

AUTISM SPECTRUM DISORDERS

CHARACTERISTICS, CAUSES & PRACTICAL ISSUES

3RD EDITION

JILL BOUCHER



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SUMMARY

AIMS

The aims of this chapter are to provide an introduction to the large and complex topic of care for people with ASD in the context of the principle of inclusion, and to demonstrate that, while examples of good practice can be cited, the ideals of inclusion are not often realised in practice.

INCLUSION

The Principle of Inclusion

Inclusion is used in this chapter in the broad sense of the moral right of every person to be included as a valued member of their society and not discriminated against because of difference (Renzaglia, Karvonen et al., 2003). According to the principles of **normalisation**¹ (Nirje, 1969), from which the concept of inclusion developed, people with disabilities should be enabled to have lives as similar as possible to those of people without disabilities; they should be enabled to achieve good quality of life; and they should have the same human rights as people without disabilities. The concepts of both inclusion and normalisation take as their starting point that diversity is to be welcomed as enriching to communities, and provision should be made for this diversity in schools, workplaces and elsewhere. The more recently evolved neurodiversity movement, referred to in the previous chapter, reasserts these principles.

In this chapter the principle of inclusion sets the standard for identifying the care needs and rights of people with ASD, and for judging the quality of the provision made. According to current ideals in most developed countries, all members of society, including those with disabilities, should be provided with or have access to the following:

- Food, shelter, warmth and protection from harm.
- Emotional and social stimulation and support.
- Opportunities for physical, mental and social activity fostering the development and maintenance of capacities and skills.
- Health care, education and employment or financial support as of right, and access to social services, financial and legal advice and representation as needed.

In addition, there should be recognition of the following rights:

- The right to self-determination in matters of care and daily living.
- The right to be valued and respected on equal terms with others.

¹Words and phrases in bold type on first occurrence can be found in the Glossary.

In what follows, the provision of care for people with ASD is considered under three main headings. First, support for families caring for someone with ASD; secondly, residential arrangements and the provision of care outside the family home; and thirdly, access to the services and rights listed under the bullet points above. Generalisations are necessarily made, which may not hold true for all countries and regions. Terms such as ‘government’, ‘State’ (with upper case initial letter, referring to a country; with lower case, referring to subregions of, for example, Australia or America), ‘local authority’, ‘public service’ are used variously and loosely to indicate the likely involvement of statutory authorities of one kind or another, while recognising that what is arranged and paid for by government-related authorities in one country or region may not be the responsibility of government-related authorities everywhere. For this reason, references to nation-specific laws or practices are generally avoided. The examples of good practice in caring for people with ASD and their families that are quoted are, however, mainly examples of provision in the UK – because these are the services I know about, not because they do not exist elsewhere.

In the final section of this chapter, which is also the final section of the book, the extent to which the ideals of inclusion have been achieved for people with ASD will be considered.

FAMILIES AND CARE

Ensuring that an individual with ASD receives the various sorts of care they need and to which they have a right is almost always critically dependent on members of the individual’s family.

Parents (or those undertaking parental roles) directly provide for the survival needs of children and sometimes also of dependent adults with ASD (see the first bullet point above). With other family members, they also contribute directly and significantly to the provision of quality-of-life needs (second and third bullet points), although external agencies also have a role here. Health care, intervention and education, etc. (under the fourth bullet point) are generally provided by agencies outside the family. However, parents are likely to be the channel through which these services are accessed and monitored. Parents may also be involved in delivering health care and intervention to children and dependent adults with ASD, either under the direction of professionals or as initiated by themselves. Finally, it is the parents who bear the brunt of the stigmatising attitudes of society and who fight the battles on behalf of their offspring for recognition of them as valued individuals.

Having a child with ASD introduces unusual stresses into a family (Hayes & Watson, 2013; Nicholas & Kilmer, 2015), and if a family breaks down, the child’s or dependent adult’s access to all the above forms of care is jeopardised. It is therefore important to identify these sources of stress so that appropriate support can be provided. Supporting families is thus a way of supporting individuals with ASD and ensuring that their care needs are met.

Sources of Stress

On parents

Sources of stress on parents include:

- The time, attention and energy needed to care for the disabled family member.
- Financial costs, often aggravated by loss of earning power.
- Loss of normal family life and leisure activities; changed and disrupted relationships among family members.

These sources of stress may be common to all families caring for a disabled child. However, caring for a child with ASD has been shown to be more stressful, generally speaking, than caring for children with other disabilities (Hayes & Watson, 2013; Gorlin, McAlpine et al., 2016). Factors that may contribute to this include:

- The child's behaviour problems, including challenging behaviours.
- The child's lack of emotional responsiveness and poor nonverbal communication.
- Parents' confusion about the nature of autism and its causes, the unpredictability of its developmental course and outcome, and controversy concerning the efficacy of intervention methods.
- The fact that autism falls somewhere between a mental health disorder and a learning disability, aggravating problems of access to provision.

Despite the numerous sources of stress, many families adjust and cope well, showing great resilience in the face of problems associated with caring for a child with ASD (Bitsika, Sharpley & Bell, 2013). The experience of stress may diminish over time, as family members individually and jointly develop strategies for coping with care for the child with ASD, and with changed family relationships. Some individuals with ASD become easier to relate to as they get older, achieving a degree of understanding of others' needs and becoming able to give back not just by being themselves, but in intentional ways. I recall the relationship between a single mother and her adult, moderately learning-impaired autistic son, which was in many ways reciprocal. He addressed her as 'dear', helped with the shopping and made cups of tea, telling her to put her feet up while he did so.

Having said this, a proportion of parents succumb to the stresses, especially in the shorter term, becoming clinically depressed or anxious, or experiencing somatic disorders, partly in response to the difficulties inherent in caring for their child, but also because of the effects on other members of the family. Mothers are particularly likely to be affected (Bitsika, Sharpley & Bell, 2013). A literature search of titles of recent articles that included words 'parenting-stress', 'mothers' and 'autism'/'autistic' produced 30 titles, whereas a search replacing 'mothers' with 'fathers' produced only one title.

Mothers and fathers tend to develop different coping strategies, some of which are more successful than others in maintaining a sense of wellbeing (Hartley & Schultz, 2015). Personality traits that have been shown to be protective against the effects of stress include 'optimism', 'hardiness' and 'resilience' (Bitsika, Sharpley & Bell, 2013).

Other factors that have been shown to reduce vulnerability to stress include the presence of a supportive partner or other close family member, and strong friendship groups (Marsack & Samuel, 2017). Secure religious faith can also be protective (Bekhet, Johnson & Zauszniewski, 2012).

On siblings

Siblings of children with ASD are also significantly affected by having a child with autism in the family. The few studies of siblings that have been carried out suggest the experience can have both positive and negative effects (Petalas, Hastings et al., 2012; Chan & Goh, 2014). This is reflected in Box 13.1, which reproduces some of the verbatim responses of siblings to informal questioning about their experiences of having a brother or sister with ASD. Several first-hand accounts of life with an autistic sibling can be also be found in Johnson and Van Rensselaer (2010).

Box 13.1 Siblings' reactions to having a brother or sister with ASD

Answers to the question 'What is the most difficult part of having a brother/sister with ASD?' included the following:

'Trying to explain to other people what his problem is, 'cos he looks normal.'

'Because he's autistic I have to help my mum more than I might otherwise.'

'You try to play with her and she doesn't like it, and then she gets in a mood 'cos she doesn't get it. She gets angry with herself. And she gets angry with everybody else.'

'If you have a guest, he won't take that into account. He'll just carry on shouting. It's quite embarrassing really. Quite often you don't want to have people around, 'cos when he's near, you just don't know what will happen.'

'If I could do something he doesn't like, like play sports or read, it would be all right. But he wants everything the way he likes it. If he's not interested in something, I have to stop it.'

Answers to the question 'What is the best part of having a sibling with ASD?'

Four of the 14 siblings questioned could think of nothing.

Six mentioned the good nature of their brother or sister, describing them as 'fun', 'funny' or 'loving'; or described playing and doing things together.

One said that she felt she had grown more mature and understanding as a result of having a sibling with ASD.

From Mascha, K. (2005), PhD thesis, University of Warwick.

Siblings often take over from their parents the major role of overseeing the continuing care of an adult brother or sister with ASD. In the remainder of this chapter,

when care of an adult is discussed, the term ‘parent’ should be understood as shorthand for ‘the responsible family member’.

Support Needs

Post-diagnosis

The period following diagnosis of any chronic childhood disability is one of particularly acute distress and family disturbance. A group of parents that included parents of children with ASD reported that following their child’s diagnosis they experienced ‘depression, anger, shock, denial, fear, guilt, grief, confusion, and despair’. These feelings were associated with ‘uncontrollable crying, sweating, headache and stomach-ache, trembling, and loss of appetite’ (Heiman, 2002; see also Fernández-Alcántara, García-Caro et al., 2016).

Parents’ need for support is therefore acute immediately post-diagnosis, including the chance to talk and to express feelings, a need for information, and advice on treatment methods as well as practical strategies to solve immediate problems and to promote development. An example of good practice in responding to these needs is described in Box 13.2.

Box 13.2 An example of good practice in supporting parents of young children with ASD post-diagnosis: Leicestershire County Council’s (UK) Autism Outreach Service

Leicestershire’s ‘Autism Outreach Service’ employs a team of specialist teachers to work with parents, extended families and schools to achieve the following aims:

- To help parents and families make sense of and come to terms with the nature of their child’s difficulties.
- To help parents to understand their child’s autism and to inform them about support services available.
- To give information about voluntary organisations that may offer help to the family.
- To help parents to develop their child’s skills, especially in communication and social interaction.
- To help parents understand and manage any challenging behaviours in their child.
- To liaise with other services that may be involved with the family and to inform parents about educational possibilities for children with autism in their area.
- To provide specialist support and training to parents in the period after diagnosis so that families can develop their own skills.

To work in partnership with parents so that children with autism reach their full potential.

To offer support and training with regard to Autism Spectrum Disorder to staff in preschool settings and receiving schools.

From www.leics.gov.uk/autism, with thanks to the Autism Outreach Manager for permission to include this information.

Ideally, all aspects of support post-diagnosis should be co-ordinated, with a range of professionals working as a team, as in the example outlined in Box 13.2, or as exemplified in 'Family-Centred-Care' programmes in Canada (Hodgetts, Nicholas et al., 2013; Christon & Myers, 2015). In the US, any child under the age of 3;0 years with a recognised disability qualifies for an Individual Family Service Plan to ensure early intervention and family support. Where an integrated service such as those described above is not available, a case manager or key worker may be appointed to ensure that a family's needs are met, and to co-ordinate input from different professionals and service agencies. Unfortunately, despite some good provision being in place, many parents report that they felt abandoned post-diagnosis (Selimoglu, Ozdemir et al., 2013; Crane, Chester et al., 2016).

During childhood

During the years in which a child with ASD is growing up within the family there are particular needs associated with enabling the family as a whole to prosper. The provision of occasional or longer-term care for the affected child outside the family is particularly important, allowing the rest of the family respite from the caring role. Occasional respite care may take the form of after-school, weekend or school holiday play and activity groups, short-term residential respite care, or befriending schemes whereby a trusted individual undertakes to look after the child in the home or to take them out on a regular basis. Longer-term respite care may be provided by residential schooling.

Other family needs during this period include support groups for siblings. These are often organised by local groups of parents who have banded together to support each other, to lobby on behalf of their children, and to plug some of the gaps in formal provision.

In adulthood

A study by Anderson, Shattuck et al. (2014) showed that over 87 per cent of young people with ASD were living with parents in the years immediately following their years in formal education. This percentage was greater than that of any of the other three disability groups studied. When their autistic child leaves school or full-time college education, the care role for parents increases because their son or daughter is no longer out for long periods of the day during term time, and the support offered by school and college staff is no longer available. As a result, parents' need for assistance to obtain work or day care for their child, and

for regular respite care, becomes paramount. Parents of young adults with ASD may also need to initiate, manage and participate in intervention programmes for their son or daughter. They may also take the lead role in planning and managing their move to substitute care.

Not all adults with ASD leave home, however. An American study of older adults reported that 38 per cent of those surveyed were living with their parents (Henninger & Taylor, 2013). This may work well if a settled pattern of routines and relationships can be established, and if the adult with ASD does not have hard-to-manage behavioural problems. However, parents with adult children living at home are vulnerable to significant stress, with adverse consequences for their health (Hayes & Watson, 2013; Sonido, Hwang et al., 2020). Moreover, if they are no longer earning, ageing parents may be in particular need of financial support, not least because lifelong caring has continuously drained their resources (Burke & Heller, 2016). They may also need advice about arrangements, financial and other, for safeguarding their child's future after they die. More is said about such arrangements in the section on 'Accessing Services and Rights', below.

Lifelong support

For most parents of an autistic child, the information, services, advice and emotional support they need must be sought out and accessed from a variety of sources, adding to the ongoing stresses and strains of caring for a child with ASD. However, in countries with a long history of catering for the needs of people with ASD and their families, organisations offering lifetime services and support may be available. 'Division TEACCH' in the US is a good example of the multiple services offered by a single provider, as outlined in Box 13.3.

Box 13.3 Long-term services and support to individuals with ASD and their families provided by Division TEACCH

The stated aim of the TEACCH approach to working with families is 'to help parents handle the special stressors that confront them and to support them in their efforts to deal effectively with their child's problems.'

Direct support for families includes:

- Provision of specialist diagnostic and assessment facilities.
- Nursery school provision and preschool intervention programmes.
- Advice on educational issues and approaches.
- Parent counselling.
- Parent group activities.

Indirect support for families is provided by services to adults with ASD, including:

Vocational guidance and employment training.

Counselling for those with relationship or mental health problems.

From Division TEACCH website: <http://teacch.com/about-us/what-is-teacch>.

OTHER CARE PROVIDERS

Substitute Care for Children

Why substitute care of children may be desirable or necessary

Parents may be unable to care for a child with ASD within the family home for a variety of reasons. These may include the fact that a child has complex disabilities (e.g. comorbid cerebral palsy or severe epilepsy) requiring exceptional levels of care – as in the case of ‘Carly’, described in Chapter 4 (Box 4.3). Parents themselves may have health problems that prevent them from looking after the child at home; or a family may have another child with a disability; or there may be intractable social, economic or emotional problems within the family, making care for the child with autism an intolerable additional undertaking. Single-parent families face particular challenges. Children with profound learning difficulties additional to their autism may also require exceptional levels of care, especially if learning difficulties are accompanied by challenging behaviour. These children are frequently excluded from local schools that are not equipped to cope, putting even greater strain on the family. Reasons of these kinds may lead parents to seek whole-year or term-time residential care and education for their children.

Another relatively common reason for a child’s living away from home during school terms is the lack of appropriate educational provision locally. High-functioning children in particular may not thrive in their local mainstream school if no provision is made for their special educational, social and other support needs. Finding an appropriate school placement is frequently a source of frustration and concern (Lilley, 2013), and some parents resort to legal action to obtain an appropriate placement (Mayerson, 2014). Figure 13.1 was drawn by a boy I will call ‘Adam’ to illustrate his distress at being bullied by other students on account of being ‘different’. Persuaded that mainstream education was not working well for Adam, the education authority in his local area agreed to help his parents fund a placement in a specialist residential school, where Adam is now thriving.

The experiences of parents seeking residential care for their children through local government agencies are, however, often negative. There is a perception that neither health care nor educational or social work agencies will take responsibility administratively or financially, and that cost-saving rather than their children’s

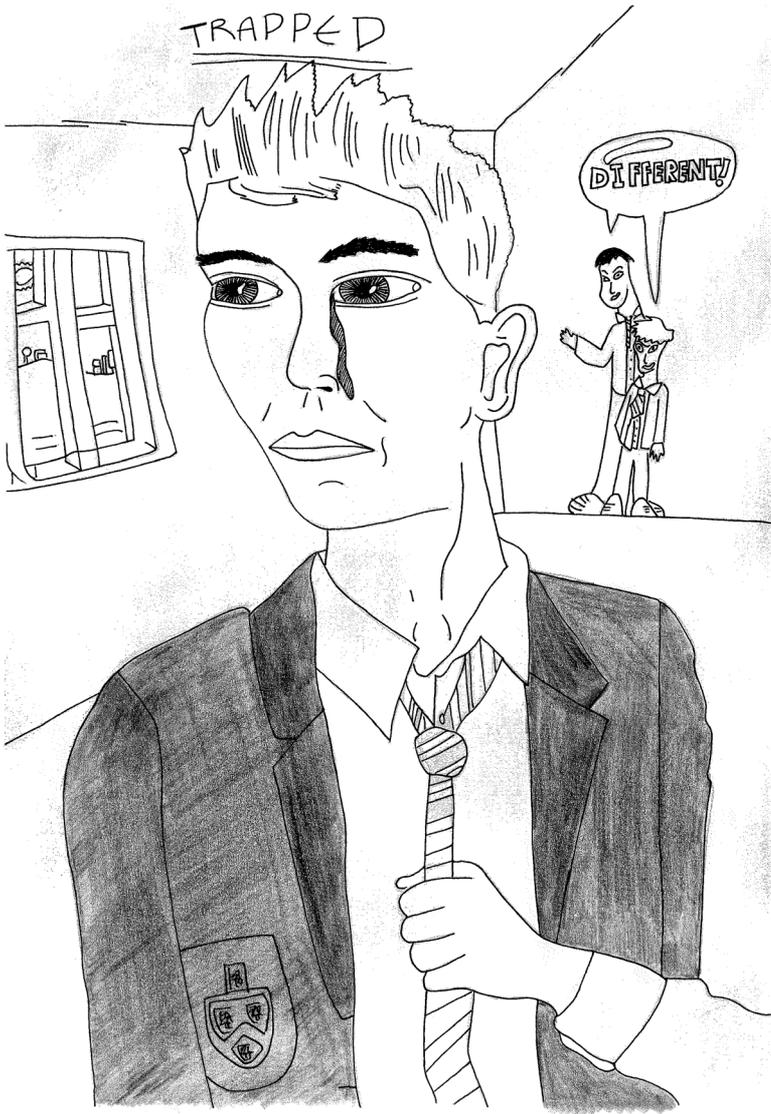


Figure 13.1 *Picture drawn by 'Adam'*

welfare is the priority (McGill, Tennyson & Cooper, 2006). Parents commonly describe the process of obtaining appropriate residential education and care as 'a battle', and formal appeals against local education authority or State/state funding decisions are common (Mayerson, 2014).

Occasionally, a child with ASD may be perceived as being at risk of neglect or abuse within a troubled or dysfunctional family, or at risk simply because a family or family member reaches breaking point (Mandell, Wallrath et al., 2005). Issues of child protection may arise in any family, but more especially in families caring

for a child or dependent adult with a disability. Individuals with ASD who cannot communicate, who are hyperactive, needing little sleep, or who have high levels of challenging behaviour may constitute an intolerable burden, and abuse may be the first sign that a family can no longer cope. In such cases, the child may be removed from family care by social services, either temporarily or permanently, and placed in substitute care, with a **guardian ad litem** appointed and a key worker charged with co-ordinating the child's care, education and access to other services in place of the parent(s).

In rare cases, an older child with ASD may be compulsorily detained as a result of having committed an offence or because of a mental health problem that makes them a threat to themselves or others.

Forms of substitute care for children

Whole-year care Residential homes and boarding schools offering whole-year care may cater specifically for children with ASD or for broader groups of children with special needs that include children with ASD. For example, the combination of severe learning disability with challenging behaviour with or without autism is relatively common, and some care centres cater specifically for this group.

Children with exceptional needs require exceptional residential provision. Specialised provision may include high levels of security (for children with extreme forms of challenging behaviours), modified environments (for children with physical disabilities), on-site medical staff (for children with chronic medical problems) and almost always one-to-one levels of appropriately trained care staff. Whole-year residential provision for children with less complex difficulties, who cannot be looked after at home as a result of family circumstances, need not be so specialised. However, whole-year residential care for any child must provide not only for the child's basic needs, but also for their emotional and social needs. Opportunities for physical, mental and social development must be provided, and access to appropriate education ensured either by locating residential provision as part of a residential school, or by locating provision near to a school or schools able to cater for the children's educational needs.

Necessary as it may sometimes be to place an autistic child or adolescent in a 52-week residential setting, a report by Pinney (2005) commissioned by the UK government noted that there were persistent concerns about the following:

- The impact on children of growing up away from their family and home community.
- The effectiveness of local arrangements for safeguarding and promoting the welfare of disabled children in residential placements.
- Difficult transitions beyond school and children's services and poor outcomes for some.
- The inappropriate use of residential placements when children's needs could have been met locally.
- The high cost of some placements.

Pinney's report made a number of recommendations. However, it appears that few, if any, were satisfactorily implemented (Tomlinson, McGill et al., 2017).

Term-time care. Residential schools offering term-time care and education should, like whole-year placements, cater for the full range of children's needs. However, links with families are more likely to be maintained when children are in termly, as opposed to whole-year, care, and major attachment figures and sources of emotional and social support are likely to come from the families rather than the school.

Some residential schools offer education and care specifically for children with ASD. Other residential special schools, for example schools catering for children with language and communication problems, may offer appropriate education for children with high-functioning ASD for whom suitable provision is not available locally. A striking example of successful specialist provision is described in Box 13.4.

Box 13.4 An unusual example of specialist educational provision: Limpsfield Grange, a mainly residential school for girls with ASD

Limpsfield Grange is a mainly residential school catering for girls aged 11–16 with ASD who have been unable to cope with mainstream school environments, even with additional support. All the students at Limpsfield follow the mainstream curriculum and work at approximately age-appropriate levels.

The school aims to provide a range of experiences that 'facilitate interaction, promote social inclusion and independence, and which empower students to understand their autism and celebrate their difference'.

To achieve these aims, the school provides a low arousal environment and a high level of targeted intervention and individualised structured activity throughout the school day. Staff development and training is ongoing, and the different professionals who may be involved in working with any one student plan and work together. Close liaison with parents and carers ensures a continuity of approach across school and home.

The school is rated as an 'Outstanding provider' by the relevant government inspectorate in the UK.

With thanks to the Head Teacher of Limpsfield Grange School for permission to include this information.

Occasionally, a local government agency will fund a place for a high-functioning child in a privately-run mainstream boarding school, but generally only if there are particular circumstances making it difficult for the child to live at home. Some parents who can afford to do so opt to send their high-functioning child to a private boarding school rather than accepting local provision. They may do this mainly for educational reasons. However, weekly or termly boarding has the additional advantage that it offers respite to other family members, while the holiday periods sustain relationships between the child and the family.

Residential schools catering for children with ASD in countries where autism has long been recognised are run under the auspices of various organisations. These include State-wide or regional education services/authorities, charitable trusts including organisations such as the National Autistic Society in the UK, and schools run by stakeholders such as educational trusts and philanthropists. Some specialist schools are, however, run by private companies with, on occasion – hopefully rarely – an imbalance between the need to make a profit for shareholders as against the needs of individuals in their care.

State provision for children at risk or detained

Children who are removed from their homes for their own or others' safety, or because they have committed a significant offence, may be cared for under the auspices of local authorities in the following types of substitute provision:

- Foster home.
- Residential care home or hostel.
- Residential school.
- Secure mental health unit.
- Young offenders' institution.

Children with ASD form a minority of the total population of 'looked-after children' cared for by local authorities, because they are more likely to be placed in residential care homes or schools than in foster homes or other family-type provision.

Adolescents with ASD who have fallen foul of the law may be detained in secure units or young offenders' institutions. Following some concerns as to the appropriateness of care in some institutions in the UK, the National Autistic Society introduced an accreditation system designed to ensure appropriate levels of staff awareness, understanding and training, as well as ensuring access to education, and to mental health services if needed. Care offered by non-accredited institutions, whether in the UK or elsewhere, is of generally unknown quality and appropriateness (see below).

Advantages and disadvantages of substitute care for children with ASD

It is difficult to generalise about the advantages and disadvantages of substitute care because the reasons why a child is placed in such care, and the kinds of provision made and the quality of provision made, are so varied.

Clearly, where substitute care offers specialised facilities that a family is unable to provide, or where it relieves a family unable to cope for unavoidable reasons, or where it offers protection from neglect or abuse, it has immediate advantages over home care. For children with ASD, the continuity and consistency of approaches to intervention and education made possible by residential schooling (the '24-hour curriculum') may be a further advantage. Termly placement in a residential school may not only benefit the child, but also provide respite for other family members, enabling a family to stay together and to provide good home care during school holidays. At its best, residential care and education for children with ASD can work

well, for children and for families (McGill, Tennyson & Cooper, 2006; see Jordan & Jones, 2012, for a broader discussion of educational options for children with ASD).

The major disadvantages of substitute care are cost (usually borne by the State) and the risk of loosening links with a supportive family, especially if substitute care is provided at a significant distance from the child's family home, which is all too often the case. There is also a risk that the care provided, if not conscientiously accredited and monitored, may fail to meet the child's needs in some way. In theory, children living away from home are protected by a raft of laws and government advice on good practice, supposedly enforced by regular monitoring and formal inspection by relevant agencies (Health, Education and Social Services). However, these procedures are often inadequately carried out in practice, mainly for reasons of cost. Some of the shortcomings and risks associated with placing vulnerable children, including those with ASD, into substitute care are highlighted in the book by Smith, Fulcher and Doran (2013) and in the review of institutional care for children across Europe, by Hamilton-Giachritsis and Browne (2012).

Residential Arrangements for Adults

Needs of those living away from home

High-functioning adults High-functioning individuals with ASD may make the transition from living with parents to living independently with relative ease. If the individual has already attended a residential school, the break from home will have already been made. For those leaving home for the first time to attend university or college, specialist support from university counsellors or supervisory staff in halls of residence may be available to support and trouble-shoot if necessary.

The ongoing care needs of those high-functioning individuals who move into long-term employment are, at best, no different from those of most neurotypical adults. There is, however, a heightened risk of social isolation and relationship difficulties. The advent of social media has reduced this risk, making it easier for able people with ASD to form friendships and sometimes life relationships. Despite this, the need for mental health care remains higher than in the neurotypical population (see Chapter 4).

Not all high-functioning individuals can achieve complete independence, however, usually because ASD is not their only disability. An example of someone I once knew who lived largely independently, but who had some special residential, social and occupational care needs, is described in Box 13.5.

Box 13.5 'Adrian': An able man with ASD and moderate visual impairment

Adrian was unable to find paid employment or to live fully independently because he suffered from moderate visual impairment in addition to his autism. He moved out of his parents' home in his mid-20s when his father developed a debilitating illness, and when I knew him, he was living in a single-bedroom flat in a small block

housing adults with a range of disabilities. There was a communal lounge in the block, communal laundry facilities, and an activities room housing computers, a small pool table, a piano and a games console. A warden occupied a ground-floor flat with a duty to ensure the safety and wellbeing of tenants. Adrian's flat had been modified to take account of his visual difficulties, and he was able to care for himself in the main, including shopping and cooking his own meals (mostly microwaved 'ready meals,' as I recall). His parents lived nearby, and his mother visited once or twice a week to 'keep an eye.' Adrian generally returned the visit after church on Sundays, to see his father and to eat home-cooked Sunday dinner.

Adrian worked for two mornings a week as a volunteer in the offices of his local Autism Support Group, mainly taking telephone calls as they came in. He also attended social gatherings and outings organised by the group. He enjoyed travel and was knowledgeable about travel firms that offered fully escorted holidays abroad for people with disabilities.

Lower-functioning adults Lower-functioning adults with ASD have all the care needs and rights listed at the outset of this chapter. During childhood, these needs have usually been met by parents either directly or indirectly. For children in substitute care, essential needs have been met by residential schools, state-run or local authority care homes, foster parents or others 'in loco parentis'. Given good care in childhood, the severity of autism-related behaviours will have diminished by the time the individual leaves school. They will also have acquired some communication capacities as well as daily living routines and some occupational skills. By the time they leave school, therefore, some capacities for independent living should have been established. Nevertheless, complete independence is unlikely to be possible. And for those autistic adults who are significantly learning- and language-impaired, who may also have challenging, hard-to-manage behaviour, specialist residential care is essential.

Forms of residential provision for lower-functioning adults

Until the middle of the last century, adults with ASD who were unable to care for themselves, and whose parents were not able to care for them at home, were looked after in long-stay hospitals alongside adults with a range of other developmental and mental health disorders. These establishments were generally large and impersonal, catering for basic needs and little else. All such institutions in the UK were closed many decades ago, once their manifold inadequacies were recognised.

Meantime, parent-led organisations had begun to establish specialist residential care homes for adults with ASD.² The first such specialist care home was opened in 1974, initially providing care for groups of adults with ASD in something like

²Parents of children with other severe or complex disabilities, such as cerebral palsy or syndromic learning disability, were also setting up residential homes or 'care villages' for their adult children by this time.

a 'guest house' or 'boarding school' setting, i.e. residents had their own bedrooms in a large house, but meals and recreational activities were provided communally. Provision in the UK is now more likely to consist of a small number of flats ('apartments') or terraced 'cottages' in which one – or sometimes two – people on the spectrum live, with some central facilities and a warden on site (see, for example, Box 13.5, above). However, full residential care is available for more severely affected autistic adults with complex needs. An example of good practice in the provision of such residential care is outlined in Box 13.6.

Box 13.6 Options Watermill: An example of good practice in the provision of group-based residential care*

Options Watermill offers long-term residential accommodation and care for both male and female adults with Autism Spectrum Conditions and complex behavioural needs.

Accommodation is provided in three different units: The House, The Bungalow and The Lodge, each offering slightly different living arrangements appropriate to the needs of those living in each unit. There are in total:

- Nine self-contained flats.
- A two-bedroom log cabin.
- A four-bedded unit offering individual spaces and communal living in The House.

Onsite facilities include:

- An activity barn.
- A soft indoor activity area.
- A multi-functional classroom facility.
- A dedicated arts and crafts room.
- A sensory room.
- A hydrotherapy suite.
- An outside recreational area which includes a trampoline, swings, seesaw and large gazebo.

Individuals also have the opportunity to access facilities at the nearby Options Roxby House, which has a woodwork room, onsite café and horticulture areas.

An onsite vocational life-skills instructor supports a variety of activities, including arts and crafts, music, sports, walking, swimming and model making, all delivered with a person-centred approach.

Overall aims and ethos:

Options Watermill develops personal programmes designed in partnership with individual residents, focusing on behavioural, sensory, communication and health needs while enabling choice and control. In this, Watermill staff are supported by the Regional Clinical Team.

Where individuals are able to communicate and understand their daily care files, these are written in formats that are relevant to each individual's preferred method of communication, using pictures, photographs and symbols. The plans are then used to help them to understand what is happening during the day.

Daily routines are designed to help promote independence and choice, while recognising individual needs for structure and consistency. Residents are encouraged and supported to learn the life skills necessary for independence, for example shopping for their own food and visiting places of interest, supported in becoming active members of their local communities.

** Options Watermill is rated as an 'Outstanding' provider by the Quality Care Commission.*

The move from providing residential care for dependent adults in large groups to providing care in individualised or small group settings reflects further changes in public policy designed to achieve a greater degree of normalisation, and to give adults as much autonomy and control over their lives as is consistent with their health and safety. Individuals with some capacity or potential to care for themselves are now likely to live in small group homes located in the broader community. For example, a small group home might be located in a large detached house in a suburban road, offering a home-like environment to five or six individuals, supported by a resident warden and care staff.

'Supported living' schemes take the move towards normalisation one step further, and are increasingly implemented by local authorities in the UK. In these schemes, individuals with disabilities that could include ASD live in their own house or flat, either alone or with a partner or other companion. They are supported by visits from paid carers who may assist with daily living tasks, and by professionals from social service departments who provide assistance of other kinds. These forms of more individualised provision are likely to become increasingly common as legislation drives change from care within large-scale units into which each individual has, to a greater or lesser extent, to 'fit', towards person-centred care in which support is customised to cater for the needs and preferences of each individual.

Financial support for all forms of residential provision for adults with ASD, as outlined above, generally comes from the State directly to the beneficiary or their representative. Legislation in the UK and elsewhere has put a statutory obligation on local authorities and health service providers to develop and implement strategies to meet the needs of adults with ASD in their area. In the past, State provision for adults with ASD has lagged behind provision for children. When the adolescent/young adult leaves school, *educational authorities* have no further statutory role; only a proportion of individuals with ASD have clinically significant mental health problems such as might make them the responsibility of *public health provision*; and *social service agencies* have, historically, offered a generic service with no specialist training or provision for working with people with autism

(D'Astous, Manthorpe et al., 2014). This situation is, however, in the process of government-led change, as reported below in the section headed 'Accessing Services and Rights'.

Problems that can be associated with residential care for lower-functioning adults

Every adult has the right to live as independently as is possible for them, and parents have the right to see their children living as independently as possible, with their needs well catered for, ensuring the best possible quality of life. The examples described above demonstrate that this can be achieved for adults with ASD, whether their needs are borderline, requiring minimal support; or complex, requiring specialised residential care with intensive individualised support.

Many problems can and do arise, however. There is the initial problem of identifying the right kind of substitute provision for any one individual, and finding where the needed provision exists, preferably close to the parental home or close to where a sibling or other involved family member lives. There is the inevitable problem of cost, and issues concerning who will bear costs, especially when specialised residential care is required. There is, as in the case of residential provision for children, the worrying problem that the prescribed processes of licensing and monitoring are not always fully adhered to (Mahase, 2020). Cases of abuse can and do arise, making headline news from time to time. Such cases generally (but not exclusively) occur in privately run 'hospitals' [*sic*] for adults with severe learning difficulties and mental health needs, including adults with ASD. One such provider was named and shamed in a much-publicised television programme in the UK some few years ago but has not, I note, gone out of business.³

Cases such as the above have increased calls for community-based supported living services to replace institutional services for people with learning disabilities. It would be less than honest, however, to claim that caring for the minority of severely learning-disabled people with ASD, who are prone to bouts of challenging and sometimes violent behaviour, is ever easy, in any setting. It can be done well, using approved and safe methods of restraint and, pre-eminently, intervention to reduce occurrences of such behaviour. However, this requires high levels of well-trained staff which, of course, comes at a cost.

Finally, individuals themselves may not want to leave home, and this can make it difficult to achieve an acceptable balance between respecting an adult's right to self-determination and acting in ways agreed by responsible others to be in that adult's best interests. For parents also, and especially for mothers, separation from a dependent child after decades of caring in which a uniquely close type of relationship may have been established can be difficult and painful. Sensitive management of the transition period, for both the individual and the parent, or

³Far from it. That particular company, now a subsidiary of an American 'Healthcare' company, runs – at the time of writing – over 100 such 'hospitals' in the UK. The operating profit of the subsidiary company was reported online to be £40,000,000 in 2017.

parents, may be critical in determining that the move away from home is experienced positively in the longer term (for discussion of support during transition periods in general, see Smart, 2004).

ACCESSING SERVICES AND RIGHTS

Previous sections of this chapter have dealt with care in the sense of where the child or adult with ASD lives – where is ‘home’ and who provides for them there. In this section, the autistic individual’s access to services and opportunities that are also identified under the principles of inclusion is considered first. The section ends with an appraisal of the extent to which people with disabilities, including those with ASD, enjoy the human rights identified under the principles of inclusion.

Services and Opportunities

Health care

Those with ASD are more vulnerable to health-related problems than most people, including allergies and digestive disturbances, accidental or self-inflicted injury, anxiety and depression (see Chapter 4). Frequent visits to clinics and hospital stays have cost implications for families and independent adults, even in societies providing free medical care. Autism-related characteristics may cause additional problems of time and cost in accessing appropriate health care. For example, dental treatment for an individual with poor communication may involve travelling to a specialised clinic or dental hospital, rather than using local services. In addition, lack of up-to-date knowledge and understanding of ASD by many healthcare workers can cause inappropriate interpretation of symptoms and inappropriate treatment advice.

This emphasises the need for training primary healthcare workers. In the UK, training is now offered by, among others, the Royal College of Nursing, the British Psychological Society, and the Royal College of General Practitioners (see their ‘Autism Toolkit’ guide). NHS Scotland has developed its own ‘Autism Training Framework’, outlining the knowledge and skills required by medical staff across the range, from those in generic services through to those working in specialist ASD services. A technology-based training package for primary care workers, the Extension for Community Healthcare Outcomes (ECHO), has been developed in the USA (Mazurek, Brown et al., 2017) and assessed for efficacy (Mazurek, Parker et al., 2020).

Education

Children with ASD have the same right of access to education as any other child. However, for children with ASD there is no clear division between education in the sense of providing a child with opportunities to acquire knowledge and skills (the goals of education as generally understood) and the provision of interventions

designed to provide children with ASD with the skills and strategies they uniquely lack as a consequence of their autism, and to modify maladaptive behaviours associated with autism. The educational needs of children with ASD are therefore 'special', or 'exceptional', even in the case of high-functioning school-age children or young adults attending college or university.

Appropriate provision for children's and young adults' educational needs could include at least the following:

- Modified environments and equipment (e.g. small classrooms/individualised work stations, secure and specially equipped playgrounds, a sensory room, additional computers).
- Modified curricula and individualised teaching programmes.
- Modified teaching methods (see references to educational methods in Chapter 12).
- Specialist training for teaching staff.
- Parental or key worker involvement to ensure continuity and consistency of educational and intervention approaches across home and school, playgroup or college.

Where and how these needs may best be met in a manner consistent with the principles of inclusion is a hotly debated issue, discussion of which is beyond the scope of this book (see Jordan, 2008, for an account of the issues). However, the principle that no one size fits all is useful to bear in mind. Each individual with ASD has different and changing educational/intervention needs. Each family has different needs, opinions and wishes for their child. Each playgroup or nursery, mainstream or special school, college or university differs in their motivation and capacity to welcome children or students with ASD into their communities. Decisions as to where a child or young adult with ASD should be educated must therefore be made on a case-by-case basis, often constrained by availability. Accessing appropriate education for their children is therefore frequently arduous and frustrating for parents, as noted above. However, where a range of autism-specific forms of provision is provided, parental satisfaction can be high (Department of Education and Science (Ireland), 2006).

Many adults with ASD continue to benefit from education in the sense of intervention to help overcome autism-related limitations and problems or to increase daily living or vocational skills (as described, for example, in Box 13.6, above). Attendance at college courses or evening classes can provide more able adults with the kind of structured social event they are able to cope with, as well as providing stimulation and practical benefits.

Employment

Examples of the kinds of employment or meaningful occupation that may be obtained by individuals with ASD were described in the section on lifespan development in Chapter 5. By 'meaningful occupation' (as opposed to employment) is meant here unpaid or nominally paid work, for example household tasks carried out in a residential setting; or work carried out on a voluntary basis or in a sheltered workshop or day care facility. The present section concerns the ability of people with ASD to access paid employment, which they have a right to expect under the principle of inclusion.

Obtaining and keeping paid employment are both problematic for people with ASD, from the least to the most able. Regarding access to employment for less able individuals and those with behavioural problems, the description of 'Nancy' (Box 5.3) provides an example of the kind of setting in which supported employment may be obtained, and the methods used to introduce the individual to a work environment and work practices so as to maintain the individual in their employment. A further example of how environmental modifications and specific task support may enable a less able person with ASD to carry out paid work in a sympathetic setting is described by Hume and Odom (2007). These authors used TEACCH principles of structuring the work environment and providing a visual timetable to enable a young man, Mark, to stay on task and complete work assignments independently of external prompting.

Encouraging as they are, the descriptions of 'Nancy' and Mark serve to underline the difficulties involved for less able individuals to access employment: at the least, it requires sympathetic employers and fellow employees, extensive and painstaking preparation and training, and continued support (Hendricks, 2010; Hedley, Uljarević et al., 2017).

A somewhat different set of problems confronts more able individuals with ASD in accessing and maintaining employment. These are vividly illustrated in quotes from people with Asperger syndrome who were interviewed about their experiences of employment (Hurlburt & Chalmers, 2004). For example, one woman reported:

I have a degree in political science and am just trying to get a decent job with decent pay and benefits. I have cleaned cat cages, done janitorial work (which is boring, boring, boring), office work ... [been] a telemarketer (which I hated, but I learned how to do public speaking!), and worked in a group home on the early morning shift. (Hurlburt & Chalmers, 2004: 218)

This woman attributed her inappropriate and changing employment to her difficulties in conforming socially. Another woman said that others in the office where she worked 'felt uncomfortable around her and tried to get rid of her'. A young man reported that he had just been laid off his job because of anxiety resulting from his inability to cope with changes in co-workers, supervisors and job coaches (compare the case of 'Mr A', described in Box 4.5).

For reasons such as the above, only a minority of high-functioning people with ASD find paid employment in jobs for which they are well qualified. However, it has been shown that supported employment schemes for more able individuals can achieve a high level of success with significant benefits to individuals themselves and society in general in terms of cost savings (Mavranezouli, Megnin-Viggars et al., 2013). Moreover, recent changes in the benefits system in the UK are designed to encourage people, including those with disabilities, to find employment; and the UK government's 'Think Autism Strategy' (2014, 2018) places an obligation on local government authorities to support people with ASD into work. The response of one local authority, working in co-operation with a charity, is outlined in Box 13.7.

Box 13.7 An example of good practice in supporting autistic adults into sustainable employment

Autism Skills Development and Employment Support (ASDES) is a Community Interest Company, operating in Wales. Its core aim is to support people who identify with autism and associated hidden impairments into work. Social gatherings and group activities are used to enhance communication and social skills, and to accustom potential job applicants to being out and about in their local community. In addition, a team of job coaches and a family practitioner offer individualised assessment, training, family group sessions and support to facilitate entry into appropriate employment. The work carried out by job coaches is critical, and includes the following:

With participants

- Building a relationship with the participants in order to identify their strengths and their development needs relating to specific job skills.
- Understanding how their hidden impairment has an impact on them personally and considering how their specific needs may be accommodated in the workplace.
- Providing training and support to increase the participant's capabilities.
- Ensuring that they have an up-to-date CV and covering letter appropriate to their job goals, and carrying out mock interviews.

With potential employers

- Seeking out appropriate job opportunities.
- Approaching potential employers and arranging interviews.
- Conducting a detailed job analysis at employers' premises in order to match an individual to the work.
- Identifying reasonable adjustments for the individual in the workplace and negotiating for these adjustments with the employer.
- Escorting the participants to interview and acting as their advocate.
- Carrying out autism and hidden impairment staff-awareness sessions with an employer.
- Accompanying the individual to work when appointed, until they are settled in.
- Providing follow-up for both the participants and the employer, including discussion of issues relating to career development.

With thanks to the Chair of ASDES for permission to include this information.

Financial assistance

The financial costs to families rearing a child with ASD are considerable (Sharpe & Baker, 2007; Parish, Thomas et al., 2015), and publicly funded financial assistance to which a family may be legally entitled rarely if ever covers these costs. In addition, accessing the various forms of financial assistance to which a family, or an

adult living independently, may be entitled is likely to involve seeking out somewhat inaccessible information, understanding regulations concerning eligibility, filling in complicated forms, and co-operating with intrusive assessments (Grant, 2011). In the US, the situation for adult claimants is particularly fragmented and complex. Peter Emch, father of an adult with ASD, wrote in 2011:

Public support consists of disparate programs, individually legislated sometimes by federal and other times by state governments – some aimed at poverty, others at disability – that are rarely coordinated. The result is a confusing mess. There is no ‘U.S. Autism Program’ (autism-matter16 website)

To the best of my knowledge, the situation in the US has not materially changed. Moreover, according to the survey by Parish, Thomas et al. (2015), private insurance (against medical costs) rarely, if ever, covers actual financial outlay.

Unsurprisingly, families caring for a child or dependent adult with autism find the processes difficult and irksome, and may need assistance with obtaining financial benefits for which they, or their dependent son or daughter, are eligible. National and local ASD support groups may provide helplines, information packs and day courses from which advice can be accessed. Some voluntary organisations also offer free **advocacy** services. However, if a claim goes to an appeal, advice and assistance from paid professionals may be necessary, incurring additional cost.

Professional assistance

Advice and advocacy by professionals such as lawyers, doctors or accountants is needed not only in appeals relating to benefit claims, but also in appeals relating to educational or substitute placements (Mayerson, 2014). Legal and financial expertise are also needed when parents make their wills, especially in cases where there is a dependent son or daughter. This usually entails setting up a Trust to administer funds for the benefit of the dependent person. Here again, useful information can be obtained from various helplines and websites dealing with issues for families with a dependent disabled child. However, the actual formulation of a legally binding will, and the establishment and financial management of a legally watertight Trust, require input from lawyers and accountants. Some legal firms specialise in helping families of disabled offspring, and contact details for such firms may be found in relevant publications and websites.

Human Rights

According to the principles of inclusion listed at the outset of the chapter, all humans have a right to self-determination in matters of care and daily living, and the right to be valued and respected on equal terms with others. To what extent are these ideals achieved? And if not achieved, why might this be the case?

The right to self-determination

This human right is generally recognised by authorities regulating substitute care and operating systems of licensing and inspection in developed countries.

Substitute care providers generally aspire to recognise this human right, according to their mission statements. However, whether or not this aspiration is met in practice is difficult to ascertain, and the fact that evidence of poor or abusive care continues to emerge via the media suggests that regulatory authorities do not always make adequate checks.

There are also real practical difficulties in cases where an individual does not have the capacity to understand why a decision has been made on their behalf, contrary to their own wishes. A woman I have known since she was a child, who is now in her late 40s, provides an example, although 'Lily', as I will call her, has cerebral palsy and mild to moderate learning difficulty, but not autism – see Box 13.8.

Box 13.8 'Lily': An example of the practical difficulty in implementing the right to self-determination

From her early 20s, Lily had lived in great contentment in a group home for physically disabled people. She called the staff and other residents there her 'family'; and she was well known and liked by people living and working in the neighbourhood where she was regularly taken to shop, or to a local café, or to 'disabled swimming' sessions.

The time came, however, when the charity running the group care home decided, with the very best of intentions, to move all the residents into their own flats or bed-sits in nearby towns, in accordance with the principles of supported living. Ironically, one of the arguments in favour of supported living arrangements for dependent adults is that it provides greater autonomy for individuals than group living can easily achieve. But Lily was distraught. To her, it was compulsory removal from her family and friends, senseless and hurtful. She did not want to live on her own, or with just one other person; nor to take on greater responsibility for her own basic needs.

In the end, and after a prolonged and ultimately unsuccessful campaign by residents' families and friends to keep the group home open, Lily's wishes were partially recognised. She moved into a group home run by a different charity, where she is now in the process of establishing a new 'family' and new friendship groups.

With thanks to 'Lily' and her mother for permission to include this account.

Regulation and inspection do not of course extend to children or dependent adults living at home. Parents and other family members must make their own compromises concerning their child's or adult son's or daughter's right to self-determination. Only extreme cases of denial of this right in the context of abuse or neglect would be likely to come to the attention of authorities with the power to improve the situation.

The right to be valued and respected on equal terms with others

The right of disabled people to be valued and respected as much as anyone else involves breaking down barriers of ignorance and prejudice. This is the case for any kind of disability, whether physical or behavioural, that makes an individual noticeably different from the majority. Governments may legislate for inclusive, non-discriminatory provision for people who are perceived as 'different', whether on account of disability, colour, age or religion, but they cannot control the attitudes and reactions of members of the general public.

Parents of children with ASD, even in so-called 'enlightened' societies, frequently report hostile or hurtful reactions to their child from, for example, parents of neurotypical children in mainstream schools, or staff and clientele in supermarkets, restaurants, libraries, swimming pools, and other public places. High-functioning children with ASD in mainstream schools are almost invariably victims of bullying. Lower-functioning adults are vulnerable to mockery in the workplace, pub or club. Even something as apparently straightforward as using public transport to travel to school or to work or to see a friend or relative can be difficult and/or unpleasant for individuals and families, provoking hostile or humiliating comments from other transport users.

Why should this be so? The reasons are almost certainly deep-seated and to do with the fact that living in social groups was a crucial factor in the evolution of the human species (Frith, 2013). Living in a group involves differentiating between members of our particular group and those who are not members of our group (Tajfel, 1981). Behaviour towards non-group members, or 'out-groups', is likely to be hostile or at best exclusionary. The human tendency to view the world in terms of in-groups and out-groups at multiple levels is, of course, what all disability rights groups fight against, including the neurodiversity movement referred to in Chapter 12. Ignorance and fear also prevent 'us' (the in-group of non-disabled people) from accepting that the facially disfigured war veteran sitting opposite us on the train, the Tourette's sufferer shouting obscenities in the street, and the autistic child rocking and making strange sounds in the café are all human beings 'like us'.

Getting to know such people as individuals is the best way to combat ignorance and fear, which is one reason why 'autism awareness' is almost always highlighted in strategy documents relating to the wellbeing of people with ASD. Fictional representations of people with high-functioning ASD (still sometimes referred to as having 'Asperger syndrome') as a bit odd but clever to the point of genius have helped those at the high-functioning end of the autism spectrum to gain acceptance and respect. People in the news who are open about being at the very high end of the spectrum (for example, Greta Thunberg, at the time of writing) are also helpful in taking the fright out of 'autism'/'autistic'. However, the publicity given to high-achieving people on the spectrum has probably made it harder, rather than easier, for people with more debilitating forms of ASD to be respected and valued as much as anyone else: unless they have some savant ability to show off, they are not clever, and their behaviour may be disconcerting or even threatening.

Another reason why people with disabilities are often undervalued and treated with disrespect is that the ideals of normalisation and inclusion have a very short history. Within living memory, parents of a baby with, for example, cerebral palsy or Down syndrome (easy to detect at birth) were commonly advised to 'put him in a home'. In such 'homes', other children with learning disabilities, including those with autism, would also be placed when their difficulties became conspicuous. Basic care needs were provided for, but only those institutions run by the most enlightened voluntary organisations would have perceived any needs for intervention, education or occupation, let alone any legal or moral right to self-determination and respect.

The ideal of 'equal value equal rights' applied to individuals with disabilities is also fragile, since it is only likely to be acted upon in societies that are not under survival pressure. When survival pressures increase as a result of war, famine, epidemic or financial depression, the needs and rights of people with disabilities of any kind, age and infirmity included, are often discounted or ignored, even in so-called civilised societies.

In view of the deep-seated roots of prejudice and discrimination, and the relative recency and fragility of the ideals of inclusion, it is not surprising that these ideals have not been fully achieved for people with ASD, even in rich, developed countries. However, within my own lifetime – now long – I have seen immense progress towards making these ideals a reality. There is some way to go. But we should not be pessimistic.

SUMMARY

The principle of inclusion sets the standard for identifying the care needs and rights of people with disabilities, and for judging the degree to which they are met. Identified needs include food, shelter and protection from harm; emotional and social stimulation and support; and opportunities for physical, mental and social development. Rights include access to health care, education and other services, and the right to self-determination and to be valued and respected.

Families are the major providers of care for people with ASD. However, caring for a child or dependent adult with ASD is demanding and stressful, involving unusual amounts of time, energy and money, and entailing loss of normal family life and disruption of within-family relationships. Support for families in their care roles is therefore important. Immediately post-diagnosis of a child, parents need information, emotional support and practical advice. Later, the pre-eminent need is for support that enables the family as a whole to prosper. This could include the provision of respite care, parent counselling and support for siblings. Parents of adults with ASD often have an increased care load when their child leaves full-time education, and the need for work opportunities, day care facilities and respite care for the dependent adult is then paramount. Throughout their lives, parents need advice and practical help in planning their children's future and in accessing available resources and services for them.

'Out-of-home' or 'substitute' care for children may be required for a variety of reasons. For example, a child may have exceptional needs that cannot be catered for at home; a family may be unable to cope for health reasons; appropriate educational provision may not be available locally. Occasionally, a child is considered to be at risk within the family and is taken into care. Substitute care for children takes various forms, from foster care to term-time or whole-year residential care and education. The advantages and disadvantages of substitute care depend on the reasons why an individual has to be cared for, and on the quality of the substitute provision. In all cases, provision is costly, and there is a risk of loosening links between the family and the affected child or adult.

Adults with ASD who are not living at home may at best live completely independently. More commonly, some degree of support is needed to ensure that the individual's needs are met. This ranges from 'keeping an eye' on someone living mainly independently, to providing intensive practical, emotional/social and occupational support to individuals living in small group homes or in individualised accommodation.

Many people with ASD have lifelong needs for the kinds of services and opportunities provided by external agencies. Accessing appropriate services may be difficult for numerous reasons. For example, appropriate health care may be unavailable because of a lack of specialist staff training. Appropriate education for a child with ASD may require modifications of standard environments, curricula, equipment and teaching methods and, again, specialist staff training. Finding and maintaining employment for an adult with ASD may require considerable time and effort from support workers. Accessing much-needed financial benefits and advice is often, again, difficult and frustrating. However, recent legislation underlines the obligations of centrally or locally run authorities to cater for the needs of people with ASD. In addition, autism support networks provide helplines, written advice, and training in advocacy designed to help individuals and carers access services to which they have a right.

The human right of self-determination and the right to be valued and respected are harder to ensure. Enjoyment of these rights is hindered by deep-rooted attitudes within society in general towards people who are perceived as 'different', whether by virtue of skin colour, religion or disability. However, progress in breaking down ignorance and prejudice against people with ASD is being made.

