# 2. INTRODUCTION TO AUTISM IN ADULTS

## 2.1 THE AUTISM SPECTRUM

### 2.1.1 History

Autism was first described in 1943 by Leo Kanner in Baltimore (Kanner, 1943) and was independently described in 1944 by Hans Asperger in Vienna (Asperger, 1944). Both of these clinical descriptions described an overlapping core set of features (social difficulties alongside highly repetitive behaviour), but in Asperger's account the children had good intelligence and language skills, whereas in Kanner's there was greater variability in intelligence quotient (IQ) and language development. The children described by Asperger at first received little attention because his account was written in German, and it was not until the 1980s and 1990s that two seminal works brought this account to the English speaking medical world: an article by Lorna Wing in *Psychological Medicine* (Wing, 1981) and a book by Uta Frith entitled *Autism and Asperger's Syndrome* (Frith, 1991). While autism was listed in the *Diagnostic and Statistical Manual of Mental Disorders* – 3rd edition (DSM-III; American Psychological Association, 1980), Asperger's syndrome was not, although it was finally included in the *International Classification of Diseases* – 10th revision (ICD-10; World Health Organization, 1992) in 1992 and in DSM-IV in 1994.

In the 1950s and 1960s autism was often attributed to purely environmental factors, such as unemotional parenting (Bettelheim, 1967). But this theory was overturned in the 1970s by Michael Rutter (Rutter, 1978) who argued that associated phenomena such as epilepsy could not be attributed to environmental factors such as parenting style and instead indicated abnormalities of brain function (which thus meant that the parents themselves were not 'bad' parents) and that the higher concordance of autism in identical as opposed to non-identical twins indicated a genetic cause (Folstein & Rutter, 1977). The idea that autism involves atypical brain development is now firmly established (Courchesne *et al.*, 2001) and that it involves many genes is also no longer in doubt (Geschwind, 2008).

From the 1950s to the 1980s autism was mostly considered to be categorical (either present or absent) and quite rare (four in 10,000 children) (Rutter, 1978). These two views were contested by Wing who found in her epidemiological study that, when partial syndromes were included, autism was much more common than had previously been realised and that autism could come by degrees, warranting the term 'the autistic spectrum' (Wing, 1988). Today we recognise that at least 1% of the population has autism (Baird *et al.,* 2006; Baron-Cohen *et al.*, 2009) rendering it as relatively common.

In the 1970s the symptoms were described as a 'triad of impairments' (Wing, 1976) that included social difficulties, communication difficulties and social imagination difficulties (together with strongly repetitive behaviour). In the planned DSM-5

(American Psychological Association, forthcoming in 2013), the triad will be reduced to two core dimensions. Social and communication difficulties will be collapsed into a single dimension called 'social-communication difficulties', to reflect that these are so intertwined that they cannot be easily disentangled. The dimension 'social imagination difficulties' will be discarded because some people on the autism spectrum demonstrate great imagination in relation to the arts (drawing, in particular) and imagination is not easily operationalised. Strongly repetitive behaviour (incorporating difficulties in adapting to change and unusually narrow interests) will become the second major dimension.

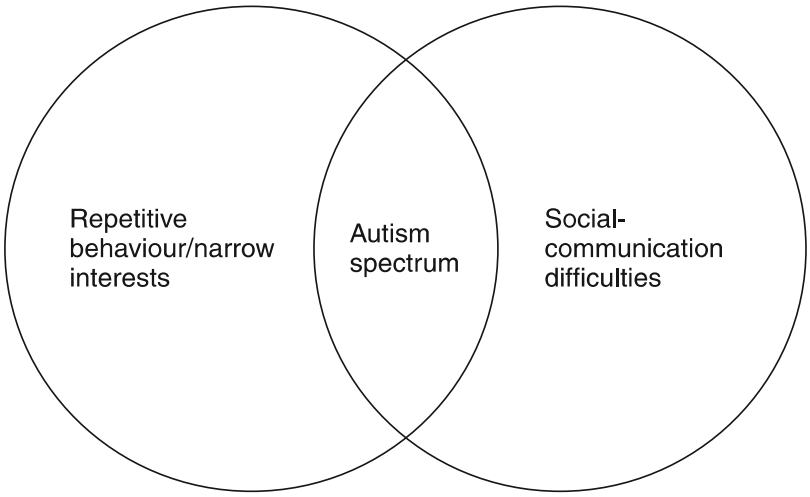
People with autism lie in the intersection of these two dimensions, meaning they show both features, as shown in Figure 1. Exhibiting just one of these features does not warrant a diagnosis on the autism spectrum, and the co-occurrence of the two dimensions means the autism spectrum can still be viewed as a syndrome.

ICD-11 is due to be published in 2015 and the changes made to the DSM-5 will be considered, however, it is not clear if the changes described above will be replicated.

### 2.1.2 Terminology

A variety of terms are used in the field, which can lead to some confusion. These include subgroup diagnostic categories such as autism, Asperger's syndrome, pervasive developmental disorders and atypical autism. In the planned DSM-5 (2013) these will all be subsumed under a single overarching diagnostic term: autism spectrum disorder (ASD). Intellectual disorder (or what is termed 'learning disability' in the UK) and language disorder will be separately coded, to reflect that these can coexist with ASD (again, it is not yet clear whether similar changes will be made to ICD-11). In the UK some authors prefer to use the term 'autism spectrum condition' because some people with autism see themselves as neurologically different (and in need of a

**Figure 1: The two main dimensions in the diagnosis of the autism spectrum (reproduced with permission [Baron-Cohen, 2008]).**



diagnosis to access support) but not necessarily 'disordered'. In the US many authors are keen to retain the term 'disorder' to reflect severity and how the symptoms interfere with everyday functioning. In this guideline, the GDG opted to circumvent the debate over whether to use ASD or autism spectrum condition by using simply 'autism' to cover the whole autism spectrum.

### 2.1.3 Features and presentation

Autism is a lifelong condition characterised by difficulties in two domains: (a) social-communication, and (b) strongly repetitive behaviour/ difficulties adjusting to rapid and unexpected change/unusually narrow interests, as described below.

Historically, classic autism[1] and Asperger's syndrome have shared the same two diagnostic difficulties above, but in classic autism the child was seen to be late to develop language (no single words by 2 years old, no phrase speech by 3 years old), and there might have been additional learning disabilities (that is, IQ might have been in the below average range[2]). In contrast, in Asperger's syndrome language was seen to develop on time (when a history was taken) and IQ was always above 70, if not above average (that is, no sign of a learning disability). While these two subgroups are delineated in DSM-IV (1994), the plan in DSM-5 (2013), as mentioned earlier, is to collapse these into a single category called ASD (while highlighting levels of severity and associated disabilities such as learning disabilities or language delay).

*Social-communication difficulties*

These difficulties can manifest in many different ways, including the following (note that none of these is necessarily or inevitably a part of autism and that different features may be evident in different individuals with autism):

- atypical eye contact (staring at people for too long or not maintaining eye contact)
- intrusion into others' personal space (standing too close to someone else, talking too loud or touching people inappropriately)
- reduced interest in socialising
- difficulties understanding others' behaviour, motives and intentions
- difficulties reading other people's facial expressions or vocal intonation
- difficulties taking turns in conversation or tendency towards monologue
- difficulties making small talk or maintaining a conversation
- social naïveté and vulnerability to exploitation
- bluntness or lack of diplomacy
- difficulties reading between the lines or picking up hints
- difficulties seeing things from another person's perspective

[1]Also called Kanner's autism, or infantile autism or autistic disorder.

[2]Learning disabilities are classified into bands according to IQ as follows: IQ <20 constitutes profound learning disabilities, IQ 20 to 34 severe, IQ 35 to 49 moderate and IQ 50 to 69 mild learning disabilities (ICD-10).

- difficulties resolving conflict
- difficulties anticipating what might offend others (faux pas)
- lack of social awareness
- difficulties keeping track of what the listener or reader needs to know
- difficulties making or keeping friends
- difficulties understanding other people's expectations
- difficulties conforming
- difficulties judging what might be relevant or irrelevant to others
- difficulties coping with or interacting in social groups
- unable to tell white lies
- difficulties coping with ambiguity in language
- becoming obsessed with a person to an intrusive extent
- social anxiety
- loneliness (and risk of depression)
- reduced empathy.

*Strongly repetitive behaviour/ difficulties adjusting to rapid and unexpected change/unusually narrow interests*

These difficulties can manifest in many different ways, including the following:

- avoiding crowded places
- difficulties multi-tasking
- doing one thing at a time
- narrow deep interests, rather than broad superficial interests
- preference for repetition and routine
- anxiety in face of change
- need for sameness (eating the same foods, wearing the same clothes, taking the same routes, going to the same places) and avoidance of novelty
- preference for predictability and predictable events (watching washing machines spinning or trains going down tracks)
- being extremely passive if an activity of interest is not available or initiated by someone else
- need for clarity and expressing a pedantic request for precision and avoiding ambiguity
- attention to small details
- development of 'fixated interests'
- need for strict order and precision.

### 2.1.4 Development, course and prognosis

Difficulties related to autism start early in life: if a developmental history is taken it is usually evident that there have been social difficulties since as early as the second year (from 18 months old) in terms of mixing with other children and adjusting to social groups and change. Average age of diagnosis of autism is in primary school (by 6 years old) (Frith, 1989) whereas Asperger's syndrome is often not diagnosed

until secondary school (by 14 years old) or even older (early adulthood or later) (Attwood, 1997). This is often because autism entails some developmental delays and so is noticeable even to an untrained observer. In Asperger's syndrome, however, good language and cognitive skills may mean the child or young person can cope academically and in primary school, which is a fairly small community (typically around 200 children), the social demands may be less challenging (the peer group may be more tolerant of a child who does not conform), whereas secondary schools are usually much bigger (from 600 to 2,000) thereby significantly increasing social demands.

Teenagers with Asperger's syndrome may be difficult for teachers to cope with because they typically demonstrate a lack of social conformity, doing what *they* are interested in rather than what the teacher expects them to do. The student can appear disruptive in a class setting, and their refusal to accept instructions without logical reasons ('do it because I told you to') may mean the student is seen as challenging. Students with Asperger's syndrome can lose motivation educationally and underperform in terms of school leaving qualifications or drop out of school entirely. They are also at risk of being bullied, verbally or physically, because of being 'loners' and not fitting in; some teenagers with Asperger's syndrome retaliate, turning from being the victim to being the bully. Some young people with Asperger's syndrome develop secondary depression and may feel suicidal, as well as showing social anxiety if expected to do group presentations (Tantam, 2000).

Some people manage to proceed through adolescence without receiving a diagnosis because their families 'cushion' them by doing everything for them or tolerating their idiosyncrasies, and the person only starts to experience difficulties at the transition to independence (for example, going to university or moving away from their family) where they may not be able to make friends, becoming depressed and isolated. They may, therefore, only seek a diagnosis in their late teens or early twenties. Others may not seek a diagnosis until mid life following a series of failed relationships, including marriage(s), and failed jobs (they might have been disciplined for having a difficult attitude towards co-workers, not been a 'team player' or simply not been promoted). A study by the UK National Autistic Society (NAS) found that 88% of adults without a learning disability on the autism spectrum are unemployed despite having skills that mean they could be working, although many might require supported or sheltered employment (Barnard *et al.,* 2001). Specific autism traits such as black-and-white thinking or empathy difficulties can also have a significant impact on interpersonal relationships and may complicate assessments, for example rigid thoughts (such as 'my family will be better off without me') can present significant challenges in risk assessment. However, it should not be forgotten that some people with autism go on to lead rich and fulfilling lives.

### 2.1.5 Impairment, disability and secondary problems

The autism spectrum is very wide, ranging from people with limited self-help, independence, academic or verbal skills through to individuals who are in the

gifted range of intelligence and fully independent but who have significant social difficulties. This wide spectrum means that how 'symptoms' present in individuals may be very different, which is in part a function of the extent to which the individual can fall back on general cognitive ability to devise coping strategies and the degree to which they are motivated to try to mask their disability in order to try to fit in.

Autism can coexist with many other diagnoses, including depression, social anxiety, obsessive–compulsive disorder (OCD), attention deficit hyperactivity disorder (ADHD), Tourette's syndrome/tic disorder, dysexecutive syndrome, developmental coordination disorder, catatonia, eating disorders, gender identity disorder, personality disorder and psychosis. A number of genetic syndromes are also associated with autism such as tuberous sclerosis, Fragile X, Angelman syndrome, Rett syndrome and Turner syndrome.

### 2.1.6 Issues of particular importance

Whereas detection and diagnosis of childhood autism now largely occurs by early childhood (age 3 to 6 years old), diagnosis of Asperger's syndrome is often overlooked until as late as adulthood and can easily be misdiagnosed as simple depression, as a personality disorder or sometimes as psychosis or schizophrenia. A developmental history is the key to making this differentiation. This guideline is, in part, a response to the under-diagnosis in adults.

Sensory and gastrointestinal issues are also very common, the former possibly seen in as many as 90% of adults with autism without a learning disability (Crane *et al.,* 2009) and the latter in almost half of adults with autism and a learning disability (Galli-Carminetti *et al.*, 2006). These should be assessed because they have major implications for management.

It is important that autism is seen not only as a medical diagnosis for which the NHS has responsibilities, but also as a social care responsibility (in the areas of education, housing and employment) because people with autism often fall through the gaps between health and social care, especially if they do not present with an accompanying mental health problem or learning disability. This presents challenges for both health and social care services in developing services that facilitate the engagement of people with autism. The rights of people with autism has become an important social issue and professionals need to be sensitive to the view that many individuals on the autism spectrum regard themselves as an excluded minority whose rights have been overlooked by a 'neurotypical' majority (see Chapter 4). Alongside using medical diagnostic terminology to define themselves, they also use the key concept of 'neurodiversity' to remind society that there are many different routes along which the brain can develop, that one is not necessarily better or worse than another, and that society has to adapt to make space for this diversity. The analogy is with left-handedness, which used to not be tolerated, but which is now seen as a natural minority subgroup in the population. Other recognised subgroups defined by atypical neurological development are

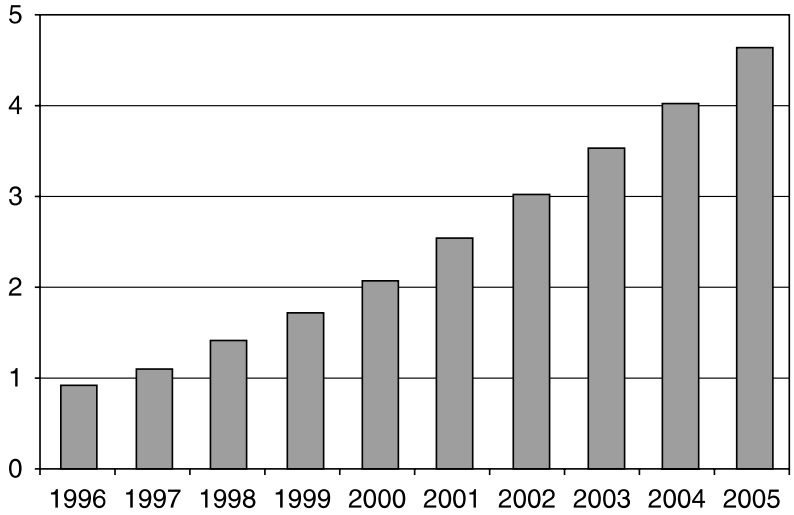
those who show a significant discrepancy between their verbal and non-verbal IQ or those with specific developmental disorders such as dyslexia or dyspraxia. Unlike left-handedness, where the individual is simply different but may not need any special support, autism involves both difference and disability, in that the diagnosis of autism is only made when the person is experiencing difficulties arising from their difference.

## 2.2 INCIDENCE AND PREVALENCE

Childhood prevalence studies suggest that autism occurs in approximately 1% of the population and that for every three known cases, there are two undiagnosed individuals who might need a diagnosis at some point in their lives (Baron-Cohen *et al.,* 2009). Prevalence in adulthood has been found to be similar at 1.1% (Brugha *et al.*, 2012). This suggests that autism is now much more common than was previously thought—in 1978 prevalence of autism was reported to be 4 per 10,000 (Rutter, 1978). This dramatic change is thought to largely reflect greater awareness, growth of services and a widening of diagnostic criteria to include Asperger's syndrome, atypical autism and pervasive developmental disorders (not otherwise specified), which was only brought into the international classification system in 1994. See Figure 2 for a schematic representation of this increase in diagnosis.

However, despite this greater awareness, studies in adulthood have shown that four out of five adults with autism find obtaining a diagnosis in adulthood difficult or not possible (Taylor & Marrable, 2011) and many will not have received a formal diagnosis (Brugha *et al.,* 2011).

**Figure 2: The rising prevalence of cases on the autism spectrum. Along the Y (vertical) axis are number of cases on the autism spectrum per 10,000 in the population (reproduced with permission [Baron-Cohen, 2008])**



## 2.3 DIFFERENTIAL DIAGNOSIS

Because OCD also involves unusually repetitive behaviour it is important to highlight some key differences between OCD and people on the autism spectrum:

- social development is not necessarily atypical in childhood in people with OCD
- repetitive behaviours result in anxiety in people with OCD, so the absence of an anxiety response precludes OCD (but the presence of anxiety does not necessarily mean that someone must have OCD and not autism).

Other possible distinguishing features of OCD are outlined in the NICE *Obsessive-compulsive Disorder* guideline (NCCMH, 2006). A person can be comorbidly diagnosed with autism and OCD.

Because personality disorders also involve social relationship difficulties it is important to highlight the key difference between people with autism and those with personality disorders (and so help avoid misdiagnosis). Personality disorders do not typically involve the 'obsessive' narrow interests or resistance to change. In addition, although empathy deficits are present in both autism and psychopathy (or antisocial personality disorder), in people with autism it is the *cognitive* component of empathy that is impaired ('theory of mind' or recognising what others may be thinking or feeling) while *affective* empathy (having an appropriate emotional reaction to/caring about other's feelings) may be intact. In contrast, whereas in psychopathy the cognitive component of empathy is intact (enabling them to deceive and manipulate others) affective empathy is impaired (they do not care about others' suffering, for example).

Autism can coexist with other conditions involving 'rigid' behaviour and cognition such as eating disorders or gender identity disorder, and a dual diagnosis might be appropriate if the difficulties related to autism predate the second diagnosis. Emotional difficulties such as social anxiety disorder or depression are also common in people with autism and are usually seen as secondary to the autism. This is because autism often develops first and can cause social difficulties including social isolation, which can then give rise to anxiety and depression. Individuals can also be diagnosed in childhood as having a language disorder, only later in life receiving a diagnosis of autism (Bishop *et al.,* 2008)

## 2.4 AETIOLOGY

As mentioned earlier, there is no longer any doubt that autism is strongly genetic (Geschwind, 2008). This evidence comes from studies of twins, family genetics and molecular genetics. To date hundreds of molecular genetic associations have been reported, and it is not yet clear which genes are necessary and sufficient to cause which type of autism. Autism is not 100% genetic (estimates of heritability are between 40 to 90% (Hallmayer *et al.*, 2011) leaving room for a gene–environment interaction, but the environmental factors are not yet known. The idea that the environmental factor was measles, mumps and rubella (MMR) vaccine damage is no longer tenable (for example, the Editors of *The Lancet*, 2010; Taylor *et al.*, 1999). Potential environmental factors include the foetal sex steroid hormones (themselves

under genetic influence) (Auyeung *et al.*, 2009) and social training/experience (Lovaas & Smith, 1988).

Autism is also now clearly understood to be neurodevelopmental, meaning that there are differences in the pattern of brain development from the earliest point. For example, early brain overgrowth has been documented in the first 2 years of life (Courchesne *et al.,* 2001), and in later development there are clear differences in the function and structure of the 'empathy circuit' of the brain (amygdala, ventromedial prefrontal cortex, temporo-parietal junction, orbitofrontal cortex, anterior cingulate cortex and other brain regions) (Lombardo *et al.*, 2011). There are also differences in connectivity between frontal and parietal lobe functions that are thought to relate to cognitive style, in particular an over-reliance on processing details and a relative under-reliance on processing gist or holistic information (Belmonte *et al.,* 2004).

## 2.5 IDENTIFICATION AND ASSESSMENT

The process of identification and assessment is well understood but is limited by the availability of well-validated tools for case identification and the lack of specialist services to undertake the necessary assessments. The identification and assessment process should include a case identification phase followed by a detailed diagnostic assessment if needed. Screening instruments need to be age-appropriate, severity-appropriate, and brief, but are not themselves diagnostic. A typical diagnostic assessment may take at least 2 hours in carefully documenting the developmental history, in order to ensure that the differential diagnoses outlined in Section 2.3 have been excluded. Diagnostic assessment, which in the UK uses ICD-10, is often within a multidisciplinary team but at a minimum is by a qualified clinician, usually a clinical psychologist, psychiatrist or neurologist. In the case of children this is also often conducted by a paediatrician together with a speech therapist. The considerable variability in the nature of autism, the presence of mental and physical health comorbidities, and the apparent skills learnt through observation and structure (rather than through innate ability) can present particular challenges in assessment.

## 2.6 CURRENT CARE IN ENGLAND AND WALES

### 2.6.1 Strategic plans for England and Wales

In 2008 the Welsh Assembly Government developed *The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales* (Adult Task and Finish Group, 2009), which set out a number of recommendations and actions, supported by £5.4 million given to the 22 local authorities in Wales to implement them during the period 2008 to 2011. A further £2 million in funding was announced to support autism services in Wales for 2011 to 2012.

As part of *The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales* a national clinical network for assessment and diagnosis was established in 2011 and is

hosted by Betsi Cadwaladr University Health Board. The network has been involved in developing and implementing a standards-based assessment pathway in all the Welsh Health Boards through the education and training of relevant clinicians, the development of teams with local expertise and the support of experts at a national level.

In England, the Autism Act (Her Majesty's Stationery Office [HMSO], 2009) and the subsequent Autism Strategy (Department of Health, 2010) required all NHS trusts to define an autism care pathway by the end of 2011, particularly for adults with autism, since, in many areas, the childhood pathways are already well established.

In Wales diagnostic and assessment survives were established as part of the Strategic Action Plan but few specialist services for the assessment and diagnosis of adults with autism currently exist in the England, such as the Sheffield Asperger Syndrome Service, and fewer are in a position to provide appropriate interventions. The number of adults with autism in contact with specialist mental health services is not known but probably includes a significant number of people whose autism is unrecognised. Developing these care pathways represents a considerable challenge as there are many parts of the UK where there is insufficient training or knowledge about autism and that it may take some time to put in place a care pathway in all regions.

A key purpose of the guideline is to provide evidence-based recommendations that will support the further implementation of the Autism Strategy in England and *The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales*.

### 2.6.2 The National Health Service

Care pathways in the NHS need to start with identification and diagnosis and culminate in a full package of support to meet the needs of the individual, taking into account that the person might need support across their lifespan. At present the level of training in and knowledge about autism is limited among primary and secondary care professionals (Punshon *et al.*, 2009) and will need specific attention if the recommendations developed in this guideline are to be of real benefit. Access to interventions for adults with autism is also limited and may extend beyond mental healthcare to access to physical healthcare.

### 2.6.3 Social care

Difficulties related to autism can cross all areas of life. As such, it is important that the NHS works closely with other services. This can produce benefits in how well people access the other services, as well as how they access the NHS. In England the Autism Strategy (Department of Health, 2010) is clear that diagnosis of autism is a sufficient ground for offering an assessment for social care services, so there needs to be a clear pathway after diagnosis (or when entering adult services) from health to social care.

In England, councils with adult social care responsibilities use Fair Access to Care Services (FACS), which is a national eligibility framework (amended in 2010) for allocating social care resources. It uses a grading system with four bands (critical,

substantial, moderate and low), which assess eligibility in terms of risk to an individual's independence, wellbeing and the consequences of their needs not being met. The Social Care Institute for Excellence (SCIE) has produced a booklet *Facts about FACS 2010: A Guide to Fair Access to Care Services* (Brand *et al.*, 2010a) that clearly explains the criteria for each part of the grading system (this is to be reviewed in April 2013). They have also produced a leaflet *Facts about FACS 2010: Your Questions Answered* (Brand *et al.*, 2010b) for people using or seeking services and support.

At present, due to local budgetary considerations, most areas in England will only offer services if people have critical or substantial needs. However, this guideline recognises that universal services need to be expanded for the general population and work needs to be done to strengthen communities. In order to access any service, people need good social-communication skills in order to request help, complete assessments and engage with new people. These areas can be very difficult for people with autism and access to services are often dependent on support from families, partners and carers.

### 2.6.4 Other services

As outlined above, the NHS needs to work closely with social care and education services since autism does not just affect mental health but has an impact on independent living (housing, employment, social networks, leisure, shopping and travel) and education at all levels (school, college and university). Care pathways should therefore include liaison with these other agencies and with disability resource centres in colleges or with human resources departments in the workplace.

## 2.7 ECONOMIC COST

Autism has lifetime consequences and significant economic impact because of the enormous implications for the individual with the condition and their family, partners and carers. Management and support of people with autism incurs substantial costs to the health and social care services and the wider public sector, through provision of services and lost employment. Baird and colleagues (2006) estimated that 116 in every 10,000 children aged 9 to 10 years have autism, which is substantially higher than previous estimates.

Knapp and colleagues (2009) estimated the costs of supporting children and adults with autism in the UK, using published estimates of the prevalence of autism, prevalence of learning disabilities among people with autism, data on accommodation placements, as well as data on support services and interventions used by this population as a consequence of having autism. Costs covered health and social care services, special education, housing placements outside the parental home (for children) or in staffed or supported settings (for adults), leisure services, and included out-of-pocket payments made for services as well as productivity losses for adults with autism and their family, partners and carers. Benefit payments were also considered.

Using a prevalence of autism in children and in adults of 1%, Knapp and colleagues' (2009) study estimated an annual cost of supporting children with autism of £2.7 billion; for adults this cost amounted to £25 billion (in 2005/06 prices). These cost estimates excluded benefits but included lost employment for individuals and hence lost productivity to society. The total estimated UK cost of approximately £28 billion averages out at £500 each year for every person in the country. Ninety percent of the overall cost of supporting individuals with autism relate to supporting adults. The public sector covers the major component of costs of supporting people with autism. The study estimated that, out of the total cost of £25 billion of supporting adults with autism, 59% is attributed to publicly-funded services, 36% to lost employment for the person with autism and the remaining 5% to family expenses (Knapp *et al.,* 2009).

Sensitivity analysis demonstrated that, using a higher prevalence rate of autism of 1.16%, as reported in Baird and colleagues (2006), the total UK cost for children and adults with autism was £3.15 million and £29.56 million, respectively, reaching a total cost of £32.7 (2005/65 prices). This estimate may be more realistic, given that recent research estimated the prevalence of adults with autism at 1.1% (95% confidence interval [CI], 0.3 to 1.9) (Brugha *et al.*, 2012).

Adults with autism have high needs of support at their place of residence. The proportion of people with autism with a learning disability living in institutional facilities is considerably higher than in people without a learning disability (Knapp *et al.*, 2009). Baird and colleagues (2006) estimate that 56% of people with autism have a learning disability. The major component of the total cost (£25 billion) of supporting adults with autism is attributed to the cost of supporting adults with a learning disability, which is almost two thirds (£17 billion) of the total cost. A large proportion of people with autism with a learning disability live in residential care (52%), supported living accommodation (7%) or hospitals (6%) (Knapp *et al.,* 2009). Residential care constitutes a major component of the total cost associated with supporting people with autism as the annual costs per person are very high, ranging from approximately £87,500 per annum for supported accommodation to £98,000 per annum for living in hospital.

One study found that very few people with autism were in employment, because there was little or no support available to get them into work (Howlin *et al.,* 2005). It is estimated that only 12% of adults with autism without a learning disability have full-time jobs (Barnard *et al.,* 2001), leaving 88% unemployed, which has huge costs to the economy in terms of lost productivity. This productivity loss is conspicuous because adults with autism without a learning disability could be employed through supported employment programmes. Järbrink and Knapp (2001) demonstrated that the lack of supported employment programmes for people with autism has negative resource consequences for the economy.

In the UK, the lifetime costs of an individual with autism without a learning disability is estimated at £3.1 million (discounted cost £0.8 million using a rate of 3.5%) and of an individual with autism and a learning disability £4.6 million (discounted cost £1.23 million) (Knapp *et al.,* 2009). Ganz (2007) estimated the lifetime per capita incremental societal cost of autism at $3.2 million in the US

(discounted estimate). The substantial costs are borne by adult care and lost productivity of individuals with autism and their family members and carers. Knapp and colleagues (2009) converted the US estimate equivalent to £2 million using gross domestic product purchasing power parity and explained that the different methodology, availability of data, different support systems and the assumption of a different discount rate in the US contributed to the higher estimate of lifetime cost in the US. Ganz (2007) estimated the total annual cost of autism at $35 billion to US society. The medical costs were estimated at $29,000 per person per year, which included physician and outpatient services, prescription medication, and behavioural therapies; non-medical costs were estimated at $38,000 to $43,000 per person per year, depending on the level of disability, including costs of special education, camps and childcare (Ganz, 2006)

The substantial societal cost of autism in adults requires provision of effective interventions that will improve the quality of life of people with autism and their families, partners and carers and will reduce the costs borne to the health services, people with autism and their families and the wider society.