

# **CHAPTER 1**

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## Key Points

- Disabled children and their families have the same human rights as others, including the right to the same quality of life as those who do not live with disability. The social model of disability assumes that some of the most oppressive and limiting aspects of disabled people's lives are caused by social, environmental and political factors which can be changed.
- The state has core responsibilities to promote the human rights of disabled children and their families and to counter the discrimination they experience.
- Around 7 per cent of children in the UK are disabled, using the Equality Act 2010 definition. The majority live at home with their families.
- Disabled children and their families are worse off financially and have markedly poorer standards of living than those families who do not live with disability. Expenditure is higher but opportunities for earning through paid employment are reduced, particularly for mothers. Many families are in debt and live in unsuitable housing.
- Families provide high levels of care for their disabled children.
- Disabled children and their families face substantial barriers in everyday living and experience high levels of social exclusion.
- Many children and their families have difficulty in accessing services to meet their needs. Provision is complex and information about entitlements frequently unavailable.
- The combination of high levels of need, poor circumstances and lack of support services can have an impact on the health, well-being and opportunities of all family members.
- The early times when disability is identified are stressful for many families.
- While many parents report that they are satisfied with their disabled children's schools, many also experience problems in accessing suitable education provision.
- Many disabled young people face considerable difficulties in transition from childhood to adulthood and from children's to adult service provision.
- A minority of disabled children live away from their families for some or all of the year: in residential schools, healthcare settings or 'looked after' by local authorities.
- Children and their families need person-centred services which promote full social participation and enable them to maximise their health, well-being and life chances.

## **Introduction**

1.1 This handbook provides a comprehensive review of the law, particularly social care, education and healthcare law, as it applies to disabled children and their families. We have aimed to write something that is useful for everyone interested in the lives of disabled children whether they are lawyers or non-lawyers. We hope that families themselves, as well as individuals and organisations representing their interests will continue to make use of it.

1.2 The nature of the difficulties faced by disabled children and their families means that a handbook devoted solely to the law would be a rather inadequate tool. In order to understand how the law can be used to help them, we need first to appreciate the common problems they encounter and the services and other arrangements that would make a positive difference to their lives. The purpose of this chapter is to set out some of the most important principles and 'facts of life' as they affect disabled children and those close to them. In order to do this, we draw on the ideas and expertise of disabled children and their families, on official reports and on research about their circumstances and experiences. The aim is that anyone unfamiliar with the issues disabled children and their families face, can get up to speed fairly quickly, that individuals and organisations working on their behalf can have access to reliable source material and that disabled young people and their families can check out their individual experience against the broader picture.

1.3 Throughout the guide, 'children' is used to mean those from birth to 18 years unless it is otherwise specified. In certain specific contexts a child becomes a 'young person' at around 16. We make this clear throughout the text. The words 'young adults' refer to adults up to the age of 25 years.

1.4 Some parents known to the authors of this handbook have discussed the difficult balancing act involved in trying to raise awareness of the problems families face without unwittingly feeding the prejudices of those who view their lives as overwhelmingly negative. Recognising the adversity that disabled children and their families face need not involve undermining the integrity of their personal and family life. Equally, challenging inadequate support for one child or family can lead to improvements for all families.

## **Underpinning principles**

### **An ordinary life**

1.5 An underpinning principle of this handbook and of the rights-based approach it adopts is that disabled children and those close to them are entitled to enjoy the same human rights as others. This can be summarised as the right to live an ordinary life.

1.6 Disabled children's and their families' needs and priorities may be different in some ways from those who do not live with disability. This does not mean that they should be precluded from participating in ordinary social, economic and cultural experiences enjoyed by others. Disabled children and their families, however, may need additional supports and different arrangements to enable

them to participate in things that are part and parcel of an ordinary life. Living an ordinary life carries with it the presumption that like any children, those who are disabled should usually be brought up in a family setting – one of the principles embedded in the Children Act 1989 (see chapter 3 at para 3.12).

## The social model of disability

1.7 In the past 30 years, disabled writers and activists have developed an approach known as the 'social model of disability'.<sup>1</sup> While there are of course differences in emphasis and understanding between some of those developing these ideas, there are a number of common areas of agreement. The social model of disability has contributed to re-shaping the way that disability is understood and has been influential in relation to government policy,<sup>2</sup> international treaties<sup>3</sup> and international classification systems of health, illness and disability.<sup>4</sup>

1.8 The social model makes a distinction between impairment and disability. 'Impairment' is used to refer to a person's physical, sensory and intellectual characteristics or limitations. 'Disability' on the other hand, is seen as the restriction, disadvantage or oppression experienced by those living with impairment. In the words of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD):

... disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others<sup>5</sup>

Crucially, this approach challenges the notion that a child's impairment or medical condition is solely or even primarily responsible for any restrictions they face. It argues that many of the common problems they encounter are not a necessary consequence of living with impairment. By contrast, a much greater emphasis is placed on the disabling impact of the physical, social, cultural, political, and legal environment. It reminds us of the importance of context in shaping people's lives and opportunities: individual characteristics including impairments, are important, but the context in all its complexity, has the power to increase or reduce the disability that children and their families experience. This context includes the services that are available to them. This handbook adopts this approach and, therefore, pays particular attention to the circumstances in which disabled children

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<sup>1</sup> For example T Shakespeare, *Disability rights and wrongs revisited*, Routledge, 2013; N Watson 'Theorising the lives of disabled children: how can disability theory help?' (2012) 26(3) *Children and Society* pp192-202; M Oliver and C Barnes, *The new politics of disablement*, Palgrave Macmillan, 2012; J Morris, *Pride against prejudice*, Women's Press, 1991.

<sup>2</sup> Prime Minister's Strategy Unit, *Improving the life chances of disabled people*, The Stationery Office, 2005.

<sup>3</sup> UN Convention on the Rights of Persons with Disabilities (2006).

<sup>4</sup> World Health Organisation, *The international classification of functioning, disability and health: children and youth version*, 2007.

<sup>5</sup> UN Convention on the Rights of Persons with Disabilities (2006), Preamble, para (e).

and their families live and to features of the social context that act as barriers to their living ordinary lives. It emphasises the importance of arrangements and services that enable disabled children and their families to flourish: circumstances which aim to create equality of opportunity between those who live with disability and those who do not.

## The relevance of human rights

1.9 In addition to the influence of the social model of disability, there has also been growing recognition of the importance of a human rights approach to enhance understanding of the experience of disabled children and to bring about improvements in their lives.<sup>6</sup> This approach has been summarised as follows:

At its most basic, it affirms without qualification that disabled people are not 'other': they are unquestionably included within the category and meaning of what it is to be human, and may, therefore, expect all the rights derived from that status. By employing such a normative and unifying approach, the things that happen to disabled children and adults, the lives they lead and the goals they aspire to, may be evaluated against norms or benchmarks established by consensus and sometimes by law, as universal human rights.<sup>7</sup>

In keeping with the fundamental purpose of the UNCRPD, our goal should be to try to reduce barriers that hinder the full participation of disabled children and their families in society and to ensure their enjoyment of the human rights and freedoms that everyone should be able to expect.

1.10 In chapter 2 we consider, in outline, the international human rights treaties of greatest relevance to the issues considered in this handbook – the European Convention on Human Rights (ECHR), the UN Convention on the Rights of the Child (UNCRC) and the UNCRPD (see paras 2.10–2.37 below). Reference is also made to the rights safeguarded by these conventions at key points in this text, where they are of particular relevance. It is important, however, to be aware of specific key human rights principles that underpin many of these specific rights – and these include:

- the core responsibilities of the state;
- the principle of non-discrimination;
- the principle of dignity;
- the principle of independent living;
- the principle of choice;
- the principle of cost effectiveness.
- The core responsibilities of the state

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<sup>6</sup> J Bickenbach, 'Disability rights, law and policy', in G Albrecht, K Seelman and M Bury (eds), *The Handbook of Disability Studies*, Sage, 2001.

<sup>7</sup> L Clements and J Read, 'Life, disability and the pursuit of human rights', in L Clements and J Read, *Disabled people and the right to life*, Routledge, 2008, p6.

1.11 Given that many of the factors that restrict disabled people are socially created, it follows that addressing these and the consequent exclusion and disadvantage they experience is a core responsibility of the state. As the UN has observed, in a binding (2003) statement:<sup>8</sup>

*The obligation of States parties to the Covenant to promote progressive realization of the relevant rights to the maximum of their available resources clearly requires governments to do much more than merely abstain from taking measures which might have a negative impact on persons with disabilities. The obligation in the case of such a vulnerable and disadvantaged group is to take positive action to reduce structural disadvantages and to give appropriate preferential treatment to people with disabilities in order to achieve the objectives of full participation and equality within society for all persons with disabilities. This almost invariably means that additional resources will need to be made available for this purpose and that a wide range of specially tailored measures will be required.*

1.12 This core obligation, which is given further emphasis in General Comments to the UN Convention on the Rights of the Child,<sup>9</sup> is on the state, not on families or charities. Families are already 'disabled by association'<sup>10</sup> and many carers experience similar levels of social exclusion to those for whom they provide care. This has been recognised by guidance concerning the rights of carers,<sup>11</sup> which states that social workers should not 'assume a willingness by the carer to continue caring, or continue to provide the same level of support'. The law reflects this approach, placing duties on the state to provide a level of support to all disabled people (children and adults) that respects their human rights.

## The principle of non-discrimination

1.13 The principle of non-discrimination runs wider than the obligations under the Equality Act 2010 (see chapter 9) and is essentially the core obligation in the UN Convention on the Rights of Persons with Disabilities (see, for example, articles 3, 4, 5 and 6) to provide for true equality of disabled people before the law, to effective legal protection and the right to 'reasonable accommodation'. It brings with it the requirement, for example, that the arrangements for disabled children should not be inferior to those for non-disabled children; that disabled children should not be inappropriately excluded from mainstream schooling;<sup>12</sup> and that all disabled children be treated equally whatever their impairments or conditions.

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<sup>8</sup> General Comment 5 concerning persons with disabilities and the International Covenant on Economic, Social and Cultural Rights, para 9.

<sup>9</sup> General Comment 9, para 20.

<sup>10</sup> *Coleman v Attridge Law* C-303/06 [2008] All ER (EC) 1105, ECJ, considered at paras 9.4-9.5.

<sup>11</sup> Department of Health, *Practice guidance to the Carers (Recognition and Services) Act 1995*, LAC (96)7, para 9.8.

<sup>12</sup> See paras 4.220-4.229 in relation to school exclusions.

## The principle of dignity

1.14 The concept of 'dignity' is central to many human rights treaties and bodies<sup>13</sup> and is often expressed in terms of respect for 'personal autonomy'/'physical integrity' and of a right to a level of support that does not lead to 'indignity', and that compensates for the disabilities faced by disabled people.<sup>14</sup> In England, the binding legal basis for the duty on the state to ensure that disabled children are treated 'with dignity' derives from articles 3 and 8 of the ECHR: the basic obligation is to ensure that no one is subjected to degrading treatment (article 3) and that 'respect' is shown for a person's private life (article 8). In this context, 'private life' has a broad ranging meaning encompassing a 'person's physical and psychological integrity' and their 'relations with other human beings' and their immediate environment.<sup>15</sup>

1.15 The European Court of Human Rights (ECtHR) has expressed the obligation this imposes in the following terms:

*In a civilised country like the United Kingdom, society considers it not only appropriate but a basic humane concern to try to improve and compensate for the disabilities faced by a person in the applicant's situation. In my opinion, these compensatory measures come to form part of the disabled person's physical integrity.*<sup>16</sup>

1.16 Much has also been said of the obligation to protect dignity in domestic court judgments, including:

*The recognition and protection of human dignity is one of the core values – in truth the core value – of our society and, indeed, of all the societies which are part of the European family of nations and which have embraced the principles of the Convention. It is a core value of the common law, long pre-dating the Convention.*<sup>17</sup>

1.17 The principle of dignity, therefore, requires action to promote the inclusion of disabled children and their families in all aspects of social, economic and political life. It requires that the state treats disabled children as individuals in their own right – and not as objects. It means that (where necessary) urgent action be taken

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<sup>13</sup>See, for example, the comments of the European Court of Human Rights in *Pretty v United Kingdom* (2002) 35 EHRR 1 at [65].

<sup>14</sup>Judge Greve in her concurring opinion in *Price v UK* (2002) 34 EHRR 1285 at 1296 and see *R (A, B, X and Y) v East Sussex CC and the Disability Rights Commission (No 2)* [2003] EWHC 167 (Admin); (2003) 6 CCLR 194 at [86].

<sup>15</sup>*Botta v Italy* (1998) 26 EHRR 241.

<sup>16</sup>The concurring opinion of Judge Greve in *Price v United Kingdom* (2002) 34 EHRR 1285 at 1296.

<sup>17</sup>Munby J (as he then was) in *R (A, B, X and Y) v East Sussex CC and the Disability Rights Commission (No 2)* [2003] EWHC 167 (Admin); (2003) 6 CCLR 194 at [86].

to ensure that they do not experience indignity due, for example, to inadequate bathing<sup>18</sup> or toileting<sup>19</sup> facilities or an inability to access their home or communities (see para 3.77 and paras 6.41–6.77 below in relation to the duty to adapt disabled children’s homes to meet their needs). However, the principle of dignity has its limits, including resource considerations where article 8 of the ECHR is involved.<sup>20</sup> Resources play no part in the duty to avoid degrading treatment contrary to article 3 of the ECHR.

## The principle of independent living

1.18 The right to independent living – at its most basic – means that disabled people should not be excluded from mainstream society, for example by being placed unnecessarily in a care home or hospital. The concept of independent living is, however, much more expansive and is expressed in article 19 of the UN Convention on the Rights of Persons with Disabilities (a convention the UK has ratified – see para 2.28 below) in the following terms:

- Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement
- Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

1.19 The courts have held that preserving independence should be a fundamental aim of all social care interventions,<sup>21</sup> that inappropriate institutionalisation is a form of discrimination against disabled people<sup>22</sup> and that

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<sup>18</sup>See Complaint nos 02/C/8679, 8681 and 10389 against Bolsover DC, 30 September 2003, where the local government ombudsman held that the ability to manage ‘bathing with dignity’ was the entitlement of everybody. See also Complaint no 07C03887 against Bury MBC, 14 October 2009, where the local government ombudsman referred to the ‘breathtaking insensitivity’ of the council in failing to secure immediate arrangements to enable a mother to bathe her disabled sons.

<sup>19</sup>See, for example, *R (Bernard) v Enfield LBC* [2002] EWHC 2282 (Admin); (2002) 5 CCLR 577, where Sullivan J found a violation of article 8 due to delayed provision of proper toileting for the applicant – holding (at [33]) that such facilities ‘would have restored her dignity as a human being’.

<sup>20</sup>*McDonald v United Kingdom*, Application no 4241/12, (2015) 60 EHRR 1, (2014) 17 CCLR 167.

<sup>21</sup>*R v Southwark LBC ex p Khana and Karim* [2001] EWCA Civ 999; (2001) 4 CCLR 267 and see also *R (B) v Cornwall CC* [2009] EWHC 491 (Admin) at [10]. The Department of Health’s *Care and Support Statutory Guidance* (2014) lists, at para 1.15, ‘supporting people to live as independently as possible, for as long as possible’ as expressed in the UN Convention on the Rights of Persons with Disabilities, article 19, as a ‘guiding principle’.

<sup>22</sup>*Olmstead v LC* 527 US 581 (1999), in which the US Supreme Court held that the Americans with Disabilities Act 1990 gave disabled people a qualified right to live in the community rather than in institutions.



while cost may be a factor in deciding whether a care home placement is to be preferred to a community living alternative, it is unlikely ever to be permissible for it to be the determinative factor.<sup>23</sup> These rights apply equally to disabled children as to disabled adults. Indeed disabled children have the protection that their best interests must be treated as a primary consideration in all actions and decisions affecting them.<sup>24</sup>

## The principle of choice

1.20 Respect for a person's identity and physical integrity (as protected by article 8 of the ECHR<sup>25</sup>) brings with it a requirement to respect their choices and preferences. Where the state provides support or otherwise intervenes in a disabled person's life, it should, so far as is consistent with its other obligations, ensure that its action promotes the disabled person's and their family's aspirations. A key aspect of this obligation is the duty to take full account of the wishes of the disabled child and the family – in every aspect of the support provided – be it from health, social care, education and so on. This means that the family's and disabled child's preferences should not be sacrificed merely because they are in conflict with what a council considers to be 'best'<sup>26</sup> and that planning should be 'person centred' and where possible should yield to the personal preferences of the family and disabled child.

## The principle of cost-effectiveness

1.21 While respect for individual and family preferences is an important principle in relation to meeting the needs of disabled children, it is subject to the principle of 'cost-effectiveness'; as a general rule, choice does not trump 'cost'. Where the state has an obligation to meet a disabled child's needs (eg special educational or social care needs), if it is able to meet these fully in one way, it is permitted to refuse to meet them in an alternative, more expensive, way. The principle of cost effectiveness is in reality an essential component of the state's core obligation to 'promote progressive realisation' of the rights of disabled people 'to the maximum of [the state's] available resources': such an obligation requires it to devise cost effective procedures that ensure as many people as possible benefit from its limited resources. However, 'cost-effectiveness' should not lead to a minimalist approach to meeting disabled children's needs. Critically, although cost may trump choice, it must not trump dignity or other fundamental human rights. The courts may hold, however, that a disabled person's sense of dignity can be overridden if

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<sup>23</sup>See, for example, *Gunter v South West Staffordshire PCT* [2005] EWHC 1894 (Admin); (2006) 9 CCLR 121 at [20].

<sup>24</sup>UN Convention on the Rights of the Child, article 3, which informs the rights protected by article 8 of the ECHR and the other ECHR rights; see the extensive discussion by the Supreme Court in *R (SG) v Secretary of State for Work and Pensions* [2015] UKSC 16; [2015] 1 WLR 1449.

<sup>25</sup>See, for example, *Botta v Italy* (1998) 26 EHRR 241, considered at paras 1.14, 2.15, 5.77 and 9.143.

<sup>26</sup>For a graphic example of this, see *R (CD) v Anglesey CC* [2004] EWHC 1635 (Admin) considered at paras 3.141 and 10.11.

the service or provision which they consider will uphold their dignity is significantly more expensive than an alternative service which can properly meet their needs.<sup>27</sup>

## Consulting disabled children and young people and their families

1.22 A fundamental requirement under the obligation to show respect for a person's private and family life (in ECHR article 8) is to involve them in decisions which concern them, regardless of the nature of their impairments and the extent of their support needs. This duty is reflected in the guidance concerning the assessment of children's social care and special educational needs (see respectively chapter 3 at paras 3.26 and 3.33 and chapter 4 at paras 4.123–4.129 below). The courts have emphasised the absolute importance of communicating with disabled people to ascertain their wishes, feelings and preferences<sup>28</sup> and made it clear that this obligation includes proper consultation with family members noting that in many situations:

*the devoted parent who ... has spent years caring for a disabled child is likely to be much better able than any social worker, however skilled, or any judge, however compassionate, to 'read' his child, to understand his personality and to interpret the wishes and feelings which he lacks the ability to express.*<sup>29</sup>

1.23 Disabled children and members of their families should, therefore, be listened to about both the barriers that get in the way of living an ordinary life and the things that would remove these barriers and help them. They should also have the right to participate so that their ideas are central to any decision-making. This applies to the planning and operation of services as well as to assessment and service-delivery at an individual level.<sup>30</sup> Whatever the nature of the issues that they are facing and whatever the type of service they are dealing with, children and their parents have the right to expect that professionals and service-providers treat them with respect and recognise the knowledge and expertise that they have gained through experience.

1.24 Individuals within families may have different priorities and different wishes, but all have a right to be heard. While parents may understandably have to prioritise such things as care, finance, housing, health and education, it should come as no surprise that children may put a premium on play, leisure, friendships and school.<sup>31</sup> In recent years, there has been greater recognition of the importance

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<sup>27</sup>*McDonald v United Kingdom* (2015) 60 EHRR 1.

<sup>28</sup>See for example, *R (A and B) v East Sussex CC (No 2)* [2003] EWHC 167 (Admin); (2003) 6 CCLR 194.

<sup>29</sup>*Re S* [2002] EWHC 2278; [2003] 1 FLR 292 at [49].

<sup>30</sup>For example, A Franklin and P Sloper, *Participation of disabled children and young people in decision-making relating to social care*, Social Policy Research Unit, University of York, 2007; Triangle *A bit good but a bit not good too. Children and young people's views about specialist health services*, Triangle Services, Brighton, 2012.

<sup>31</sup>B Beresford, R Parvaneh and P Sloper, *Priorities and perceptions of disabled children and young people and their parents regarding outcomes from support services*, Social Policy Research Unit, University of York, 2007.

of seeking the views of disabled children and young people themselves and understanding their perspectives. In the past, these were often neglected, particularly if children did not use standard forms of communication. There are now many tried and tested ways of finding out what disabled children and young people want, using forms of consultation and communication appropriate to their needs.<sup>32</sup> Seeking the advice of those who know them best about how to find out the detail of what is important to them is crucial.<sup>33</sup>

1.25 An obligation to consult with children and young people inevitably invites a discussion about their capacity to understand, the weight that should be given to their views and their right to make decisions about certain matters – not only in their dealings with public bodies but also in the context of their families. In all families, children and adults develop their own ways of negotiating decisions large and small and dealing with conflicts of view and differing individual priorities. The approaches they adopt will vary considerably depending for example, on their personal, social and cultural backgrounds, the ages of those involved, their circumstances, the decisions to be made and so on. Like other families, those with disabled children and young people also develop their own ways of dealing with these matters but, as we shall see later in this chapter, they are often having to sort out complex issues in particularly challenging circumstances. It is reasonable to assume that the application of the law to day-by-day decision-making in the family is probably not an all-consuming preoccupation for most of the time. The rights that children, young people and young adults have to make decisions about matters that affect them and to be free from unwarranted restriction or from having their views disregarded in the private as well as the public sphere are, however, of utmost importance.<sup>34</sup> The way that the law approaches questions of mental capacity and decision-making in relation to disabled children, young people and young adults both within their families and in relation to external organisations is covered in chapter 7.

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<sup>32</sup>For example, A Knight, A Clark, P Petrie and J Statham, *The views of children and young people with learning disabilities about the support they receive from social services: a review of consultations and methods*, Thomas Coram Research Unit, University of London, 2006; The Communication Trust and Early Support, *Misunderstood. Supporting children and young people with speech, language and communication needs*, 2012; J Bradshaw 'The use of augmentative and alternative communication apps for the iPad, iPod and iPhone: an overview of recent developments', (2013) 18(1) *Tizard Learning Disability Review*, p31; Council for Disabled Children and Participation Works, *How to involve children and young people with communication impairments in decision-making*, 2015.

<sup>33</sup>G Hanrahan, *Moving into adulthood and getting a life. Becoming an adult: A guide to the Mental Capacity Act for families of young people with learning disabilities*, Oxfordshire Family Support Network, 2014.

<sup>34</sup>For a discussion of these issues written by parents of disabled young people, see for example: G Hanrahan, *Moving into adulthood and getting a life: a guide to the Mental Capacity Act for families of young people with learning disabilities*, Oxfordshire Family Support Network, 2014.

## Disabled children and their families: numbers, characteristics and circumstances

1.26 Data about the population of disabled children and their families are collected for different purposes and this affects not only the type of information gathered but also the ways in which the children and their characteristics are described.<sup>35</sup> For example, while there is considerable overlap between children defined as 'disabled' according to the Equality Act 2010 and those identified as having special educational needs (SEN), the two groups are not the same.<sup>36</sup> At an individual level, how children are defined can also affect what others see as their primary needs and whether they can access all services that they and their families may need.

### The population of disabled children

1.27 Using a disability definition equivalent to that in the Equality Act 2010, there are about 0.9 million disabled children aged 0–18 in the UK or approximately seven per cent of the child population.<sup>37</sup> A study using data from the Family Resources Survey (FRS)<sup>38</sup> found that the children's most commonly-reported difficulties are with memory, concentration, learning and communication. It also showed that many children have difficulties in more than one area of daily living: around a third of disabled children experience between two and four difficulties and more than 10 per cent experience five or more difficulties.

1.28 Since the 1980s there have been changes in the population of disabled children. Increasing numbers of those with multiple and complex impairments are living longer and being cared for at home. This is due, in part, to improved survival rates for low birth weight and extremely premature babies.<sup>39</sup> This trend has significant implications for the children and their families as well as for services attempting to meet their needs. When children have higher support needs or complex impairments, some parents may have to take responsibility, for example, for administering medication, tube feeding, assisted ventilation and resuscitation

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<sup>35</sup>Department for Work and Pensions, *Making disability data work for you*, 2014.

<sup>36</sup>Some estimates indicate that three quarters of disabled children are also assessed as having special educational needs. See for example, J Porter, H. Daniels, J Georgeson, J Hacker and V Gallop, *Disability data collection for children's services*, Department for Children, Schools and Families Research Report, 2008; S Parsons and L Platt, *Disability among young children. Prevalence, heterogeneity and socio-economic disadvantage*, Centre for Longitudinal Studies, Institute of Education, University of London, 2013.

<sup>37</sup>Department for Work and Pensions, *Family Resources Survey*, 2012/2013.

<sup>38</sup>C Blackburn, N Spencer and J Read, 'Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey', (2010) *BMC Pediatrics* 10, p21.

<sup>39</sup>A T Gibson, 'Outcome following preterm birth', (2007) 21(5) *Best practice and research clinical obstetrics and gynaecology*, pp869–882; EPICure, *Population based studies of survival and later health status in extremely premature infants*, 2008.

procedures, as well as other treatments and interventions.<sup>40</sup> It is estimated that around 18,000 children and young people in England have multiple and complex impairments which result in their needing some form of palliative care.<sup>41</sup> In addition, recent years have seen a marked reported increase in numbers of children identified as having autistic spectrum disorders<sup>42</sup> and attention-deficit hyperactivity disorder (ADHD).<sup>43</sup> It is important to acknowledge that when disabled children have multiple impairments, it is not uncommon for some of their needs and difficulties to go unrecognised by service providers and practitioners because the diagnosis of one condition may overshadow another. For example, attention has been drawn to the neglect of the mental health needs of those with learning disabilities<sup>44</sup> despite the fact that around 36 per cent of learning disabled children and young people have been diagnosed as having a psychiatric disorder.<sup>45</sup>

#### Family composition

1.29 The majority of disabled children are brought up at home by their families of origin and almost two-thirds of them live in two-parent households. The proportion being brought up in lone-parent households (32 per cent) is significantly greater, however, than that for non-disabled children (22 per cent).<sup>46</sup> A number of studies have highlighted disabled children's increased chances of being brought up by lone parents, the majority of whom are mothers,<sup>47</sup> but the reasons for this are not clear. Some research suggests that any increased risk of separation or divorce is most likely to be seen when a disabled child is very young, particularly between the ages of 12 months and two years<sup>48</sup> but it needs to be

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<sup>40</sup>C Glendinning, C Kirk, S Guiffreda and D Lawton, 'Technology-dependent children in the community: definitions, numbers and costs', (2001) 27 *Child: Care, Health and Development*, pp321-334.

<sup>41</sup>H Cochrane, S Liyanage, R Nantambi, *Palliative care statistics for children and young adults*, Department of Health, 2007.

<sup>42</sup>S Levy, D Mandell and R Schultz, 'Autism', (2009) 374 *The Lancet*, pp1627-1638.

<sup>43</sup>E Taylor, 'Developing ADHD', (2009) 50 *Journal of Child Psychiatry and Psychology*, pp126-132.

<sup>44</sup>C Burke, *Feeling down. Improving the mental health of people with learning disabilities*, Foundation for People with Learning Disabilities, 2014; C Blackburn, J Read and N Spencer, 'Children with neurodevelopmental disabilities', *Annual Report of the Chief Medical Officer 2012, Our Children Deserve Better: Prevention Pays*, Department of Health, October 2013, chapter 9.

<sup>45</sup>E Emerson and C Hatton 'Mental health of children and adolescents with intellectual disabilities in Britain', *British Journal of Psychiatry*, November 2007, 191 (6) pp493-499.

<sup>46</sup>Department for Work and Pensions, *Family Resources Survey*, 2012/2013.

<sup>47</sup>H Clarke and S McKay, *Exploring disability, family formation and break-up: reviewing the evidence*, Research Report No 514, Department for Work and Pensions, 2008; C Blackburn, N Spencer and J Read, 'Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey', (2010) *BMC Pediatrics* 10, p21.

<sup>48</sup>H Clarke and S McKay, *Exploring disability, family formation and break-up: reviewing the evidence*, Research Report No 514, Department for Work and Pensions, 2008; D Risdal and G Singer, 'Marital adjustment in parents of children with disabilities: a historical review and meta-analysis', (2004) 29 *Research and Practice for Persons with Severe Disabilities*, pp95-103.

recognised that this is also a time when there is a risk of relationship breakdown for those who have young non-disabled children. In addition, one study found that while families with children with cognitive delay were more likely to experience changes in family composition and marital status than those with more typically developing children, the increased levels of family change could be put down to differences in socio-economic circumstances rather than being specifically related to the child's disability.<sup>49</sup> However lone parenthood comes about, it is crucial to be aware that it has considerable implications for the children and families concerned. As we discuss later, it is associated with increased levels of poverty together with restricted access to essential goods and services. When combined with the high parental workloads associated with caring for some disabled children, this means that some lone parents and their children are very hard-pressed indeed.

1.30 Recent research has also pointed to the clustering of childhood and adult disability within households.<sup>50</sup> A 2010 study reported that almost half of disabled children, compared with about a fifth of non-disabled children, live with a parent who also is disabled. In addition, around a quarter of disabled children live with one or more siblings who are also disabled.<sup>51</sup> While further research is needed to help understand how this comes about, it is crucial to recognise the level of need and additional difficulties that may arise when parents and children in the same household are disabled.

## Socio-economic disadvantage, low income and debt

1.31 A 2013 UK government report drew attention to the fact that the association between poverty and child disability means that disabled children in the UK are significantly more likely to live under conditions that have been shown to impede development, educational attainment and adjustment and increase the risk of poor health, additional impairment and social exclusion.<sup>52</sup> In other words, in addition to the impact of living and growing with disability, the well-being, choices and life chances of many disabled children and their families are also insidiously eroded by living for substantial periods without the basic resources that would allow them a reasonable standard of living. Many families who are not living on the lowest incomes nevertheless deal with the increased demands of living with disability without sufficient human and material resources to offset them.

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<sup>49</sup>C Hatton, E Emerson, H Graham, J Blacher and G Llewellyn, 'Changes in family composition and marital status in families with a young child with cognitive delay', (2010) 23(1) *Journal of Applied Research in Intellectual Disabilities*, pp14-26.

<sup>50</sup>H Clarke and S McKay, *Exploring disability, family formation and break-up: reviewing the evidence*, Research Report No 514, Department for Work and Pensions, 2008; C Blackburn, N Spencer and J Read, 'Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey', (2010) *BMC Pediatrics* 10, p21.

<sup>51</sup>C Blackburn, N Spencer and J Read, 'Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey', (2010) *BMC Pediatrics* 10, p21.

<sup>52</sup>Department for Work and Pensions, *Fulfilling potential. Building a deeper understanding of disability in the UK Today*, 2013.

1.32 Prevalence of childhood disability is socially patterned: its distribution follows a social gradient with the highest prevalence found among children whose parents are the least well off.<sup>53</sup> As a group, disabled children in this country and elsewhere are in substantially more disadvantaged financial and material circumstances than non-disabled children.<sup>54</sup> The reasons for this are not fully understood.<sup>55</sup> There has been a long-standing debate on whether disability should be seen as a cause or a consequence of socio-economic disadvantage, though characterising the explanation in this way is an over-simplification. Recent research using longitudinal data, has indicated, however, that young non-disabled children living in socio-economically deprived households have a greater risk of developing disabling chronic conditions later in childhood than those in better off circumstances. The odds of their developing a disabling condition increases significantly as the level of socio-economic disadvantage rises.<sup>56</sup>

1.33 In addition, a considerable body of research draws attention to the impact that the presence of a disabled child in a household has on both income and expenditure. Growing up with disability and caring for a disabled child involves the need for substantial additional expenditure.<sup>57</sup> Simultaneously, however, the demands of caring reduce the options available to the adults in the family, particularly mothers, to bring in income by having paid employment.<sup>58</sup>

1.34 Calculations using FRS data indicate that when all groups in the population are taken together, the income for a household with a disabled child is around 13 per cent lower than for households with non-disabled children. There are variations between some groups, however, and the lowest incomes are to be found

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<sup>53</sup>N Spencer, C Blackburn and J Read, 'Prevalence and social patterning of limiting long-term illness/disability in children and young people under the age of 20 years in 2001: UK census-based cross-sectional study', (2010) 36(4) *Child, Care, Health and Development*, July 2010, pp566-573.

<sup>54</sup>C Blackburn, N Spencer and J Read, 'Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey', (2010) *BMC Pediatrics* 10, p21; N Spencer, C Blackburn and J Read, 'Disabling chronic conditions in childhood and socioeconomic disadvantage: a systematic review and meta-analyses of observational studies', *BMJ Open*, 2015.

<sup>55</sup>S Parsons and L Platt, 'Disability among young children. Prevalence, heterogeneity and socio-economic disadvantage', CLS Working Paper 2013/11, November 2013.

<sup>56</sup>C Blackburn, N Spencer and J Read, 'Is the onset of disabling chronic conditions in later childhood associated with exposure to social disadvantage in earlier childhood? A prospective cohort study using ONS Longitudinal Study for England and Wales', *BMC Pediatrics*, 26 June 2013.

<sup>57</sup>The Children's Society, *4 in every 10. Disabled children living in poverty*, 2011; M Woolley *How do they manage? Income and expenditure of families with a severely disabled child*, Family Fund, 2004.

<sup>58</sup>E Emerson and C Hatton, 'The socio-economic circumstances of children at risk of disability in Britain', (2007) 22 *Disability and Society*, pp563-580; S McKay and A Atkinson, *Disability and caring among families with children*, Research Report No 460, Department for Work and Pensions, 2007.

among lone parents, black and minority ethnic families and those with disabled parents and disabled children in the same household.<sup>59</sup>

1.35 The combination of all of these factors means that in many households there is a shortfall between income and necessary expenditure. As a consequence, living standards in families with disabled children are lower across the board than those of their non-disabled peers. On almost every measure of material deprivation, disabled children are more likely than other children to live in households which are unable to afford things that are generally regarded as important and ordinary for children in the twenty-first century, such as having more than one pair of shoes, access to outside play space, participating in a leisure activity once a month or buying some basic toys.<sup>60</sup> In some surveys, substantial numbers of families report being unable to afford adequate food and heating.<sup>61</sup> Standard consumer durables such as cars, central heating, washing machines and dryers are essential items for families with disabled children if they are to meet their children's needs and offset the additional demands of living with disability. For those on low incomes, they are expensive to buy and maintain. Heavy usage of some items means that running costs and wear and tear are high too.<sup>62</sup> Given their circumstances, it is unsurprising that households with disabled children (26.5 per cent) are also more likely than those with non-disabled children (16.2 per cent) to report one or more debts. The highest proportion of families reporting being behind with payments are those where there are both disabled children and disabled adults.<sup>63</sup>

1.36 Organisations representing the interests of disabled children and their families have drawn attention to the fact that the material hardship many face has worsened in recent years.<sup>64</sup> Research commissioned by the Equality and Human Rights Commission has assessed the cumulative impact of government changes to public expenditure, taxation and benefits on specific groups within the whole population between 2010 and 2015. The study found that the impacts of tax and welfare reforms both in cash terms and as a percentage of net income are more negative for families with a disabled child than for those with non-disabled children. These negative impacts are particularly marked for those already on low

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<sup>59</sup>C Blackburn, N Spencer and J Read, 'Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey', (2010) *BMC Pediatrics* 10, p21.

<sup>60</sup>C Blackburn, N Spencer and J Read, 'Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey', (2010) *BMC Pediatrics* 10, p21.

<sup>61</sup>Contact a Family, *Counting the Cost*, 2014.

<sup>62</sup>Contact a Family, *Counting the Cost*, 2014.

<sup>63</sup>C Blackburn, N Spencer and J Read, 'Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey', (2010) *BMC Pediatrics* 10, p21.

<sup>64</sup>Contact a Family, *Counting the Cost*, 2014.



incomes, with the hardest-hit being households where there is both a disabled child and a disabled adult.<sup>65</sup>

## Housing problems

1.37 Restricted financial resources are also partly responsible for many disabled children and their families living in poor or unsuitable housing.<sup>66</sup> Disabled children are more likely to live in rented accommodation and with fewer rooms than non-disabled children. Lack of space and poor access both outside and within the home are commonly reported problems. Even when families are living in accommodation that might be judged reasonable according to general criteria, it is often unsuitable for disabled children and their carers. Physical barriers inside and outside the home can make it difficult for children to take part in ordinary childhood and family activities. Inaccessible toilets, bathrooms and kitchens as well as a lack of space for storing essential equipment are problems faced by many.<sup>67</sup> Some of the most severe housing difficulties are experienced by families with the lowest incomes and those from black and minority ethnic groups. Families who find themselves in unsuitable housing but who are unable to access financial assistance for adaptations frequently overstretch themselves by moving house or by undertaking building work at their own expense. See further chapter 6 in relation to disabled children's housing needs.

## Living with disability: parents' and children's experience

### At home

1.38 In addition to managing the higher costs of living with often very limited resources, families also have to meet their disabled children's needs for care. The care of a disabled child frequently makes demands that exceed what is required of parents of non-disabled children. Studies have recorded the on-going and longterm nature of the caring commitments and have described the often high levels of personal and practical care being provided by parents to their disabled

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<sup>65</sup>H Reed and J Portes, *Cumulative Impact Assessment: A Research Report by Landman Economics and the National Institute of Economic and Social Research (NIESR) for the Equality and Human Rights Commission*, Equality and Human Rights Commission, Research report 94, 2014.

<sup>66</sup>C Blackburn, N Spencer and J Read, 'Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey', (2010) *BMC Pediatrics* 10, p21; E Emerson and C Hatton, *The socio-economic circumstances of families supporting a child at risk of disability in Britain in 2002*, Institute of Health Research, University of Lancaster, 2005; B Beresford and D Rhodes, *Housing and disabled children: round-up: reviewing the evidence*, Joseph Rowntree Foundation, 2008.

<sup>67</sup>B Beresford and D Rhodes, *Housing and disabled children: round-up: reviewing the evidence*, Joseph Rowntree Foundation, 2008.

sons and daughters of all ages.<sup>68</sup> While needs vary depending on the individual child, their circumstances, age and impairments, caring for them may involve help with bathing, washing, eating, toileting, mobility and communication. Parents may also be responsible for managing dietary requirements, administering medication, using technological equipment and procedures as well as undertaking physiotherapy and other activities designed to keep children well or assist learning and development. Some children need careful supervision if they are to be safe while others need a great deal of fine-tuned attention, guidance and stimulation if frustration or distress is to be kept at bay.

1.39 Getting out and about and doing things that other adults and children regard as ordinary often needs a great deal of planning and organisation. Going shopping, getting a haircut or having a day out can be made difficult by a combination of such things as transport problems, an inaccessible physical environment, a restricted budget and the need to transport bulky equipment – as well as parental fatigue.

1.40 Caring for a disabled child is a workload undertaken in private, day after day, and for some children, during the night too.<sup>69</sup> Often it has to be accomplished by parents who also have to attend to the needs of other family members, particularly other children. Parents of disabled children may find that informal arrangements with family and friends such as 'child-swaps' or babysitting are less easy to come by. Formal childcare, as we shall see later, is also not as easily available as for non-disabled children. In households where money is very tight, parents do not have the option of paying for some extra help or buying in something that makes life a little easier or more enjoyable for the children and adults. Consequently, unless they are provided with support from statutory services, less well off families often have only their own muscle-power, energy and ingenuity to fall back on.

1.41 The patterns of care in households with a disabled child tend to reflect childcare arrangements in families more generally. In both lone-parents and two-parent households, the caring workload overall tends to be weighted towards mothers and this has an impact on their employment and career opportunities.<sup>70</sup> Women with disabled children are less likely than other mothers to be in paid work. When working, they are less likely to be employed full-time. Overall, couples with disabled children are less likely both to be in paid work compared with couples

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<sup>68</sup>For example B Dobson, S Middleton and A Beardsworth, *The impact of childhood disability on family life*, Joseph Rowntree Foundation/York Publishing Services, 2001; S McKay and A Atkinson, *Disability and caring among families with children*, Research Report No 460, Department for Work and Pensions, 2007; G M Griffiths and R P Hastings, "'He's hard work but he's worth it". The experience of caregivers of individuals with intellectual disabilities and challenging behaviour: a meta-synthesis of qualitative research', (2014) 27(5) *Journal of Applied Research in Learning Disabilities*, pp401-419.

<sup>69</sup>J Heaton, J Noyes, P Sloper and R Shah, 'The experience of sleep disruption in families of technology-dependent children', (2006) *Children and Society*, pp196-208; Family Fund, *Tired all the time. The impact of sleeping difficulties on families with disabled children*, 2013.

<sup>70</sup>N Coleman and L Lancely, *Lone parent obligations: supporting the journey into work*, Department for Work and Pensions Research Report 736, 2011.

who have non-disabled children.<sup>71</sup> While fathers' employment rates are less affected than mothers', twice as many couples with a disabled child are jobless, compared with those who do not have a disabled child.<sup>72</sup> In addition, studies point to the difficulties reported by men who are the single wage-earners in couple households. They describe tensions around the conflicting demands of employment and the need to provide care or to attend to other matters related to their disabled child.<sup>73</sup> (see chapter 8, paras 8.10–8.11 and 8.17 for carers' rights in relation to support for paid employment).

1.42 Some parents, particularly those raising children alone, feel that the level and range of care and the commitments involved with bringing up a disabled child mean that employment outside the home is simply not practical.<sup>74</sup> For others, the lack of affordable and suitable childcare for disabled children of all ages, and a lack of suitably trained staff to deliver it, are significant barriers to taking up work or, indeed, simply having time out from their caring responsibilities to attend to other important issues. Childcare costs for disabled children also tend to be considerably higher than for those who are non-disabled.<sup>75</sup>

1.43 While there is a great deal of evidence about the taxing workloads managed by parents, it is important to stress that studies have indicated time and time again that parents are not prone to characterising their disabled children as burdensome. Research has repeatedly highlighted the strength of parents' understanding, love and appreciation of their children. They are acutely aware of the limitations placed upon them and their restricted opportunities. Parents tend to focus on the personal and practical arrangements which would enable their families to achieve a decent quality of life.<sup>76</sup> Studies also indicate that parents know only too well that many others do not see their children in the same way. Managing other people's misunderstanding of their children and hurtful attitudes

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<sup>71</sup>S McKay and A Atkinson, *Disability and caring among families with children*, Research Report No 460, Department for Work and Pensions, 2007.

<sup>72</sup>S McKay and A Atkinson, *Disability and caring among families with children*, Research Report No 460, Department for Work and Pensions, 2007.

<sup>73</sup>J Harrison, M Henderson and R Leonard (eds) *Different Dads: fathers' stories of parenting disabled children*, Jessica Kingsley Publishers, 2007; Contact a Family, *Fathers*, 2008.

<sup>74</sup>Department for Work and Pensions, *Fulfilling potential. Building a deeper understanding of disability in the UK Today*, 2013.

<sup>75</sup>For example, Daycare Trust, *Listening to parents of disabled children about childcare*, 2007; H Cheshire, V Brown, I Wollny, E Ireland, S Scott, P Jessiman, C Blackburn, J Read, S Purdon, and D Abbott, *Impact evaluation of the Disabled Children's Access to Childcare Pilot (DCATCH)*, Research Report DFE-RR168, Department for Education, 2011.

<sup>76</sup>For example, Contact a Family, *Our Family, Our Future*, 2009; G M Griffiths and R P Hastings, 'He's hard work but he's worth it'. The experience of caregivers of individuals with intellectual disabilities and challenging behaviour: a meta-synthesis of qualitative research', (2014) 27(5) *Journal of Applied Research in Learning Disabilities*, pp401-419.

towards them can be yet another problem to be dealt with.<sup>77</sup> Around a third of parents report that one of the main barriers their children face is still the attitudes of others.<sup>78</sup> Disabled children and their families report that they often experience insensitive reactions by other people and that public spaces and arrangements that may suit the majority are not designed to include them.<sup>79</sup>

1.44 Rates of reported bullying are higher for young disabled people than for other young people<sup>80</sup> and there has been a growing body of evidence that disabled children have an increased risk of exposure to violence<sup>81</sup> and abuse.<sup>82</sup> Disabled children in a large-scale US study were found to be 3.4 times more likely overall to be abused or neglected than non-disabled children, with similar levels of mistreatment identified in smaller-scale UK studies.<sup>83</sup>

1.45 There is frequently a substantial gap between the aspirations and activities regarded as ordinary for non-disabled children and their disabled peers. Across their childhoods, many disabled children are excluded from age-appropriate experiences that may be regarded as important for all children, and they have a far greater chance of having a more restricted and confining social and personal life. Leisure, play and time with friends are often more limited for disabled children and young people.<sup>84</sup> The Life Opportunities Survey allows us to compare the participation and restrictions experienced by disabled children and their non-disabled peers aged 11–15 years. There were substantial differences between the two groups in relation to personal relationships, education, transport and leisure or play, with disabled children and young people being disadvantaged in all

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<sup>77</sup>J Read, *Disability, the family and society: listening to mothers*, Open University Press, 2000; S Ryan, ‘‘I used to worry about what other people thought but now I just think ... well I don’t care’’: shifting accounts of learning difficulties in public places’, (2008) 23 *Health and Place*, pp199–210.

<sup>78</sup>Department for Work and Pensions, *Fulfilling potential. Building a deeper understanding of disability in the UK Today*, 2013.

<sup>79</sup>S Ryan, ‘‘People don’t do odd, do they?’’ Mothers making sense of the reactions of others towards their learning disabled children in public places’, (2005) *Children’s Geographies*, pp291–306.

<sup>80</sup>Department for Work and Pensions, *Fulfilling potential. Building a deeper understanding of disability in the UK Today*, 2013.

<sup>81</sup>L Jones, M Bellis, S Wood, K Hughs, E Mc Coy, L Eckley, G Bates, C Mikton, T Shakespeare and A Officer, ‘Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies’, (2012) *The Lancet*, pp899–907.

<sup>82</sup>K Stalker, and K McArthur, ‘Child abuse, child protection and disabled children: a review of recent research’, (2012) *Child Abuse Review*, pp24–40.

<sup>83</sup>National Working Group on Child Protection and Disability, ‘*It doesn’t happen to disabled children’: child protection and disabled children*, NSPCC, 2003.

<sup>84</sup>For example P Murray, *Hello! Are You Listening? Disabled teenagers’ experience of access to inclusive leisure*, Joseph Rowntree Foundation, 2002; H Clarke, *Preventing social exclusion of disabled children and their families*, Research Report RR782, DfES, 2006; G Bielby, T Chamberlain, M Morris, L O’Donnell and C Sharp, *Improving the wellbeing of disabled children and young people through improving access to positive activities*, Centre for Excellence and Outcomes in Children and Young People’s Services, 2009.

areas.<sup>85</sup> Children and young people with complex impairments and high support needs and those who have learning disabilities and behaviour that may challenge, frequently experience a high degree of social exclusion.<sup>86</sup> Earlier, we referred to the impact on parental employment of lack of available childcare for disabled children of all ages. Another consequence of limited access to childcare is that the children have fewer opportunities to mix with others and benefit from the activities they enjoy.<sup>87</sup>

1.46 Parents may also express concern about the impact on their non-disabled sons and daughters of the circumstances that go along with living with disability.<sup>88</sup> In addition to research on the experience of parent carers, there has been growing recognition of the amount of care and support that some siblings offer to their disabled brothers and sisters. Sometimes, they may provide help or assistance directly to their disabled brother or sister; at other times, they may do things to support a parent who is undertaking most of the care. (See chapter 8 at paras 8.26–8.59 below for the law in relation to young carers). Whether or not brothers and sisters are involved in care, there has been a recognition of the need to understand their experiences and to learn from their perspectives.<sup>89</sup> Studies which have consulted siblings directly report mixed reactions to their situations.<sup>90</sup> Many speak positively about their relationship with their disabled brother or sister and have straightforward attitudes towards their impairments and support needs. Others, as might be anticipated, do not get on so well. Some report being upset by the attitudes of other people towards their brother or sister and it is also not uncommon for them to describe being teased or bullied themselves. A review of research on siblings of children with learning disabilities or autism, concludes that overall, the evidence indicates that neither the well-being of the majority nor their relationships with a disabled brother or sister are negatively affected. It has been suggested, however, because some research indicates that there is a risk to the well-being of some siblings of children with high levels of behaviour problems, we might do well to pay particular attention to this group. Research on siblings is

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<sup>85</sup>Office for National Statistics, *Life Opportunities Survey. Interim Results 2009/2010*, ONS, 2010.

<sup>86</sup>J Morris, *That kind of life? Social exclusion and young disabled people with high levels of support needs*, Scope, 2001; E Emerson and S Einfeld, *Challenging behaviour*, 3rd edition, Cambridge University Press, 2011.

<sup>87</sup>For example, Council for Disabled Children, *Extending inclusion. Access for disabled children and young people to extended schools and children's centres: a development manual*, DCSF Publications, 2008; Daycare Trust, *Listening to parents of disabled children about childcare*, 2007.

<sup>88</sup>Contact a Family, *Siblings*, 2011.

<sup>89</sup>Contact a Family, *Siblings*, 2011; C Connors and K Stalker, *The views and experiences of disabled children and their siblings – A positive outlook*, Jessica Kingsley Publishers, 2002; R Hastings, *Children and adolescents who are siblings of children with intellectual disabilities or autism: research evidence*, Sibs, 2014.

<sup>90</sup>N Atkinson and N Crawforth, *All in the family: siblings and disability*, NCH Action for Children, 1995; K Stalker and C Connors, 'Children's perceptions of their disabled siblings: "She's different but it's normal for us"', (2004) *Children & Society*, pp218–230.

limited in a number of respects, however, and this leaves gaps in our knowledge about this group of children and young people.<sup>91</sup>

1.47 In many families, the health of parents may suffer. As a group, parents of disabled children are reported to experience higher levels of stress and lower levels of well-being than those of non-disabled children.<sup>92</sup> Some studies have highlighted the negative impact on the emotional well-being of parents of any behavioural difficulties their children may have.<sup>93</sup> Mothers of some groups of disabled children have been found to be particularly vulnerable to poorer health and well-being and some studies have suggested that this increased risk may be attributed in part at least, to the socio-economic disadvantage that frequently goes hand-in-hand with disability.<sup>94</sup>

## Dealing with services

1.48 In addition to the caring work and the practical and financial problems to be tackled at home, parents of disabled children have to have dealings with a wide range of health, education and social care professionals and their organisations. Good services can make an essential contribution to the health, development and well-being of disabled children. They can also be a powerful mediator of stress for parents and other family members. Parents have consistently reported, however, that dealing on a regular basis with poor services and those that are difficult to access can be one of the most stressful aspects of bringing up a disabled child. Contact with such services and battling for what they feel their child needs, often constitutes additional, tiring and frustrating work for already over-stretched families. Over a considerable period of time, a number of themes have consistently emerged from studies which have explored parents' and children's experience as service users.

1.49 There are high levels of unmet need for provision, with many finding that they are not eligible for services that would help them, or that the things that are provided are not suitable. It is not uncommon for families to have lengthy waiting times for an assessment and, subsequently, for the provision of essential equipment, adaptations and other services. Waiting times for services and equipment also vary considerably from area to area. Parents say that they have to be very persistent and active if they are to access provision that they feel would really help their child and other family members. Often children and young people with a range of complex needs – for example those with learning disabilities who

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<sup>91</sup>R Hastings, *Children and adolescents who are the siblings of children with intellectual disabilities or autism: Research evidence*, Sibs, 2014.

<sup>92</sup>P Sloper and B Beresford, 'Families with disabled children', (2006) 333 *BMJ*, pp928-929. M Hirst, 'Carer distress: a prospective, population-based study', (2005) 61 *Social Science and Medicine*, pp697-708.

<sup>93</sup>R Hastings, 'Parental stress and behavior problems of children with developmental disability', (2002) 27(3) *Journal of Intellectual and Developmental Disability*, pp149-160.

<sup>94</sup>E Emerson, C Hatton, G Llewellyn, J Blacker and H Graham, 'Socio-economic position, household composition, health status and indicators of well-being of mothers with and without intellectual disabilities', (2006) 50 *Journal of Intellectual Disability Research*, pp862-873.

also experience mental distress or challenging behaviour are not well served. Many families report that they need to travel some distance to access services for their child.<sup>95</sup>

1.50 Services are commissioned and delivered by specialists working in systems of baffling complexity which undergo regular re-organisation. There are problems associated with co-ordination and joint planning between key agencies and disciplines at all levels, resulting in serious problems for children and their parents in relation to essential provision. Studies and official reports have repeatedly called for better service co-ordination and have pointed to the importance of families having a key worker or lead practitioner who acts as a reliable point of contact to help them through the maze and ensure that essential services are delivered.<sup>96</sup> Some of the provisions of the Children and Families Act 2014 which are explained later in this guide, represent the most recent attempt on the part of government to address the problems of fragmented health, education and care services for disabled children and their families.<sup>97</sup>

1.51 In addition to the difficulty of accessing specialist services for their children, families also report that they often meet barriers or problems when they use universal facilities and services which should be accessible to all. Exclusionary practices and limited appreciation of theirs and their children's needs and rights can create considerable difficulties.<sup>98</sup>

1.52 Attention has also been drawn to the particular barriers which disabled parents face and the difficulty of accessing services to assist them in their

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<sup>95</sup>For example, M Hirst, 'Carer distress: a prospective, population-based study', (2005) 61 *Social Science and Medicine*, pp697-708; G M Griffiths and R P Hastings, 'He's hard work but he's worth it'. The experience of caregivers of individuals with intellectual disabilities and challenging behaviour: a meta-synthesis of qualitative research', (2014) 27(5) *Journal of Applied Research in Learning Disabilities*, pp401-419. Ofsted, *The special educational needs and disability review 090221*, September 2010; Care Quality Commission, *Health Care for Disabled Children and Young People*, 2012; E Brawn and C Rogers, *Keep us close. Ensuring good, inclusive and accessible local services for disabled children and their families*, Scope, 2012; J Sunman, *A Local Experience of National Concern*, Oxfordshire Family Support Network, 2014; Care Quality Commission, *From the pond into the sea: Children's transition into adult health services*, 2014.

<sup>96</sup>For example, V Greco and P Sloper, 'Care co-ordination and key worker schemes for disabled children: results from a UK-wide survey', (2004) 30 *Child: care, health and development*, pp13-20; 2004; P Sloper, J Beecham, S Clarke, A Franklin, N Moran and L Cusworth, *Models of multi-agency services for transition to adult services for disabled young people and those with complex health needs*, Social Policy Research Unit, University of York, 2010; Children's Workforce Development Council, *Lead professional: practitioners' and managers' guides*, 2007, refreshed March 2010; HM Government, *Working together to safeguard children: A guide to inter-agency working to safeguard and promote the welfare of children*, March 2015.

<sup>97</sup>Department for Education/Department of Health (2015) *Special Educational Needs and Disability Code of Practice: 0 to 25 Years*, January 2015.

<sup>98</sup>For example, *The Parliamentary hearings on services for disabled children*, October 2006; Contact a Family, *Putting families with disabled children at the heart of the NHS reforms in England*. 2011.

parenting roles.<sup>99</sup> Their difficulties may often be exacerbated by the lack of effective collaboration between children's and adult social services. Given that recent research has highlighted a clustering of childhood and adult disability in a significant proportion of households,<sup>100</sup> it is reasonable to assume that many disabled parents and their disabled children are vulnerable to having serious levels of unmet need.

## Problems with information

1.53 Across the whole of childhood and through transition to adulthood, disabled children and their families say that they have difficulty in finding useable information at a time when they need it.<sup>101</sup> It is difficult for families to find essential information about such things as access and entitlements to services and benefits; approaches to managing aspects of a child's condition, development or behaviour; different services to meet different needs; the responsibilities of various organisations; and where to find key contacts. For whatever reasons, it has proved difficult for service-providers to develop systems that are sufficiently sophisticated and user-friendly to cope with both the complexity of the information to be delivered and the diversity of circumstances of those needing it. The important requirement for a new 'local offer' in every local area in England under the Children and Families Act 2014 is a legislative response to this problem.<sup>102</sup>

1.54 A number of studies have described what families regard as the key elements of effective information systems.<sup>103</sup> Parents say that they want short, clear, written guides to local services with more in-depth materials geared to key periods in their children's lives. They also need information on other important matters such as benefit entitlements, disabling conditions and interventions of proven value to their children. Parents want information to be jargon-free and in different formats.

1.55 Government, service-providers and organisations for disabled children and their families have increasingly been using the internet to disseminate information.<sup>104</sup> While this is undoubtedly making a positive difference to many,

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<sup>99</sup>CSCI, *Supporting disabled parents: a family or fragmented approach?* Commission for Social Care Inspection, 2009.

<sup>100</sup> C Blackburn, N Spencer and J Read, 'Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey', (2010) *BMC Pediatrics* 10, p21.

<sup>101</sup> W Mitchell and P Sloper, *User-friendly information for families with disabled children: a guide to good practice*, York Publishing Services, 2000; Contact a Family, *We're listening*, 2003.

<sup>102</sup> Children and Families Act 2014 s30.

<sup>103</sup> W Mitchell and P Sloper, *User-friendly information for families with disabled children: a guide to good practice*, York Publishing Services/Joseph Rowntree Foundation, 2000; Contact a Family, *We're listening*, 2003.

<sup>104</sup> See for example, Special Educational Needs and Disability Regulations 2014 ('SEND Regs 2014') SI No 1530 reg 57, which requires that a local authority must publish its 'local offer' by placing it on its website, in line with Children and Families Act 2014 s30.



there was initially some concern about the position of families on low incomes on account of their having more limited internet access than others.<sup>105</sup> It was argued that the 'digital divide' might actually exacerbate existing inequalities.<sup>106</sup> This situation may be changing, however, as smart phones, already many people's preferred means of accessing routine information, become more affordable. However good the provision of information becomes, many parents say that it is not enough on its own. They stress the importance of having a person who can act as a key contact for information and other purposes, to make sure that they get what they and their children need.

1.56 A time when information (among other things) is particularly crucial is when children and families find themselves at a critical transition stage – ie a point when something important changes and a significant adjustment of circumstances and arrangements is required. This is sometimes related to a child's age or development, to external arrangements and services, to family circumstances or to a combination of some or all of these. These transitional periods merit attention because of their potential to be hazardous and stressful for the children and adults concerned. Typically at one of these points, the territory is unfamiliar and new knowledge and information have to be found, absorbed and applied to get a satisfactory outcome for the child and family. While these challenging periods may vary with individuals and their circumstances, there are some transitional stages which are predictable and which affect most children and families: (1) the early years when disability may be identified; (2) accessing education; and (3) the transition to adulthood.

## The early years

1.57 For almost all parents, the time when their child was identified as being disabled is highly significant. This remains the case whether disability is identified in the early years of a child's life or later. Parents' accounts suggest that the process of finding out that they have a disabled child is experienced as exceptionally stressful by many.<sup>107</sup> In this section, we focus mainly on the experience of pre-school children and their families, given that improvements in diagnostic techniques mean that more disabled children are being diagnosed at a younger age. We recognise, however, that some parents and their children may be dealing with these issues at a later time.

1.58 As negative perceptions of disability are so widespread, it is not surprising that some parents initially approach the experience of finding that they have a disabled child with at least some of the negative attitudes that they may later

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<sup>105</sup> C Blackburn and J Read, 'Using the internet? The experiences of parents of disabled children', (2005) *Child: care health and development*, pp507-515.

<sup>106</sup> C Blackburn and J Read, 'Using the internet? The experiences of parents of disabled children', (2005) *Child: care health and development*, pp507-515; K Baxter, C Glendinning and S Clarke, 'Making informed choices in social care: the importance of accessible information', (2008) *16 Health and Social Care in the Community*, pp197-207.

<sup>107</sup> B Dobson, S Middleton and A Beardsworth, *The impact of childhood disability on family life*, Joseph Rowntree Foundation/York Publishing Services, 2001; *Right from the start*, Scope, 2003.

come to modify or reject. It is not uncommon for people to describe feeling shocked and overwhelmed.<sup>108</sup> Some may be unsure whether they can cope with what they think will be demanded of them and others may not wish their lives to change in ways that they assume will happen. Many of these concerns are of course entirely understandable, given the attitudes that many encounter and the scarcity of good quality service provision for disabled children in many areas. Personal reactions are diverse and complex but many parents report that getting to know their child through a loving, care-giving relationship means that their initial attitudes change.

1.59 In addition to any personal reactions they may have, studies have identified issues related to the nature and organisation of services that present problems for some parents during the early years. There tends to be agreement among key organisations for disabled children and their families, however, that early years services have improved for at least some groups of children.<sup>109</sup> Some of the progress has been attributed to the highly praised Early Support Programme that operated across the whole of England from 2002–2015 and which introduced a key worker system to help families access the services they needed.

1.60 Notwithstanding the positive support received by some, there are still concerns about the pitfalls for children and families at this crucial time. Common problems include: the stress involved in the process of getting a confirmed diagnosis of their child's impairment or condition;<sup>110</sup> insensitive or inappropriate practice on the part of some professionals and service providers; a lack of information at the right time about key services and benefits; a lack of consistency and co-ordination between multiple service providers; exclusion from key mainstream and community service providers and facilities.<sup>111</sup> As we have seen, some of these barriers are experienced by parents and their children throughout childhood but in the early years they are likely to be dealing with them for the first time and in a situation where both the idea and experience of living with disability are new. Parents can spend a great deal of time and energy trying to find their way around the complex maze of unfamiliar services. Some studies point to the particular difficulties experienced at this time by families from minority ethnic groups and those whose first language is not English.<sup>112</sup>

1.61 Depending on the child's condition, parents may also be extremely concerned about the child's health or even survival. As health and other

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<sup>108</sup> B Dobson, S Middleton and A Beardsworth, *The impact of childhood disability on family life*, Joseph Rowntree Foundation/York Publishing Services, 2001.

<sup>109</sup> *The Parliamentary hearings on services for disabled children*, October 2006.

<sup>110</sup> Care Quality Commission, *Special review. Healthcare for disabled children and young people*, 2012.

<sup>111</sup> Department for Education and Skills, *Together from the start: practical guidance for professionals working with disabled children (birth to third birthday) and their families*, 2003; *The Parliamentary Hearings on Services for Disabled Children*, 2006.

<sup>112</sup> C Hatton, Y Akram, R Shah, J Robertson and E Emerson, *Supporting South Asian families with a child with severe disabilities*, Jessica Kingsley Publishers, 2004.

professionals assess their child and plan and provide interventions, they may find themselves attending frequent appointments with a range of unfamiliar specialists in different settings. Arrangements may be particularly demanding if the child has quite complex impairments. One report illustrated this with reference to the experience of the family of a 13-month-old child who had, over a nine-month period, attended a total of 315 service-based appointments in 12 different locations.<sup>113</sup>

1.62 Parents may also have to learn new, sometimes highly technical skills for the first time as they begin to care for their child at home.<sup>114</sup> It is not difficult to see how in this situation, some other aspects of family life may be put on hold.

1.63 As they undertake this taxing level of activity and try to test out the living arrangements that work for them, they may also find that money worries can be a further cause of stress. The impact of the higher costs of disabled living and reduced income can bite quite early. There may be an immediate impact on parents', particularly mothers', choices about working outside the home. As we have seen, suitable and affordable day care is often hard to come by, making the demands of caring and working very difficult to manage (see chapter 8 on carers' rights). As we noted earlier, considerable numbers of lone parents manage all of this unaided by a partner. We have also seen that the first two years of a disabled child's life, may be a time when some adult relationships come under pressure.<sup>115</sup>

1.64 Successive governments have recognised the importance of early intervention to support children and families and to improve long-term outcomes for them. Recent work has drawn attention to the fact that while children with learning disabilities are at greatly increased risk of developing behaviour difficulties, often resulting in a poorer quality of life for children and their families, far too few are provided with effective, evidence-based early interventions.<sup>116</sup>

## Getting an education

1.65 Like all children, disabled children have a right to suitable education. In 2014, the English government introduced a number of measures to reform the system of education for children who have special educational needs (SEN) and disabilities. These recent changes are explained later in this handbook (see chapter 4). In this section, we consider the majority of disabled children and young people who go to day schools within travelling distance of home. The experience

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<sup>113</sup> Department for Education and Skills, *Together from the start: practical guidance for professionals working with disabled children (birth to third birthday) and their families*, 2003.

<sup>114</sup> S Kirk and C Glendinning, 'Developing services to support parents caring for a technology-dependent child at home', (2004) 30 *Child: care, health and development*, pp209-218.

<sup>115</sup> H Clarke and S McKay, *Exploring disability, family formation and break-up: reviewing the evidence*, Research Report No 514, Department for Work and Pensions, 2008.

<sup>116</sup> Challenging Behaviour Foundation, *Early intervention for children with learning disabilities whose behaviours challenge*, Briefing Paper, 2014.

of those who attend residential schools is considered in a later section about children who live away from home.

1.66 The term 'special educational needs' (SEN) was introduced into policy and law in the early 1980s following the Warnock report.<sup>117</sup> Children were deemed to have special educational needs if they had a significantly greater difficulty in learning than most children of the same age. Those with higher levels of need that required the local authority to arrange additional or different educational provision were given a statement of SEN produced in accordance with prescribed statutory procedures. In 2015, 15.4 per cent of children in England were identified as having SEN and just under three per cent had a statement or an EHC plan.<sup>118</sup> Pupils with SEN are drawn disproportionately from more disadvantaged backgrounds and there is substantial variation between geographical areas in the proportion of children deemed to have SEN.<sup>119</sup> Almost all children with SEN who do not have statements (these are now being converted to 'education, health and care (EHC) plans' – see paras 4.134–4.163 below) are educated in mainstream schools while 4 in 10 of those with a statement are placed in special schools. Autistic spectrum disorder is the most common primary need for children with statements. Among pupils placed in special schools, the most frequent primary needs are identified as severe learning difficulty (24.7 per cent), autistic spectrum disorder (21.5 per cent) and moderate learning difficulty (17.8).<sup>120</sup>

1.67 Some children with SEN and disabilities and their parents undoubtedly have good experiences of well-managed, high quality education services<sup>121</sup> and the majority of parents report that they are satisfied with their children's educational provision as a whole.<sup>122</sup> A recent review of evidence by the Department for Work and Pensions, indicates that in the past few years, levels of educational attainment for children with SEN at key stages 2 and 4 have improved overall though the gap between those without SEN and those who have SEN with a statement has widened. The proportion of disabled 19-year-olds without a Level 3 qualification has also fallen in recent years from 74 per cent to 53 per cent and is converging towards the average for non-disabled young people.<sup>123</sup>

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<sup>117</sup> Department of Education and Science, *The report of the committee of enquiry into the education of handicapped children and young people* (the Warnock Report), Cmnd 7212, HMSO, 1978.

<sup>118</sup> Department for Education, *Statistical release. Children with special educational needs 2015. An analysis*, 2015.

<sup>119</sup> Ofsted, *The Special Educational Needs and Disability Review 091221*, 2010.

<sup>120</sup> Department for Education, *Statistical release. Children with special educational needs 2015. An analysis*, 2015.

<sup>121</sup> Ofsted, *The Special Educational Needs and Disability Review 091221*, 2010; Lamb Inquiry, *Special educational needs and parental confidence*, DCSF, 2009.

<sup>122</sup> Lamb Inquiry, *Special educational needs and parental confidence*, DCSF, 2009.

<sup>123</sup> Department for Work and Pensions, *Fulfilling potential. Building a deeper understanding of disability in the UK Today*, 2013.

1.68 Despite these improvements, a range of research studies<sup>124</sup> and official reports<sup>125</sup> suggest that substantial numbers of children and their parents are not well-served in the education system, and encounter serious problems as they try to navigate what is a very complex system. Common themes emerge from these sources. Parents report experiences that are stressful and difficult and they often describe protracted battles to gain access to what they regard as essential services for their children. While many parents may value the confidence and security derived from having a statement/plan, they can feel disadvantaged in a system that is unfamiliar and difficult to understand. Some parents and children have difficulty in finding the information they need, preparing the necessary written submissions as well as reading and commenting on professional reports. Being in disagreement with the school, individual professionals or the local authority and going through procedures to resolve disputes is also experienced as highly stressful. Even when parents are satisfied with how processes work and with the outcomes, they often report that they have had to be engaged very actively with the system and to have worked very hard to make progress for their children. A 2014 report by the local government ombudsman<sup>126</sup> identified six key main areas of concern:

- delays in the process which can often lead to other problems, such as the loss of education;
- inadequate assessment and review of statements of SEN;
- poor planning of an individual's SEN support, particularly in the key transition phases;
- failure to provide specific SEN support, such as qualified specialists;
- unlawful exclusions, children wrongfully excluded from the educational system due to their SEN; and
- failure to ensure suitable SEN provision in a council's area.

There is also increasing recognition that between local authorities there is not only substantial variation in the proportion of children identified as having SEN but also in the nature and quantity of services provided for them.<sup>127</sup>

1.69 Within education for children with SEN and disabilities, a key issue remains the setting where they should be educated. From the late 1970s onwards, there has been a growing challenge to the then established wisdom that it was both necessary and desirable for disabled children to be educated in separate schools

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<sup>124</sup> R Tennant, M Callanan, D Snape, I Palmer and J Read, *Special educational needs disagreement resolution services: national evaluation*, Research Report DCSF-RR054, DCSF, 2008. See also C Penfold, N Cleghorn, R Tennant, I Palmer and J Read, *Parental confidence in the special educational needs assessment, statementing and tribunal system: a qualitative study*, Research Report RR117, DCSF, 2009.

<sup>125</sup> Lamb Inquiry, *Special educational needs and parental confidence*, DCSF, 2009; Ofsted, *Special education needs and disability review*, 2010.

<sup>126</sup> Office of the Local Government Ombudsman, *Special Educational Needs: preparing for the futures*, 2014.

<sup>127</sup> J Lewis, A Mooney, L Brady, C Gill, A Henshall, N Willmott and J Statham, *Special educational needs and disability: understanding local variation in prevalence, service provision and support*, DCSF Research Report DCSF-RR211, 2010.

from their non-disabled peers. By the mid-1990s, the inclusion of disabled children in mainstream schools had gained official support.<sup>128</sup> Increasingly, law, policy and practice assumes that mainstream schooling is the appropriate option for disabled children unless there is a particular reason why their needs cannot be met in this way. In recent times, inclusion in education has come to be seen as one crucial aspect of disabled children's right to social inclusion more generally. As might be expected, there is variation in the reactions of disabled children and adults and their families to these shifts in thinking and to the experiences of both inclusive and separate education.<sup>129</sup> Some of these variations may be explained by the different educational needs of some groups of disabled children: for instance, children with autistic spectrum disorders compared with those who have physical or sensory impairments.

1.70 Parents of disabled children have to make difficult choices about what they regard as being in their children's interests at any particular time. They have to consider the information that is available to them, take all circumstances they can into account and decide on what seems to them to be the best option for their children.

1.71 The government in England has argued that it has introduced its most recent reforms in response to the evidence that the existing system was complex and that it was often difficult for children and young people to get the help they needed at the right time.<sup>130</sup> Statements are being phased out and replaced by a single assessment process and a combined EHC plan in an effort to integrate the planning and delivery of education, health and social care from birth to 25 years of age. In addition, the stated aims of the reforms are to involve parents more in assessments, to give them greater control over the funding allocated to their children and to offer greater choice of school placement.<sup>131</sup> See chapter 4 at paras 4.21-4.31 for an overview of the reforms. It is too early to tell what the impact of the reforms will be but experience dictates that there is no credible 'quick fix' in a system which has to attempt to meet the differentiated needs of a complex population of disabled children within the resources that local and central government deem to be available.

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<sup>128</sup> Department for Education and Employment, *Excellence for all children, meeting special educational needs*, The Stationery Office, 1998.

<sup>129</sup> M Priestly and P Rabiee, 'Hope and fears: stakeholders' views on transfer of special school resources towards inclusion', (2002) 6 *Inclusive Education* pp371-390; C Rogers, 'Experiencing an "inclusive" education: parents and their children with "special educational needs"', (2007) 28 *British Journal of the Sociology of Education*, pp55-68; Ofsted, *Inclusion: Does it matter where pupils are taught? Provision and outcomes in different settings for pupils with learning difficulties and disabilities*, 2006.

<sup>130</sup> Department for Education, *Increasing options and improving provision for children with special educational needs (SEN)*, 2014.

<sup>131</sup> Department for Education, *Support and aspiration: A new approach to special educational needs and disability*, 2011.

# Transition to adulthood

1.72 The limited opportunities afforded to young disabled people during the transition to adulthood and beyond, have long been a cause for serious concern. Research and official reports have consistently documented the things that make it an exceptionally hazardous time for many disabled young adults and their families. It is little wonder that it has become common for many disabled young people and their parents known to the authors, to refer to this period in their lives as 'the transition cliff'. Bringing about improvements in the experience of transition and their lives as young adults, is held to be a key focus of the current reform of the law, including the extension of the scope of EHC plans to the age of 25. Consistent themes emerge from the large number of official reports<sup>132</sup> and research studies<sup>133</sup> on the experience of transition.

1.73 While there have been some improvements in the experience of disabled young people (see below), it is all too easy for many to leave school and find themselves living a different life from that they would wish and one that is significantly more restricted than their non-disabled peers. For many, there are low expectations about what they have a right to look forward to as adults and a lack of meaningful consultation with them and their families about their aspirations and the decisions to be made. If they are to maximise their health, well-being and life chances as adults, disabled young people together with their families, will need to have the opportunity to identify the outcomes they want and to plan the arrangements and services that will enable them to happen. Identifying young disabled people's needs and wishes in relation to post-school education, health, social care, independent living and employment is fundamental.

1.74 Despite the raft of existing legal duties intended to ensure that this type of assessment and planning take place in a timely fashion (see chapter 10), there is widespread under-recognition of need, inadequate planning and poor coordination between services. There is variation in practice in different areas of the country,

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<sup>132</sup> For example, HM Treasury and Department for Education and Skills, *Aiming high for disabled children: better support for families*, 2007; Commission for Social Care Inspection, *Growing up matters: better transition planning for young people with complex needs*, 2007; Department for Education, *Support and aspiration. A new approach to special educational needs and disability*, 2011; Department for Work and Pensions, *Fulfilling potential. Building a deeper understanding of disability in the UK Today*, 2013.

<sup>133</sup> For example, M Knapp, M Perkins, J Beecham, S Dhanasiri and C Rustin, 'Transition pathways for young people with complex disabilities: exploring the economic consequences', (2008) 34 *Child: care, health and development*, pp512-520; J Beecham, T Snell, M Perkins and M Knapp, *After transition: health and social care needs of young adults with long-term neurological conditions*, PSSRU Research Summary 48, London School of Economics, 2008; S Beyer, A Kaehne, J Grey, K Sheppard, and, A Meek, 'The transition of young people with learning disabilities to employment: what works?' (2008) 14:1 *Journal of Developmental Disabilities*, pp85-94; P Sloper, J Beecham, S Clarke, A Franklin, N Moran and L Cusworth, 'Transition to adult services for disabled young people and those with complex health needs', *Research Works*, 2011-02, Social Policy Research Unit, University of York; B Beresford, N Moran, P Sloper, L Cusworth, W Mitchell, G Spiers, K Weston and J Beecham, *Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions*, Working Paper no DH 2525, Social Policy Research Unit, University of York, 2013; J Sunman, *A Local Experience of National Concern*, Oxfordshire Family Support Network, 2014.

and young people and their parents may find that they have to be extremely well informed and persistent to gain access to the supports that they need. Important systems, organisations and funding streams are often complex, and many young people and their parents do not feel clear about the options available to them. The young people who do best, tend to be those who have family, friends, and significant other people in their lives who are able to help shape and sustain their aspirations through school and give them active practical help and advice as they negotiate their way through post-school provision.

1.75 Disabled 16-year-olds' aspirations about post-school education and employment have risen and are now not significantly different from those of their non-disabled peers but sadly for many, these aspirations are not translated into comparable attainments in post-school education or employment. However positive their aspirations may have been at 16, by the time they reach the age of 26, there is a widening gap between them and their non-disabled peers in terms of their subjective sense of well-being as well as their confidence about their abilities in relation to employment.<sup>134</sup> Data from the 2011 Youth Cohort Study shows that by the time they reach 18, 30 per cent of those who had a statement of SEN when they were in Year 11, and 22 per cent of those who had declared that they were disabled, were not in any form of education, employment or training, compared with 13 per cent of their non-disabled peers.<sup>135</sup> In the UK, there are around 200,000 disabled young people age 16–24 in this category.<sup>136</sup>

1.76 The difference in the rate of unemployment between disabled and non-disabled young people is reduced as the level of qualifications increases. Earlier in this chapter, we saw that while there have been improvements overall in the school-age educational achievements of disabled children and young people, the poor educational outcomes of many continue to be a cause for concern. This may account in part, for the restricted options that are available to some young people in transition and early adulthood, particularly in employment. There is also variation in employment by the type of impairment a young person has. Young people with learning disabilities and those who face mental health issues consistently have fewer opportunities.<sup>137</sup>

1.77 Improving access to appropriate courses in further and higher education may be crucial to some disabled young people's future well-being and success.<sup>138</sup> Funding arrangements for further education (FE) have often been regarded as

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<sup>134</sup> T Burchardt, *The education and employment of disabled young people*, Joseph Rowntree Foundation, 2005.

<sup>135</sup> Ofsted, *Progression post-16 for learners with learning difficulties and/or disabilities*, 2011.

<sup>136</sup> Department for Work and Pensions, *Fulfilling potential. Building a deeper understanding of disability in the UK today*, 2013.

<sup>137</sup> Department for Work and Pensions, *Fulfilling potential. Building a deeper understanding of disability in the UK today*, 2013.

<sup>138</sup> National Audit Office, *Oversight of Special Education for Young People age 16–25*, 2011.



complex and difficult to manage.<sup>139</sup> Ofsted found that the multi-agency assessments carried out by local authorities to determine a young person's support needs and programme requirements prior to transfer to post-16 education, were frequently of an inadequate standard and that many young people entitled to them had not been assessed at all.<sup>140</sup> Provision varied considerably from area to area and for those with the highest levels of need, there was very little choice locally. While the inspectorate found good provision in a range of specialist and mainstream settings, they found too little attention paid to learning opportunities linked to future employment. Funding restrictions meant that some students were only able to have around three days per week foundation learning which was not adequate to prepare them for other destinations, including employment. In addition, Ofsted drew attention to the absence of systematic ways of collecting information about what happened to young people once they had left their FE college or of monitoring the effectiveness of this provision in supporting progression.

1.78 An increasing number of disabled young people are entering higher education (HE) and once there, their attainments are comparable to those of non-disabled students. Having a degree level qualification also significantly improves a young person's employment prospects, bringing them almost in line with their non-disabled peers in this respect. In 2010/11, 40,000 disabled people qualified from full-time HE courses. Those who receive a disabled student allowance (DSA) are less likely to leave a course early than those who do not.<sup>141</sup> The DSA is used to purchase equipment and other forms of study support to enable disabled students to participate fully as learners (see chapter 10, paras 10.91–10.93). In 2014, the government proposed changes to the DSA which would entail institutions of HE taking greater responsibility for meeting disabled students' learning and support needs as part of the way that they discharge their duties under the Equality Act 2010.<sup>142</sup> Following a challenge to this proposal by a range of groups and organisations, the government postponed the introduction of these changes until the academic year 2016/17 and made them subject to the outcome of a public consultation.<sup>143</sup>

1.79 In terms of social care support, young people and their families will almost certainly come across problems as responsibilities for their support and assistance are transferred from children's to adult services. Some services which young people have had access to as children are discontinued and are not replaced by age-appropriate provision for young adults. Local authority financial restrictions

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<sup>139</sup> Department for Education, *Support and aspiration: A new approach to special educational needs and disability*, 2011.

<sup>140</sup> Ofsted, *Progression post-16 for learners with learning difficulties and/or disabilities*. 2011.

<sup>141</sup> Department for Work and Pensions, *Fulfilling potential. Building a deeper understanding of disability in the UK today*, 2013.

<sup>142</sup> Department for Business, Innovation and Skills, *Written Ministerial Statement by David Willetts, Minister for Universities and Science*, 7 April 2014.

<sup>143</sup> Department for Business, Innovation and Skills, *Written Ministerial Statement by Rt Hon Greg Clark, Minister of State for Universities, Science and Cities*, 12 September 2014.

have had a substantial negative impact on adult social care<sup>144</sup> and as a consequence many disabled young adults have inevitably been deemed ineligible for social care services or only offered a limited range of supports. Health services too, have frequently seemed unequal to the task of co-ordinating and delivering healthcare to young people and young adults with complex needs.<sup>145</sup>

1.80 As with any young adult, options for greater independence in adulthood can encompass a wide range of arrangements depending on the circumstances, needs and wishes of those concerned and the resources made available to them. For example, a young person's choices about living separately from their family of origin will be affected among other things, by the accommodation and supported living opportunities available to them, money, their educational opportunities, their culture and social background, their relationships inside and outside the family and so on. Some young people and their families may wish to continue to live together but want the chance to pursue separate interests, activities and lifestyles; some young people may favour group living with others of a similar age, some may want to work towards getting a place of their own and so on. Available evidence suggests, however, that choices are severely restricted for many young disabled adults who find that they continue to be very dependent on their parents for every day living arrangements whatever anyone might otherwise wish. Long-term unemployment and reliance on benefits has a range of negative personal and financial consequences for many disabled young adults and their families.<sup>146</sup>

1.81 While many disabled young people experience an unsatisfactory transition to adulthood and adult services, the experiences of three groups merit particular attention on account of their circumstances or unmet needs. Firstly, because other people may have a limited view of what is appropriate and possible, those with complex impairments and high support needs may be allowed a very restricted range of opportunities and aspirations and are likely to be offered only segregated services as young adults. Recent work following the revelations of abuse at Winterbourne View hospital in 2011, has drawn attention to the limited community-based provision available to young people with learning disabilities whose behaviours challenge. Some may have autism or mental health issues in addition.<sup>147</sup> Families of these young people have pointed to the risk of their being placed inappropriately in hospital settings when other options are not available in the post-school period.<sup>148</sup> In 2013, more than 20 per cent of people occupying in-

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<sup>144</sup> ADASS, *Annual Budget Survey*, June 2015.

<sup>145</sup> Care Quality Commission, *Special review. Healthcare for disabled children and young people*, 2012; Care Quality Commission, *From the pond into the sea: children's transition into adult health services*, 2014.

<sup>146</sup> M Knapp, M Perkins, J Beecham, S Dhanasiri and C Rustin, 'Transition pathways for young people with complex disabilities: exploring the economic consequences', (2008) 34 *Child: care, health and development*, pp512-520.

<sup>147</sup> National Audit Office, *Care services for people with learning disabilities and challenging behaviour*, 2015.

<sup>148</sup> J Sunman, *A Local Experience of National Concern*, Oxfordshire Family Support Network, 2014.

patient beds for mental and behavioural healthcare were between the ages 18–24 years, a sharp rise from the proportion who were under 18 (5.7 per cent).<sup>149</sup>

1.82 By contrast, the second group comprises young people who have lower support needs, including those with mild learning disabilities and those with a diagnosis of autism but with no learning disability. Their needs may not be met because they are regarded as ineligible for support services. They may find themselves in jeopardy as a result.<sup>150</sup>

1.83 The final group of young people are those who have spent time in residential placements away from their families and neighbourhoods. The majority on leaving school return to their areas of origin. Most appear either to return to live with their families or to have some form of residential care and it is reported that choices offered to them are limited and frequently not well-planned.<sup>151</sup>

## Children who live away from home

1.84 While the majority of disabled children live with their families of origin and go to day schools, a minority live away from home for all or some of the year. Some are in boarding schools in term-time and go home to their families for holidays and some weekends; some are weekly or two-weekly boarders; some stay at school 52 weeks a year (see chapter 4 at paras 4.202–4.205); some are in healthcare settings and others are 'looked after' (see chapter 3 at paras 3.144 and 3.147) by local authorities. These categories of placements and settings are not entirely separate as there may be some overlap. For example, a looked-after child may go to residential school.

1.85 There is no doubt that for a long time, disabled children who lived away from home were a very neglected group who did not feature in the main policy agendas.<sup>152</sup> The past ten years have seen some attention being given to this population of children and young people in research and official reports,<sup>153</sup> but the

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<sup>149</sup> Health and Social Care Information Centre, *Learning Disabilities Census Report*, 2013.

<sup>150</sup> Prime Minister's Strategy Unit, *Improving the life chances of disabled people*, TSO, 2005; Commission for Social Care Inspection, *Growing up matters: better transition for young people with complex needs*, 2007; B Beresford, N Moran, P Sloper, L Cusworth, W Mitchell, G Spiers, K Weston and J Beecham, 'Transition to adult services and adulthood for young people with autistic spectrum conditions', Working Paper no DH 2525, Social Policy Research Unit, University of York, 2013.

<sup>151</sup> P Heslop and D Abbott 'Help to move on - but to what? Young people with learning difficulties moving on from out-of-area residential schools or colleges', (2008) 37 *British Journal of Learning Disability*, pp12-20.

<sup>152</sup> J Morris, *Gone missing? A research and policy review of disabled children living away from home*, Who Cares Trust, 1995.

<sup>153</sup> For example, D Abbott, J Morris and L Ward, *Disabled children and residential schools: a survey of local authority policy and practice*, Norah Fry Research Centre, University of Bristol, 2000; A Pinney, *Disabled children in residential placements*, DfES, 2005; Regional Partnerships, *Analysis of Out of Authority Placements*, July 2008; P McGill, 'Residential schools for children with learning disabilities in England: recent research and issues for future

information that we have about them remains inadequate, for example, about the numbers and characteristics of children and young people, the triggers and pathways that take them to particular settings away from home, their educational and other personal outcomes, and what happens to them as they reach adulthood.<sup>154</sup>

1.86 A report by the Office of the Children's Commissioner for England provides an extremely useful summary of the information that is available on disabled children in residential education.<sup>155</sup> It indicates that there has been a year on year decline in numbers of children boarding in recent times. In 2014, there were 6,070 children and young people placed in residential special schools of all types. Across all sectors, there are 379 schools catering for children and young people from the ages 2 to 25 years. There is a concentration of schools in the south of England and over half of the children who are boarders are placed in the southern regions of the country. A total of 192 residential special schools have dual registration as children's homes. Dual registration is required if any child stays for more than 295 days per year. Children in these settings are generally assumed to have more complex and higher support needs than those in other boarding schools and it is also thought that a higher proportion are likely to be looked-after children. Independent providers account for 88 per cent of dual registered schools, and they provide for 79 per cent of children needing such settings.

1.87 The information provided by the annual school census on individual pupils at residential school, is severely limited as it excludes details on the characteristics of those attending independent boarding schools. These schools make up nearly half of all residential schools. The information collected about children and young people at other boarding schools indicates that 75 per cent were boys and that 60 per cent of pupils were aged 12 to 16 years. In terms of the children's primary special educational needs, 29 per cent were identified to have emotional, behavioural and social difficulties, 18 per cent autistic spectrum disorder and 14 per cent hearing impairment. More than a quarter of boarders were placed over twenty miles from home and nearly a third in schools outside their own authorities. 10 per cent of boarders in the non-independent schools were looked-after children, the majority of whom (61 per cent) were there through a voluntary agreement under section 20 of the Children Act 1989.

1.88 Not all looked-after disabled children go to residential special schools. Again, it is widely recognised that the information that we have about the whole

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provision', (2008) 13(4) *Tizard Learning Disability Review*; P Heslop and D Abbott, 'Help to move on - but to what? Young people with learning difficulties moving on from out-of-area residential schools or colleges', (2009) 37 *British Journal of Learning Disability*, pp12-20; Health and Social Care Information Centre, *Learning Disabilities Census Report*, 2013.

<sup>154</sup> Audit Commission, *Out of authority placements for special educational needs*, Audit Commission Publications, 2007; Department of Health, *Valuing people: a new strategy for learning disability for the 21st century*, TSO, 2001; Commission for Social Care Inspection, *Growing up matters: better transition for young people with complex needs*, 2007; A Pinney, *Children with learning disabilities whose behaviours challenge. What do we know from national data?*, Challenging Behaviour Foundation and the Council for Disabled Children, 2014.

<sup>155</sup> The Office of the Children's Commissioner, *The views and experiences of children in residential special schools: overview report*, 2014.

group of looked-after disabled children is incomplete.<sup>156</sup> While the special educational needs profile of children who are looked after by local authorities, is in many respects similar to all children with SEN, there are some differences. Those who are looked after are most likely to have been assessed as having behavioural, emotional and social disorders. In 2014, this applied to 40 per cent of looked after children who had statements of SEN. They were also more likely to have moderate learning difficulties (17.7 per cent) compared with their peers who were not looked after (15.5 per cent). A major difference was also that only 8.7 per cent of looked-after children with SEN were identified as having autistic spectrum disorders compared with 21.9 per cent of all children with statements of SEN.<sup>157</sup> Even though the information on the whole population is fragmented, some research has indicated that looked-after disabled children are likely to remain in care for longer than their non-disabled peers, less likely to return home and have a higher risk of being placed inappropriately. For many, there appear to be barriers to achieving permanent and stable living arrangements.<sup>158</sup>

1.89 We do not know enough about disabled children placed in healthcare settings. However, the learning disability census introduced in the wake of revelations in 2011 of abuse of people with learning disabilities at Winterbourne View hospital, has begun to fill major information gaps about a particular group of children and young people. It provides an annual snapshot of all children and adults with a learning disability, autistic spectrum disorders and/or behaviour that challenges, who are in in-patient settings. Of the 3,250 counted in the 2013 census,<sup>159</sup> 185 were under 18 years of age. While these facilities are supposed to be mainly for short-term assessment and treatment, the census shows that many do not operate in that way. A 2014 report which analysed additional unpublished data from the learning disability census on the 236 children and young people aged under 19 years, found that 41 per cent stayed in hospital for up to three months and 74 per cent for up to a year. 14 children and young people had been in these units for five years or more.<sup>160</sup> 29 per cent of the children were placed more than 100 km from home. Frequency of the use of restrictive practices such as restraint and seclusion were issues of concern. At the time of writing, all available evidence indicates that efforts to meet the formal government target of moving people from the assessment and treatment units to appropriate

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<sup>156</sup> A Pinney, *Disabled children in residential placements*, DfES, 2005; C Baker, *Permanence and Stability for Disabled Looked After Children*, Institute for Research and Innovation in Social Services, 2011.

<sup>157</sup> A Pinney, *Children with Learning Disabilities Whose Behaviours Challenge. What do we know from national data?*, Challenging Behaviour Foundation and the Council for Disabled Children, 2014.

<sup>158</sup> C Baker, *Permanence and stability for disabled looked after children*, Institute for Research and Innovation in Social Services, 2011.

<sup>159</sup> Health and Social Care Information Centre, *Learning Disabilities Census Report*, 2013.

<sup>160</sup> A Pinney, *Children with learning disabilities whose behaviours challenge. What do we know from national data?*, Challenging Behaviour Foundation and the Council for Disabled Children, 2014.

community-based provision have failed.<sup>161</sup> This failure has led to the publication of a government consultation on a series of proposals, including for law reform, to drive change for this particularly vulnerable group.<sup>162</sup> While the focus of this programme is clearly on adults, it is important to many families with children who look towards their sons' and daughters' future lives with considerable concern.

1.90 Too little is known about what determines whether children leave home and live apart from their families for some or all of the time. Some parents and children feel that a placement in residential school, for example, is a positive choice and one which works to the child's benefit.<sup>163</sup> Unfortunately for others, a placement away from home (whether in a school or some other setting) appears to happen more because other preferred services (including appropriate child and family support) are not available.

1.91 There are indications that the age of the young person may be a factor in placement decisions. Information on looked-after children and those in residential schooling shows that the majority are beyond primary school age<sup>164</sup> and that there are also substantial numbers of teenage boys assessed as having emotional, behavioural and social disorders, challenging behaviour and autism in residential schools. Many parents look after their children with little outside support for years before taking a decision to find some form of residential provision. A limited amount of research on residential schooling as well as anecdotal accounts suggest that as some children get older, particularly if they have high support needs or challenging behaviour, their families may not feel that they can continue to provide the levels of support and care that they require.<sup>165</sup> It is sometimes suggested that even when a child goes away from home for primarily social or family reasons, some parents may find residential schooling a preferable and less stigmatising option to other provision.<sup>166</sup>

1.92 In some cases, residential schooling is required only because there is no suitable educational provision to meet the child's needs in his or her own locality. As rates of placement in residential school vary substantially from one local

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<sup>161</sup> National Audit Office, *Care services for people with learning disabilities and challenging behaviour*, 2015; J Sunman, *A local experience of national concern*, Oxfordshire Family Support Network and Healthwatch Oxford, 2014.

<sup>162</sup> Department of Health, *No voice unheard, no right ignored - a consultation for people with learning disabilities, autism and mental health conditions*, March 2015; Department of Health, *Government response to No voice unheard, no right ignored - a consultation for people with learning disabilities, autism and mental health conditions*, November 2015.

<sup>163</sup> The Office of the Children's Commissioner, *The views and experiences of children in residential special schools: overview report*, 2014.

<sup>164</sup> Lamb Inquiry, *Special educational needs and parental confidence*, DCSF, 2009.

<sup>165</sup> D Abbott, J Morris and L Ward, *Disabled children and residential schools: a survey of local authority policy and practice*, Norah Fry Research Centre, University of Bristol, 2000.

<sup>166</sup> D Abbott, J Morris and L Ward, *Disabled children and residential schools: a survey of local authority policy and practice*, Norah Fry Research Centre, University of Bristol, 2000.

authority to another,<sup>167</sup> it is reasonable to conclude that decisions have as much to do with local policy and resources as with children's educational needs. The same point may be made in relation to out-of-area services for looked-after disabled children and young people.

1.93 Studies of children with complex needs who spend substantial periods in healthcare settings have suggested that a lack of appropriate community-based services for them and their families contributes to their being admitted and remaining in hospital for long stays.<sup>168</sup> Even if a hospital admission may be appropriate for some children, and young adults who face a health crisis, this should not become a long-term option simply because there is nothing else available or because the fact that funding does not follow the patient, means there is no financial incentive for local areas to bring them home.<sup>169</sup>

1.94 Lengthy out-of-area placements are likely to result in some children and young people becoming cut off from their families.<sup>170</sup> It appears, however, that the majority of children in residential special schools go home regularly and that many schools see facilitating contact between children and their families as an important element of their work.<sup>171</sup> Despite this, maintaining contact can be particularly challenging for some, due, for example, to distance, transport arrangements and expense.

1.95 While some children and young people may benefit overall from placements away from home, some may not. Some placements may deny a child the chance to participate in ordinary features of life. Many families and children have concerns about safeguarding and protection from abuse in residential settings<sup>172</sup> and this is small wonder given the recent evidence that has come to light about some health settings. In any event, being separated from family is clearly a significant matter for any child. This makes it crucial that it is not a placement that happens because of deficits in other community-based services or that arrangements do not isolate a child from significant family and community relationships. Some studies indicate that young disabled people are very likely to return to their family or area of origin

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<sup>167</sup> D Abbott, J Morris and L Ward, *Disabled children and residential schools: a survey of local authority policy and practice*, Norah Fry Research Centre, University of Bristol, 2000.

<sup>168</sup> K Stalker, J Carpenter, R Phillips, C Connors, C MacDonald, J Eyre and J Noyes, *Care and treatment? Supporting children with complex needs in healthcare settings*, Pavilion Publishing, 2003; J Sunman, *A Local Experience of National Concern*, Oxfordshire Family Support Network and Healthwatch Oxford, 2014.

<sup>169</sup> National Audit Office, *Care services for people with learning disabilities and challenging behavior*, 2015.

<sup>170</sup> D Abbott, J Morris and L Ward, *Disabled children and residential schools: a survey of local authority policy and practice*, Norah Fry Research Centre, University of Bristol, 2000.

<sup>171</sup> A Pinney, *Disabled children in residential placements*, DfES, 2005.

<sup>172</sup> The Office of the Children's Commissioner, *The views and experiences of children in residential special schools: overview report*, 2014; J Sunman, *A local experience of national concern*, Oxfordshire Family Support Network and Healthwatch Oxford, 2014.

after they have finished in residential school, making the maintenance of those personal links even more crucial.<sup>173</sup>

## Services for disabled children and their families

1.96 At the beginning of this chapter we said that disabled children and those close to them are entitled to enjoy the same human rights as others. Even though some of their needs and priorities may be different from those who do not live with disability, this does not mean that they should be prevented from participating in ordinary experiences that others may take for granted. Disabled children and their families may need additional supports and different arrangements to enable them to participate in things that are part and parcel of an ordinary life. The aim of policies and services should be to enable them to maximise their health, well-being and life chances and to promote opportunities for full social participation. This includes universal services and organisations as well as those that are more specialist or targeted. Universal services are required by the reasonable adjustments duty in the Equality Act 2010 to make adjustments to improve their accessibility to disabled children.<sup>174</sup>

1.97 As far as services and other arrangements are concerned, it has long been accepted as good practice that one size does not fit all and that a much more flexible approach to meeting children's and families' needs is required. The principle is well established that children and their families, jointly with relevant professionals, should be able to identify outcomes that are important for living an ordinary life and then, together, plan arrangements and services which enable those outcomes to be achieved. The test as to whether the plan works, is whether the outcomes are realised. The child and the family, rather than service providers, commissioners and other professionals, should be at the centre of this process which should be driven by their needs, choices and aspirations. The professionals and their organisations should collaborate effectively with each other in order to plan and deliver.<sup>175</sup> It is also well-established that what is provided does not need to take the form of familiar services, though sometimes it may – some children and families, for example, may wish to access existing short break facilities because they find them beneficial.<sup>176</sup> While some parents and their children may be clear about what would work best for them, others may find it helpful to gain

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<sup>173</sup> P Heslop and D Abbott, 'Help to move on - but to what? Young people with learning difficulties moving on from out-of-area residential schools or colleges', (2009) 37 *British Journal of Learning Disability*, pp12-20.

<sup>174</sup> Equality Act 2010 ss20-22. See chapter 9 at paras 9.39-9.42.

<sup>175</sup> See for example, Department for Education and Skills, *Together from the start: practical guidance for professionals working with disabled children (birth to third birthday) and their families*, 2003. HM Government, *Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children*, March 2015; G Hanrahan, *Moving into adulthood and getting a life: getting started*, Oxfordshire Family Support Network, 2014.

<sup>176</sup> C Hatton, M Collins, V Welch, J Robertson, E Emerson, S Langer and E Well, *The impact of short breaks on families with a disabled child over time*, DFE-RR173, 2011.



from the ideas and experiences of other families and organisations representing their interests, as well as service providers. For example, a range of information materials and case studies are now available to assist young people and their families as they decide what might be the most preferable options for them in the transition to adulthood.<sup>177</sup> As we have seen earlier in this chapter, however, it is not always easy for young people and their families to access the appropriate and up-to-date information they need.

1.98 These basic ideas were first taken forward in the field of adult social care with the development of what became known as the 'personalisation agenda'. Personal budgets and 'self-directed support', key features of personalisation, are now being introduced and promoted for disabled children and their families.<sup>178</sup> A personal budget is a sum of money that is allocated to an individual or family to spend on help and support to meet their assessed eligible needs and to achieve agreed outcomes. According to the personalisation principles, this aims to give the child and family more control. Families can access their personal budgets through a direct payment or, if they do not wish to do this, can manage them with the assistance of a third party, including the local authority. Direct payments for disabled children and their families are not new. Instead of having local authority social care services provided in kind, families have been able to choose to have a direct payment equivalent to the cost so that they may purchase them themselves.<sup>179</sup> To begin with, personal or individual budgets only applied to social care support funded by social services but at the time of writing, they are in the process of being extended to some forms of health and educational provision. Families are also able to have a personal budget as part of an EHC plan, covering all three types of provision.<sup>180</sup>

1.99 Some children, young people and their families have undoubtedly found that direct payments and personal budgets suit them very well and are satisfied with the type of support offered and the degree of control they have.<sup>181</sup> It is important, however, to recognise that they are unlikely to suit everyone. While many may subscribe to the principles of personalisation, of having a greater degree of flexibility and control and of shifting the existing balance of power more in their favour, not everyone believes that personal budgets are the necessary vehicle to achieving this and to bringing about the promised improvements in people's lives. Some raise questions about whether personal budgets may place

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<sup>177</sup> See for example, K Sibthorpe and T Nicoll, *Making it personal. A family guide to personalisation, personal budgets and education, health and care plans*, Kids/In Control, 2014; G Hanrahan, *Moving into adulthood and getting a life*, Oxfordshire Family Support Network, 2014; Challenging Behaviour Foundation, *Positive Behaviour Support Planning*, 2015.

<sup>178</sup> K Sibthorpe and T Nicoll, *Making it personal. A family guide to personalisation, personal budgets and education, health and care plans*, Kids/In Control, 2014.

<sup>179</sup> These were first made available by the Carers and Disabled Children Act 2000.

<sup>180</sup> K Sibthorpe and T Nicoll, *Making it personal. A family guide to personalisation, personal budgets and education, health and care plans*, Kids/In Control, 2014.

<sup>181</sup> J Waters and C Hatton, *Measuring the outcomes of EHC plans and personal budgets*, Lancaster University and In Control, Summer 2014.

additional stress on some families who are already overstretched, and also draw attention the fact that the new system will not solve the problem of the shortfall of skilled support to meet some children's needs.<sup>182</sup> There is no doubt, too, that like any other system, the new arrangements may fall foul of austerity measures, leaving children and families without adequate support. A personal budget is after all, only available to pay for assessed, eligible needs (see chapter 3 at paras 3.103–3.107).

1.100 Some families' concerns about new policies come from their experience of the harsh day-to-day reality of trying to obtain what they believe their children need and should have a right to, rather than because they lack vision. In a recent workshop organised by the Challenging Behaviour Foundation, parents and children were asked to say what they would like and they produced the messages shown opposite.

## Conclusion

1.101 This chapter has emphasised that disabled children and those close to them are entitled to enjoy the same human rights as others and to expect a quality of life comparable to that of their peers who do not live with disability. However, as can be seen from the level of social exclusion that they experience and the barriers they face, the aspiration of a more ordinary way of life is still beyond the reach of many disabled children and their families. Challenging the social exclusion and discrimination faced by these children and families and bringing about positive change for their benefit is a considerable task requiring on-going political, social and legal action. This book focuses on the contribution that the law can make towards the collective effort of bringing about improvements in the lives of disabled children both individually and as a group, and in particular how the law can be used as a tool to help children and their families achieve the goals that they value.

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<sup>182</sup> For example, J Sunman, *A local experience of national concern*, Oxfordshire Family Support Network, 2014.