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Definitions and the current situation in education, health and social care

This chapter explores:

- definitions of autistic spectrum disorders (ASDs);
- key characteristics and features of ASDs;
- existing provision across education, health and social care services for young people (aged over 16) and adults with ASDs.

Introduction

We are now increasingly living in times where acceptance of difference is more commonplace and education, mainstream secondary schools, further education (FE), higher education (HE) and adult services are expected to provide for the needs of more and more young people and adults (aged 16 years plus) with a range of difficulties who might have previously been placed in special schools or long-term institutions. However, while 'informed' members of society may be more accommodating of adolescents and adults with disabilities we are still a long way off living in a totally inclusive society in which each and every person is accepted and offered every life chance and opportunity to achieve their full potential.

For those adolescents and adults with autistic spectrum disorders (ASDs) life can be complex and confusing. On the one hand a person may be verbally fluent yet on the other hand be unable to go to the corner shop to purchase a few necessities. An ASD is a 'hidden' disability and invariably those with an ASD look just like everyone else but may engage in some very different and unusual behaviours and experience significant social and communication difficulties. To the general public those with ASDs may present as odd, eccentric or even bizarre and their lack of knowledge and ignorance may lead to an internal

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fear which results in avoidance. Understanding and awareness of ASDs is therefore crucial in our society to enable increased acceptance of all those with ASDs. Likewise within the education, health and care sectors all staff should have a thorough awareness of the features of ASDs and appropriate methods of support in order to further the lives of those with whom they work.

Special needs, learning difficulties and/or disability

The way our lives work, both personally and professionally, encompasses a need to categorise for a range of purposes; perhaps, most significant is the need to have order and structure in our lives. So it has been, over past and present times, that we have developed terms to describe and define ourselves and our lives such as gifted, educated, poor, affluent, tall, short, competent, sensitive, athletic, able-bodied, disabled and so on. What we should never overlook is that we are all individual human beings with individual and unique facets, so we present as a collection of these terms. The government, local authorities and service providers also use categories to clarify provision such as health, social services, education, private, state or voluntary. Within each service are sub-categories that further segregate those involved into allotted boxes, such as mental health difficulties, dyslexic, addiction, in need, truant, residential care and ASD. The planning that then takes place will also be labelled differently, according to the service provider: care plans, care assessments and individual education plans are each discipline specific. However, the adolescents and adults we are focusing on within this book may span several disciplines so common language is imperative to ensure understanding by all involved and also to offer clarity to parents/carers. Whatever we feel about the rights and wrongs of utilising such categories, they are factors in our lives so when referring to adolescents and adults experiencing difficulties accepted terminology will be used throughout this book. People with ASDs will be referred to as such.

Categorising and labelling

If we are to welcome an adult with an ASD into our work setting we may make assumptions regarding their difficulties according to our knowledge and understanding of ASDs, but this may well deprive or limit the opportunities made available to that adult, thus compounding their difficulties further. In addition the label of autism may limit the range of provision available to that adult to the standard 'set' pathway for those with ASDs, which may well adequately support their needs but may not allow them to develop to their fullest potential. It could therefore be argued that such a pathway does nothing to support increased inclusion within society. On the other hand the label of ASD may well secure increased funding and access to provision not otherwise available, which is clearly a positive aspect. The dilemma is evident.

Current legislation and guidance documents all use terminology specific to their discipline base and this can only lead to increased confusion for all. It also

supports the philosophy that special needs provision or provision for those with learning difficulties or disabilities is separate and different from regular provision and as such is exclusive. There exists legislation and guidance for all human beings but then there exists a range of separate documentation for those with special needs, disabilities and/or ASDs. When we can consider all human beings as individuals who each have a range of needs (albeit some more severe than others) which should be provided for appropriately, then we will be nearer to an inclusive society. Should we not be working towards provision for all members of society that automatically accommodates everyone?

Terminology used is therefore often directly linked to provision but when considering appropriate provision for any adolescent or adult experiencing a difficulty it is preferable to start with the individual and explore their strengths and weaknesses, likes and dislikes as well as their areas of specific difficulty. This way our planning and activities are more likely to be individual-specific as opposed to difficulty-specific, which will be implicitly more appropriate and likely to ensure greater success and progress.

Labels and diagnosis

Misdiagnosis is arguably the most disastrous of outcomes as provision is often allocated according to diagnosis. If a 23-year-old male with autism and mental health problems is misdiagnosed as severely mentally ill and unstable he is most likely to be treated for the mental illness. If the staff working with him are not aware of the autism and its effects then any treatment is unlikely to address all his difficulties appropriately and, at worst, treatment may compound his difficulties further. Peeters (1997: 7) concluded that: 'This is not how it should be, but it is still the case that the quality of an autistic person's life depends more on the place where he was born and whether it is a place where autism is properly understood.' So while we acknowledge the importance and value of diagnosis we must ensure diagnoses result in positive provision.

A further issue arises when diagnosing adults with ASDs as questioning the adult will, quite rightly, be involved. The very nature of ASD informs us that conversations may create incredible difficulties for someone with an ASD and to bring the questioning to a speedy conclusion adults may well answer what they think will make the professional end the process or just answer 'yes' to everything. Their understanding may be severely restricted so any responses must be interpreted within the context of the individual's conversational and linguistic abilities. Their understanding is also predominantly literal so questions must be presented in an unambiguous manner to support understanding. Howlin (2004: 284) illustrates this effectively:

If someone with autism is asked a standard diagnostic question, such as 'Do you ever hear voices when no one else is in the same room?', most will answer 'Yes' – for of course we *all* hear voices when people are not actually in the same

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room. This failure to interpret the underlying meaning of the question is likely to lead to a positive response by someone with autism, even though there is no real evidence of delusions or hallucinations.

Paranoid behaviours can also be misinterpreted when in fact it is the adult's lack of ability to cope with a life that is riddled with confusion and contradiction that results in clinical depression and paranoia. The aggression can be a result of the depression and/or their reaction to failing to cope – either of which can be the result of the ASD. Until the root problem (the ASD) is addressed there is unlikely to be significant progress and in the meantime the adult may be supported by those unaware of the ASD and thus engaging in inappropriate strategies.

Alternatively, however, accurate diagnosis can lead to appropriate provision and can help those with ASDs to understand their own behaviour more readily. This can also be a positive support for their families. Wendy Lawson, well known as a writer and lecturer who has Asperger syndrome, relays clearly how her misdiagnosis of 'intellectually disabled and schizophrenic' caused her significant problems for many years and only when Asperger syndrome was diagnosed did she truly begin to understand her own behaviours more appropriately and put in place appropriate strategies to support herself and her life more positively (Lawson, 2000, 2002). Clearly the key issue is that accurate diagnoses are essential for those with ASDs.

A further issue to consider is that of consent for assessment and diagnosis from the adult with ASD themselves. Current UK legislation and policy make it clear that everyone should agree to any process or intervention they are to be a part of, but do we allow all adults with ASDs this right and offer them support?

Professionals are under increasing pressure to validate, justify and evidence every aspect of their work and at the same time service users are becoming more proactive in their fight for equality and improved services. As a result our provision needs to accept these changes and find ways to move forwards. Arguably for adolescents and adults with ASDs the most significant and basic change needed is increased understanding and knowledge of ASDs by society and all professionals responsible for service delivery. Sadly, until this occurs, professionals are likely to continue compounding the difficulties for their service users through ignorance, a situation we clearly need to resolve.

Autism and Asperger syndrome

Prior to being identified as a unique disability ASDs were considered within the realms of mental illness and at one point children with ASD-like symptoms were considered to be the recipients of 'frigid parenting' wherein they received little or no love and attention from their main carers. As a result they withdrew from the world for fear of further rejection and became aloof and lone individuals. This belief was held by both Kanner and Bettelheim but was soon

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disputed by other eminent scientists and researchers. Once Kanner's later work emerged in the 1940s and the term 'early infantile autism' was introduced into medical terminology, clarification of the differences between autism and other mental illnesses was established. Wing (1976), however, suggested that Kanner's reference to early infantile autism was 'inappropriate' as it implied the onset of autism in infancy. In reality for many children onset is during their second or third year so 'early childhood autism' could be more appropriate.

Asperger's work then followed identifying a separate group of children with similar symptoms to the group with autism, but with some significant differences and hence Asperger syndrome became recognised.

Bernard Rimland had experienced autism first-hand as his son was diagnosed with the disability. Rimland established the Autism Society of America and his first work to have major impact was to question the theory of frigid parenting as he gathered evidence from experience and research highlighting the possibility of a biological theory of autism. His ongoing work in the field continues to inform policy and practice.

From the start of the 1950s concerns emerged in Europe and the United States regarding provision for children with disabilities and at the same time changes in society were evolving producing a more caring and politically aware people who began to fight for their rights and against injustice, both as individuals and as powerful groups. Since then campaigning groups for disabilities and ASDs have continued to emerge and parents have also become a powerful force to make representation to policy-makers as well as being more involved in the provision arrangements and development of their child or adult son or daughter. In the 1960s and 1970s intervention approaches also began to emerge for a range of disabilities, including ASDs, such as the Lovaas approach and TEACCH (Treatment and Education of Communication Handicapped Children). It was also during the 1960s that the Society for Autistic Children was created (now the National Autistic Society – NAS) by a group of parents who felt that appropriate care and support was not available.

Autism, as with many other conditions and disorders, is individual and manifests in different ways in different people. However, as a lifelong developmental disability autism was considered to be an extreme mental disorder until Kanner's work in the United States culminating in his paper of 1943 characterising 'early infantile autism'. He identified there were some similarities between the characteristics of autism and other existing conditions but highlighted several unique features:

- Lack of desire to communicate verbally
- Echolalic verbal utterances
- Fear in strange or unexpected situations
- Lack of imaginative play activities
- Repetitive behaviours demonstrated. (Wall, 2004: 6)

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At the same time Hans Asperger was developing his own research in Austria identifying similar difficulties and characteristics but focusing more on individuals with greater ability. Interestingly both Kanner and Asperger were born in Austria but Kanner emigrated to the United States in his late twenties to pursue a career in child psychiatry. Asperger's work identified the same fundamental difficulties but also highlighted differences with milder impairments, reduced language delays, higher IQs and increased adaptability (Siegel, 1996; Howlin 2004).

Triad of impairments

Three classic areas of difficulty (the triad of impairments) which should all occur for a diagnosis, are evident in everyday life for those with autism (see Figure 1.1). These areas of difficulty are:

- Social interaction
- Social communication
- Imagination

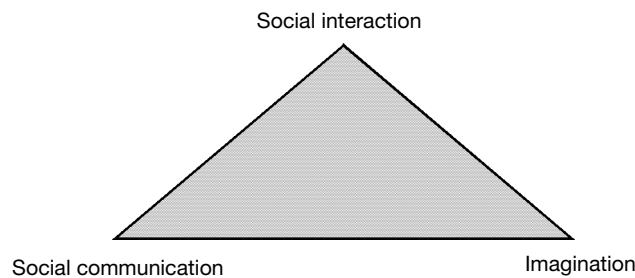


Figure 1.1 The triad of impairments

Impairments in one or more of these areas would not, in itself, warrant an ASD diagnosis but all three must have been present by the age of three years. It is important to extend our knowledge and understanding of ASDs so that all those with ASDs can be supported appropriately. Effective and thorough planning, informed by regular observation, will support this process.

The DfES/DoH document *Autistic Spectrum Disorders: Good Practice Guidance* (2002b: 6) offers a description of ASDs which although relating to children incorporates the key features:

... all children with an ASD share a triad of impairments in their ability to:

- understand and use non-verbal communication

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- understand social behaviour which affects their ability to interact with children and adults
- think and behave flexibly – which may be shown in restricted, obsessional or repetitive activities

Some children with an ASD have a different perception of sounds, sights, smells, touch and taste, which affects their responses to these sensations. They may also have unusual sleep and behaviour patterns and behavioural problems. Children of all levels of ability can have an ASD and it can occur with other disorders (for example, with sensory loss or Down's syndrome).

Prevalence

Prevalence figures are always subject to ongoing change but in general we know that ASDs are now more frequently diagnosed. This does not necessarily relate to increases in the numbers of people with ASDs but is more likely to be related to improved diagnostic processes, knowledge and understanding. There are also complications within the diagnostic processes due to coexisting conditions that may predominate so the autism may be overlooked, and further issues surround the similarities and differences between classic autism, Asperger syndrome or even non-pervasive developmental disorder – not otherwise specified (PDD-NOS). The skills of the diagnostic professional will be paramount in securing an accurate diagnosis (Siegel, 1996).

In 2003 the National Autistic Society identified a rate of 90 per 10,000 people, taking into account the whole spectrum of ASDs (Wall, 2004), but currently they are suggesting 1 in 100. Figures also suggest that classic autism is more likely in boys than girls, with a ratio of 4 : 1. For any professional working with adolescents and adults it must be assumed that they are very likely to be working with someone with an ASD during their career, and for some it will be many more. More recently, a study by Baird of Guy's and St Thomas's NHS Foundation Trust examined rates of ASDs in around 57,000 children aged nine to ten and concluded that 38.9 per 10,000 had autism, 77.2 per 100,000 for other ASDs and 116.1 per 10,000 for total ASDs (Baird, 2006).

Clearly this holds implications for those working with adolescents and adults as the numbers progressing through to adulthood and thus needing services will increase substantially over the coming years. This issue has been raised within the NAS report *Tomorrow's Big Problem* (Harker and King, 2004: 16):

It is abundantly clear that all local area services will need to plan for these increased levels of demand on already over-stretched existing services and consider the impact on current practice of service delivery.

Key features of autism and Asperger syndrome

The main distinguishing features between autism and Asperger syndrome are the presence of relatively average cognitive skills and the lack of early language delay in the Asperger group:

Wing (1991) offers clarity of understanding:

Kanner's autism – key features:

- Lack of desire for contact with others
- Obsessive resistance to change
- Fascination for objects
- Lack of meaningful verbal language
- Ability to complete performance tests or memory skills
- Impairment of non-verbal aspects of communication
- Some aspects of physical agility yet lack of coordination with some basic physical skills
- Stereotyped movements (rocking, toe-walking, flapping)
- Unusual responses to sensory stimuli
- Lack of ability to imitate
- Feeding difficulties
- Temper outbursts and aggressiveness ignorant of their effects on others.

Asperger additional features:

- Speech before school age
- Social isolation yet awareness of others
- Inappropriate social behaviours
- In-depth knowledge of some areas, occasionally with little obvious use
- Odd in appearance.

(Adapted from Wing, 1991: 95–7)

The reality for adolescents and adults with ASDs

In today's society there will be many adolescents and adults who either received a late diagnosis or remain undiagnosed. Able to attend mainstream schools they may have adapted their own coping strategies to overcome their difficulties and due to their attention to detail those with ASDs may have performed extremely well in some curriculum areas. Additionally, their lack of

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social appropriateness will make it difficult for them to engage meaningfully in the social aspects of education and will probably have led them to being more focussed on their academic work.

Perhaps continuing in education through to A level studies/sixth form college, further education (FE) or into higher education (HE), such successful individuals may then secure places at HE level, proceeding to graduate in their chosen studies. In my own experience, young adults with ASDs do, however, struggle greatly with the changes from their previous school and the expectations of FE/HE, as well as the social side of FE/HE life, particularly for those living away from home. Knowledgeable and caring tutors will be essential to offer appropriate and ongoing support for both academic and non-academic issues. Yet how many lecturers, senior lecturers and principal lecturers are likely to have a working knowledge of ASDs? Whitaker (2001: 7–8) suggests the following difficulties as typical for those with ASDs:

- being frightened or stressed by contact with other people
- being bothered about pleasing other people/making friends
- causing offence without realising/appearing insensitive
- misunderstanding people's intentions
- going too far without realising
- not knowing how to react to other people's feelings
- forming and keeping friendships
- keeping a conversation going
- knowing if another person is interested
- being able to read body language/tone of voice
- how to tell if someone means what they are saying.

Much can be learnt from listening to those adolescents and adults that have experienced secondary education FE, HE and employment as they are most likely to offer truly informed suggestions for improvements within the institutions as well as strategies for those with ASDs to use. Professionals should not make assumptions on behalf of individuals with ASDs but should involve them in decision-making relating to their own, appropriate support. Morgan (1998) offers insights into the world of employment for those with ASDs, such as the example of a man with autism writing an article for his work colleagues explaining the differences between his own behaviours and those of his workmates in the hope they would be more aware and understanding of him. While we rightly need to ensure our work with and for those with ASDs is appropriate we should not overlook the difficulties that have been experienced by, and in many cases are continuing to affect, the individuals and their families.

For those less able adolescents and adults the picture can look very different and while many texts will explore the difficulties experienced by more able individuals,

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offering strategies to support their development and progress for the individuals, professionals and families, we need to address all issues for all individuals. The NAS report *Ignored or Ineligible: The Reality for Adults with Autistic Spectrum Disorders* highlights some significant facts and issues for us all to reflect upon:

- Only 38% of people with autism and Asperger syndrome have a community care assessment. Only 16% were actually offered one; others had to fight for one. Only 45% are actually receiving the services specified in the assessment.
- At the point of transition from adolescence to adulthood a little over half of families (53%) had a transition plan in place. Only 16% have had their identified needs met in full.
- 18% of lower functioning adults were not diagnosed until beyond the age of 16 whilst 46% of people with Asperger syndrome were not diagnosed until over the age of 16.
- 59% agreed that responsibility for funding and providing care and support fell between agencies.
- ASDs constantly fall through the gap between mental health and learning disability.
- 70% of parents felt their son/daughter would be unable to live independently and less than 10% can manage the most basic household tasks such as shopping, preparing meals, paying bills, laundry ...
- Only 12% of higher functioning adults are in full-time paid employment.
- 65% of parents said their sons and daughters and difficulty making friends had 72% said their son or daughter had behaviours which other people find unusual or anti-social.
- 32% of parents reported that their son or daughter had experienced mental ill health. 56% had suffered with depression, a further 11% a nervous breakdown and 8% felt suicidal or had attempted suicide. (Barnard et al., 2001: 6–7)

Clearly this is not a picture of an inclusive society that provides effectively for its members with ASDs and this is a situation that must be addressed as a matter of urgency. When this is considered beyond the human costs we discover significant issues such as the emotional, physical and economic costs to the families and individuals themselves, as well as the estimated costs through life for a person with an ASD: £2,940,538 (Knapp and Jarbrink, 2001).

Developments in education

Since the Education Act of 1944 (Ministry of Education, 1944) when special education was first addressed in legislation, educational provision has undergone progressive changes. Prior to this time diagnoses and subsequent provision were within the remit of health professionals but as from 1944 the

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responsibility was passed to local education authorities (LEAs). Through the steady expansion of special school provision from the 1950s onwards we have recently experienced a turnaround in policy and many of these special schools are now being closed down with increasing numbers of pupils being accommodated in mainstream schools in a move towards greater inclusion for all pupils. Each school has a special educational needs coordinator (SENCO) who has responsibility for coordinating the special provision in the school and ensuring staff are able to support the children within the establishment appropriately. Governed by the SEN Code of Practice (DfES, 2001b) they ensure the staged approach is activated when a student of concern is highlighted. The student is placed on *School Action* and special support is set in place to help them achieve success and move forwards. If this is unsuccessful or little progress is made the child would be moved to *School Action Plus* which could culminate in a Statutory Assessment of their needs and a Statement of Special Educational Needs. Parents are seen as partners throughout this process. Teachers working with children with ASDs can utilise the *Autistic Spectrum Disorders: Good Practice Guidance* (DfES, 2002b), referred to earlier in this chapter, but in my own experience during training for practising teachers I was saddened to discover that the majority had not heard of or seen this useful publication.

Children with special needs should hopefully be accommodated within their local mainstream provision but those who are unable to cope in mainstream settings can be placed in a range of special units, special schools or schools solely for children with ASDs, although these are few and far between and are thus not available to all.

Over the years teachers have been able to access training on a range of educational issues but within initial teacher training there can be a distinct lack of input regarding provision for children with special educational needs, let alone children with ASDs. This being the case how can we ensure that all teachers of young people with ASDs in secondary education can understand their needs and difficulties and provide appropriate activities and support to ensure success? Howlin (2004: 182) supports the need for specialist training for all teachers.

All young people within secondary education (11 years +) will follow the National Curriculum which encourages teachers to 'modify' programmes of study to ensure all pupils, including those with special needs, are able to access appropriate learning opportunities. For children with severe and complex needs head teachers have the authority to 'disapply' the National Curriculum as appropriate. The subjects to be taught are laid down, with English, Mathematics, Science, ICT, Physical Education and Citizenship being compulsory at every stage of education.

In 2005 the Education and Skills White Paper set up planned reforms for the education of 14–19 year olds, aiming to broaden options for learners, to establish a rise in those staying in education till 18 years of age and to try to re-engage disaffected students. All students aged 13–19, and for those up to 25 if they have learning difficulties or disabilities, have access to a local Connexions Service

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which offers personal advisers who can give: 'information, advice and practical help with all sort of things that might be affecting you at school, college or work or in your personal or family life' (Internet 3).

From the age of 16 the young person's future options begin to expand as they may continue with education into sixth-form college, FE or HE or leave school and progress into the world of work. The Connexions service and/or careers department at school will be able to advise their choices at this juncture. If continuing in education the student with special needs may attend the local FE college for life skills classes or, for the more academically able, a range of courses will be available. Similarly at HE level a range of higher academic courses will be available. Within FE and HE institutions students with ASDs can be supported by Disability Officers who offer support and, advice on all aspects of student life (academic and personal). Knowledgeable academic tutors can also be allocated to students with ASDs to support their academic studies and, equally, student study support services are available to support students. Yet this depends on those tutors having ASD knowledge.

Developments in health and social care

Historically people with learning disabilities or mental health problems were likely to be detained in depressing institutions where only the basic food and accommodation needs were met, often being called 'imbeciles' or 'mad'.

The NHS came into being in 1948 when medical technologies and treatments were beginning to see changes and improvements for the treatment and care of patients. The original NHS was divided into three parts:

- Hospitals
- Family doctors, dentists, opticians and pharmacists
- Local authority health services, community nursing, midwifery, health visiting, maternal and infant welfare clinics, immunisations and the control of infectious diseases. (Internet 4)

During subsequent years the NHS has undergone considerable change and continues to outspend the financial budget awarded it. However, for young people and adults with ASDs the current situation should mean easier access to GPs for general health needs and referrals to specialist services and to dentists and opticians. Welfare benefits also support those with disabilities to enable them to lead more fulfilling lives and to secure medicines and treatments as well as supporting living allowances. From the evolution of the NHS until quite recently consistent changes have occurred but these have generally related to funding and budget holding control, or the expansion or restructuring and/or amalgamation of NHS trusts to reduce costs. The actual services available to the public have continued to expand and more specialist hospital facilities now exist, which are a result of improving knowledge, science and technology enabling more advanced techniques to be developed.

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Perhaps the most significant development in health of late is the Every Child Matters initiative (DfES, 2004a), applying to all children, young people and families. This innovative and far reaching initiative sets out to 'provide the national framework for 150 local programmes of change to be led by local authorities and their partners' (Internet 5) and is based around five key outcomes for all children and young people:

- 1 Being healthy
- 2 Staying safe
- 3 Enjoying and achieving
- 4 Making a positive contribution
- 5 Achieving economic well-being.

Focusing on proactive early intervention as opposed to reactive intervention processes the Children Act 2004 gives the legislative foundation for the implementation of change. Also integral to Every Child Matters is the National Service Framework (NSF) for Children, Young People and Maternity Services (DoH, 2004a) whereby all agencies working with families will work within a Common Assessment Framework aimed at improving inter-agency working for the benefit of all children, young people and their families. A ten-year strategy, the NSF includes eleven standards which should be met by the year 2014. Standard 8 refers specifically to those with disabilities and defines the quality of services that should be developed by 2014:

Children and young people who are disabled or who have complex health needs receive coordinated, high-quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives.

(DoH, 2004: 7)

This is an ambitious target for professionals and decision-makers to meet but there is a hint of realism in the statement as it states 'where possible', so one could argue this is the 'get-out' clause. In 2005 the ECM agenda was followed by Youth Matters (Her Majesty's Government, 2005a: 1) which aims:

... to make sure that all young people are given the best chance in life to succeed – by improving their qualifications, getting better jobs and making positive contributions to their local communities.

The Children's Trusts at local levels will be responsible for producing a range of appropriate activities to engage young people and offer them a more successful future to reduce the numbers of disaffected adolescents. This initiative extends to cover further help to those young people who are over 16 years of age 'to help think through post-16 options, personal and health issues and career choices' (ibid., p. 8).

Young people with disabilities receive scant reference within this strategy: 'Young people with disabilities tell us that they want to be able to take part in the same range of activities and opportunities as any other young person but

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they encounter additional barriers to access, (DfES, 2006: 2.16). A range of strategies are proposed to ensure greater participation for those with disabilities, all to be implemented by 2008.

Care services

Young people in residential care are perhaps some of the most disadvantaged in the country as they will already have experienced upheaval, upset and possibly severe trauma, which may have resulted in a range of behaviours of a behavioural, psychological, social, emotional, physical or cognitive nature that have created problems for them in their everyday lives. For a variety of reasons a young person with an ASD may be placed into care, be adopted or placed in a residential children's home, therefore the staff/carers will need to have knowledge and understanding of issues relating to ASDs to be able to provide appropriate support. If they do not have this knowledge they could inadvertently be compounding their difficulties further. The National Autism Plan for Children (NAS, 2003: 48), although referring to young children up to age seven only, recommended that 'Each local area should develop a multi-agency coordinating group that will oversee development of ASD services' and continued that local area training in ASD should be available to all community groups. To ensure the quality of services for adolescents and adults with ASDs it could be suggested that these issues are relevant for all people of all ages with ASDs, for if we fail to provide appropriately for the younger children how can we expect to pick up the pieces later when their difficulties are likely to be compounded?

Within care services we currently have a range of housing options for young people and adults with autism. For the under 16 age group the adolescents are likely to be in their own family homes or other family homes (if fostered, adopted or on a very short-term placement) or residential homes run by the local council. However, when councils have insufficient places in their own care homes they often secure placements at private care homes. Care work is renowned for being underrated and underpaid and in my own experience the qualifications of staff may be limited, so for private care homes that cater for young people with learning difficulties (which are constantly increasing in numbers) the knowledge of learning difficulties among the staff may be limited. This clearly needs to be addressed, possibly through a nationwide training programme for all such care workers. For the over 16 age group with ASDs the following housing and options are available:

- *Sheltered housing* – where residents can live in flats, bungalows or shared houses but are supported by a warden, either living-in or on call.
- *Council homes* – following assessment by the council adults with special needs may have the opportunity of securing a council house, flat or bungalow, to enable independent living.
- *Care homes (council or privately owned)* – for respite care or longer-term placements. Staff will work on a rota system and there is always a member of staff

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present during the night. All registered care homes are inspected by the Commission for Social Care Inspectorate (CSCI).

- *Support within their own homes from specialist carers and/or nurses.*

In 2003 the Supporting People programme evolved which funds, plans and monitors housing support services. The programme:

... provides housing related support to help vulnerable people to live as independently as possible in the community, whether in their own homes or in hostels, sheltered housing or other specialised supported housing. Supporting People only funds housing support but this can be part of a package of differently funded but co-ordinated support which meets the needs of individuals.

(Internet 6)

Summary

Education, health and social care have progressed away from Victorian institutional life for adolescents and adults with severe learning difficulties, mental health issues and/or ASDs to more community-based provision. The quality of the provision offered, however, will vary and may or may not meet the needs of those with ASDs effectively. Training, and therefore funding to support it – will be essential if we aim to ensure the individual needs of adolescents and adults with ASDs can be met and each individual is supported and motivated to make consistent progress and aim for greater independence. As we will see in Chapter 2 a raft of legislation, guidance and reports has been published over recent years to support progress in this crucial area.

For any professionals or carers wishing to secure a diagnosis it would be useful to use the Autism Screening for Adults checklist available on the NAS website to inform the decision.

Key issues



- ❖ There is now a multitude of legislation, guidance and government initiatives to support our work with adolescents and adults with ASDs, but much of this is generic, referring to learning difficulties or disabilities rather than relating specifically to provision and support for ASDs.
- ❖ Training is essential for *all* those working with people with ASDs. This has funding implications.
- ❖ Lack of training is likely to result in appropriate support which may compound the difficulties already being experienced.
- ❖ Outcomes for adults with ASDs are not generally good and the government should consider the recommendations made within key reports to inform future policy.
- ❖ A National Autism Plan for Adults is essential (as drafted by the NAS).

Some suggestions for discussion (professionals)

1. With your colleagues discuss the collective knowledge of ASDs and whether ASD training is needed.
2. If training needs are identified find ways to make it happen.

Some suggestions for discussion (parents)

1. If your son or daughter attends a school, college and/or care setting, find out how knowledgeable staff are regarding ASDs and how to support your son/daughter.
2. How can you, as a parent, influence the policy and practices within your son/daughter's placement? What mechanisms are in place to enable communication and discussion? If you are unsure as to the answers to these questions consider finding ways to improve the situation. Perhaps consider working with other parents if you share similar issues.

**Suggested further reading**

- Howlin, P. (2004) *Autism and Aspergers Syndrome: Preparing for Adulthood*. (2nd edition.) London: Routledge. (Chapters 1 and 2.)
- Jordan, R. (1999) *Autistic Spectrum Disorders: An Introductory Handbook for Practitioners*. London: David Fulton. (Chapter 1.)
- Wall, K. (2004) *Autism and Early Years Practice*. London: Paul Chapman. (Chapter 1).