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Public Health Institute of Scotland

# Autistic Spectrum Disorders

Needs Assessment Report



December 2001

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**The range of expertise and professions represented by the working group during the period March to November 2001 has included:** clinical psychology, education, educational psychology, paediatrics, parents, psychiatry, psychotherapy, public health, social services (adults and children's services), speech and language therapy and the voluntary sector.

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Further copies of this report and other Scottish Needs Assessment Programme (SNAP) and Public Health Institute of Scotland (PHIS) Needs Assessment Reports are available from Anita Hastie, PHIS, Clifton House, Clifton Place, Glasgow G3 7LS, tel: 0141 300 1013.

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### Summary and recommendations

**Aim:** To provide information for service commissioners on the best available knowledge about autistic spectrum disorders (ASD) and current service provision in Scotland, and guidance on how these services might better meet the needs of both children and adults with autistic spectrum disorders in the future.

**Epidemiology:** The most recent, rigorous studies have estimated that the overall population prevalence of ASD in children is approximately 60 per 10,000. There has been no formal work to identify the prevalence of ASD amongst adults, however there are more children and adults being identified as having disorders on the autistic spectrum than in the past. This is having a considerable impact on the demands made on statutory and voluntary services. The lack of historical data and the problems in gathering consistent data mean it is unlikely that it will be possible to determine accurately if this apparent increase is real.

**'Ideal' services:** Ideal services should aim to deliver:

- Joint assessment, delivery and review of care in a way that involves the relevant agencies, services and professionals.
- Active involvement of the family and, where possible, the individual with ASD.
- Early identification.
- Appropriate early interventions.
- Provision of a range of services delivered seamlessly to meet the various and differing needs of people with ASD which are planned and developed in a truly multi-agency and seamless way.
- Well planned and sensitive management of the transition between childhood and adulthood within and between agencies.
- All planning carried out should place the person at the centre of services and ensure that individual needs are addressed.

In order to do this services need:

- Joint policies, strategies and operational arrangements between agencies.
- An adequate number of skilled and experienced professionals.
- Targeted funding for ASD services across organisations.

**Current services:** Current service provision is patchy and inadequate for the number of individuals with ASD requiring support. Health care, education and social services vary depending on local resources and there are marked differences in ease of access to services due to limited facilities in some geographical areas. Although there are some examples of good, innovative, multi-agency practice across Scotland, some areas and some client groups, particularly adults and their families experience long delays and inconsistencies in the delivery of services and inadequate support after diagnosis.

**Recommendations:** In order to adequately meet the diverse needs of this client group a range of services must be available which are co-ordinated, multi-agency and seamless. This needs assessment makes 32 recommendations which are detailed in full in the final section of this report. The key recommendations are summarised overleaf.

## Summary of recommendations

### Standards and Monitoring

- A working party should be established by the Scottish Executive to develop global standards for lifelong services for those people with autistic spectrum disorders (ASD) that require it. It should also review current training provision in Scotland.
- Thereafter the Scottish Health Advisory Service (SHAS), or an alternative body, should monitor these standards.
- A request is made to the Scottish Intercollegiate Guidelines Network (SIGN) to develop guidelines for evidence based approaches to the diagnosis and management of ASDs.
- A conference is planned for 2002 and should be used to bring together interested parties to discuss the implications of this document.

### Matching Resources to Need

- Development of services for people with ASD should be sought through local health and joint planning mechanisms. Plans for development should be based on audit of current service provision, expenditure and training and should cover all the relevant agencies. The Scottish Executive should ensure that the audit, planning and relevant action has taken place in each area. This should build on the mapping exercise being carried out by the SSA and NAS in Scotland.
- Resources for systematic development of services for those with ASD should await completion of this audit.
- Each NHS board with its local authority partners should ensure that existing resources are reshaped to address the issues raised in this report.
- Thereafter additional resources should be allocated according to identified gaps in local provision.

### Training

- A national audit of training should be included in the remit of the working party to be established to develop standards of services to assess training needs and gaps. (see Standards and Monitoring above)
- Local training audits should also take place in each NHS board area as part of the wider audit recommended with a view to addressing training needs and gaps. (see Matching Resources to Need above)

### Research

- Research funding bodies should encourage further research into autistic spectrum disorders.
- A working group should be convened to consider the practicalities of establishing a database of people with ASD in Scotland.

### Diagnosis and assessment

- Primary care professionals should consider including assessments of the triad of impairments as a standard part of all routine surveillance for infants within primary care.
- In order to limit waiting times and improve services for assessment and diagnosis of children and adults, resources are required to train and employ more specialist professionals in all agencies.



## 1. Introduction

### 1.1 Background to the Needs Assessment

Autistic spectrum disorders (ASD) have been the subject of considerable political and media attention in recent years. This needs assessment report is therefore timely, pertinent and will be of interest to a wide audience.

In the past, autistic spectrum disorders have had a relatively low profile. This has resulted in what can seem like a lifelong battle for many affected families to win appropriate services, resources and support in a system that does not appear to understand their complex needs. In recent years, however, awareness of autistic spectrum disorders has grown amongst both professionals and the public largely due to the media and public interest in a number of proposed but unproven causes of autistic spectrum disorders.<sup>1</sup> This has also drawn attention to a number of weaknesses in current service provision and a growing recognition that providing appropriate services for this client group throughout their lives has considerable long-term implications for healthcare, social work, education and the voluntary sector.

This document is based on the current state of knowledge, evidence and understanding of autistic spectrum disorders. Although much is known, and developments in knowledge have been significant in recent years, there is much still to learn. The content will therefore be subject to change as understanding, technology and care patterns evolve.

### 1.2 Aim of the Needs Assessment

The aim of this needs assessment is to provide information for service commissioners on the best available knowledge about autistic spectrum disorders and current service provision in Scotland, and guidance on how these services might better meet the needs of both children and adults with autistic spectrum disorders in the future.

This needs assessment is primarily intended as guidance for service commissioners and providers to assist the development of a more comprehensive, proactive and appropriate network of services that will better meet the needs of this complex client group. It will also be of professional and personal interest to others, however it should be noted that the document is not intended to represent a standard of care.

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(i) Particular controversy has been caused by the unproven hypothesis that the measles-mumps-rubella (MMR) vaccine is associated with inflammatory bowel disease and disorders with autism-like manifestations in some children. A link has not been established scientifically though research and debate continues in this area. The Medical Research Council ([www.mrc.ac.uk](http://www.mrc.ac.uk)) was commissioned by the UK Department of Health to provide it with a clear picture of what scientific research has revealed about the epidemiology and causes of autistic spectrum disorders, and to make recommendations about strengthening research in the future.

### 1.3 Why Autistic Spectrum Disorders matter

- Autistic spectrum disorders can cause complex communication difficulties and social impairments that require sophisticated and co-ordinated approaches to service provision across education, health, social services and the voluntary sector.
- An autistic spectrum disorder may be associated with severe disability and handicap but there are also individuals who fulfil the criteria for ASD who may experience fulfilling lives without any professional support, or with episodic treatment only at times of high stress.
- Greater numbers of people are being recognised as having an autistic spectrum disorder than in the past.
- Autistic spectrum disorders cut across all geographical and social class boundaries and racial and ethnic groups.
- Autistic spectrum disorders are not just a condition of childhood but are lifelong disorders with lifelong needs.
- Early identification and therapeutic and educational interventions can benefit people with autistic spectrum disorders and their families.
- There is a lack of understanding amongst current service providers and commissioners of the nature of autistic spectrum disorders and the resultant service implications.
- Current service provision is patchy, inconsistent, lacks co-ordination both across and within provider organisations and often depends largely on the motivation of individual professionals.
- Because of the difficulties inherent in effective joint working, resources can be wasted because services that are inappropriate, or even detrimental, are being provided. This results in a human cost to people with the disorder and their carers, and in ongoing, unnecessary costs for health and social services.
- Autistic spectrum disorders have moved up the political agenda and are of considerable interest to the media and the public due to a number of widely publicised but unproven hypotheses about possible causes.
- The recent white paper on learning disabilities, *The Same As You?*<sup>1</sup> recognised the needs of people with ASD and learning disabilities and its recommendations have been welcomed by specialists in the field of autistic spectrum disorders. However, categorising ASD under learning disabilities has caused some confusion as the needs of a significant number of people with ASD will not always be met by current learning disability services.

**Autistic spectrum disorders are lifelong, complex, controversial, challenging to service providers, they can cause severe impairments and they are not uncommon.**

## 2. Autistic Spectrum Disorders: What are they?

“Autism isn’t something a person has, or a ‘shell’ that a person is trapped inside. It is pervasive it colours every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person.”

(Personal view of an adult with autistic spectrum disorder)<sup>2</sup>

### 2.1 The autistic spectrum

‘Early infantile autism’ was the term first used in by Kanner 1943 to describe children with unusual behaviour patterns present from birth or before 30 months.<sup>3</sup> Around this time Asperger described children with behaviour patterns that differed but overlapped with Kanner’s autism group.<sup>4</sup> More recently it has been demonstrated that the severity of social and communication impairments and repetitive behaviour patterns in this group was probably sufficient to meet Kanner’s criteria for autism.<sup>5</sup>

Over the last few decades a considerable amount of research has taken place and it is now known that autism is a complex, lifelong condition which manifests itself in vastly different ways. Consequently the current concept of autism is broad, recognising that it can be manifest as profoundly severe disabilities or more subtle problems of understanding and impaired social functioning. It may co-exist with learning disabilities or other disorders of development and can occur with other physical or psychological disorders. Some people will be severely affected whilst others will have more subtle impairments and may not present to agencies for support. For these reasons the concept of a spectrum has evolved and so the term ‘autistic spectrum disorders’ is often used in preference to autism.

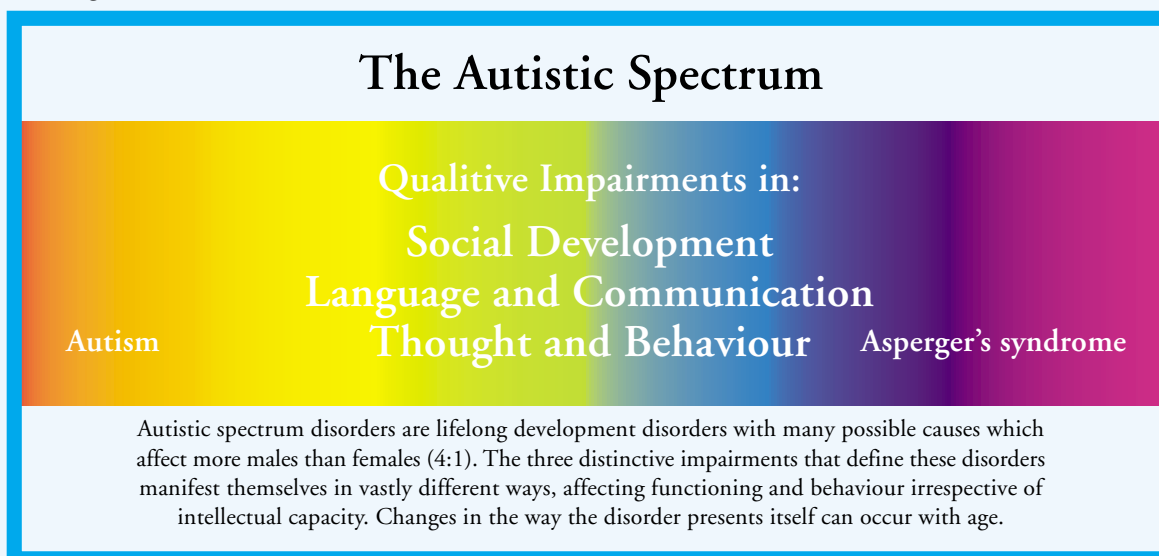
### 2.2 The triad of impairments (See figure 1)

Autistic spectrum disorders (ASD) are typically characterised by a ‘triad of impairments’.<sup>6</sup> The following description of the triad has been adapted from Jordan (1999)<sup>7</sup>:

- **Social** - Impaired, deviant and delayed or atypical social development, especially interpersonal development. The variation may be from ‘autistic aloofness’ to ‘active but odd’ characteristics.
- **Language and communication** - Impaired and deviant language and communication, verbal and non-verbal. Deviant semantic and pragmatic aspects of language.
- **Thought and behaviour** - Rigidity of thought and behaviour and impoverished social imagination. Ritualistic behaviour, reliance on routines, extreme delay or absence of ‘pretend play’.

All of the above behaviours should be out of keeping with the individual’s mental age. Individual manifestations vary with an individual’s degree of intelligence, with their individual personality and with the presence of additional disorders. In addition, changes in the way the disorder presents itself occur with age, especially in the more able individuals. Many people with an ASD also have an over-sensitivity to sound, smells, touch, taste and visual stimulation.

Figure 1



### 2.3 Diagnostic systems

The two major diagnostic systems, The International Classification of Diseases 10 (ICD-10)<sup>8</sup> and The Diagnostic and Statistical Manual of Mental Disorders 4<sup>th</sup> Edition (DSM-IV)<sup>9</sup> have similar criteria for the diagnosis of autistic spectrum disorders. These are both based on the triad of impairments previously described, although certain diagnostic categories are expanded further. ICD-10 is most commonly used in the UK and is endorsed by the World Health Organisation. In ICD-10 autistic spectrum disorders are included under the broader heading of pervasive developmental disorders (PDD). Of these, childhood (classical) autism, atypical autism and Asperger's syndrome are considered together as autistic spectrum disorders (ASD). These diagnostic sub-groups are defined by ICD-10 as follows:

- **Childhood (classical) autism** is defined by the presence of abnormal or impaired development that is manifest before the age of three years, and the characteristic type of abnormal functioning in all the three areas of the triad of impairments. DSM-IV defines this as autistic disorder (AD).
- **Atypical autism** is the term used when a disorder differs from classical autism due to a later age of onset, atypical or sub-threshold symptoms, or all of these. This category is sometimes referred to as 'pervasive developmental disorders – not otherwise specified' (PDD-NOS).
- **Asperger Syndrome (AS)** is characterised by the same type of abnormalities in reciprocal social interaction and restricted, stereotyped, repetitive patterns of interests and activities that typify autistic disorder, **however** it differs primarily in that there is no clinically significant delay in spoken or receptive language or in cognitive development. There is no requirement to have had developmental difficulties before 3 years of age.

There is continuing debate over diagnostic characteristics of Asperger syndrome.<sup>7 10 11</sup> The mainstream consensus, however, is that AS is not quantitatively or qualitatively different from autism and forms part of the spectrum of autistic disorders.<sup>2 6 7</sup>

**Subgroups within the autistic spectrum (as defined in ICD-10)**

Debate continues about the usefulness of defining sub-groups within the autistic spectrum given the range of manifestations of impairments, the range of abilities and associated longitudinal changes. Whilst sub-groups may be useful for research purposes, for example, in teasing out causal and prognostic factors, their use is less clear in routine practice and assessment of need, when the individual's overall level of ability and impairment and the potential to benefit from appropriate interventions is most important. Use of sub-groups would be important if treatment or interventions differed according to diagnosis, however it is not yet clear which interventions are associated with particular diagnoses within the autistic spectrum.

**2.4 Terminology**

There are inconsistencies in the terminology used to describe autistic spectrum disorders and this causes confusion amongst professionals, parents and people with ASD. Autistic 'tendencies', 'features' and 'traits' have been used in place of formal diagnoses, even though these terms have no defined meaning and do not correspond to diagnostic categories. Other poorly defined terms in use include mild autism, high functioning autism and communication disorder. In addition, it is not helpful to parents, professionals or the individual to avoid the term autistic spectrum disorders, as is sometimes done. The term should not be considered a label, but a signpost to appropriate treatments or interventions.

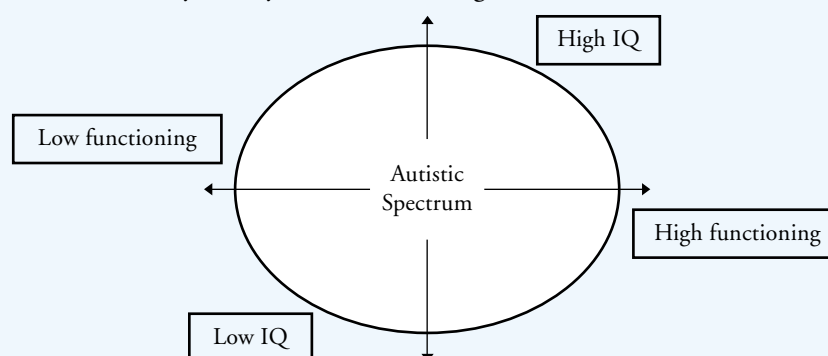
**To ensure clarity, this document will refer to 'autistic spectrum disorders' or 'ASD' and 'people with autistic spectrum disorders'. However because of the differing needs of those with Asperger's syndrome (AS) compared to autistic disorder (AD) the spectrum may be split into these components in some sections.**

**2.5 Impact of ASD on functioning**

ASD are complex and impact on individuals at a number of levels. An individual with ASD could have any level of functioning from poor to relatively high in the communication, socialisation and thought/behaviour domains, irrespective of their intellectual ability. This is conceptualised in figure 2. Therefore, those individuals with good general cognitive ability will not necessarily have fewer needs in terms of their day-to-day functioning and may have a very significant degree of social handicap.

**Figure 2: Autistic Spectrum Disorders and level of functioning**

Individuals with ASD may be anywhere on the diagram.



Of those people with autistic disorder:

- Many have learning disabilities. It was previously thought that around 75% showed cognitive impairment,<sup>13</sup> although recent studies have found lower rates of learning disabilities in those with autistic disorders.<sup>14</sup> Irrespective of level of ability, individuals with ASD have information processing problems which present them with significant difficulties.
- Many are significantly affected by co-morbid conditions which may include behavioural, psychiatric, and/or medical problems (e.g. aggression toward themselves and others, clinical depression and/or anxiety, epilepsy, sensory sensitivity (especially noise and touch), dietary problems, obsessive compulsive disorder, attention deficit hyperactivity disorder).<sup>15 16 17</sup>
- A considerable number have no speech, although studies have reported different proportions ranging from 20-50%.<sup>17</sup>

Those people with Asperger's syndrome (AS):

- Also share the triad of impairments, including significant information processing problems that impact on various areas of functioning, but most have good surface language skills and average or above average IQ.
- Are also vulnerable to increased mental health, psychological and behavioural problems.

### 2.6 Age of onset and diagnosis

The lack of understanding about the causes of autistic spectrum disorders does not allow categorical statements to be made about the age of onset. However, it is thought that the disorders are present at birth and that abnormalities in social behaviour are usually present in the early years.<sup>18</sup> Signs can sometimes be picked up during the first year and a number of studies are currently underway looking for diagnostic indicators in infants.<sup>19</sup> Often, however, problems are not recognised until later in childhood and diagnosis may not be made until considerably later, especially for those at the higher end of the spectrum. A UK study in 1997 found that children were being diagnosed earlier than in the past but that the average age of diagnosis of

ASD was around 6 years old, although the range was wide.<sup>20</sup> There were also wide regional variations in diagnosis particularly between urban and rural areas, and more children in Scotland were diagnosed before 5 years of age than in other parts of the UK.

The complexity and range of manifestations mean that diagnosis is difficult, especially at the extreme ends of the autistic spectrum.<sup>21</sup> A variety of approaches are used for diagnosis and instruments have been developed for professionals and for parents to assist the diagnostic process. However, despite their use, diagnosis ultimately depends on recognition of the complex patterns of behaviour revealed in the developmental history and current clinical picture of each individual. It therefore requires professionals with training and experience. It also requires time and may require attendance at several different centres, especially for those with a complex condition or with co-existing conditions.

These complexities and the range of components necessary as part of a diagnostic assessment, combined with the lack of awareness, lack of confidence and lack of experience with this client group that exists amongst many professionals, mean that a number of people with ASD may be diagnosed later in their life, or may not be diagnosed at all.<sup>22</sup> This is especially the case for those who do not have delayed speech development.

The loss of vocabulary and social skills after a period of apparent normal development, or regression as it is known, does occur in cases of autistic disorder.<sup>23</sup> However, estimates of the rates of regression in children with autistic disorder vary and it is not known whether the presence of regression reflects differences in the cause or course of the disorder.

### **2.7 Outcome and influences on outcome**

Autistic spectrum disorders are lifelong and individual outcomes will be affected by other associated conditions such as learning disabilities, underlying neurological disorders and epilepsy. There is increasing evidence that structured educational and therapeutic interventions in the early years of life confer great benefits in the progress of those with the disorder.<sup>24</sup> Specific benefits include improving behaviour, enhancing the development of skills and improving quality of life for the individual with ASD.<sup>25</sup> In addition, the impact of ASD on the family as a whole can be minimised by appropriate early interventions.<sup>26 27</sup> Early therapeutic and educational interventions are therefore vital and require early, multi-agency, collaborative diagnoses and assessments followed by appropriate, co-ordinated support by agencies in all sectors (education, health, social services, voluntary). Support is required for continual development throughout life for individuals with ASD.

## 2.8 Case Studies and the 'snakes and ladders' of service provision

### Case Study 1: George, aged 46, city in the central belt

George came to the attention of services at the age of 3 due to lack of speech development. He was diagnosed as being "backward".

He attended a special school but was noted to be anxious and withdrawn and had great difficulty interacting with the other children. He became increasingly violent at school and at home. He attacked other children, apparently unprovoked, and smashed up his home regularly. He lived with his mother, grandmother and sister, father having left home when George was 2.

At the age of 12 he was suspended from school and spent time wandering the streets as his mother and grandmother were unable to prevent him leaving and no offers of alternative help were available. The police regularly brought him home.

George was always noted to be a strikingly unhappy boy and was troubled by a stream of worrying thoughts. These escalated until a crisis in 1968 and he was admitted to an adolescent psychiatric unit. He was found to be too difficult for this unit and was admitted at the age of 13 to a mainstream adult psychiatric ward. Here he received a retrospective diagnosis of autism and was discharged to a learning disability service run by a religious order. He did not fit in there and was moved to another religious community in the country. Still he was very unhappy and unsettled. Although he had a diagnosis of autism there was no understanding of relevant approaches or treatment of autism and he became stressed and ultimately violent. He was then moved on to a large long stay institution in 1973 and move from ward to ward over time. His patterns of behaviour, repetitive speech and, by this time, negative self-image and negative view of the series of past events, continued to isolate and alienate him from people. Various professionals came in contact with him over this time and many of the staff became very fond of him and concerned about the best way to help him. His mood was invariably low and he tended to have episodes of violent rages. He was not an easy person to work with.

His mother withdrew completely from him in 1973 and eventually died. His father made contact and now visits once per year which is a highlight for George.

Eventually, after 25 years in the institution, he was discharged in 1998 to an apparently ideal place, a large bungalow in private grounds. The domestic scale of the house and close proximity to others and, crucially, the informal structure of living there led to an increase in stress which made life intolerable for him and the other residents due to the increase in violent rages. George was admitted to a healthcare provision for people with a dual diagnosis where he remained for over a year. In this small, structured unit with well-trained staff it became clear that he had a mood disorder and was treated appropriately. It was not a suitable place for him as it was a short-term unit with ever-changing people, often with severe mental health problems, being admitted.

He was discharged with no warning to a long stay residential unit for men with learning disabilities and other problems. Four other residents have autism and staff are working hard to put the structures and environmental changes necessary in place.

George, as is quite common with adults with autism, has a long standing mental health problem and a sad life experience. He has much to offer, he is kind and concerned for the people he manages to form a relationship with, is a talented artist and sometime surprises himself and others with his skills and mimicry. His rare laugh transforms him; it is being heard more often.



# 02

## Autistic Spectrum Disorders. What are they?

The complexity and variability of autistic spectrum disorders present challenges to agencies in providing appropriate, timeous and joined up services and many different situations can impact negatively on an individual with ASD. The concept of snakes and ladders<sup>ii</sup> is used here to help to give an impression of the importance of inter-agency, needs based service provision. Where services are well developed and families have access to them there are helpful ladders. Difficulties arise when services are not available or professional expertise is undeveloped.

The following two case studies provide examples of how service provision can have positive impacts (ladders) or negative impacts (snakes) on people with ASD and how important these can be in an individual's overall progress and outcome.

### Case Study 2: Pre-School aged child, Colin, 4 years old.

**The future:** The delay in receiving a definitive diagnosis has meant that his parents were unclear as to the diagnosis, prognosis and possible interventions for their child for a considerable time. Colin was diagnosed with classical autism at age 6 after 18 difficult months in a mainstream school with minimal support. His parents have now found support through the local voluntary organisation and have found a social worker who has training and experience in autistic spectrum disorders. Unfortunately there are few respite and support services locally and the family sometimes finds it hard to cope. They are finding it particularly hard to cope with Colin's young sister who resents the attention that Colin demands.


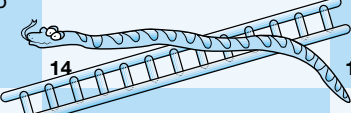

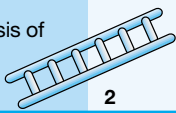
16	15	14	13
Still awaiting definitive diagnosis	Special needs placement with speech and language therapy	Referral to Educational psychologist	Paediatrician does not give clear diagnosis. Wait 3 mths
9	10	11	12
Referral to speech and language therapist and audiology: waiting list <b>MISS A TURN!</b>	Possible communication disorder – referred back to GP	Grandparents advise that father did not speak until aged 4. <b>MISS A TURN!</b>	GP refers to Child Development Centre Paediatrician
8	7	6	5
At 2 yrs parents request help from GP	Sleep patterns become poor, he eats a restrictive diet and he has become very repetitive	At 18mths Health Visitor tells parents there is no problem. <b>MISS A TURN!</b>	Parental/family distress
1	2	3	4
Difficult and distressed infant	Meets milestones at 1 year but concern over hearing	New sibling in family	Behaviour deteriorates at 15 mths. Speech lost.

**Background:** Colin was his parent's first child. As such they had little to compare his behaviour to and relied on professional opinion on whether his behaviours were 'normal'

(ii) The concept of a snakes and ladders game was originally devised by Vivienne Wire of Strathclyde University to describe the passage of people with ASD through services.

**Case Study 3: Primary aged child, Luke, 11 years old**

**The future:** Luke is more relaxed in his new primary school and as Luke reaches the age of transfer to secondary school, his parents feel more confident that his needs will be met through specialised Asperger support and information technology. They now feel able to consider some further issues that have been put to one side for them, given all the worries over Luke's being bullied and socially isolated. Luke is bright and knows he is to have specialist support, he hasn't asked why, but is increasingly aware of differences between himself and others. Once again they feel on their own in terms of finding the right kind of advice and help: where can they turn? They feel they are starting all over again, with new hopes and fears.

<p>Links made with High School which has specialist support services for pupils' with Asperger's</p> <p>17 </p>	<p>Parents consider advice on a gluten free diet</p> <p>18</p>	<p>Luke's mother recognises a growing need to explain Luke's diagnosis to him as High School entry approaches</p> <p>19</p>	<p>Parents begin search for advice and support on sharing the diagnosis with Luke</p> <p>20</p>
<p>Parents feel forced to move house in order to effect a change of primary (&amp; later secondary) school for Luke</p> <p>16</p>	<p>Continuing difficulties with bullying and social isolation: because Luke is regarded as bright and not disruptive school fails to acknowledge parents concerns</p> <p>15</p>	<p>Luke feels he is 'hopeless at everything'; low self esteem</p> <p>14 </p>	<p>Local Support Worker refused access to school.</p> <p>13 </p>
<p>Autism Outreach Service assessment requested by the school to help with difficulties: clear recommendations made to teacher</p> <p>9</p>	<p>Local Support Worker from Voluntary Agency works closely with the family <b>MOVE FORWARD 3 SPACES!</b></p> <p>10</p>	<p>Referred for Information Technology help with dyspraxic difficulties</p> <p>11</p>	<p>Luke experiences continuing difficulties in school with social isolation and bullying <b>GO BACK 1 SPACE!</b></p> <p>12</p>
<p>Referral to Educational Psychologist: feels Luke is very bright: no additional help needed in school <b>MISS A TURN!</b></p> <p>8</p>	<p>Aged 9 Luke is diagnosed with Asperger's Syndrome</p> <p>7</p>	<p>Referral to local diagnostic clinic: waiting list <b>MISS A TURN!</b></p> <p>6</p>	<p>Significant social difficulties, complex difficulties with language, special interests &amp; resistance to change</p> <p>5</p>
<p>6 years old: Community Paediatrician identifies significant co-ordination difficulties: Diagnosis of Dyspraxia </p> <p>1</p>	<p>Referred for Occupational Therapy (OT) Assessment</p> <p>2</p>	<p>Difficulties attributed to diagnosis of dyspraxia <b>MISS A TURN!</b></p> <p>3</p>	<p>Luke's case reviewed by second OT out of the area at parental request at 8 years old</p> <p>4</p>

**Background:** Luke was a passive baby who didn't ask or point for anything. There was little babbling in first year: his parents thought he might be deaf. He played solitarily lining up toys but showed little sign of pretend play before 4 years old. Development was mostly within the normal range with some delay in speech & language and marked motor co-ordination difficulties.

### 3. Epidemiological Review

#### 3.1. Studies of Autistic Spectrum Disorder

Most papers considered for this review focussed on children and this reflects the general paucity of research, knowledge and understanding of autistic spectrum disorders in adults. In the absence of more specific information, the details in this section can be considered to apply broadly to people of all ages with autistic spectrum disorders.

#### 3.2. Those affected

##### 3.2.1 Gender

ASD occurs considerably more in males than in females at a generally accepted ratio of approximately 4:1.<sup>17</sup> This ratio varies across the spectrum with an even higher boy:girl ratio observed in those without, or with less severe, learning disabilities.<sup>28 29</sup>

##### 3.2.2 Social Class

Recent studies have not found evidence to support an association between social class and ASD.<sup>30 31</sup> Early studies suggested that more affluent families were more likely to have children with ASD,<sup>32</sup> however this association with social class was later found to be misleading largely due to the status of those parents who had the resources to seek help for their children at that time.

##### 3.2.3 Ethnicity

Some authors have reported that relatively more children of immigrant parents display autism.<sup>32 33</sup> Suggested reasons for this vary and include increased maternal viral infections in pregnancy and metabolic disorders triggered by the environmental factors in the new country. However these studies were small and other authors have not observed an association between ASD and ethnicity or immigrant status.<sup>31 34</sup>

#### 3.3. How common are autistic spectrum disorders?

##### 3.3.1 Sources of information

Information which can be used to estimate the occurrence and distribution of ASD come from three main sources:

- Routinely collected data
- Surveys
- Published research studies and reviews of studies

The quality of information varies and depends on its source.

Incidence is the number of new cases that occur in a specified population in a specified time (for example, one year) and prevalence is the number of existing cases in a specified population at a point or period in time. Measurements of the incidence and prevalence of ASD will

vary depending on, for example, how the condition is defined or the criteria used in diagnosis and the case finding strategy employed by the researchers. In addition, the age range, the age at diagnosis and the prevalence measures used vary across studies, and this limits the extent to which studies can be compared.

Most recent studies have found higher prevalence rates than those reported previously.<sup>35</sup> A higher reported prevalence of ASD may be due to better recognition, a broadening of the concept of autism, or to an actual increase in the frequency of the disorder.<sup>10 36</sup> Notwithstanding these issues, a number of studies have sought to measure the prevalence of these disorders and a number of reviews of the literature have been carried out. In the absence of more rigorous information these details are the basis for informing future service provision.

### **3.3.2 Local estimates of prevalence**

Some attempts have been made to estimate the prevalence of ASD by counting the numbers of persons with ASD known to service providers. In Scotland some local authorities have data on cases for which they are responsible but often these are informally collected and recorded. In addition, some small scale or pilot studies have taken place regionally with variable results. For example, an audit conducted in Glasgow<sup>37</sup> found 42 per 10,000 children and 6 per 10,000 young people (12 to 30 years).<sup>38</sup> However, these figures were calculated by counting those diagnosed in clinics or known to services and this is not an appropriate or rigorous method of investigating current or changing prevalence: records of cases are not equivalent to prevalence.

### **3.3.3 International estimates of prevalence**

Historically the prevalence of autistic disorder was considered to be between 4 and 5 per 10,000 children although a more recent review estimated 18.7 per 10,000.<sup>17</sup> These estimates focused on childhood autism (defined variously) and excluded Asperger's syndrome, which a study in 1993 found at a prevalence of 36 per 10,000 children.<sup>28</sup> However, this estimate was based on a very few cases and should be considered as very imprecise. More recent studies consider the broad autistic spectrum as well as the autistic disorder sub-group.

The major published articles from the last thirty years which have considered ASD prevalence are summarised in Table 1 and this shows a considerable variation in reported prevalence. It has been suggested that this could be due to differences in diagnostic criteria and methodology.<sup>39</sup> The earlier studies may have underestimated prevalence rates because of lack of parental consent to participate or to weaknesses in case finding procedures.<sup>40</sup> The most recent studies, which are those that report the greatest prevalence, used the most intensive screening procedures and modern standardised diagnostic measures.<sup>39 41 42</sup> These three studies have similar conclusions with regard to the total prevalence of ASD but vary in their findings about the numbers falling into the ASD sub-groups.

**Table 1: Autistic Spectrum Disorders – How common are they?**

Summary of literature

Year	Authors	Type	Measurements	Findings information	Other
1979	Wing & Gould <sup>29</sup>	Study	Prevalence	5 per 10,000 children ('classic autism') 15 per 10,000 children (broader ASD)	
1993	Wing <sup>43</sup>	Review of 16 studies	Prevalence	3.3 to 16 per 10,000 children ('typical autism' defined variously)	
1993	Ehlers & Gillberg <sup>28</sup>	Two-stage total population study	Prevalence (children aged 7-16)	Min. 36 per 10,000 children with AS plus equivalent number who did not meet full criteria for AS	
1999	Fombonne <sup>17</sup>	Review of 23 epidemiological studies (1966 - 98)	Prevalence (children)	Minimum of 18.7 per 10,000 children (all ASD except AS)	
1999	Gillberg & Wing <sup>44</sup>	Review of epidemiological studies of prevalence of autism (1966 to 1998)	Prevalence (children up to 18)	0.7 to 31 per 10,000 Estimate made of 1 per 1,000 children for classical autism	Use of Kanner's strict criteria seems to give significantly lower rates than DSM or ICD criteria
2000	Powell & Edwards <sup>45</sup>	Study of changes in incidence rates	Lifetime period prevalence to 5 <sup>th</sup> birthday	33.7 per 10,000 for all ASDs 16.2 per 10,000 for classic childhood autism	
2000	Baird <i>et al.</i> <sup>42</sup>	Follow-up population study of prevalence	Prevalence (children aged 7)	57.9 per 10,000 for all ASDs 30.8 per 10,000 for AD	
2000	Center for Disease Control <sup>41</sup>	Prevalence study	Prevalence (children aged 3-10 yrs)	67 per 10,000 for all ASDs 40 per 10,000 for AD	
2001	Chakrabati and Fombonne <sup>39</sup>	Prevalence study	Prevalence (children aged 2.5-6.5 yrs)	62.6 per 10,000 for all ASDs 16.8 per 10,000 for AD 45.8 per 10,000 for other ASDs including AS	

### 3.3.4 Best prevalence estimates applied to Scotland

From what seems to be the most recent and most rigorous prevalence studies the most accurate overall population estimate available for the prevalence of ASD in children is approximately 60 per 10,000 children. However, findings about the sub-groupings within this differ and variations in prevalence may exist at a local level.

Table 2 shows the numbers of children under 19 that should be expected to have an autistic spectrum disorder based on prevalence rates drawn from the recent study by Chakrabati & Fombonne<sup>39</sup> (16.8 with autistic disorder per 10,000 children and 44.5 with other autistic spectrum disorders, including AS, per 10,000 children).

**Table 2: Estimate of prevalence of ASD in children under 19 in Scotland**

	Autistic Disorder	Other ASD
<b>Total (children under 19)</b>	2114	5600

Figures calculated using mid-2000 population estimates, General Register Office for Scotland<sup>46</sup>

*Note: these numbers include all children from birth although diagnosis is likely to occur after 1 year and may often occur considerably later.*

These figures refer to children and young people under nineteen. There has been no formal work to identify the prevalence of ASD amongst adults.

### 3.3.5 Evidence for increasing prevalence of ASD

In recent years there have been suggestions of an increase in the prevalence rates of autistic spectrum disorders (see table 3) and there is some evidence to suggest that the apparent increase being observed is most dramatic in the autistic disorder without learning disability sub-group.<sup>39 41</sup> Possible reasons for an apparent increase in prevalence include:

- the incidence of autistic spectrum disorders is increasing
- there is more awareness of autistic spectrum disorders which is leading to greater numbers being recognised
- the spectrum has been redefined and includes people with higher IQs and better verbal ability and those with severe learning disabilities
- or a combination of these.

An actual increase in ASD in the population can only be reliably confirmed by following a series of birth cohorts over time whilst maintaining the same diagnostic criteria and case finding strategies. Such evidence is not currently available.<sup>47</sup> It would be extremely difficult to determine if a rise has already occurred, however a future rise in prevalence could be determined using appropriately designed and rigorous studies.

Regardless of these uncertainties, more children and adults are being identified as falling within the autistic spectrum and, consequently, demands on statutory and voluntary services are increasing.

**Table 3. Autistic Spectrum Disorders – Evidence for increasing identification over time.**

Summary of literature

Year	Authors	Type	Rate	Findings	Increasing numbers identified over time?	Other information
1997	Webb <i>et al</i> <sup>48</sup>	Prevalence study of autistic disorder (3-15 years old)	Prevalence	7.2/10,000 children (3-15 years) with AD	Age specific prevalence 1977-1979: 3.3/10,000 1987-1989: 9.2/10,000	
1999	Fombonne <sup>17</sup>	Review of 23 epidemiological studies (1966 - 98)	Prevalence	Minimum 18.7/10,000 children (all ASD except Asperger's syndrome)	Prevalence rate significantly increasing with publication year. No evidence for a secular increase in incidence of autism.	Proposed that increase is due to changes in case definition and improved recognition.
1999	Gillberg & Wing <sup>44</sup>	Review of 20 epidemiological studies of prevalence of autism (1966 to 1997)	Prevalence	0.7 to 31/10,000 children (up to 18 years old). Estimated 1/ 1000 children (AD only, not including other ASD)	Prevalence increasing over time. 3.8% per year in non-US studies.	Use of Kanner's strict criteria seems to give significantly lower rates than DSM or ICD criteria
2000	Powell & Edwards <sup>45</sup>	Study of incidence rates over 3 2-year periods.	Annual incidence rate (under 5 year olds)	2.7/10,000 p.a. for 'classic' autism 0.8/10,000 p.a. for 'other ASD' (1991) 4.3/10,000 p.a. for 'classic autism' 8.9/10,000 for 'other ASD'(1996)	18% increase per year for classical autism. 55% increase per year for 'other ASDs'	

### 3.4. Causes of Autistic Spectrum Disorders

#### 3.4.1 Current research

The causes, nature and development of autistic spectrum disorders are poorly understood. There is a general consensus that autistic spectrum disorders are a heterogeneous group of disorders resulting from a number of different causes and research is increasingly demonstrating that there is a strong genetic component.<sup>iii</sup>

The variable clinical picture is likely to represent the interaction of multiple factors and it is probable that there are multiple genes of very small effect or important gene-gene and gene-environment interactions<sup>49</sup> but as yet there is little firm scientific evidence to start to explain what these are. A small proportion of those with ASD are thought to be affected by single gene disorders or chromosomal abnormalities.

Although research to date has laid the foundations for future studies examining the factors involved in the development of autistic spectrum disorders there is a limited knowledge base at present. Many studies have highlighted the methodological problems and complexity of research in this field. The epidemiology and causes of ASD were subject to a review undertaken by the Medical Research Council in 2001. The conclusions will be of great interest to many in the field.<sup>iv</sup>

#### 3.4.2 Final Common Pathway

In the absence of clear causal pathways current thinking is often in terms of a 'final common pathway'.<sup>50</sup> That is, multiple factors can interact in a variety of ways to affect development of the central nervous system and lead to the clinical presentation of an autistic spectrum disorder.

#### 3.4.3 Neuroimaging studies

Although several studies have described abnormalities seen on scans of the brains of subjects with autistic disorder, there are considerable methodological problems inherent in these and the results to date have been inconsistent and non-specific.<sup>51</sup>

#### 3.4.4 Genetic, neuropathologic and metabolic disorders

Neurological damage secondary to infection (e.g. intrauterine rubella or herpes simplex), brain tumours or metabolic disorders (e.g. phenylketonuria) can result in clinical presentations meeting the diagnostic criteria for autistic spectrum disorders. However, advances in molecular biology have meant that more recently the focus has been on autistic spectrum disorders occurring in recognised genetic syndromes such as Fragile X, Tuberous Sclerosis & Down's syndrome.

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<sup>iii</sup> A summary of current knowledge on the genetics of autistic disorder can be found on the internet at [www.ncbi.nlm.nih.gov/omim/](http://www.ncbi.nlm.nih.gov/omim/). This is the Online Mendelian Inheritance in Man (OMIM) which is a catalogue of human genes and genetic disorders authored and edited by Dr. Victor A. McKusick and his colleagues, and developed for the World Wide Web by the National Center for Biotechnology Information (NCBI). The database contains textual information, pictures, and reference information.

<sup>iv</sup> More information on this review can be found at the website [www.mrc.ac.uk](http://www.mrc.ac.uk).



### **Tuberous Sclerosis**

Tuberous Sclerosis (TS) is a genetic disorder that occurs in approximately 1 in 10,000 people. It is characterised by benign tumours in the brain and many other organs such as the skin, kidneys, heart and lungs.<sup>52</sup> Several epidemiological studies have set out to describe the association between tuberous sclerosis and autism. One review reported that the frequency of autistic disorders in individuals with TS is about 25%, with 40-45% meeting the wider criteria for ASD.<sup>53</sup> A further link is suggested by the finding that among individuals diagnosed with autistic disorder 1-4% have TS and among the subgroup of autistic individuals with a seizure disorder this is 8-14%.<sup>17</sup>

### **Fragile X Syndrome**

Fragile X Syndrome is the commonest inherited cause of learning disability in males. One in 2,500 males have fragile X syndrome and 1 in 10,000 females are carriers. Although some studies have found much higher rates, it is estimated that around 2% of people diagnosed with autism have fragile X syndrome.<sup>54</sup> Amongst individuals with confirmed fragile X approximately 25% have autism. Whilst these findings suggest a link between fragile X and autistic spectrum disorders the nature of the association is far from clear. For example, when groups are matched for level of learning disability, the rates between the fragile X and non-fragile X groups are comparable.<sup>55 56</sup> Some authors feel that although individuals with fragile X have a similar presentation to autism, there are differences.<sup>57 58</sup>

A great deal of research surrounding fragile X is ongoing. Despite the difficulties in establishing the nature of the association between fragile X and autism, it is hoped that the links that are being made between molecular genetics, development of the brain and the phenotype of fragile X will prove useful.

### **Down's Syndrome**

Epidemiological studies have found rates of autism between 1 and 7 % amongst groups of individuals with Down's Syndrome.<sup>59 60 61 62</sup> As these rates are comparable to those found in groups with learning disabilities they do not suggest a specific link between trisomy 21 and autism. Similarly, although there have been several case reports of autism occurring in individuals with other disorders such as William's syndrome<sup>63</sup> there is no suggestion of a specific causal link.

#### **3.4.5 Learning disability, epilepsy and autistic disorder**

Historically, epidemiological information has suggested that intellectual functioning is within the normal range in 20% of persons with autistic disorder.<sup>13</sup> However, recent studies have indicated lower rates of learning disabilities in children with ASD.<sup>39 41</sup> This may be because previous surveys focussed on those with considerable cognitive and language limitations or because more recent studies have considered the wider spectrum of autistic disorders. It has been estimated that the prevalence figures for autistic spectrum disorders is approximately 20% in children with severe learning disabilities and 5% in those with mild learning disabilities.<sup>64</sup>

The prevalence of epilepsy varies with the level of learning disability.<sup>65</sup> Thus, amongst individuals with a mild level of learning disability, 5% have epilepsy but this increases to 50% in those with a profound learning disability.<sup>66</sup> Epilepsy occurs in 20-30% of people with autism<sup>67</sup> however it has been suggested that, other than in individuals with profound learning disabilities, the prevalence of epilepsy in autism is not associated with the severity of learning disability.<sup>68</sup>

Although the associations between autism, epilepsy and learning disabilities are of considerable importance in considering the needs of individuals with autistic spectrum disorders, and their families, there is very little evidence to allow the nature of these links to start to be unravelled.

It is estimated that, excluding epilepsy, around 10% of individuals diagnosed with autistic spectrum disorders have associated medical conditions and these might not be causally associated with the development of ASD.<sup>13 69</sup> However it is hoped that by studying these instances, some clues as to the causes and origins of autistic spectrum disorders may be revealed.

#### **3.4.6 Family and genetic studies**

Studies of pairs of twins have demonstrated that there is an increased concordance of autism in monozygotic twins compared to dizygotic twins.<sup>70 71 72</sup> In first-degree relatives of persons with autism there is an increased risk of autistic spectrum disorders.<sup>73 74 75 76</sup> These studies also found that the relatives of autistic subjects had high rates of more subtle impairments of communication and social interaction. These studies clearly highlight a contribution of genetic factors in the aetiology of autistic spectrum disorders.<sup>77 78 79 80</sup> The likelihood of a genetic role does not rule out the possible importance of environmental factors.

#### **3.4.7 Environmental factors**

Various external factors have been proposed as possibly linked to the onset of ASD (including environmental factors both during pregnancy and subsequent to birth).<sup>81</sup> In recent years there has been particular attention on this area following reports that the mumps-measles-rubella (MMR) vaccine might act as a trigger for autistic-like disorders in genetically predisposed individuals. In 1998 Wakefield *et al* proposed the possibility of an association of autistic disorder with inflammatory bowel disease and the MMR vaccine.<sup>82 83</sup> Despite the widespread and ongoing media interest, no evidence has been found which supports such an association in any of the subsequent epidemiological reviews or studies which have taken place<sup>84 85 86 87</sup> and bodies such as the Joint Committee on Vaccination and Immunisation and the Committee on Safety of Medicines have all concluded that there is no evidence of a link between the MMR vaccine and autism. Even so, there are some calls for more epidemiological research in order fully to reject a causal relationship.<sup>30</sup>

### 3.5 Secondary morbidity

The sections above have briefly discussed medical conditions associated with ASD with an emphasis on genetic and developmental disorders and their relation to causal factors in autism. It must also be recognised that people with ASD are more vulnerable to a variety of other mental illnesses. Depression, anxiety, obsessive compulsive disorders and other psychiatric conditions are not uncommon particularly amongst adolescents and adults with autistic spectrum disorders. Indeed many adolescents and adults with previous unidentified ASDs (including AS) are likely to be referred to psychiatric or psychotherapy services for these symptoms and so these professionals may be the first to identify ASD in such clients.

### 3.6 Impact on other family members

Depression, anxiety and other psychiatric conditions have been observed in parents and other family members of children with autism.<sup>26 48</sup> One study found this distress to be greater in mothers of children without a specific ASD diagnosis and in mothers of severely affected children.<sup>88</sup> Earlier identification and a definite diagnosis were related to greater parental satisfaction with the experience of diagnosis. Professionals working in the field have reported higher levels of marital breakdown and family discordance in families with children on the autistic spectrum. Sources of stress reported by parents include symptoms of the child's autism, time demands, concerns for the future and lack of access to appropriate services.

### 3.7 Estimated cost of ASD

Jarbrink and Knapp (2001) have attempted to estimate the economic consequences of autistic spectrum disorders on society by reviewing previously published international evidence.<sup>89</sup> Although limited by the lack of definitive prevalence statistics and other information on family inputs and geographical variations in services and service provision, which necessitated a number of assumptions, their results offer a conservative but relatively comprehensive estimate of the associated costs.

Including costs for service use (hospital services, other health and social services, living support, voluntary support, special education, medication, sheltered work, day care provision), time and productivity and family expenses, they estimated that the lifelong cost for a person with autistic disorder and additional learning disability was £2.94 million and for those without a learning disability as £785,000. Costs for living support accounted for 70% of the total cost. Day care provision (14%) and special education (7%) were also significant costs. The lack of information on family inputs results in a low and probably inaccurate representation of the time and resources expended by them, however a study of the time costs of caring for children with a range of severe disabilities, including autistic disorder, found that the significant care needs of these children did not allow their mothers to work and thus reduced the family income considerably.<sup>90</sup>

### 3.8 Beneficial interventions

Evaluation of the effectiveness of different treatments and programmes is problematic due to the variability in behavioural characteristics of those with ASD, the difficulty in ensuring consistency in programme delivery and in measuring the small changes in behaviour that might occur.<sup>91</sup> In addition, there has been little good quality research that has compared treatments. However, there is evidence that appropriate, early therapeutic and educational interventions may significantly improve developmental and behavioural outcomes<sup>92 93 94</sup> although the heterogeneity of manifestations of autistic spectrum disorders means that no single mode of treatment will be effective for all children and all families.<sup>2 24 95</sup>

#### 3.8.1 Educational and social interventions

A recent review of the evidence of the effects and features of educational interventions for young children with autism conducted by the Committee on Educational Interventions for Children with Autism formed by the National Research Council in the USA concluded that “Many specific techniques and some comprehensive programmes have clear effects on important aspects of these children’s learning. Yet links between interventions and improvements are also dependent on the characteristics of the children being assessed...”.<sup>24</sup> In the future, with improved understanding of autistic spectrum disorders it may be possible to recommend specific treatments for specific individuals however, at the present time, evidence suggests that the most effective approaches for children with ASD include early intervention, low pupil-teacher ratio, individualised instruction and family involvement along with regular evaluations of the child’s progress and modifications of the approach as necessary.<sup>24</sup> Appropriate interventions at an early life stage or, if diagnosis is later, soon after diagnosis can help people with ASD maximise their potential, and minimise the social and financial costs to society.<sup>24</sup> Rogers, in her review of six treatment programmes, found that developmental rates were accelerated and that language skills and social behaviour were improved especially when the intervention is begun between ages 2 and 4.<sup>96</sup>

Whilst early identification and subsequent early intervention will not ‘cure’ ASD and research is still needed to identify if any programmes are more effective than others, evidence shows that structured, behavioural and communication based intervention programmes can have positive benefits for many individuals with ASD. They therefore have the potential to lessen the debilitating effects of autistic spectrum disorders, reduce the lifelong cost of autism to society, and improve the quality of life and life circumstances for those with autistic spectrum disorders and their families.

#### 3.8.2 Biological interventions

In the UK, the use of medication is a very small part of the management of autistic spectrum disorders. Nonetheless, as summarised in two recent reviews, there is evidence for the effectiveness of some biological interventions<sup>97 98</sup> which has led to larger, multi-centre trials in the USA.<sup>99</sup> Significant concerns remain over the potential adverse effects of such treatments and further work will be required before the routine use of biological interventions can be recommended.

#### **4. 'Ideal' services for people with autistic spectrum disorders**

The 'ideal' described below includes a range of services that are together considered as providing the optimum medical, educational, social and support services for people with autistic spectrum disorders and their families and carers (based on existing evidence, knowledge and examples of good practice). What is described here is an ideal and it is not feasible to expect current services to replicate all aspects of it, however the detail is intended to be used to inform the development of current services as they work towards this ideal.

##### **4.1 Key principles for 'ideal' services**

###### **Ideal services should aim to deliver:**

- Joint assessment, delivery and review of care in a way that involves the relevant agencies, services and professionals.
- Active involvement of the family and, where possible, the individual with ASD.
- Early identification.
- Appropriate early interventions.
- Provision of a range of services delivered seamlessly to meet the various and differing needs of people with ASD which are planned and developed in a truly multi-agency and seamless way.
- Well planned and sensitive management of the transition between childhood and adulthood within and between agencies.
- All planning carried out should place the person at the centre of services and ensure that individual needs are addressed.

###### **In order to do this services need:**

- Joint policies, strategies and operational arrangements between agencies.
- An adequate number of skilled and experienced professionals.
- Targeted funding for ASD services across organisations irrespective of co-existing learning disabilities.
- A jointly shared record or register of needs of those people currently identified as requiring support because of an autistic spectrum disorder.

## 4.2 Diagnosis and assessment <sup>v</sup>

### 4.2.1 Key aims

The early recognition, assessment and diagnosis are the crucial first steps towards meeting the needs of individuals with these disorders. It is important to raise awareness and knowledge amongst the general public and those professional groups likely to come into contact with people with ASDs to increase the likelihood of early recognition. Specifically targeting training at front line professional groups working with these individuals may facilitate early diagnosis (for example, health visitors, teachers, school doctors, nursery staff, general practitioners, speech and language therapists).

**The key aims of the assessment and diagnostic process are:**

- To inform a decision as to whether or not an individual has an ASD, based on existing diagnostic criteria (ICD-10 in the UK).
- To provide information about the individual's unique profile of strengths and weaknesses in several key domains, such as communication, social abilities or level of functioning and to assess any additional physical and/or psychiatric symptoms that may indicate an associated co-morbid condition
- To allow provision of appropriate supports, services and interventions that will address the needs of the individual and their family or support workers.

Templates setting out the key stages of the diagnostic process for children, adolescents and adults are shown in figures 3 and 4. As well as a diagnosis, a detailed assessment of individual need, covering the relevant domains illustrated in figure 5, is required. This figure illustrates the complex range of needs of this client group. Addressing these needs requires effective, multi-agency, multi-professional working.

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(v) The American Academy of Neurology and the Child Neurology Society have published consensus quality standards, endorsed by several key professional and voluntary organisations for the screening and diagnosis of autism in children.<sup>101</sup> In addition, the American Academy of Pediatrics have endorsed and accepted these guidelines as its policy (<http://www.aan.com/public/practiceguidelines/autism.pdf>). In the UK, the National Initiative on Autism Screening and Assessment (NIASA) has been set up by the Royal College of Paediatrics and Child Health, the Faculty of Child and Adolescent Psychiatry and Royal College of Psychiatrists with the support of the National Autistic Society and the All-Party Parliamentary Group on Autism with the task of facilitating the development of working guidelines and protocols for screening, diagnosis and early intervention of ASD in pre-school and school aged children. Their conclusions are expected in 2002.

**Box 1: The process of diagnosis and assessment: General Principles**

Regardless of the age of an individual there are some universal principles which should guide best practice.

- The most reliable process for diagnosis involves a range of specialist, multidisciplinary, multi-agency professionals making a consensus diagnosis, with reference to accepted diagnostic criteria (e.g. ICD-10)<sup>8</sup> and to a comprehensive developmental history. The more information informing the consensus decision the better.
- The professionals involved in diagnosis and assessment will vary depending on, for example, the age of the individual but might include clinical psychologists, psychiatrists, paediatricians, speech and language therapists and occupational therapists as well as educational psychologists, specialist teachers and social services professionals.
- Diagnosis and assessment are not equivalent and, even before a diagnosis is given, assessment and support to the individual can and should take place. Information from the comprehensive assessment is crucial to informing the final diagnosis. Individualised care packages (particularly educational input) should not be dependant on a firm diagnosis.
- Developmental history is very important. Families should be supported in observing, recording and retaining information about relevant developmental attainments and anomalies. They should be advised to keep this information throughout the person's life.
- Assessment of co-morbid conditions and of each individual's need is essential.
- Effective communication between professionals in different agencies (health, social services, education and the voluntary sector) and between professionals and families is essential.
- Complex processes involving multi-agency working, as illustrated by the diagnostic templates in figures 3 and 4, can use integrated care pathways to improve effectiveness and allow ongoing monitoring the individuals journey through the process.
- This is a time of considerable stress for individuals and their families. Every effort should be made to address this by providing clear and comprehensive information about the reasons for assessment and what is involved. It is important that families know what to expect at each stage and feel part of the process.
- Consideration needs to given as to how best to inform individuals and their family that a diagnosis of ASD seems likely. Presenting information in an understandable way, allowing adequate time for questions and providing adequate support in the initial stages following diagnosis are crucial, as is the provision of information about the next stages in accessing services. Although a diagnosis can be helpful it can also be distressing and stigmatising to those involved.

**Box 2: Key issues at stages of the diagnostic process (all ages)****Stage one: Recognition of difficulties**

- Concerns of individuals and their families must be taken seriously and addressed appropriately.
- Professionals should have adequate knowledge and training in the presentation of people with ASDs
- The use of screening tools, such as the Checklist for Autism in Toddlers (CHAT),<sup>42</sup> can assist professionals in identifying those with a possible ASD when used appropriately.
- Prompt referral takes place whenever there are cases of concern.
- Referral pathways to stage two must be clear and effective.

**Stage two: General Assessments**

- Assessments are broad based, in recognition of the diversity of problems that will be referred.
- If assessments are unable to rule out an ASD, referral should be made for an ASD specific assessment (stage 3).
- Consideration should also be given to referral for a pre-school or other educational/social services assessment at this stage.
- Prior to referral for an ASD specific assessment, the reasons why this is thought to be necessary, what it involves and the fact that this does not mean that an individual definitely has an ASD need to be discussed with the individual and/or their family.
- Referral pathways to stage three are clear and effective.

**Stage three: ASD specific assessments**

Assessments must be multi-professional and collaborative with involvement from other appropriate agencies including education and social work. Professionals involved should be experienced and confident in assessing and diagnosing ASD.

Useful information includes:

- Clinical history with particular emphasis on a detailed developmental history. This may be complemented by the use of a semi-structured ASD specific interview, although obtaining an overall picture of the individual's behaviour is more important.
- Additional information from all other involved agencies or relevant sources such as parents, teachers and support workers.
- Direct observation and assessment of the individual in a number of settings including school, nursery or at home.
- Assessments of current level of functioning in areas such as communication, information processing/cognitive functioning, adaptive behaviour, emotional development and social relationships.
- Neuropsychological profiling.

The information provided by such assessments will be integrated to make a clinical diagnosis.

It will also contribute to the development of a profile of strengths and deficits for each individual which should be used in planning appropriate interventions and services.

**Tertiary services**

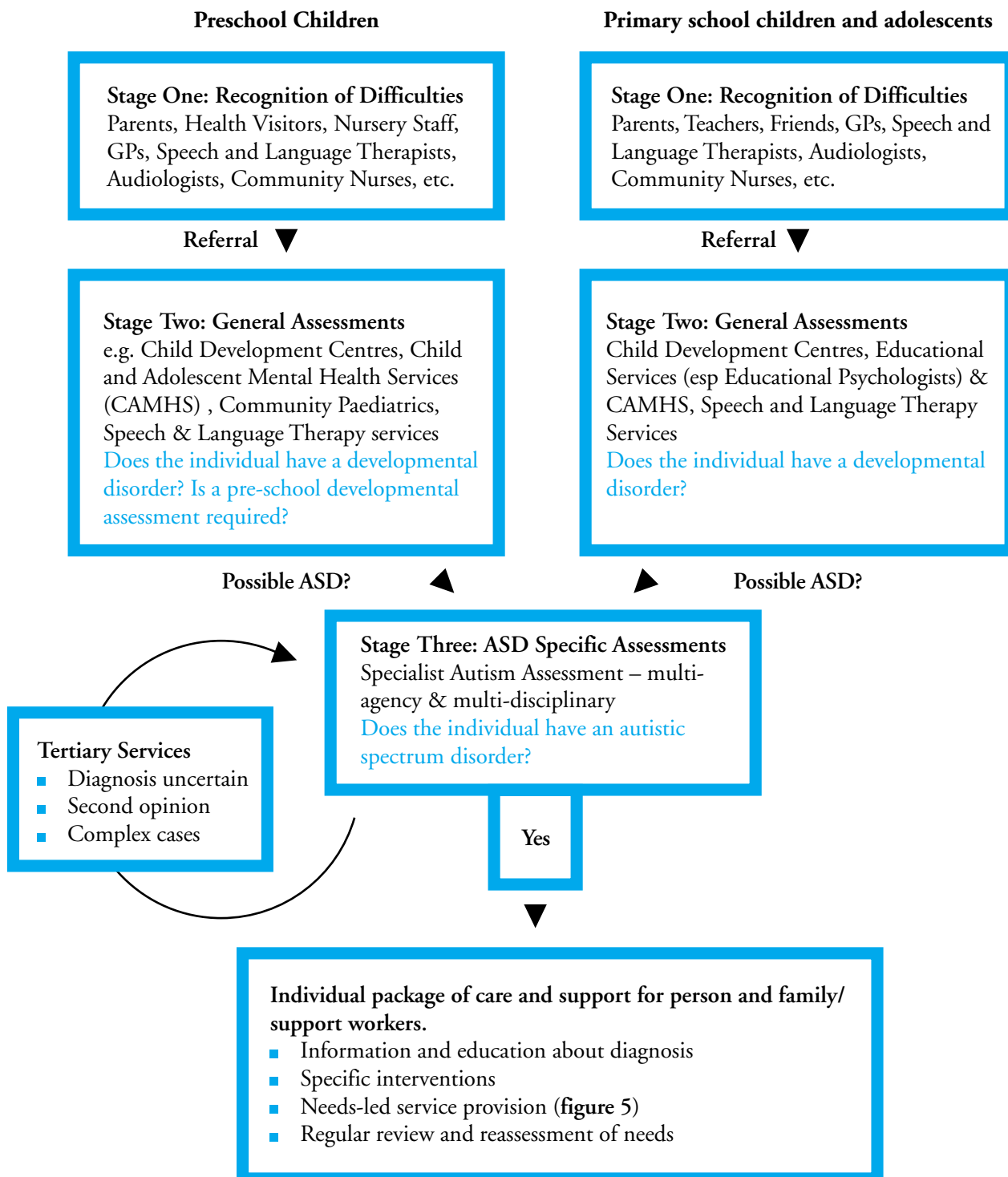
Tertiary diagnostic services provide a range of specialist services for children with ASD. They take referrals for complex cases and can offer a second opinion in cases where there is uncertainty or disagreement over the diagnosis. Tertiary services also have an important role in the training of other professionals.



# 04

## 'Ideal' services for people with autistic spectrum disorders

Figure 3. Diagnostic services for children and adolescents



#### 4.2.2 Assessment and diagnosis: Preschool children (see figure 3)

To allow children to benefit from early interventions it is vital that adequate resources are provided to facilitate early detection and diagnosis of autistic spectrum disorders in preschool children. A UK study found that parents of children with ASDs often have concerns when their child is 18 months old.<sup>20</sup> However, the researchers found an average delay of 6 months before parents discussed these concerns with a professional, and that in fifty per cent of cases the parents were reassured and told not to worry. The usual time between the parent's first concerns and a diagnosis being made was four years.

**Early intervention is important in maximising the behavioural and educational outcome of children with ASD, in supporting their family and in minimising the adverse emotional impact of the condition on the child and other family members. Therefore, a key aim needs to be minimising the delay between the initial concerns of parents, a diagnosis being made and provision of appropriate interventions and supports.**

##### Stage One: Recognition of difficulties

It is important that parents who have concerns over the development of a child have access to appropriately trained health visitors, community nurses and GPs. These concerns should be listened to, taken seriously and addressed in all cases.

In addition, every preschool child is offered the opportunity of routine developmental surveillance as part of their regular contact with health visitors and, in the ideal service, all aspects of the autistic spectrum should be considered specifically as part of this surveillance.<sup>101</sup> Some tools are available to assist the identification of young children with autistic spectrum disorders. Different tools will be appropriate in different circumstances and evidence to date does not yet allow a recommendation of which is most appropriate however, of those available, the CHAT<sup>42</sup> is the most prominent attempt to develop a general population screen. The CHAT does not in itself provide a definitive diagnosis but does identify some children who require thorough assessment. When used in a two stage way (those who initially screen positive receive a second administration of the screen one month later) with children at 18 months it has a high specificity (a low false positive rate) and a high positive predictive value. It is therefore useful as a screening instrument to help the early identification of children who should be referred for further assessment, but its low sensitivity means that it will miss a considerable number of children with ASD. However, research to date suggests that the increased knowledge and understanding of autistic spectrum disorders amongst those trained to use the CHAT was of great benefit in increasing earlier referral of children with ASD and other developmental problems<sup>100</sup> hence the need for broad checks to be placed within a standard surveillance programme. What is vital, however, is that all key front-line professional groups (health visitors, nursery/pre-5 education staff, general practitioners, teachers and others) receive training to increase their awareness of the presentation of ASDs at various ages and their confidence in referring on for further investigations. It is also vital to note that a child who fails a screen but does not have ASD may have other developmental problems that warrant assessment and/or specific services.

**Stage Two: General Assessments**

Those identified in stage 1 may have a range of differential diagnoses, including speech and language disorders and attention deficit and hyperactivity disorder (ADHD), amongst others. The role of the service at stage 2 is for detailed developmental assessments to be carried out by a number of professionals working together that will allow identification and appropriate referral of non-ASD cases, and referral of those children whose presentation is suggestive of ASD onto stage 3 for specialist assessment.

In order to minimise the time to a definitive diagnosis being made, in cases where referral from stage 1 is strongly suggestive of ASD, it is appropriate for the assessment to be passed directly to stage 3.

If referral to an educational psychologist for a preschool developmental assessment and/or a Record of Needs report has not already occurred this should be considered in order to ensure appropriate interventions at the earliest opportunity.

The anxiety that parents experience when told that their child is being referred for assessment is an important consideration. Ideally, throughout stages 1 and 2 parents would be made aware that there are a range of problems that are being considered and it would also be made explicit that one of these is an ASD. If referral is being made for ASD specific assessment the reasons for this must be discussed with parents and/or the individual in an honest and sensitive way.

**Stage 3: ASD specific assessments**

Discussion of the issues at this stage and detailed recommendations are given by Filipek et al (2000).<sup>101</sup> UK specific guidelines are being developed by the NIASA (see page 27).<sup>y</sup>

The information provided by specific assessments will be integrated to make a clinical diagnosis and also to highlight an individual's particular profile of strengths and deficits across these various domains. This will be via a consensus, multi-disciplinary, multi-agency process. With this knowledge targeted interventions and services can be planned.

It is helpful to appoint a key person who will represent the team view and be the main communication link with the family. This could be any of the professionals involved though some families may prefer this to be someone out with the clinical team assessing their child.

**Tertiary Provision**

Where there is uncertainty about a child's diagnosis, in complex cases or when second opinions are required, children can be referred on to more specialist tertiary services. Not only would these tertiary services offer diagnostic services for such cases but they would also provide support, examples of good practice and secondment opportunities to other professionals in order to develop their skills and confidence in working with children with autistic spectrum disorders. Ideally, the processes of assessment, diagnosis and intervention at the tertiary level within health care services will be linked to education and social care considerations.

#### 4.2.3 Assessment and diagnosis: School age children and adolescents (see figure 3)

Even within an ideal service, some children, particularly those with Asperger's Syndrome and autistic disorder without a co-existing learning disability, will not present with difficulties until they are older. The first years of primary school, secondary school and then later adolescence (e.g. times of change or transition between schools or other services) are periods when problems can arise.

##### **Stage one: Recognition of difficulties**

With the wide range of presentations during childhood and adolescence it is important that professionals working with these age groups have a working knowledge of ASDs. Alongside parents, teachers, primary care professionals and the school medical service have a key role in recognising the difficulties a young person is experiencing. Therefore, these professionals require training on the recognition of social and communication problems and referral procedures.

Academic problems are easier to pick up than the subtle social and communication impairments. Indeed, many children with undiagnosed ASDs will already be receiving some degree of learning support. Discussions between parents, teachers and, when appropriate, children or adolescents should take place at an early stage and those children recognised to be experiencing problems should be referred to an educational psychologist for assessment.

Other young people with underlying ASD may present initially with emotional or behavioural problems to educational psychologists, school medical services, primary care or child and adolescent mental health services (CAMHS). These professionals should be familiar with the presentation of ASDs and the relevant referral process.

Social services professionals should be involved at this early stage, not only for support of the individual being referred but also for support of the family and other siblings. In the ideal service these professionals would have an understanding of the complex nature of ASD, experience in working with this client group and knowledge about the range of relevant services available locally.

##### **Stage two: General assessments**

Educational psychology services and CAMHS will receive initial referrals of young people recognised by, for example, the school medical services and primary care professionals to have difficulties at stage 1. In order not to overlook any cases of ASD, for every referral and assessment it is important that professionals always include this amongst a list of possible diagnoses and that this is specifically excluded. In cases of apparent late onset, medical causation must be excluded. If it is not possible to rule out an ASD, referral should be made for a specific ASD assessment (stage 3). Other developmental problems identified at this stage should be referred on appropriately.

**Stage three: ASD specific assessments**

The principals described in **Box 2** are applicable.

Although similar methods for assessment and diagnosis are used, older children and adolescents will have widely varying presentations quite different to those of preschool children. Many will have insight into their condition and be able to describe the difficulties they experience. Whilst it will be a relief for many adolescents to have their problems assessed with a view to receiving appropriate supports, this can be very stressful. Professionals must be sensitive to the emotional impact of assessment and diagnosis on both the young person and his or her family.

**Tertiary Provision**

Where there is uncertainty about a young person's diagnosis, in complex cases or when second opinions are required, children can be referred on to more specialist tertiary services. Not only would these tertiary services offer diagnostic services for such cases but they would also provide support, examples of good practice and secondment opportunities to other professionals in order to develop their skills and confidence in working with individuals with autistic spectrum disorders. Ideally, the processes of assessment, diagnosis and intervention at the tertiary level within health care services will to be linked to education and social care considerations.

**4.2.4 Information for parents of children of all ages**

Once a diagnosis has been made, verbal feedback should be given in person to the parents and adequate time allowed for questions and the immediate consequences of the diagnosis to be discussed. Explanations about what happens next and the involvement of the various agencies should be given. Written information should be provided which has details about ASDs, local resources and voluntary organisations including family support services. Information should also be provided on access to a key worker and/or an independent advocate.

Parents of all children who have received a diagnosis of ASD and adults diagnosed with ASD should automatically be asked to contribute to the assessment report and will receive a copy of the final document. It should also be normal practice to offer parents and adults a follow up meeting with members of the diagnostic team when they have had time to reflect on the diagnosis and the consequences of this.

#### 4.2.5 Assessment and diagnosis: Adults (see figure 4)

For adults identified as possibly having an ASD, the diagnostic process should be similar to that described for children and young people but with different professionals involved at different stages. There are two groups likely to present for assessment and diagnosis for the first time in adulthood.

- Individuals with Asperger's syndrome and more able people with autistic disorders who have found ways of managing throughout childhood and adolescence. It is often on entering higher education or employment that problems arise in these cases, often manifest as mental health problems.
- Adults with severe learning disabilities where problems in childhood were attributed to a generalised developmental delay and ASDs were overlooked. With the closure of large institutions hundreds of adults with learning disabilities are now living within their local communities again. The increased awareness amongst professionals has provoked interest in undiagnosed ASDs amongst this group.

The experience of professionals working in the field of adult care is that, even in adulthood, diagnosing an ASD and providing appropriate support packages can bring considerable improvements to behaviour, mental health and quality of life.

##### **Stage one: Recognition of difficulties**

For adults to receive appropriate services, an awareness that people with an ASD can present for help for the first time in adulthood is necessary amongst general practitioners, adult mental health services, community nurses, university health and counselling services and occupational health departments. In addition, support workers of adults with learning disabilities should be encouraged to question whether or not their client has an undiagnosed ASD and should be familiar with the system of referral to stage 2.

##### **Stage two: General assessments**

Initial referrals will often be made to Community Mental Health Teams (CMHT) or Community Learning Disability Teams (CLDT). Once again professionals carrying out assessments should have a working knowledge of ASDs and be aware that these disorders can present for the first time in adulthood. Marginal cases should be referred for further investigation.

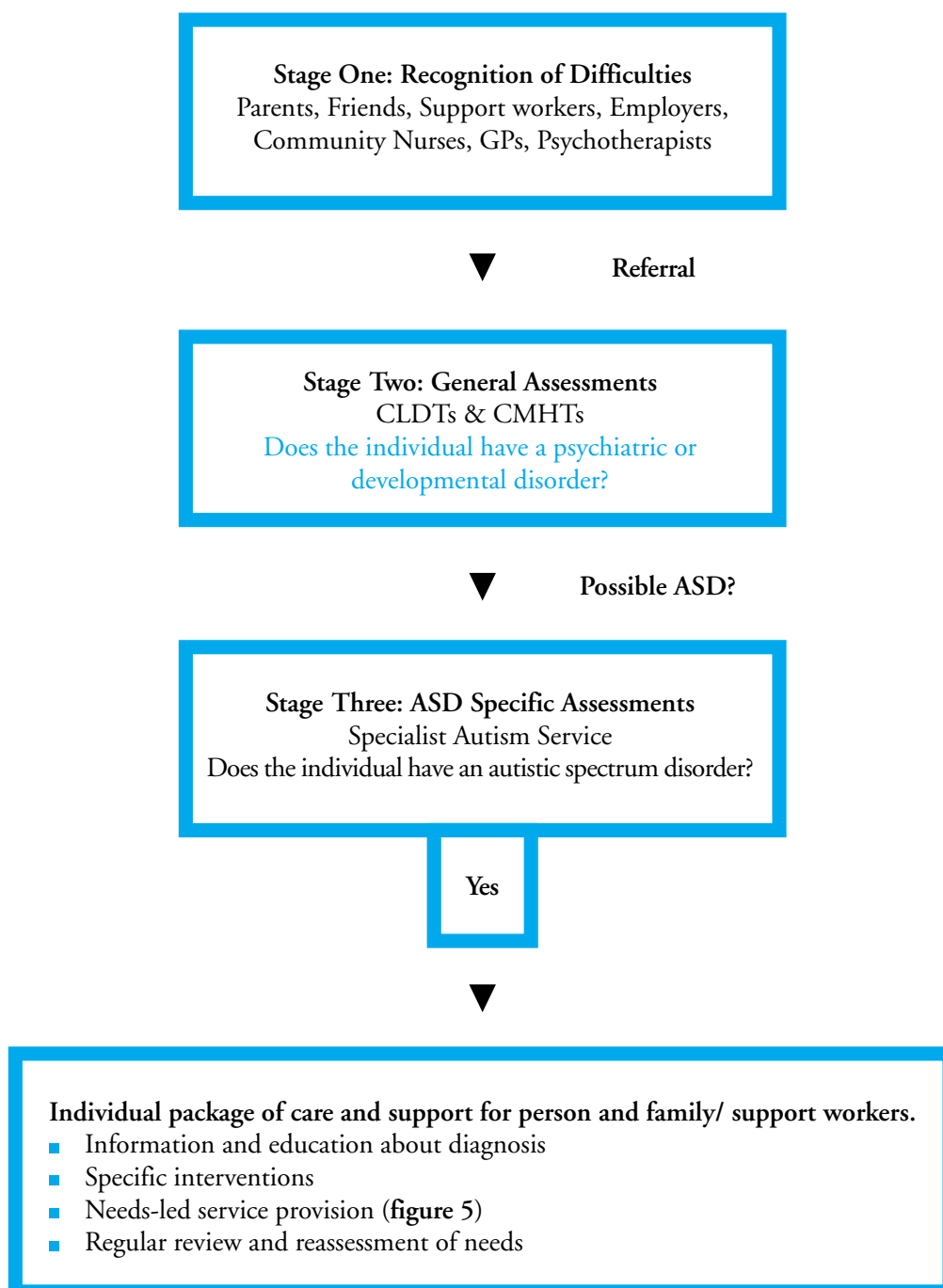
##### **Stage three: ASD specific assessments**

Appropriate multidisciplinary professionals drawn from those mentioned in Box 1 should work together provide a specific diagnostic service to adults which takes referrals from CMHT and CLDT (stage 2). This service may be provided by a specialist team or may draw on a number of professionals with specific skills in this area, depending on local resources. Irrespective of the model, this diagnostic service should work jointly with other local agencies to assess the needs of diagnosed individuals and develop a joint planned package of care to be delivered within the individual's own community. The key feature of this core service is that it should not be linked to level of ability and so be able to work with people with disorders anywhere on the spectrum.

# 04

## 'Ideal' services for people with autistic spectrum disorders

Figure 4: Diagnostic service for adults



### 4.3 Post-diagnosis support and care

#### 4.3.1 General Principles

Once diagnosed, all individuals with ASD, irrespective of age, require ongoing developmental support for their core disorder according to an agreed individual plan (developed jointly by health, education, voluntary and social services), with treatment of any co-morbidity as required. There are a number of key principles for professionals, and for the services in which those professionals work, which should be adhered to in an ideal service.

#### Box 3: General principles for services working to support people with ASD

A person with ASD requires access to services which:

- **Are multi-agency and multi-professional and work effectively together to address the needs of this lifelong developmental condition**

Support after diagnosis and assessment requires ongoing multi-professional input to implement individual care plans and to regularly review and revise them over time. Systems must be in place that ensure this occurs in all cases. The model for multi-agency collaboration and identification of the lead agency may vary according to local circumstances and, indeed, may change over the life span.

- **Manage the transition between their services with sensitivity and with consistency.**  
All services must be flexible and sensitive of the impact of the transition on the individual. 'Transitions' in terms of both major life changes and small, seemingly insignificant changes in routine may cause people with ASD a crisis. People with ASD have difficulty in coping with change therefore services need to have ways of working that are sensitive to the individual's ability to cope in such circumstances. Ideal services are flexible enough to recognise and appropriately react to these sensitivities especially at service boundaries (e.g. between child and adult services, during the transition between schools) and this will require less rigid demarcations between services and their roles.

In order to help address the stress experienced by families after the period of assessment and diagnosis, there should be some opportunity to reassure families of the ongoing multi-professional support both across and between agencies which will straddle the period from childhood into adulthood or movement between services.

- **Ensure their staff are appropriately trained in autistic spectrum disorders**  
Training for all those who live and work with people with ASD is of paramount importance. Of particular value is familiarity with the course of the disorder and the range of possible outcomes. A wide range of training is required to meet the differing needs of, for example, day-to-day carers (including parents) in residential and day care settings, staff of educational establishments, social workers specialising in this field and health care staff who need to develop specialist skills including GPs, specialist psychiatrists, therapists, nurses, dentists, psychologists, and people involved in health promotion.

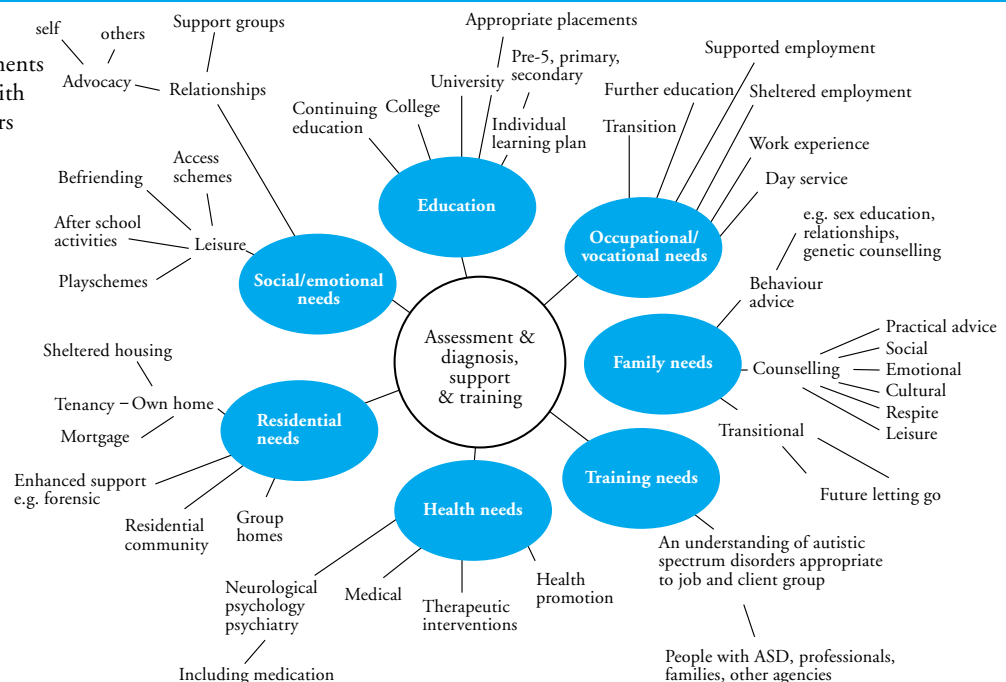


### Box 3 cont.

- Provide timely and appropriate patient/parent information**  
 Information is required after diagnosis that is appropriate to the life stage and during the transition between services. This will assist the individual with ASD and the family to understand and plan appropriately for the changes in their lives, and to access appropriate information and support.
- Have guidelines and systems in place to monitor services**  
 Clear agency and interagency guidelines and communication structures, defined care pathways and service standards should all be in place. These will have been defined locally and agreed between the relevant agencies. This document recommends that national global standards for lifelong care are developed by a multi-agency, multi-disciplinary working group. Once developed these should influence local guidelines.
- Provide the opportunity of key workers and/or advocacy services for all those with autistic spectrum disorders**  
 A key worker model (where jointly funded, jointly resourced key workers support individuals throughout the system) should be available to all people with autistic spectrum disorders (irrespective of IQ) immediately after the diagnosis of an ASD, irrespective of the age at which this happens. This key worker model must also be supported by a individual care plan to which all services have contributed and which is regularly reviewed. In addition, advocacy services should also be available to all individuals with ASD. For some individuals, particularly those with Asperger's Syndrome, access to advocacy services may be more appropriate than a key worker.

**Figure 5 :**

Range of service requirements for children and adults with autistic spectrum disorders



This model is not all inclusive.

Reproduced and adapted with permission from the National Autistic Society Scotland.

There are a variety of ways of addressing the principles in Box 3 and systems may vary locally according to specific circumstances. However, it is crucial that services work collaboratively to meet the range of needs of people with ASD. Some of these needs are outlined in figure 5 (adapted from the National Autistic Society) which illustrates the complex and diverse range of potential needs of this client group. These needs are discussed in more detail in the remainder of this section. However it should be noted in all cases that the appropriate level of intervention for any individual should reflect the needs of that individual. The nature of the autistic spectrum is such that needs will vary significantly between people on that spectrum and at different life stages.

#### **4.3.2 Inclusion**

Currently many people find that they are excluded from society, their peers and their communities because of their autistic spectrum disorder. The impact of the social and communication difficulties that are shared by all people with ASD pervade into every aspect of their lives and result in exclusion from the experiences of the non-autistic world. For people with ASD to be included in this world, it is essential that the impact of the autistic disorder is addressed and that appropriate support is offered. Therefore, the most inclusive services are primarily focussed on addressing the impact of ASD in order to resolve the root of the person's exclusion.

#### **4.3.3 Education**

All children should have access to some form of pre-school assessment<sup>vi</sup> as soon as there is concern indicating a developmental problem.

Involvement of parents and first line professionals should be encouraged from the outset, with the aim of working with them to address the communication and behaviour management issues so they are better able to meet future challenges.

There should be a variety of educational placements available at all levels from pre-5 to tertiary education and individuals should be placed according to their specific profile of needs. There will be children who can manage the mainstream curriculum but require support with the social and interpersonal demands. Children and young people should be placed in local educational establishments when possible. When it is appropriate for the child, integration with mainstream peers should be a goal but this will depend on individual needs. In line with current policy, social inclusion remains an aim but in some cases this might be best achieved with ASD specific or residential services in a way that meets individual needs. The concept of social inclusion should be interpreted in line with the needs of the individual.

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(vi) In some parts of Scotland there is a planning and review system for pre-school children who may experience special education needs which are significant and are likely to be long term. The Pre-School Community Assessment Team (PRESCAT) is co-ordinated by the Psychological Service within Educational Services. The PRESCAT group comprises parents and representatives of agencies participating in the assessment, intervention, resource planning and provision for children experiencing special educational needs. PRESCAT meetings co-ordinate assessments and plans for pre-school children and their families and focuses particularly on entry to nursery and school placement. The major function of PRESCAT is to ensure the suitability of the educational provision for the child.

All children should have access to appropriate professionals such as a child and adolescent psychiatrist, clinical psychologist, dietitian, educational psychologist, occupational therapist, paediatrician, school doctor/nurse, speech and language therapist and teaching and support staff who have skills and experience in autistic spectrum disorders.

Educational establishments which take pupils with ASD should be geared to addressing the needs of those with ASD and should meet agreed quality standards, which require to be developed and agreed by the relevant parties. These should apply to practice, evaluation and audit and should be standardised nationally. Irrespective of whether educational establishments are mainstream or ASD specific, they should provide structured education for pupils with ASD. This may be supplemented or informed by intensive intervention programmes as appropriate but the focus must be on the provision of a good education. A good educational provision should ensure that the child's ability to participate in an age-appropriate curriculum is balanced with their need for support to enhance their understanding of social communication.

All children with significant impairments should have an individualised educational programme (IEP) which should include long and short term targets relating to their personal and social development. The IEP should be reviewed regularly with the child, his or her parents and other relevant agencies. Aspects of good practice relating to special educational needs are covered in A Manual of Good Practice in Special Educational Needs.<sup>102</sup>

The Records of Needs process should adhere to principles of good practice, which include multi-agency assessment in partnership with parents and identification of needs leading to an individualised educational programme. This should be reviewed by a multidisciplinary team and modified according to changing need over time.

From an early stage multi-agency plans must be in place for the transition of the individual between educational establishments.

#### **4.3.4 Further education, vocational and occupational needs**

These should all be assessed by appropriately skilled individuals. It may be that the adult with ASD could benefit from further education, depending on ability, and support for this should be available. Specialist support should also be available to enable people to gain employment whether this be work experience initially building up to supported, structured or open employment if this is what the individual wants or can reasonably cope with.

Day services of other types should also be available. The key should be flexibility and responsiveness to individual need.

The careers service should be involved with all young people receiving a Future Needs Assessment from this point. Schools should ensure that young people with ASD who do not receive a Future Needs Assessment but who could benefit from specific careers advice are referred. A range of opportunities should be available including further and higher education and supported employment and for those who require it, a named contact should be available to assist the young person in this educational or vocational setting. It is also vital that social services and other appropriate agencies are involved from an early stage to ensure that young people who require it receive social skills development to assist them in adapting to this new environment.

#### **4.3.5 Family needs**

Families require information about ASD, the professionals likely to be involved and the likely process and timescale. They also require information about other services and groups they may wish to contact. Families, and the individual with ASD, should feel that they are working in partnership with the multi professional teams from the first time a concern is raised through the diagnostic assessments, post diagnostic support and individual care plan development.

Individuals with ASD and their parents and siblings should have the opportunity of respite services, counselling and support groups, advocacy services, subsidiary services such as suitable hairdressers, advice and support with discussing the disorder within their family, and on behaviour management. Genetic counselling should also be available to parents or individuals who wish it.

Social services should play a key role in the assessment team to ensure that appropriate support services for the individual and the family are considered from the point of initial assessment. It is also important that a relationship is established between social services and the family from the outset to help assure parents that any difficulties in future years will be responded to in routine and positive ways and with joint agreement.

#### **4.3.6 Training needs**

Training is vital for all those working or living with people with ASD. These will include a wide variety of groups with varying training needs. Multi professional training and staff development will also assist cross agency working and involvement of local parents and carers, after appropriate training, can assist in building understanding between professionals and carers. Raising awareness amongst the public and amongst peer groups will increase recognition and understanding of the disorder.

#### **4.3.7 Health needs**

A range of health needs exist after diagnosis has taken place, irrespective of the age of diagnosis. These will mean ongoing contact with services regarding aspects of the disorder which may include paediatricians, appropriate therapists, clinical psychologists, dietetic services and psychiatrists. For some, the use of specific health services will be episodic, being

required for example during periods of transition or high stress. Mainstream health services may be inappropriate for some of these patients and so specialist services should be available especially for those who develop co-morbid psychiatric problems.

Health services to meet day-to-day health needs unrelated to the autistic spectrum disorder, such as dentistry, optician services, and mainstream primary and acute health care services will also be required by people with ASD and services that understand appropriate approaches should be available.

#### **4.3.8 Residential needs**

Children and young people should be assisted to live at home where appropriate and if this is possible, and this may be complemented by a range of respite or other peripatetic support services aimed at maintaining the individual within his/her family or home setting. The decision for a young person to enter residential care has a number of implications and should be taken with care and in full consultation with the individual and his/her family.

For young people and adults, a range of residential accommodation should be available, from fully independent to fully supported. Individuals who are able should be assisted to live in their own homes, either as tenants or homeowners. Access should be available to independent living schemes, vocational training, suitable adapted housing and community support to enable them to achieve independence consistent with their abilities and wishes. Some people may benefit greatly from an autism specific environment as provided by specialist organisations. Others may not need such a high degree of ASD specificity and the structure and predictability could be provided in a less specific setting.

Residential schools or units or 'core and cluster' models of provision should be planned and developed in consultation with all relevant local agencies and services. The health care of people in these facilities may make significant demands on local services and these needs should be considered, planned and developed from the initial residential care commission. In addition, there should be a clear agreement between the school, the family and relevant professionals about which health board or service is responsible for providing a follow up service for children to be educated in residential provision.

Some people may be happier to remain with parents and family members. Careful advance planning should enable a smooth move to alternative accommodation in the future for these individuals.

A number of people with ASD have their needs further complicated by mental health problems. This may fluctuate and constant residence may not be necessary especially if appropriate day services are available. However, there should be appropriate provision for in-patient neuropsychiatric assessment and treatment of individuals with ASD whose problems are sufficiently severe and complex to require it. These services should be developed by the NHS in partnership with other organisations. A small number of individuals will require secure accommodation and this should be age appropriate.

There is also a small percentage of people with autism who have severe co-existing conditions, such as epilepsy, for whom provision of specialist care should be made.

Consideration must also be given to specialist provision for people with ASD who have offended or are at risk of offending. Access to forensic psychiatric services should be available when appropriate. A recent study in England found that although the numbers of individuals with ASD that fall into this category are small, they pose specific challenges in terms of management and treatment.<sup>103</sup>

#### **4.3.9 Social/emotional needs**

Post diagnostic support should be available for the individual and their parents and siblings. The emotional impact on parents and siblings of those with ASD, as well as the individuals themselves may be considerable and the collective needs of the family should be assessed and addressed. This may take many forms but might include individual counselling and/or family work, either formally or informally. Links with voluntary services can be especially useful.

Support groups should be available locally for individuals and their families and befriending schemes and social and leisure activities should be enabled as required.

Assistance should be given with developing self-advocacy skills and independent, trained advocates should be available to represent individuals if necessary.

Opportunities to improve social skills can be achieved in a variety of different ways and a range should also be available. Examples include informal means such as buddying or mentoring, or more structured ways either in groups or on an individual basis.

Families may need specific assistance regarding aspects of the individual's behaviour and future developments.

## 5. Current Services

This document has described the knowledge to date about autistic spectrum disorders and how, ideally, a network of services might ensure the best outcome for those with ASD. This chapter provides a summary of some of the features and difficulties in current services identified from a number of sources (see appendix one). A national mapping project of ASD services in Scotland is underway by the Scottish Society for Autism and the National Autistic Society and due for completion in Summer 2002. The findings from this will provide further vital information about current services.

It is one of the key recommendations of this report that service providers review their services in the light of this document. Though this review should focus on the 'ideal' (see Chapter 4) a recognition of the obstacles that may stand in the way of this, and some current developments which are described in this chapter, may aid this assessment.

There are examples of good, innovative and multi-agency practice across Scotland however, in general, such provision is patchy and inadequate for the numbers requiring support. Provision varies depending on local resources resulting in, what might be called, a 'post-code lottery'. Adults are particularly poorly served in terms of both diagnostic services and post diagnostic support. In addition, whilst those clients with a learning disability can access services delivered as part of learning disability funded programmes, those people with ASD but without a learning disability are often unable to access any appropriate services or support.

### 5.1 Assessment and diagnosis

- a) Although examples of good practice do exist, accurate identification of those with ASD is often haphazard and poorly organised. This results in frustration and isolation for many parents who have had concerns dismissed or ignored for a number of months or years prior to referral of their child for further investigations. There are virtually no services in Scotland geared up for the identification, diagnosis and assessment of adults with ASD and few professionals are skilled in this area.
- b) Health visitors, general practitioners, audiologists, nursery nurses, community paediatricians and school staff have key roles to play in identifying possible developmental problems and referring children promptly for further investigation. However many of these professionals do not have an adequate understanding, unless they have been motivated themselves to undertake further study in this area, and so lack the confidence or experience to identify signs that suggest prompt referral is appropriate.
- c) For children, there are various models of referral for further investigation in place across Scotland, with service provision in some areas highly dependent on the particular professionals working in the locality. Some families are so frustrated at the lack of professionals or services in their area that they are motivated to move house in order to access services that are able to assess their child. For adults, again, there are no formal systems in place for diagnosis and assessment.

- d) Upon referral, a number of medical tests and assessments are required to eliminate alternative diagnoses, to identify co-existing conditions and, in some instances, to establish the causes of the autistic condition. In many areas, access to a range of medical tests is limited.
- e) Multi-agency assessment is essential if an appropriate diagnosis and subsequent, holistic and co-ordinated care plan is to be developed. However, true multi-agency assessment appears to occur in a very limited way across Scotland with most agencies working in relative isolation in most areas. The reasons for this are likely to include lack of resources including skilled, trained professionals with dedicated time for work on autistic spectrum disorders, lack of co-ordinated planning systems across (and within) agencies, ring-fenced budgets that limit the extent of joint working across agencies, the lack of co-terminosity between agencies (e.g. local authorities and NHS boards) and increasing numbers of identified individuals with ASD without equivalent increases in service provision.
- f) A long waiting time for diagnosis is often required which can be multiplied several times because of further referrals on to tertiary services. This can extend the waiting period prior to diagnosis and to resultant support services by months, and sometimes years. This has obvious implications in terms of the opportunities for early intervention as well as causing considerable anxiety to parents.
- g) The number of specialist professionals is inadequate to meet the current number of children being referred for further investigation. This impacts on the waiting time for assessment and results in later intervention than would be ideal. An increased focus on prompt and early referral of children for further investigation, as recommended in this report, would place further demands on these professionals. There are virtually no health care professionals funded to carry out this role for adults.
- h) The voluntary services offer useful information on autistic spectrum disorders and good support services for families, siblings and individuals with ASD, however currently this often has to be sought out individually and many find unhelpful and misleading information on the internet during this search. Parents and individuals often receive little if any information about the disorder, the pathway to diagnosis or the options available for support and development after diagnosis, and for some the possibility of a diagnosis of ASD may not have been mentioned to them. This results in confusion, fear and isolation for those with ASD and their families.



## 5.2 Services post-diagnosis

- a) This report considers the prevalence estimate of ASD of approximately 60 per 10,000 children under 19 to be the most accurate to date (see Chapter 3). Current services in health, education, social services and the voluntary sector are not resourced or geared to deal with this number of clients. Any improvement in identification and diagnosis, both in terms of numbers identified and age of diagnosis, as advocated in this document, will require to be matched by a suitable increase in provision of a range of health, educational and social support services for children and adults with ASD, and their families, in order to cope with the diagnosis and ensure the best outcome for both the individual and the family.
- b) Currently, social services may only be involved in the assessment process at points of crisis, for example, challenging behaviour or exclusion from school. Crisis requests and crisis responses are costly for social services, as well as difficult to manage. Early involvement of both social services and voluntary support services would allow more support at early ages which may prevent such crises occurring. Appropriate early social services involvement can also help families' understanding of the condition and their ability to deal appropriately with it. It is also important in improving an individual's ability to cope with vocational placements or further education opportunities. A recent English study found that social services were only involved in 30% of transition plans for persons with ASD.<sup>104</sup> At the present time social services departments, like a number of other related professions, are currently experiencing significant problems recruiting staff and this further limits the extent to which they are able to be involved.
- c) There is a lack of co-ordination and collaboration between services and within services. This does not only mean that individuals with ASD experience fragmented, uncoordinated and patchy services with no obvious lines of responsibility, but also that these services have no data on the numbers of young people with ASD currently in the system and possibly requiring support in future years. One social services department commented,

*“At present the data available to social work services is related only to those families receiving services rather than to prevalence and need across the locality”.*

This makes it almost impossible to organise, plan and resource adequate and coherent services for people with ASD as they age. Current problems are largely because of poor communication between the different departments within agencies (children, adult, learning disabilities), poor communication between local authorities and health care services, insufficient resources, the different budgets for different services, the lateness of social services involvement and the lack of timely information that allows planning of services. There is also a view that the financial costs of what can be expensive resources required to address the needs of this client group are not shared equally between the agencies involved.

- d) Autistic spectrum disorders are hugely variable in their manifestation and a spectrum of services is required in order that the variable needs of individuals with the disorder are appropriately met. Multi-agency diagnosis, assessment and ongoing support requires that an adequate range of education, social service and family support services are available that cover this spectrum of needs through all the life stages. Auxiliary support within mainstream provision across all sectors (social services, education and health care), as well as ASD specific service provision for the more acutely affected individuals, are currently inadequate to meet the numbers being diagnosed with ASD. Currently, many individuals are placed in services because that is all there is available locally rather than because they meet the identified needs of the individual.
- e) There has been a significant expansion in educational provision over the last five years in response to the increasing numbers of young people being diagnosed with ASD. However the increasing demands are stretching these services.
- f) The Beattie Committee proposals <sup>105</sup> have the potential to make more effective planning for young people with ASD in the transition from school to adult life.
- g) The decision by a small but significant number of parents to engage in intensive home-based programmes for their children has significant implications for the assessment and monitoring processes of all agencies normally involved with these children.
- h) 'The Same as You?'<sup>1</sup> a review of services for people with learning disabilities published in 2000, suggested that services for those with ASD should be provided by learning disability services. However, individuals with ASD at the more able end of the spectrum are frequently dealt within mainstream services. At the present time many specialist services are not available to people with ASD unless they have a learning disability even though they may have many complex needs. Consequently, some people are falling through a gap in services and this needs to be addressed.
- i) There is very little appropriate in patient provision for individuals with ASD who have severe and complex problems that require neuro-psychiatric assessment and treatment. This small group of people have specific needs which challenge current services.
- j) The Careers Service supports many young people with ASD with finding appropriate further educational and vocational opportunities. However, vocational and employment opportunities for adults are exceptionally limited, despite most of those at the more able end of the spectrum having considerable qualities to offer employers. Many adults are doing nothing at all with their days.

- k) Housing needs are currently inadequately met. Often elderly parents are left to look after their adult children with little support, and fear what will happen when they are unable to provide this care. A recent NAS survey in England found almost half of the adults surveyed living at home without any social services support.<sup>104</sup>
- l) Leisure and other life enhancing opportunities are generally unavailable to those with ASD. There is a need for some services, e.g. befriending services, to be developed and access to others, e.g. clubs, sporting activities and other social opportunities, to be improved.
- m) Families with a child with ASD are often excluded from 'normal' life. The major disruption caused by the burden of care impacts significantly on the social life of the family, parental careers, mental health of parents and siblings, and marital relationships. There is a need for support for families in understanding and managing the communication and behavioural problems associated with the condition, and for practical support at times of particular stress.
- n) All types of respite and short breaks are vital e.g. school breaks and out of school care, sibling support and respite for parents. There is a particular lack of appropriate day and respite services for adults. Flexibility dependent on the needs of individuals and staff skills is important. Current services are inflexible and lack imagination in provision although examples of innovative projects exist across the country e.g. family based respite has been working in some places and could be developed. In addition, the block booking of places, though easier for services, may not be the best use of money in terms of meeting individual need.
- o) The voluntary sector currently provides a range of support services for families, children and adults with ASD that cover the spectrum of needs that exists. There are also examples of joint working between the voluntary and statutory sector. Current support services, however, are not able to deal with the current and growing demand.
- p) Advocacy services are limited and many find it difficult to get information on local services suitable for people with ASD. This is particularly the case for adults.

### 5.3 Databases and registers

Currently there is no register of cases, or nationally organised data collection on ASD. There is a national Special Needs System, although it is not implemented nationally. Currently about six or seven NHS Board areas are using it, although not all are using it throughout. In the boards using the system, children diagnosed with autistic spectrum disorders or pervasive communication disorders should be recorded on the system. The data is not held centrally at present so information about the quality, completeness and consistency of the data within and between boards is not known.

#### 5.4 Training

- a) Strathclyde University is the major training provider at higher educational level, being the only university sector provider in Scotland of a validated multi-professional post-graduate certificate, diploma and masters levels award in autism. This award links to, but is not part of the national training framework for special educational needs for teachers, since the autism courses are multi-professional in nature. These courses are offered at a local level in various locations in Scotland and are open to the full range of professionals, to parents and to people with ASD who are appropriately qualified. Some other higher educational institutions offer single modules in this area.
- b) A considerable number of professionals are currently involved in providing local training however this is often done without additional resourcing or cover and is therefore limited by clinical pressures and other professionals and external demands.
- c) A social work project is underway in Scotland which has been funded by the Scottish Executive for a three year period from April 2000 and aims to deliver on three fronts:
  1. To deliver basic autism awareness training to all social work grades and ancillary staff.
  2. To set up steering groups (involving health, education social work, parents/ carers as well as possibly individuals on the autistic spectrum) to develop training to meet more complex need.
  3. To provide and produce a training pack for the use of parents/ carers.

To date there has been training provided in 17 authority areas with approx. 4000 social services staff attending. This model is one that could be replicated for other professions.

## 6. Recommendations

A range of services must be available to adequately meet the differing needs of those with disorders on the autistic spectrum. These services require to be co-ordinated, multi-agency and seamless. This echoes recent government reports which have emphasised the need for improved and innovative joint working between statutory and voluntary agencies and joint management and resources for services for a number of client groups.<sup>106 107 108 109</sup>

Although many of the problems and issues raised in this document are similar across the country, solutions may be different depending on geographical location. The following recommendations of this report should be considered with this in mind.

### Summary of recommendations

#### Standards and Monitoring

- A working party should be established by the Scottish Executive to develop global standards for lifelong services for those people with autistic spectrum disorders (ASD) that require it. It should also review current training provision in Scotland.
- Thereafter the Scottish Health Advisory Service (SHAS), or an alternative body, should monitor these standards.
- A request is made to the Scottish Intercollegiate Guidelines Network (SIGN) to develop guidelines for evidence based approaches to the diagnosis and management of ASDs.
- A conference is planned for 2002 and should be used to bring together interested parties to discuss the implications of this document.

#### Matching Resources to Need

- Development of services for people with ASD should be sought through local health and joint planning mechanisms. Plans for development should be based on audit of current service provision, expenditure and training and should cover all the relevant agencies. The Scottish Executive should ensure that the audit, planning and relevant action has taken place in each area. This should build on the mapping exercise being carried out by the SSA and NAS in Scotland.
- Resources for systematic development of services for those with ASD should await completion of this audit.
- Each NHS board with its local authority partners should ensure that existing resources are reshaped to address the issues raised in this report.
- Thereafter additional resources should be allocated according to identified gaps in local provision.

#### Training

- A national audit of training should be included in the remit of the working party to be established to develop standards of care (recommendation 1) to assess training needs and gaps.
- Local training audits should also take place in each NHS board area as part of the wider audit recommended (recommendation 5) with a view to addressing training needs and gaps.

#### Research

- Research funding bodies should encourage further research into autistic spectrum disorders.
- A working group should be convened to consider the practicalities of establishing a database of people with ASD in Scotland.

#### Diagnosis and assessment

- Primary care professionals should consider including assessments of the triad of impairments as a standard part of all routine surveillance for infants within primary care.
- In order to limit waiting times and improve services for assessment and diagnosis of children and adults, resources are required to train and employ more specialist professionals in all agencies.

### Standards and Monitoring

1. The Scottish Executive should establish a working party with appropriate representation to develop global standards for lifelong services for those people with ASD that require it. This should have appropriate multi-agency representation, including voluntary organisations, and should include in its remit educational, health care and social care standards. More focused guidelines by the Clinical Standards Board and others should follow.
2. Once national standards have been agreed and published, this report recommends that Scottish Health Advisory Service (SHAS) be tasked by the Executive to consider whether they will be in a position to monitor these standards in a manner that fully reflects the multi-disciplinary and multi-agency nature of the provision of services to children, young people and adults with ASD. The group that has authored this report would be available to discuss this further with the Executive if alternative arrangements are considered more suitable.
3. The Scottish Intercollegiate Guidelines Network (SIGN) should be requested to develop guidelines for health care professionals on evidence-based approaches to the diagnosis and management of ASDs.
4. The ASD conference being organised for 2002 should be used to bring together interested parties from health, education, social services and the voluntary sector as well as parents and persons with ASD to discuss the implications of this document.

### Matching Resources to Need

5. Development of services for people with ASD should be sought through local health and joint planning mechanisms. Plans for development should be based on an audit of current service provision, expenditure and training and should cover all the relevant agencies (health, education, social services and voluntary sector for both children and adults). The Chief Executive of each local authority and each NHS board should ensure that the relevant joint planning groups carry this out and the Scottish Executive should ensure that the audit, planning and relevant action has taken place in each area. The mapping exercises underway by the Scottish Society for Autism and the National Autistic Society should provide information that will assist this.
6. Audit and future plans should address, amongst others, the following:
  - the implementation of systems and structures that support effective and consistent joint working at strategic and operational levels, and address any potential problems where co-terminosity does not exist.
  - joint-service agreements which define roles and lead agencies.
  - level of training and knowledge expected of specialist and front line staff.
  - the diagnostic provision to be available.
  - the medical and other assessments that should be considered.
  - how transitions from child and adolescent services will be managed.
  - joint commissioning across relevant statutory and voluntary organisations should be the norm (in order to ensure, for example, that suitable support services are planned alongside any residential provision).

7. Chief Executives of NHS boards and local authorities should identify officers as local co-ordinators for ASD Services, who will audit local practise in health, education and social services against the published national standards (recommendation 1) and be able to report on progress towards these standards to the appropriate national monitoring body (recommendation 2).
8. For children and young people, the Records of Needs and Future Needs Assessments must accurately reflect the needs being assessed and the relevant authorities should ensure that appropriate services are delivered. The Record of Needs process should adhere to principles of good practice which include multi-agency assessment in partnership with parents and identification of needs leading to individualised educational programmes which are reviewed and modified according to changing need over time.
9. Local authorities and NHS boards must ensure that the needs of children and adults with autistic spectrum disorders are included in relevant plans, such as Children's Service Plans and Community Care plans, and that appropriate opportunities for developing further services are exploited, e.g. through Children Services Funds, etc.
10. The recommendations in 'The Same as You'<sup>1</sup> are welcomed and endorsed however clarification is required from the Scottish Executive on whether these recommendations include or exclude people with ASD but without a learning disability. People with ASD with no associated learning disability also have extremely complex needs and there are few services available to them. More specialist services are required to address the specific and complex needs across the autistic spectrum but this should not be at the expense of services for those with learning disabilities. Improved services and respite facilities are required for the whole ASD group.
11. Local PIPS (partnerships in practice) should be required to include proposals for how local authorities and their partners will meet the needs of people with ASD in the area and cover both mainstream and specialist services. The Scottish Executive is asked to confirm whether these PIPs should address the needs of all those with ASD irrespective of a co-existing learning disability. If this is not the case, the Scottish Executive is asked to clarify who should have responsibility for services for persons with ASD but without a learning disability.
12. Accreditation of services for people with ASD (mainstream and specialist) should be advocated and encouraged. Specialist accreditation is currently available from the Autism Service Accreditation Programme (ASAP) and some education and adult services, including residential and day care services, in Scotland have achieved this or are working towards it.
13. 'The Same as You'<sup>1</sup> recommendation for local area co-ordinators and Personal Life Plans for all is endorsed and all those with ASD (irrespective of intellectual ability) should have this opportunity.
14. The national and local audits being undertaken (recommendations 1 & 5) should identify current resources dedicated to addressing the needs of this client group.

15. Resources for systematic development of appropriate methods of multi-agency service delivery for this client group should await audit completion however some resources will be required for specific developments in the interim, such as pilot developments in diagnosis, screening and intervention.
16. Failure to carry out the audit should not be a reason to deny resources for service development.
17. Existing resources should be reshaped to ensure provision of services which are flexible and responsive to local individual and family needs. The following services should be considered:
- Improved identification amongst front line staff both for children and adults and prompt referral for further assessment.
  - Prompt multi-agency, multi-professional diagnosis and assessment for those referred for further investigation.
  - Easily accessible, appropriate and timely information on ASDs for individuals with ASD and their families. This should include what is known/not known about causes, incidence, prevalence and effective management of ASDs.
  - Mechanisms to identify and follow up those who do not progress through the referral system as they should.
  - Joint, seamless support for individuals and their families after diagnosis.
  - Early and appropriate interventions. This should be achieved by increasing the focus on early identification in young children and improving both the range and number of appropriate and focused services for pre-5s, and through prompt identification and appropriate treatment for adults.
  - Follow up and early review should be available for all clients and families.
  - Access to a key worker or local area co-ordinator and the opportunity of a 'personal life plan' as advocated in 'The Same as You'<sup>1</sup> should be available to all those with ASD irrespective of the co-existence of a learning disability.
  - Active involvement of social services professionals from the point of diagnosis to assist in the development and delivery of the personal life plan for the client and ensure suitable service provision through life.
  - Access to an independent advocate.
  - Genetic counselling for families and individuals who wish it.
  - Systems and funding mechanisms that ease the transition between services for individuals with ASD.
  - Provision and development of a range of appropriate day, respite, shared care and leisure services for children and adults with ASD and their families.
  - Appropriate nursery, primary and secondary provision and increased specialist outreach to mainstream schools.
  - Parental involvement in the education programme and the availability of home-link teachers to deal with certain complex cases.



- Improved access to a range of recreational activities.
- Improved vocational and other education opportunities.
- Increased and improved options for living arrangements which allow people with ASD to be as independent as possible.
- Support for those who choose to live with their parents, for both client and parents.
- A range of psychological supports including counselling and psychological therapies.
- Support with financial planning and applications for welfare benefits.

18. Additional resources should be allocated accordingly to areas of recognised need.

### **Training**

19. Training is vital for a wide range of professionals working with people with ASD. Improved training underpins many of the recommendations in this report. It is recommended that the group established to consider service standards (recommendation 1) includes in their remit a review of current training provision for autistic spectrum disorders in Scotland. This should include identification of training currently available for those associated with the provision of services for this client group and existing gaps at vocational, undergraduate and post-graduate levels, with a view to developing a targeted national training framework for autistic spectrum disorders.

20. At a local level, NHS boards and local authorities should carry out an audit of the relevant training that exists in their area and the gaps that exist. This review of training provision should be included in the local audit of services (recommendation 5).

21. More training and awareness is vital for those who are in a position to first recognise a possible autistic spectrum disorder in order that they are confident in identifying possible signs and referring appropriately. This is important to a wide range of professionals including health visitors, general practitioners, school medical staff, teachers, CAMH, CLDT, CMHTs, social workers, nursery staff. Early recognition requires professionals to have an understanding of the disorder. Professionals who have skills and expertise in this area may be able to provide training but will require resources to do this - services should consider this when planning training. In addition, academic and professional training providers are asked to include ASD at undergraduate level and in CPD requirements.

22. Awareness and training is vital for the wide range of professionals, carers and specialists who come into contact with people with ASD (adults and children) to ensure appropriate practice and in order to gain parents' and carers' confidence in services. To help improve multi-agency working, training organised locally by health service or local authority bodies should seek to include staff from a range of organisations as well as parents and persons with ASD. The Centre for Education and Training in Autism (CETA) located with the Scottish Society for Autism, and the Scottish Office of the National Autistic Society, both of whom already provide a range of training, along with the Scottish Consortium for Learning Disabilities are likely to play a key role in training provision.

## Research

23. The Scottish Executive should request that research funding bodies and the Scottish Consortium for Learning Disabilities encourage further research into all aspects of autistic spectrum disorders (including medical, speech and language, educational, psychological, etc.).
24. Future research should take cognisance of the conclusions of the Medical Research Council review of evidence on the causes of autism.<sup>110</sup> Research into aetiology and other epidemiological issues such as changing prevalence should not be done in isolation of other ongoing work both nationally and internationally.
25. In terms of improving service provision, which is the focus of this needs assessment, broad areas for research include:
- Further research into the appropriateness and applicability of screening tools to assist early identification.
  - Assessment and development of early interventions with a particular focus on longer term outcomes.
  - Further research into appropriate treatments and effective interventions at all life stages.
  - Further research into the lifelong patterns of ASD, especially changes in severity/adult outcome and how different interventions influence this.
  - The prevalence of ASD amongst those within the criminal justice system, their needs and appropriate interventions for this client group.
  - Appropriate services and interventions for adults with Asperger's syndrome.
  - Research into the needs and appropriate service provision for older persons with ASD.
  - Pilot projects investigating best practice in joint, multi-agency working as this principle should underline all service developments.

Is it recommended that researchers and professionals work with research funding bodies to identify priorities within these areas and develop specific research proposals.

26. Priority should be given to the establishment of a database on persons with ASD in Scotland. A working group should be convened to develop this initiative. This group should consider the scope and practicalities of such a project, for example, the utility, benefits and limitations of databases, registers and other means of gathering epidemiological information and service use. It should identify what would be most appropriate to allow adequate planning and provision of services and collation of epidemiological information whilst protecting the confidentiality of individuals.

### Assessment and diagnosis

27. Consideration of the triad of impairments should take place as a standard part of all routine surveillance for infants within primary care. To help ensure this happens, all health visitors should receive some training on ASD and be confident in recognising and referring on those who may be at risk. Training in the Checklist for Autism in Toddlers (CHAT) has been found to be a useful way of raising awareness and understanding.<sup>42</sup>
28. This report has made it clear that multi-professional, multi-agency work must be truly integrated and collaborative. Arrangements should be made between professionals to ensure that collaborative working takes place. Integrated care networks should be considered as possible models of working. Heads of education, social services and NHS boards should support integrated and collaborative arrangements.
29. There are currently too few professionals in diagnostic and assessment services to meet the demand although this varies dramatically across Scotland. In many areas, there are long waiting lists to see professionals. In most areas there are no services for the assessment and diagnosis of adults. More professionals in all agencies are required to be trained and employed in order to limit waiting times.
30. There is a concern that some individuals with ASD do not progress through the referral and follow-up system as they should and are therefore lost to the system. Mechanisms are required to be developed to avoid this. Local joint planning groups should consider how systems can be developed to ensure diagnosis is translated into appropriate provision.
31. Information should be available during and immediately upon diagnosis for both clients and their family. This should provide information on support, on the next stages in the assessment process and the options for support thereafter. Diagnostic centres and voluntary organisations should also consider developing links, e.g. 'drop in' times, in order to ease the initial approach to voluntary organisations.
32. Currently there are a range of tertiary services in Scotland providing assessment and treatment of variable complexity to children with ASD. Most of these operate at local level providing a service to their catchment population. In addition there are some supra-regional services providing assessment for more complex problems and providing a second opinion and consultation resource to local services. The Scottish Centre for Autism at Yorkhill provides a national resource and plays a key role in providing second opinion, consultation and training to other services. It receives the majority of its referrals from NHS boards throughout Scotland. In the past 3 years, it has supported the development of a growing network of local ASD specific assessment teams. This has been achieved via arrangements such as secondments, case review mechanisms and consultation. It is recommended that discussion takes place as to the possible extension of this network, possibly using a managed clinical network model, to make the expertise and support available to a broader group of professionals in other regions throughout Scotland.

## Glossary

AD – Autistic disorder

ADHD – Attention deficit hyperactivity disorder

**aetiology** - The study of factors associated with the causation of diseases/disorders

AS – Asperger syndrome

ASD – Autistic spectrum disorder

CAMH – Child and adolescent mental health

CETA – Centre for Education and Training in Autism

CHAT – Checklist for autism in toddlers

CPD – Continuing professional development

CLDT – Community learning disability teams

CMHTs – Community mental health teams (?)

CSB – Clinical Standards Board

CSO – Chief Scientists Office

GP – General Practitioner

IEP – individualised educational programme

**phenotype** - Characteristics of an individual that are due to environmental factors and genetic make-up

PIPs – Partnerships in practice

**prognosis** - A forecast of the probable course and outcome

NAS – National Autistic Society

NHS – National Health Service

NIASA – National Initiative on Autism Screening and Assessment

PRESCAT - Pre-School Community Assessment Team

SALT – Speech and language therapy

SIGN – Scottish Intercollegiate Guidelines Network

SHAS – Scottish Health Advisory Service

SSA – Scottish Society for Autism

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