Identification of concerns
It is important to document the concerns of the parents as well as the referrer and to be aware of any disparity so that it can be dealt with sensitively.

4.2.2.2 **Developmental and Family history**
This documents the child's history, antenatal and perinatal , early health and developmental milestones of the child, family history and functioning.

4.2.2.3 **Paediatric physical and neurodevelopmental examination**
This provides information on the child's current health, including growth, dysmorphism, neurocutaneous markers and neurological signs. A baseline

profile of general development is completed. Many UK Local areas and CDCs use specific instruments for their developmental assessments.

The outcomes of the GDA should include the developmental diagnostic formulation including the differential diagnosis, an assessment of need, a plan of care and a written report for parents, appointment to review the report, notification to education with parental permission if indicated, entry on special needs registry (with parental permission if indication)

4.2.2.4 **Further investigation**
 These may include appropriate further examinations including hearing and vision assessment and laboratory investigations.

4.2.2.5 **Outcomes of GDA and if ASD is suspected**
- This will mean referral for a multidisciplinary/multi-agency assessment (Stage 2: MAA). In some local areas, components of MAA may have been carried out already during the GDA. All children with ASDs should receive all the components of a multi-agency assessment
- Care needs to be taken in introducing the possibility of ASD prior to the diagnostic assessment however where one or more professionals experienced in ASD have assessed a child for GDA at Stage 1, and it is clear that the child has an ASD, it may well be appropriate to discuss the diagnosis with parents at this stage.
- All the core components of ASD-specific assessment and management not yet completed, should then be organised. The management plan for the child should include the same measures as for a child who has gone through the MAA assessment at Stage 2. The MAA team should be informed about the child.

- Plans to provide appropriate support and provision should commence at this stage and should not await the outcome of the ASDs -specific diagnostic assessment. **A named professional** who can act as a **key worker** (see Appendix) should, with the agreement of the family, be appointed **within 4 weeks** of the end of Stage 1 (GDA). This professional should have knowledge of the MAA process. It is expected that for pre-school children this role would usually be taken by the child's health visitor or early educator and for school aged children the SENCO or school nurse. For some children other professionals may be more appropriate

4.2.2.6 The use of **Secondary screening tests for ASD(ie, a test used for a population already at risk for developmental disorders)**
When a child has been seen for a general assessment by a member of the child development team, there may be a concern that an ASD assessment is needed. Currently there is no evidence on which to base recommendations for the use of any particular autism specific screeners in the UK . Some ASD screening tools such as the Social Communication Questionnaire (SCQ) (Rutter et al, 2002), the Pervasive Developmental Disorders Screening Test (PDDST) Seigel (1998), Childhood Asperger's

Syndrome Test (CAST) (Scott et al, 2002) may assist in the identification of those who need an ASD assessment.

: 4.2.3.6

4.2.4 Stage 2: Multi Agency Assessment (MAA)

4.2.4.1 **Who contributes to a Multi Agency Assessment Team?**
MAA: has been used throughout this document (with permission) to emphasise that the team is multi-disciplinary, working in every local area and that the professionals involved must be able to work across existing professional and service boundaries. By working together the Team co-ordinates and determines what forms of assessment are needed, what the goals of the assessment are to be, and clarifies what role different professionals will play. All the essential components of assessment should be provided by the local services within local area.

All members of the Team should have specific ASDs training with at least one member trained in assessment and diagnosis of ASDs using standardised assessment tools such as the Autism Diagnostic Interview – Revised (ADI-R) (Lord, Rutter and Le Couteur 1994) or the Diagnostic Interview for Social and Communication Disorders (DISCO) (Leekam et al 2002).

It is the expert skills and clinical judgment of the individuals involved that is important not necessarily their professional background.
Key roles and personnel include
- Psychological (educational or clinical psychologist)
- Educational (specialist teacher (or early years professional) and/ or educational psychologist
- Linguistic/ communication (Speech and Language therapist)
- Developmental Medical & Psychiatric (Community Paediatrician, Child and Adolescent Psychiatrist) some teams have a child and adolescent psychiatrist and /or a consultant child and adolescent learning disability consultant in the core team.
- ASDs family support worker
- Administrator

(West Midlands Identification Working Party 2001 – see English, 2002)

Social Services should be involved in the care planning and implementation of appropriate early support (Hart, Geldard and Geldard, 2001).

For some children other assessments such as occupational therapy, physiotherapy, dietician and nutrition etc., may also be part of the assessment procedure. All Child Development Centres should include Occupational Therapy, Physiotherapy and Dietician services

4.2.4.2   **Time frame.** The **recommendation** is that the period for the Stage 2 Multi agency ASD Assessment (MAA) assessment to the feedback to the family should be no more than **17 weeks**. Local services should audit access to Stage 2 MAA and timeframe to minimise the risk of delay for concerned families.

See table 1 – Appendix 5.2.3

4.2.4.3.   **Components of Multi Agency Assessment (MAA).** The assessment should provide a differential diagnosis of possible ASDs, exclusion of other recognised disorders of aetiological significance, a baseline assessment of skills and difficulties for both the child and the family; identify any co-morbid conditions and produce information which will lead to the production of a Care Plan.

- **Co-ordination of Existing Information from all Settings** (with parental consent) to avoid repetition for the child and family. Where this is available before the diagnostic interview it should be collated and made available at the time of the appointment. For example children with statements of special educational needs will have already been assessed for this purpose. The LEA will have requested advice from parents, school or early education setting, medical, psychological, social services, and any other advice considered desirable. Similarly for children with Special Educational Needs (SEN) but without a statement, schools and early education settings should have information about the child's needs that will inform the MAA.

- **Specific** ASD **Developmental History**. There is no evidence base for any particular framework for history taking. However a systematic approach to history taking is essential for all children and should include a family genetic history, a lifetime account and a description of the current functioning of the child. Aspects of daily living including motor planning/execution difficulties, sleep patterns; nutritional/feeding difficulties; diet, bowel and bladder function; sensory sensitivities; behaviour and mental state should be included. The headings within the ICD-10 diagnostic guidelines provide a framework for the ASDs specific developmental history. The history should be undertaken by an experienced member of the multidisciplinary team with recognised ASDs training (Recommendation 4.6: Training). Semi-structured interviews such as the ADI-R or DISCO can be used when more information is required for a diagnosis. Training in one of those instruments is valuable (Recommendation 4.6 Training)**.** Where the interviewer is not medically qualified, then the specific medical history and examination must be conducted by a medical practitioner at another time.

- **Focused Observations Taken Across More Than One Setting**,(This could include school, nursery, home setting) using an agreed framework for both informal and specific observational recording are recommended. These observations need to be conducted in a manner that is sensitive to parents' concerns. Children with possible ASDs may perform very differently in different settings. Naturalistic observations will complement the information obtained at the initial appointment at the child

development centre and assist in the understanding of the child's profile of relative strengths and weaknesses. There is no generally agreed evidence-based checklist/framework. An analysis of the child's environment is important when considering influences and factors that might be contributing to the child's behaviour. These observations can provide diagnostic information and help to inform assessment of needs. This information should be obtained from both community and education based staff working with the child and family. For the older school children focused observations will need to be obtained from a broader range of settings, for example: - assessment through teaching (see Appendix). Information may need to be obtained from school and education support staff; specialist community nurses other community mental health workers, social work and respite care staff. Further assessment, focusing on the child's behaviour, daily living skills and level of independence may be aided by checklist or structured interview schedules (such as Vineland Adaptive Behaviour Scale,, Sparrow et al, 1984)

- **Direct Observational Assessments.** A systematic approach to direct observation is recommended to examine communication, social interaction and play skills. Standardised semi-structured assessment tools such as the Autism Diagnostic Observation Schedule (Lord et al, 2000) are available (although training is required and limited in availability)

> *Details of some of the more commonly used specific diagnostic assessments tools and tests used for the assessment of individual pre-school and school aged children are listed in Appendix

Cognitive Assessment (Pre School & School Aged)

> It is essential to establish a baseline assessment of a child's profile of skills and impairments. Although it is sometimes suggested that formal cognitive assessments for this group of children are inappropriate, long-term research studies indicate that if suitable tests are used the findings are both valid and highly reliable, often over many years. Whilst non-standardised observations in naturalistic settings are an important part of the assessment process, these alone may not necessarily reveal the full picture of a child's particular profile of skills and weaknesses. However generally a single test will not be sufficient (Lord and Bailey, in press)

> Although the overall score may be helpful in clarifying the extent of a child's intellectual impairment, it is often the uneven *pattern* of functioning shown by the child in different areas that is more important in determining educational needs. Children's responses during psychometric testing can also provide valuable information on their general learning style; approach to novel and /or challenging stimuli; behaviour and co-operation in one to one structured settings; memory and attentional skills; motivation and determination; and abnormal behaviours such as perseveration, repetition and resistance to change.

> There are many different tests designed for use with pre-school and school age children. However, there is no evidence base on which to determine the most valid tests for children with ASDs of different ages, or cognitive and linguistic levels. All tests have advantages and disadvantages and to some extent choice will depend on the tester's

particular preference, and the nature of the child's difficulties. Tests with a high verbal loading, for example, are of little use for non-verbal children. Similarly, more information may sometimes be obtained from a less well standardised test (such as the Merrill Palmer) in which the contents seem to appeal to children with autism, than from a better standardised test (such as the WPPSI) with less "engaging" tasks.

Care is also needed in deciding on the best setting in order to achieve a successful cognitive assessment. If it is necessary to adopt non-standardised testing strategies (e.g. while following the child around the room) such modifications to recommended procedures should be noted. Assessment should be undertaken by a psychologist (either clinical or educational) with expertise in ASD. Assessments that rely on parent report (such as Vineland Adaptive Behaviour Scale and Griffiths) may sometimes overestimate observed skills but do at least make it possible to obtain a cognitive profile for almost all children.

For some children cognitive assessments may be available from the school based assessments. Any additional investigations should complement existing reports.

Communication, Speech and Language Assessment (Pre School & School Aged) An initial framework of assessment (Aarons and Gittens,1992). to include communication strategies, social interaction, joint attention; learning potential and preferred learning style; readiness to engage, listen and attend; play skills; mental state as well as receptive and expressive competencies is needed. It should be undertaken by a Speech and Language Therapist with ASD training or another professional with explicit training in this field.

The choice of language assessments used will depend on individual factors within the child (see Appendix). These assessments do not provide a comprehensive picture of the child's overall communication skills and the information they provide must be viewed qualitatively together with more informal but semi-structured techniques in order to evaluate a child's social understanding and pragmatic use of language.

School Aged Children The focus of assessment will need to include their functioning in an educational setting. Structured observation periods in both the classroom and the playground are needed to evaluate sitting, looking, listening and turn taking; interest in and focus on classroom activities; general classroom behaviour; participation in class; awareness of others; voice quality and speech difficulty; response to teacher's instructions; spontaneous social communication; behaviour and social interaction in playground.

Other Assessment s- more occupational therapy etc – ALC to check*

Behaviour and Mental Health Assessment. It is important to include a specific mental health assessment of the child's temperamental

characteristics, behavioural profile and mental state to identify psychiatric and neurodevelopmental co-morbidity. In particular, the assessment should consider behavioural and psychiatric symptoms such as anxiety, over activity, impulsivity, conduct/oppositional behavioural difficulties, obsessive compulsive symptoms, vocal and motor tics, mood disturbance etc.

Family Assessment

An assessment of the needs and strengths of all family members –(parents /carers, siblings and the extended family) and psychosocial factors should be undertaken by the key worker in conjunction with the MAA team. A Social Services assessment using the Framework for Assessing Need is necessary to agree any further appropriate interventions and support. This assessment will draw on much of the information gathered throughout the MAA.

Physical Examination - Recommended Assessments in all

- Height, weight and head circumference should be measured and charted in all children. Parental head circumference should be measured if child has a large or small head (Woodhouse et al, 1997, Filipeck et al, 2000). Hearing and Vision should be assessed in all. Questions about eating, bowel and bladder function and sleeping should also be part of the routine history taking. Specific enquiry about epilepsy is needed.
- Physical Examination and Neurological Examination should include skin examination with and without Woods Light particularly in response to clinical indicators such as unusual motor movements any suggestion of regression, fits and significant learning difficulties (Bailey 2002, in press)

Medical Investigations

The working party concluded on the basis of research evidence that medical causes are found only in a very small percentage of children with autism. (Shevell et al, 2001, MRC Review 2001)

Recognised medical conditions are more often associated with a somewhat a- typical clinical picture in those individuals with more severe learning difficulties (Fombonne et al, 1999). Where a neurobiological disorder is postulated, but no cause is yet identified, parents are naturally impatient to investigate. They may be vulnerable to theories and treatments that have little scientific evidence. Thus investigations should take place in an accredited laboratory and the resulting treatments should be evidence based. The Working Party was concerned that families use a variety of laboratories for investigations that frequently lack an evidence base.

Further Assessments recommended for some children

- Chromosome karyotype and specific DNA testing for the Fragile X chromosomal anomaly is recommended where there is evidence of significant language or learning difficulty in addition to ASDs. If these tests are done in children with normal IQ, an audit of the results

should be undertaken. The yield of abnormal results in high functioning children is likely to be low

- Consideration should be given to testing for Rett Syndrome in both males and females with a history of regression and significant learning difficulties. There is expanding literature about the prevalence and variability of the wider Rett phenotype but at this moment no recommendation for routine tesing in autism for MECP2 gene(Kerr, 2002)

- Lead screening is recommended on clinical suspicion of pica and changes of behaviour etc. but not routinely in ASD.

- Full blood count and film particularly looking for iron deficiency anaemia should be done in any situation of dietary concern

- Metabolic investigations. None should be undertaken routinely. It is important to consider the clinical history and presentation to determine which investigations would be appropriate. For example the presence of learning difficulties, fits or an unusual clinical presentation such as recurrent vomiting, presentation with variable levels of consciousness etc. should influence clinical practice

- Creatinine phosphokinase (CPK) should be estimated in boys with learning difficulties, language delay, or delayed walking (i.e. beyond 18 months) in a child who has crawled and in certain situations of motor impairment (e.g. cannot run/get up from the floor easily)

- An EEG is not recommended routinely for all children, but as part of the clinical investigations when considering the differential diagnosis and a possible diagnosis of epilepsy. The NIASA Working party recommends a high level of clinical sensitivity particularly where there are accounts of a possible regression (loss of use of words, social withdrawal) in the second year, or a fluctuating clinical course where skills seem to come and go or other unusual behaviour or movement disorder of variable and fluctuating presence. Although epileptiform EEG's are common in autism with and without regression there is insufficient evidence upon which to base any specific treatment in the absence of clear epilepsy (for which the usual antiepileptic medication would be prescribed). A history suggestive of regression, in a previously normal child after the age of 2 years, requires a detailed assessment and a series of neurological investigations including EEGs. *Fombonne/Tuchman Rapin for EEG results*

- Neuroimaging such as MRI (magnetic resonance imaging) and CT (computerised tomography) is not recommended unless there are specific neurological signs or other indications such as a focus on EEG or consideration of a diagnosis of tuberose sclerosis.

- Thyroid function tests should only be undertaken in children with evidence of significant learning difficulties who were not tested in the neonatal period.

- Although routine investigation of the gastro-intestinal tract is not recommended, an adequate clinical history of bowel function based on standard best paediatric clinical practice with knowledge of normality and abnormality at appropriate ages is recommended. More detailed investigations are recommended in situations of failure to thrive and other clinical indicators of inflammatory bowel disorder (for example

evidence of blood in the stools, ulceration of oral mucous membrane, fever and chronic ill health). Constipation with overflow may need to be specifically enquired for and if present investigated by abdominal examination and/or plain abdominal X-ray

- Referral for occupational therapy and physiotherapy assessment should be available for those children identified on clinical history and physical examination with difficulties in fine and/or gross motor co-ordination

Not Recommended.

- **At** the present time there is no evidence to recommend the routine testing of bowel permeability, blood or urine opioids or peptides, vitamin or trace elements, gut antibodies, sulphate or other metabolic functions. However these recommendations should be regularly reviewed in the light of new research findings.

All these assessments need to be co-ordinated as part of the MAA and completed within a **4-8 week period**. Clinical practice should be regularly audited in all local areas. The **Local ASDs Co-ordinating Group** should review local practice with the Regional ASDs Network (Recommendation 4.5 Tertiary Services)

As always in clinical practice if there is an alteration in a child's behaviour a clinical examination as well as a detailed careful history can be helpful. However it is important to remember other relevant external events may have occurred. Young people with autism are as prone to ordinary accidents and illnesses as others and should not be excluded from the general medical preventive health services including immunisation (Tuffrey & Finlay, 2001) and prompt medical investigations that are available to the rest of the population.

4.2.5.   **End of ASD assessment process**
Assessment is an ongoing process and it is important to recognise that a clear diagnosis may not necessarily be made at the end of the initial assessment process. This should NOT prevent the development of a needs based intervention plan and provision of appropriate support and interventions (see Recommendation 4.3 Interventions). However as soon as a diagnostic formulation has been made this should be shared with the parents. The discussion should involve more than one member of the diagnostic team. The key worker should be appropriately involved in all these discussions. Parents should be offered:

4.2.5.1   An informed discussion about the needs of their child and family which takes into account the impact of a diagnosis of ASDs for their particular child and their individual family circumstances.

Genetic predisposition counselling should be discussed with every family. In idiopathic 'autism' it is known that there is an increased family risk of autism (in particular siblings risk is 5 per 100) and an increased risk for a broader autism phenotype is 20 per 100. This represents a specifically

increased risk compared with the general population risk. (Simonoff, 2000). For those families with more than one affected child there will almost certainly be additional difficulties. Burden of care also noted in 4.2.5.12.

If there is a known medical cause for the autism for example Tuberous sclerosis, or Fragile X chromosomal anomaly, the genetic risks are those of the underlying medical condition

4.2.5.2   A written report of the outcome of the assessment, summary of the discussion and the diagnosis and care plans should be given to the parents. Parents should be encouraged to contribute to the report and in particular to identify any errors of factual content.

4.2.5.3   **Time Frame:** The revised report (dated and signed) should be provided within **17 weeks of the start of the stage 2 MAA**. With the parents' agreement, the revised report should be given to the referrer, the key worker, the General practitioner and health visitor, early education or school staff and the LEA, and/or local professionals working with the child and family

4.2.5.3   As well as receiving a copy of the report, parents should be provided with copies of information leaflets about ASDs, the National Autistic Society (NAS) or local autistic society (LAS) parent and other independent support network and charities such as Contact a Family and written information about **local** multi-agency services
The literature about local interagency networks should include information about, available benefits, (e.g. Disability Living Allowance) education and therapeutic interventions and other resources that families can access. This information should be available in English and other languages as appropriate. It may be developed as a **local booklet** and updated annually by the **Local ASD co-ordinating group**. This should be co-ordinated through the information role of the local authority, usually now developed in partnership with the Children Act register

4.2.5.4   Information should also be given about Local Education Authority provision and SEN procedures. Every LEA has a Parent Partnership service which provides neutral and factual information on all aspects of the SEN framework and local provision. Details of the service in each LEA are set out in the DfES publication *Special Educational Needs (SEN): a guide for parents and carers* (available from DfES Publications 0845 6022260 ref: 800/2001)

4.2.5.5.   **Information** about internet sites, publications; training opportunities; conferences and academic/ research initiatives co-ordinated through Regional networks with local/Region/national/international perspectives should also be available to parents/carers and key worker

4.2.5.6   Information about any further referrals and diagnostic assessments for example to the **Tertiary Service** (see Recommendation 4.5) should be given to parents and key worker if there are diagnostic uncertainties or other complexities influencing the diagnostic process and formulation.

4.2.5.7   Parents should be involved in all discussions concerning further investigations and/or treatments of any identified medical condition and plans for follow-up of the relevant difficulties

4.2.5.8   **Explicit p**lans should be made for the **"next steps"** in the development of a Care Plan. The co-ordination of interventions and supports for the child and the family (this applies for both those children WITH and WITHOUT an agreed diagnosis) should be outlined, with time scales and dates agreed. The early key worker may or may not be the CARE\MANAGER for the plan.Particular consideration may need to be given to the future needs of siblings. This may be addressed through the core assessment carried out by Social Services

4.2.5.9   **The d**ate for next review appointment with named representatives of the MAA team should be confirmed (including a named senior clinician from the 'base service'). For most children the 'base service' will be the Child Development Centre or equivalent). For some older children the community Child and Adolescent Mental Health service or the community child learning disability service may be designated as the 'base service' to provide continuity of clinical information and care. This arrangement should be reviewed/audited by the **local ASD Co-ordinating Group**

4.2.5.10   At **subsequent review appointments** the detailed management plan/Care Plan containing the recommendations for future provision and support should be reviewed

4.2.5.11   Once the initial diagnosis and Care Plan have been established, there should be a **regular review of the Care Plan on at least an annual basis**. Where a child has a statement of special educational needs it is good practice to co-ordinate the review of the Care Plan with the annual review of the statement. This has significant resource and personnel implications for all local areas/ local health communities

4.2.5.12   Continuity of care and access to support throughout childhood is recommended for all children with complex developmental disorders such as ASD and their families. It is important to remember that there may be more than one family member affected with ASD, the broader phenotype or a co-morbid disorder. This will affect the level of burden of care. The key worker should provide ongoing support and inform the named senior clinician at the base clinical service. The child and family may not necessarily meet regularly with this named clinician if the routine management of the child is successfully progressing as identified in the Care Plan

4.2.5.13   It is the responsibility of the senior responsible clinician and the base clinical service to oversee the treatment needs of the child over time and

/or make appropriate referrals as necessary to any relevant specialist service. Particular attention needs to be made to any evidence of general or specific learning disability; any change in clinical state; onset of additional co-morbidity such as epilepsy, bowel dysfunction; psychiatric disorder (such as Attention Deficit Hyperactivity; social phobia, affective disorder, Obsessive Compulsive Disorder, Tourette's (this is not an exhaustive list)); any evidence of regression; newly emerging behavioural or other disorders (including sleep disturbance) and make the necessary adjustments to the Care Plan.

4.2.5.14   Parental permission should be requested to include the child on local. Health and Local Authority Special Needs register and ASD specific registry if appropriate

4.2.5.15   Families should be introduced to other services (including health) as appropriate e.g. **Child and Adolescent Mental Health Services** and/ or **Community Learning Disability Team** or equivalent

4.2.5.16   Resources need to be identified and monitored for each local area. This should be a task for the **local ASDs Co-ordinating Group** in conjuction with Primary Care Trust

4.2.7   **Resource Requirements for Stage 2 MAA *Gillian, should this also go to Appenix*yes the detailed costings but headings should be 1. Joined up working—health, camhs with paeds, ed soc serv**

4.2.8   **2. The secxtion that is noww 4.4 and then 3. Training referring to later section the 4. costs**

Examples of costs for Stage 2 assessments:

4.2.7.1.   Multi-ethnic population inner-city location
This proposal includes costings for the full assessment of 60 children per year, and the provision of a limited package of support for families of children newly diagnosed (i.e. Early Bird or equivalent) and specialist early intervention for children under 5. As noted earlier, these guidelines were not developed for older children with ASD, for school leavers or those making the transition to adult services. A further national initiative should be convened to undertake this work (Appendix).

Inner City Local Area :Health Costs

Estimated cost of diagnostic and early intervention service for children with ASD and their families *(60 new referrals per year)		
ASD Assessment Team	**WTE**	**£)**
Consultant	**0.90**	**65,000**
S&LT	**1.00**	**36,000**
Psychologist	**1.00**	**40,500**
Support Worker Also what type of person is this?	**0.60**	**16,000**
Admin	**0.50**	**10,000**
TOTAL	**3.80**	**167,500**

The support worker can be a family support workereg. Voluntary sector/statutory agencies shaere funding; or disability social worker or special needs HV with ring-fenced time

     * For more detailed workings of costing estimates contact NIASA

4.2.8   Indications for Tertiary Referral (stage 3) (See 4.4 Tertiary Services) move this section

The :Local ASD MAA team may refer to the tertiary service if there is:

- parental request for a second opinion
- persisting doubt about the diagnosis
- complexity of diagnosis, e.g. co-morbidity; family psychopathology
- need for further specialist advice or intervention, e.g. access to expertise in psychopharmacology
- specific need for specialist advice at key transition stages, e.g. secondary transfer.

4.3 Interventions *Gillian still needs some text to justify and reference*

> The label ASDs should not be regarded as a label but as a signpost to point us in the right direction.
>
> (Exley, cited by Jordan 1999)

The concern of all parents is to identify problems, seek a cause and ensure methods to promote their childs' skills and minimise disability. Research in autism shows that specifically targeted interventions as early as possible do show benefits. Pat needs to provide ref. These guidelines provede for the minimum general and specific support and interventions that should be made available in a local area. D

4.3.1 General Interventions-which may be common to all disabilities Once the child's needs have been identified the child and family have a right to a coordinated programme of intervention to support the development of the child and family.   All involved services should contribute to the coordinated Care Plan.   These services include the statutory funded authorities and the voluntary sector.
The **Key worker** (see Appendix) will act as an advocate for the child and family with other services, provide support for the family, access information, co-ordinate clinical reviews and transitional planning, attend meetings and review appointments (if appropriate for the family) (The Key Worker is not specific to ASD and is a model effective for supporting families and coordinating care for all complex needs).

.Services currently involved
- **Health Services** Therapy serices generally through health. work should be co-ordinated within the Care Plan and accessed through Community Child Health,CAMHS and/or CLD teams.

- **Social Services** contact details should be given to families and key worker and advice about **Benefits or signposting to access** local facilities for children including those identified for children with special needs, disability, ASDs
    Family support services, both mainstream and specialist
    Childcare, Respite Services and breaks away from home

- **Local Education Authority** and SEN Parent Partnership Service contact
  details and information about Mainstream provision and support
  ASDs early years and school age provision (main stream based and special)
  Information about SEN Code of Practice

- **Voluntary Sector –**
  Contact details of co-ordinator for local parent support groups, such as local branches of National Autistic Society, local Autistic Societies, Contact a Family or other local independent initiatives should be given to parents/carers and key worker

4.3.2 **Specific Interventions** If an ASD is identified then the co-ordinated programme should be ASD specific. Many parents will have no awareness of the level of ASD training and specialist knowledge available in their local area. Currently this lack of information reduces confidence (English & Essex, 2001)
The key worker acts as the Care manager (see above)

4.3.2.1. **Family support, therapeutic interventions and information**
Family Education, Training, Therapeutic Interventions and Support
Although not all families wish for direct help interventions they should be informed about local training opportunities. This may take the form of a group training approach such as 'More than Words (Sowter et al 2002) (definite diagnosis of ASDs not required); Early Bird and HELP (Shields, 1999; NAS 1999) (diagnosis of autism/ ASDs is required for both these NAS initiatives). Other initiatives might include individual professional/parent led home based training (such as Portage and any available Visiting Teacher programmes).
Immediately after they have received a diagnosis they should receive information about local provision from a professional knowledgeable about the training **within 4 weeks** of the ASDs diagnosis. Very early interventions that assist families to develop appropriate management strategies in the infant/pre school years and increase social-communication skills for the child and family may well prevent the development of secondary behavioural problems. The treatment programmes, for both parents and professionals that seem to be most widely effective at this stage are those that:

- teach an understanding of the role played by the fundamental deficits in autism in causing and maintaining behavioural problems.
- employ a functional approach to problem behaviours
- build on basic behavioural strategies such as prompting and shaping techniques, to develop more complex skills and the systematic breakdown of complex tasks into their component tasks to enhance learning
- use naturally occurring reinforcers (i.e. resulting from the successful completion of the task itself, or using the child's special or obsessive interest)
- make use of visual strategies to emphasise meaning

- use predictability, routine and consistency as important elements in the teaching of new skills and reducing problem behaviours
- offer small group social opportunities for children and their families

Parents/Carers may also require information about other local services to meet their own adult needs e.g. psychiatric support or individual counselling. Such requests should be co-ordinated through the parents own general practitioner.

Local Parent Support Groups
If there are local support groups available then telephone contact or home visit should be offered by local group co-ordinator

4.3.2.2   **Child focused interventions/information**
It was clear to the Working Party that good practice exists already in some areas. **For pre-school children** all local area services should have a trained professional skilled in ASDs who can set up a developmental/communication/social and cognitive Individual Education Plan (IEP) at home/nursery for each child and family within 6 **weeks of diagnosis**

For school children each local area service should have an educational resource /specialist teacher who can visit a child in school **within 6 weeks** of diagnosis. This individual must possess the skills to support autism specific educational needs in a range of settings.

Pre-School Education Opportunities
The educational programmes that have tended to prove most effective for young children with autism are those that:
- take account of the characteristic behavioural patterns of children with autism,
- employ a structured, approach to teaching
- focus on the development of specific skills, and on increasing   social communication and understanding
- foster integration with typically developing peers

The optimum length of such programmes is uncertain but there is some evidence that access to "autism specific" programmes of this kind for around **15 hours a week** with specifically trained staff/ workers (i.e. equivalent to a half -time nursery placement) is likely to result in more enduring gains than much briefer, or non-autism specific forms of intervention. These fifteen hours of specific interventions with an experienced worker could be undertaken either at home or in a nursery. The Working Group is aware that from September 2004, all 3 and 4 year olds will be entitled to government funded nursery/early education placement of 12 ½ hours per week. Fifteen hours of specialist input will have significant training and resource implications for all local areas.

There is a substantial number of studies showing the value of learning amongst one's peers (Lord & Mcgill-Evans (1995); Strain & Hoyson

(2000). However, there is no evidence that placing all children with ASDs in mainstream nursery or school settings, without adequate support and structure will lead to positive gains. Indeed, there is some evidence that it may be detrimental and lead to further social withdrawal.

The strategies employed to enable the child to progress should be recorded within an Individual Educational Plan (IEP) which is kept under regular review. The child's specific programme should be designed to:
- develop more effective communication skills (both verbal and non-verbal). This can result in a significant decline in behaviour problems, as well as a marked increase in communication skills
- enhance social interaction -in this age group *adult directed* access to socially able peers seems to be particularly valuable
- offer direct teaching of communication, social understanding and play skills
- teach daily life skills, including feeding, exercise and toileting

Educational Interventions for School Children
(With and without defined learning disability) The features associated with identified good practice in ASDs are described in Appendix

Once a child has received an ASDs diagnosis all educational and community staff working with that child and family need to develop an awareness of the child's strengths and difficulties. The Care and Individual Educational Plans need to include clear strategies for all staff to use. These plans should be reviewed at least once a year or more frequently as required.

In school, staff should be encouraged to use an Observation Profile format to identify the child's particular areas of need. Whilst there is no evidence on which to base specific recommendations, the "Observation Profile" developed by Cumine, Leach and Stevenson, (1998) provides a good framework for children in mainstream education, whether or not they have additional learning difficulties. When schools are providing advice to the LEA for children who are being assessed for statements of SEN, it would be helpful to include any results from a framework such as an Observation Profile that may have been undertaken. The guidelines of Jordan & Jones (1999) for mainstream children and Jordan (2001) for children who also have severe learning difficulties are also of value.

Recommended

- access to appropriate teaching aids with particular attention to the less structured times within the school/ educational timetable (such as break and lunch times)
- whole school awareness, training and planning for children with ASDsautism spectrum disorders
- planned additional individual and small group social skills opportunities tailored to the needs of the child
- facilitatory learning environments including some form of structured teaching (see Appendix)

- continued emphasis on communication regardless of spoken language ability
- functional and positive support for behaviour
- ongoing liaison between school, parents/ carers and community based professionals to ensure consistency of approaches in home, school and any other environment for the child.

Statements and Records of Special Educational Needs
Recommendations
- Detailed assessment of a child's educational needs should be part of the diagnostic process and the statutory process of drawing up a statement or record. It will involve personnel (including advice from the educational psychologist, teachers, health, social services etc.) knowledgeable about autism and the local services.
- The same professionals should liaise with the provision in which the child is placed (or is seeking a placement) to check the capacity of the placement to meet the child's needs or to make recommendations on adjustments to be made or training to be undertaken.

Inclusion versus Specialist Educational Provision

Recommendation
- Parents should have access to an informed professional (advisory teacher, educational psychologist) who can support them in making an informed choice about placement.
- There should be a range of provision available locally, wherever feasible, but placement recommendations should be based on clear realistic aims
- The principle of 'least restrictive environment' in which the child's needs can be met, should inform the decision on placement.
- Support assistants for children with ASD should receive training in ASDs and have some employment security that enables them to develop their expertise and provide an ongoing resource to the LEA/EA
- The emotional needs and reactions of the child must be considered

4.3.2.3   **'Other treatment' interventions**

- Although there are anecdotal reports suggesting that certain interventions (such as dietary, vitamin or psychopharmacological treatments) may benefit some children, they may be entirely unhelpful for others. For these reasons no definite recommendations can be made about specific therapies. There is also emerging evidence that some therapies previously advocated by professionals and parents are no more effective than a placebo condition, whilst others are now strongly discouraged because of adverse side effects or other risks to the child (see Appendix)

- However, scientific evidence of efficacy assumes a homogeneous population. Since children with ASDs present as a heterogeneous

group it remains possible that treatments that do not have demonstrated effectiveness across the population, may, nevertheless, be highly efficacious in a small sub-set of that population. Thus, if there is some a priori rationale for using a specific treatment with a particular child, this should be carefully monitored. Single subject case designs should be utilised to assess efficacy and monitor side-effects. Future research initiatives should include published summated case studies. These may provide evidence of more general effectiveness and, given sufficient individual detail, might lead to the identification of treatment-sensitive sub-groups

- Parents who wish to explore specific "alternative" therapies for their child should do so with the support and knowledge of their named senior clinician from the base service and their named key worker. Any additional assessments and interventions can then be negotiated with the **local ASD Co-ordinating Group**. The child should remain on the Special Needs register and the annual review of the Care Plan should also continue so that all agencies remain aware of the needs of the child.

- As noted above, there is limited evidence for the effectiveness of any one specific treatment and no one approach to treatment can be recommended for all children with autism. Nevertheless, evidence from psychological and educational research can be used to indicate the types of strategies that are most likely to be helpful for this group of children. The involvement of families/ parents in any therapeutic intervention is crucial. Helping them to develop ways of fostering social- communicative interactions with their child is particularly effective. Teaching parents to understand and communicate more successfully with their child may also enhance parental self-esteem and their ability to cope.

4.3.2.4. **Special Medical Interventions –should be considered as adjunct to the behavioural and educational approaches** of the multi modul treatment and individual Care Plan. It is important to distinguish treatments for autism from treatments aimed at the many behaviours and comorbid disorders that are associated with autism/ASD. There is very little evidence that any treatment alters the core symptomatology (du-Verglas, Banks & Guyer, 1988) (Chez et al., 2000) (such as use of naltrexone (Campbell, 1996) or diet (Knivsberg, Reichelt, Høien, & Nødland, 1998)). However on the other hand, there is a place for the use of medication in the management of comorbidity in its own right, whether it is epilepsy, anxiety, obsessive- compulsive disorder (OCD) depression or (see two recent reviews) to control behavioural disturbance (Gringras, 2000; Santosh & Baird, 1999). Parents and professionals should be advised to avoid excessive claims. There is no data on the short term and long term effects of the use of medication. Some recent reports of promising trials with atypical antipsychotic medication and use of selective serotonin reuptake inhibitors (SSRI) (Lord & Bailey, in press)

4.3.2.5. Additional and on-going problems of behaviours and /or learning with consequent effects for the child and family members are common in ASD. Local area services need to be able to provide both continuity of care and reassessment as situations and concerns arise. The services also need to be able to provide appropriate interventions and liaise with all members of the Multi-Agency group working at home, school and with the child or family separately and together. Specialist CAMHS services (psychiatry, psychology, nursing and social work) with a knowledge of ASD are required in every local area.

4.3.2.6. Respite services also with specific ASD knowledge may be needed. Some children need a 24 hr. placement in an environment that is structured, predictable and supports the optimum function of the child in communication, personal independence and safe leisure skills. Each Local area should know how many children at what ages will have needs of such services and work collaboratively with neighbouring local areas to make such provision. It is possible that timely and more effective early support and appropriate management of children with ASD may reduce the need for full time 24 hr placements of young children.

4.3.2.7.

some children with associated comple xmedical conditions the involvement of tertiary neurology services may be needed both for invetigatiosn and management eg complex epilepsy, cerebral palsy and autism, rare syndromes and particular behavioural phenotypes, gastroenterology.

4.4 Local area ASDs Co-ordinating Group

Most local areas have already co-opted some form of ASDs planning or special interest group in response to the growing awareness of the needs of children with ASD and the level of demand for services in their local area.

The recommendation is that

4.4.1 **Each local area should develop a Co-ordinating Group that will oversee the development of local area ASD services.**

4.4.2 The group will be made up of representatives from local parent and voluntary services and the key services that provide Multi-Agency Assessments, ASD interventions and support services.

4.4.3 Membership should include:
Representatives from **local parent and voluntary** services
Strategic Managers from Health, Education and Social Services
The named senior **clinicians** (or representative for) from the health 'local area base services':
Primary Care Trust Lead
Lead **clinician with special expertise in ASD, * Child Development Centre** and manager of special needs register
Lead clinician with special expertise in, ASD *** Child and Adolescent Mental Health Services (CAMHS)**
Lead clinician with special expertise in, ASDs ***Community Learning Disability Services (CLDS)**

Speech & Language Therapist with ASD expertise
Educational psychologist and/or LEA SEN officer with ASD expertise
Clinical Psychologist with ASD expertise
Specialist teacher with ASD expertise
Representative of therapeutic services (e.g. occupational therapy, music therapy, etc)
Liaison Health Visitor
ASD support worker and/or Social Services representative

*if not the named senior clinician from the base services

4.4.4   The responsibilities of the Group include:
- Liaison with and advice to local commissioning agencies
- Local Area **training** in ASD for all local community groups (the quality of the training should be monitored and/or externally validated)
- Maintenance and supervision of the ASD **database** and special needs register
- **Auditing** effectiveness of local identification, diagnosis and intervention services
- **Co-ordination of service planning** and new developments informed by 'local' clinical need
- Provision of Tertiary clinical services and/ or maintain close links with Regional service for Tertiary clinical needs
- Co-ordination of academic and training links with Regional network to ensure new developments inform local area practice at all levels from community-wide ASD awareness to the specific diagnostic assessment practices employed and the portfolio of intervention expertise required within the area —coordinating training relevant for professionals working at stages 1,2,3.
- The development and planning of specific support/intervention services within both specialist and mainstream settings on a local or regional basis

4

4.5 Tertiary Services should the whole of tertiary go herer
- Each local area will have links with a Specialist Tertiary ASD team. In some local areas the Tertiary service may include members of/ or comprise the local Stage 2 MAA. In other local areas the referral pathway to the Tertiary service (and the links with the Regional ASD Academic centre) will be negotiated and overseen by the local ASD Coordinating group.
- Assessment should be undertaken by a multidisciplinary team with specific clinical ASD training. (These staff will usually have a designated special clinical/academic interest in the diagnosis and treatment interventions for pre-school and school aged children with ASDs).

4.5.1.   The core team should provide access to:
- neurodevelopmental paediatrician and / or child psychiatrist with specific expertise in ASD

- specialist psychologist (educational/ clinical)
- specialist speech and language therapist
- specialist teacher
- specialist occupational therapist and access to other therapeutic assessments
- specialist social worker
- Access to other specialist opinions such as genetics, paediatric gastroenterology, paediatric neurology, immunology (as before this list is not exhaustive) should be negotiated as part of the tertiary assessment plan. Some services have art and music therapists
- Access to in-patient facilities for assessment/management within CAMHS service –the need for this to be audited across local areas.

4.5.2   The Tertiary team should have access to reports of all previous assessments, investigations and interventions used to avoid repetition, prior to undertaking any additional diagnostic assessments

4.5.3   The planned use of a tertiary assessment / intervention service should, as far as is practicable, be negotiated with the family and referring local area team involved in the Care Plan, to ensure that the new interventions complement the local ongoing management plans for the child and family. If the child is school-aged then it is essential that the tertiary team link and liaise with the LEA when considering plans for intervention.

4.5.4   The tertiary assessment will be planned around the specific question asked and this is often a reflection of complexity/parental wish for second opinion/specific management advice including psychological and pharmacological. Assessment may consist of:

- **Specialist Developmental History** using a standardised diagnostic assessment tool such as the ADI-R or DISCO or equivalent as new assessment procedures are developed and rigorously evaluated.
- **Additional Individual Observations** and **investigations** to compliment initial local area ASD **diagnostic investigations.** These might include Further Cognitive Assessment, Speech and Language Therapy, Occupational Therapy, Physiotherapy or any other Therapeutic Assessment procedures required for that individual child. Additional assessments, as part of a research/ training protocol (with the consent of the young person (as appropriate) and/or responsible adults) may also be considered.
- **Additional medical investigations** should complement the Stage 2 work up and will be dictated by clinical need (see above) unless specific consent has been obtained to undertake specified research investigations.
- **Assessments** may take place across different settings to investigate situation specific features and degree of pervasiveness of particular behaviours.

4.5.5.   The outcome of a tertiary referral will usually take the form of a diagnostic formulation report with proposals for future provision and support. As with local area diagnostic formulation reports, a Tertiary

service report should initially be sent to the parents for revision of any errors of factual content. The revised report (dated and signed) should, with the parents' agreement, then be circulated to the referrer, the General practitioner/primary care team and be available to all other professionals working with the child and family.

4.5.6   Referring agency (and included in the costing of the tertiary opinion) to discuss the implications of the diagnostic formulation. Parents may wish to bring other local support to the follow-up meeting

Alternatively the follow up appointment may take the form of a local multi-agency Consultation meeting with representative(s) from the Tertiary service in attendance, to consider the implications of the tertiary opinion.

- The waiting time for a tertiary referral should not exceed **3-6 months** initially (in line with the NHS Plan Modernisation Targets) and the tertiary assessment process should be completed within **6-8 weeks**, unless additional investigations or a period of specific treatment or admission to a day or in-patient service is negotiated.

- The tertiary service will provide the link for the local referring local areas, via each local ASD Coordinating Group, with the Regional and National ASD network thus facilitating the dissemination of new information about evidence based clinical practice, research and training initiatives (see below).

- Funding and Resource implications. The aim is a seamless service most efficiently and conveniently delivered to families to their satisfaction and in a way that promotes best practice. This may mean that the tertiary team works best in an advisory role either in localities or through teaching and telephone/ Email consultation. Funding for tertiary services is currently based on face to face patient contact and mitigates against the above way of working. Strategic planning/methods of payment in the Health services to fund tertiary services differently needs to be considered.

4.6   Training

4.6.1.   Local Area ASD Training

4.6.1.1.   Professionals: This report places a heavy emphasis on three levels of
specific Autism   Spectrum Disorders training:

- Training in increasing awareness of ASDs is needed for all community based staff
- Specific skills in the diagnostic assessment of ASDs and related disorders is required for all professionals involved in Stage 2 Multi-Agency Diagnostic Assessment

- 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

4.6.1.2 Training is a requirement for all those who come into daily contact with children with ASD including parents/carers, adults, early educators, teachers and all support staff,

4.6.1.2 **Parents/Carers and Families**
(Including professional carers such as shared care, foster care, specialist short break and residential care)
Training for families must be ongoing as individual needs change according to age and circumstances. All authorities should offer a variety of training courses for parents/carers in the understanding and management of ASD and any additional behavioural difficulties. This training should be delivered by a multi-agency team. Early parent led interventions such as More than Words and Early Bird should be available in all local areas. Follow up parent training initiatives need to be promoted for parents/carers

4.6.1.4 Opportunities to access training on a flexible local basis for parents and professionals need to be identified e.g. distance learning, video and on-line training. 'Quality time' (i.e. during working hours) should be identified to deliver training courses in addition to the reliance on 'twilight hours' for training courses.

The presentation and needs of children with ASD are diverse. No one-off training package focussing on a single approach or intervention will be able to meet the training needs of any professional group.

4.6.1.5 All local area provisions should keep a database of the ASD knowledge and experience of the staff. This information would increase parental confidence in local provision.

4.6.1.6 A local area multi agency rolling programme of initial ASD awareness raising together with specific locally run (or locally delivered, distance) accredited courses, in conjunction with, neighbouring local areas (as part of a Regional Education Development network) could provide a model for joint training initiatives and promote high quality multi agency working (English and Essex, 2001)

4.6.1.7 The proposed NIASA guidelines highlight the need for co-ordination and collaboration between all agencies contributing to assessments, interventions and the regular review of children with ASD and their families. The NIASA recommendations endorse the work and recommendations of the West Midlands SEN Regional Partnership (see Appendix and English and Essex, 2001).

4.6.1.8 This report recommends a mechanism for the co-ordination of ASD services, on-going training and development of new funded initiatives for the Local Health Community through the **ASD co-ordinating Group**. This ASD co-ordinating group is also the mechanism for having a

strategic overview of Tertiary clinical Services and the Regional and National ASDs Networks for updated information on training, diagnostic instruments, treatment evaluation and new treatment initiatives, research findings and academic collaboration opportunities

(see Figure 2).

Figure 2 to be added

4.6.2   Regional ASD Network: Training and Academic Developments

4.6.2.1.   With the increased ASDs awareness and demand for services and for training, many local area services are already developing local training initiatives to meet local professional needs. Some of this training is single agency/disciplinary and some multi-agency and includes parents/carers. There are a number of examples of good and innovative   training in different parts of the UK.

4.6.2.2.   Within any Region there may be some local areas with the expertise to deliver high quality in house training and other local areas without the necessary specialism

4.6.2.3.   Regional regions have gone—strategic authorities ? size policies on training that link together multi-agency planning need to be developed. A model proposed in the West Midlands SEN Partnership identified major training needs and suggested two related solutions: 1) each region should appoint a region wide teacher/ early educator with responsibility for ASD training across the region, and 2) Regional Health Authorities in conjunction with Education, Social Services and the voluntary sector should develop a Forum for **Regional Education Development (FRED)**

4.6.2.4   Such Fora may in turn provide the basis for a national UK network for ASD research and training

4.6.3.   National ASD Network ? appendix

4..6.3.1   Historically there have been very few sites in the UK providing clinical and multi-agency training in the diagnosis of ASDs. 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.

4.6.3.2   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 ASDs) has established standards of training and practice, which have been incorporated into the DfES and Teacher Training Agency approved standards for Specialist Training (* ref ask Rita) COSPPA. (a professional organisation for service providers for ASDs) has developed

an induction pack for minimum standards for staff working with individuals with. ASD

Still to do

4.6.3.3   NIASA has been informed about a number of Academic and independent institutions providing ASDs specific training for parents/carers and professionals in different parts of the UK (See appendix)

4.6.3.4   There is a need to develop a national training strategy and agree appropriate training packages for the different groups of professionals who need training in ASDs 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.

4.6.3.5   The dangers of failure to ensure high quality for early identification, assessment, diagnosis and intervention, education and support services for children with ASDs and their families is both the inevitable distress of unmet need and the inability for affected individual to achieve their full potential

4.6.4   UK Training Recommendations in appendix as one proposal Means we need to emphasise problem of paying for tertiary services as above

4.6.4.1   A **virtual "Institute"** of training centres should be developed to 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

4.6.4.2   The UK clinical and non clinical training needs and responsibilities should be overseen by a **UK ASDs training committee,** with representation from the regional academic clinical centres, existing ASDs training institutes, local area ASDs co-ordinating groups, all statutory agencies (health, education and social services) together with voluntary agencies and lay representatives (including parent).* Gillian, Rita does not approve of this * What do you think? I will reword following your regional suggestions*

4.6.4.3   Such a training committee will urgently need to develop a UK wide training strategy to meet the current clinical and non-clinical training needs across the UK.

4.6.4.4   The training strategy should build on 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).

4.6.4.5   Much of the existing successful training in the UK has been developed in non clinical training institutes. The University of Birmingham course, for instance (see appendix) provides ASD training for a range of

professionals (including clinical and non clinical individuals) working with children with ASD.

4.6.4.6   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 packages, to coordinate the training and to monitor the quality of the training initiatives.

4.6.4.7   Funding will need to be available to provide the personnel and infrastructure support and to manage this considerable training agenda. Consideration should be given to joint funding from the three relevant services, Health, Education and Social Services.

4.6.4.8   Initially it may be more efficient to use funding initiatives 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 opportunities such as distance education, web training may be the best way forward to increase capacity.

4.6.4.9   A network of mobile training teams supervised by the 'Virtual institute' should be able to provide individualised packages of multi-agency and multidisciplinary training appropriate for the differing training needs of local area services in different parts of the UK.

4.6.4.10   Once the national training strategy has been established, the ongoing training needs of particular local areas and professional groupings can be reviewed within and between Regional networks.

4.6.4.11   Further, as academic progress is made in ASD research, there will be the need to develop new diagnostic assessment measures for both clinical and research work. It should be the responsibility of the UK ASD Training committee to ensure that the UK continues to lead both in the field of instrument development and that the information is disseminated throughout the UK to ensure best evidence based clinical practice.

4.6.4.12   In summary the UK ASD Training committee will have the responsibility to oversee training programmes for
- all community staff in ASD awareness
- local area staff involved in Stage 2 diagnosis, Tertiary diagnostic services and clinical Academic Research Needs
  dissemination of information related to evidence based effective interventions in ASD

4.6.5.   Professionals Groups
Training for Professional Groups

Each core working group member was asked to briefly summarise the training requirements for each professional group (see appendix)

- For each professional group some ASDs awareness should be incorporated in the core professional training curriculum.
- Evidence of ASDs awareness raising training should also be used as a service quality standard in postgraduate continuing professional training. This should be stated in the Children's National Service Framework. Such experience working with children with a complex mix of social communication and behavioural developmental skills and deficits enhances the precision of clinical skills in a number of different areas of practice (ref)
- In each local area at least one staff member of each professional group should receive additional ASD training and develop specific expertise in. ASD. This should include training in currently recommended assessment tools.
- For details for each Professional Groupings see Appendix.

Research appendix to follow – see separate e-mail

4.7   Summary of Main Recommendations – Ann Le Couteur's PowerPoint slides to be added * Do we need this* How should this report end? Needs something
APPENDICES TO FOLLOW