

CHAPTER 1

Understanding disabled children's lives

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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 non-disabled children and families.
- Most parents of disabled children describe the joys of bringing up their child and the new experiences and perspectives their children bring.
- 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 eight 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 disabled children and their families have difficulty in accessing sufficient services to effectively support them. Provision is complex and information about entitlements frequently unavailable.
- A lack of appropriate support services and information can have an impact on the health, well-being and opportunities of all family members.
- The early years of a child's life, when disability is most likely to be identified, can be a difficult time 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.
- Disabled 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.
- There are many examples of parents of disabled children using the law successfully to challenge the exclusion and disadvantages their children face.

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. This follows a period of legislative and policy change for disabled children under the Children and Families Act (CFA) 2014. We have tried 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 people and organisations representing their interests, will continue to make use of it.
- 1.2 In this chapter we set out some of the most important principles and issues underpinning the lives of 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 refer to 0–18 year olds unless 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, including some of the parents who are authors of this chapter,¹ have discussed the difficult balancing act involved in trying to raise awareness of the problems that families may 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. Nor does a recognition of adversity deny the joy disabled children bring to their families and communities. 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 differ in some ways from those of non-disabled children and families, but they are no less important. The presence of disability does not mean that disabled children and their families should be unable to participate 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 do 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'.² While there are

1 S Ryan, and K Runswick-Cole, (2008) 'Repositioning Mothers: Mothers, Disabled Children and Disability Studies', *Disability and Society*, 23 (3): 199–210.
 2 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.

differences in emphasis and understanding between some of those developing these ideas, there are a number of 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,³ international treaties⁴ and international classification systems of health, illness and disability.⁵

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) (a convention the UK has ratified – see para 2.28 below):

... 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.⁶

Crucially, this approach challenges the notion that a child’s impairment or medical condition is solely or even primarily responsible for any restrictions he or she faces. It argues that many of the common problems children may 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 (including the services and supports that are available) has the power to increase or reduce the experiences of barriers and discrimination that children and their families face. This handbook adopts this approach and, therefore, pays particular attention to the circumstances in which disabled children 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:

3 Prime Minister’s Strategy Unit, *Improving the life chances of disabled people*, The Stationery Office, 2005.

4 UN Convention on the Rights of Persons with Disabilities, 2006.

5 World Health Organization, *The international classification of functioning, disability and health: children and youth version*, 2007.

6 UN Convention on the Rights of Persons with Disabilities, 2006, Preamble, para (e).

circumstances that 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 been growing recognition of the importance of a human rights approach to enhance understanding of the experiences of disabled children and to bring about improvements in their lives.⁷ 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*.⁸

In keeping with the fundamental purpose of the UNCRPD, our goal should be to try to reduce barriers that prevent 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 key human rights principles that underpin many of these specific rights – 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.

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

8 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.

Regarding the current situation in the UK, the UN Committee on the Rights of Persons with Disabilities produced its concluding observations on their initial report concerning the rights of disabled people in the UK in 2017.⁹ In relation to children with disabilities, the UN Committee reported the following concerns:

- a) the lack of a policy framework addressing the poverty of many families with children with disabilities;
- b) the failure to incorporate the human rights model of disability in public policies and legislation concerning children and young persons with disabilities;
- c) the lack of monitoring mechanisms and reliable indicators, particularly concerning bullying against children with disabilities in school;
- d) the absence of a general statutory duty upon public authorities to ensure adequate childcare for children with disabilities;
- e) the reported increase of incidents of bullying, hate speech and hate crime against children with disabilities.

The core responsibilities of the state

- 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:¹⁰

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

9 UN Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland, UN: Geneva, 2017: <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhspCUnZhK1jU66flQJyHIkqMIT3RDaLiqzhH8tVNxhro6S657eVNwuqlzu0xvsQ UehREyYEQD%2bl dQaLP31QDpRcmG35KYFtgGyAN%2baB7cyky7>.

10 General Comment 5 concerning persons with disabilities and the International Covenant on Economic, Social and Cultural Rights, para 9.

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,¹¹ is on the state, not on families or charities. Families are already 'disabled by association'¹² and many carers experience similar levels of social exclusion to those they care for. This has been recognised by guidance concerning the rights of carers¹³ 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 UNCRPD (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;¹⁴ and that all disabled children be treated equally whatever their impairments or conditions.

The principle of dignity

- 1.14 The concept of 'dignity' is central to many human rights treaties and bodies¹⁵ and is often expressed in terms of respect for 'personal autonomy'/'physical integrity' and of a right to a level of support that

11 General Comment 9, para 20.

12 *Coleman v Attridge Law* C-303/06 [2008] All ER (EC) 1105, [ECJ], considered at para 9.51.

13 Department of Health, *Practice guidance to the Carers (Recognition and Services) Act 1995*, LAC (96)7, para 9.8.

14 See paras 4.216–4.225 in relation to school exclusions.

15 See, for example, the comments of the European Court of Human Rights in *Pretty v UK* (2002) 35 EHRR 1 at [65].

does not lead to ‘indignity’, and that compensates for the disabilities faced by disabled people.¹⁶ 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.¹⁷

- 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.¹⁸

- 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.¹⁹

- 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 to ensure that they do not experience indignity due, for example, to

16 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].

17 *Botta v Italy* (1998) 26 EHRR 241.

18 The concurring opinion of Judge Greve in *Price v UK* (2002) 34 EHRR 1285 at 1296.

19 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].

inadequate bathing²⁰ or toileting²¹ facilities or an inability to access their home or communities (see paras 3.77 and 6.57–6.93 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.²² 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 UNCRPD in the following terms:
- a. 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;
 - b. 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;
 - c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

20 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 07/C03887 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.

21 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'.

22 *McDonald v UK*, Application no 4241/12, (2015) 60 EHRR 1, (2014) 17 CCLR 167.

- 1.19 The courts have held that preserving independence should be a fundamental aim of all social care interventions,²³ that inappropriate institutionalisation is a form of discrimination against disabled people²⁴ and that 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.²⁵ 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.²⁶

The principle of choice

- 1.20 Respect for a person's identity and physical integrity (as protected by Article 8 of the ECHR²⁷) 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'²⁸ and that planning should be 'person centred' and where

23 *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); (2009) 13 CCLR 381, 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'.

24 *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.

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

26 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.

27 See, for example, *Botta v Italy* (1998) 26 EHRR 241, considered at paras 1.14, 2.15, 5.81 and 9.144.

28 For a graphic example of this, see *R (CD) v Isle of Anglesey CC* [2004] EWHC 1635 (Admin); (2004) 7 CCLR 589 considered at paras 3.142 and 10.13.

possible should yield to the personal preferences of the disabled child and family.

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 the service or provision which the person or their family consider will uphold their dignity is significantly more expensive than an alternative service which can properly meet the person's needs as judged by the court.²⁹

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 4.95–4.101 below). The courts have emphasised the absolute importance of communicating with disabled people to ascertain their wishes, feelings and prefer-

²⁹ *McDonald v UK* (2015) 60 EHRR 1; (2014) 17 CCLR 187.

ences³⁰ 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.³¹

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.³² 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.³³ The importance of seeking the views of disabled children and young people and understanding their perspectives is clear, including seeking the views of children who do not use standard forms of communication. There are many tried and tested ways of finding out what disabled children and young people want, using forms of consultation and communication appropriate to their

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

31 *Re S* [2002] EWHC 2278 (Fam); [2003] 1 FLR 292 at [49].

32 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; *A bit good but a bit not good too. Children and young people's views about specialist health services*, Triangle Services, Brighton, 2012.

33 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.

needs.³⁴ Seeking the advice of those who know them best about how to find out the detail of what is important to them is crucial.³⁵

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, their economic circumstances, the ages of those involved, 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 complicated issues in 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 right that children, young people and young adults have to make decisions about matters that affect them, and their right 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.³⁶ 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.

- 34 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.
- 35 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.
- 36 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.³⁷ 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) in the education system, the two groups are not the same.³⁸ 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 1.1 million disabled children aged 0–17 in the UK or approximately eight per cent of the child population.³⁹ A study using data from the Family Resources Survey (FRS)⁴⁰ 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 ten per cent experience five or more. Recent FRS data report the most common impairments among

37 Department for Work and Pensions, *Making disability data work for you*, 2014.

38 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.

39 Department for Work and Pensions (2019), *Family Resources Survey, 2017/18*: www.gov.uk/government/statistics/family-resources-survey-financial-year-201718; Office for National Statistics (2018). Estimates of the population for the UK, England and Wales, Scotland and Northern Ireland: www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland

40 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.

disabled children to be social/behavioural (43 per cent of disabled children), learning (36 per cent), stamina/breathing/fatigue (24 per cent), mental health (23 per cent), mobility (19 per cent), 'other' (18 per cent), memory (11 per cent), dexterity (11 per cent), vision (nine per cent) and hearing (eight per cent).

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 into and through adulthood. This is due, in part, to improved survival rates for low birth weight and extremely premature babies, although statistics suggest that this trend may have stalled in recent years.⁴¹ 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, for example, administering medication, tube feeding, assisted ventilation and resuscitation procedures, as well as other treatments and interventions.⁴² It is estimated that around 18,000 children and young people in England have multiple and complex impairments which result in their need for some form of palliative care.⁴³ In total, 40,000 children and young people in England are estimated to be living with a life-limiting condition.⁴⁴ In addition, recent years have seen some marked changes in the numbers of children identified within education services and in research studies as having specific primary educational needs. Increases have been reported in the numbers of children identified as having autistic spectrum conditions⁴⁵ and attention-deficit

41 AT 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; Office for National Statistics, *Statistical bulletin: Child mortality in England and Wales 2016*, 2018.

42 C Glendinning, C Kirk, S Guiffrida and D Lawton, 'Technology-dependent children in the community: definitions, numbers and costs', (2001) 27 *Child: Care, Health and Development*, pp321–334; C Glendinning, S Kirk and P Callery, 'Parent or nurse? The experience of being a parent of a technology-dependent child'. *Journal of Advanced Nursing*. 2005; 51(5), 456–464.

43 H Cochrane, S Liyanage, R Nantambi, *Palliative care statistics for children and young adults*, Department of Health, 2007.

44 National Institute for Health and Clinical Excellence (NICE). *End of life care for infants, children and young people with life-limiting conditions: planning and management*, Clinical guideline NG61, 2016.

45 S Levy, D Mandell and R Schultz, 'Autism', (2009) 374 *The Lancet*, pp1627–1638.

hyperactivity disorder (ADHD),⁴⁶ and decreases in the numbers of children given a label of ‘moderate learning difficulty’.⁴⁷ There is a question about the extent to which these changes in identification rates reflect ‘real’ changes or changes in diagnostic and identification practices.⁴⁸ 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 disabilities⁴⁹. Rates of psychological distress and other mental health issues can be much higher among children and young people with learning disabilities, although much of this increased risk is accounted for by the disadvantaged circumstances that families with a child with learning disabilities are more likely to experience.⁵⁰

Family composition

- 1.29 While most disabled children live in two-parent households, a greater proportion of disabled children (32 per cent compared to 22 per cent of non-disabled children) are brought up in lone-parent households.⁵¹

- 46 E Taylor, ‘Developing ADHD’, (2009) 50 *Journal of Child Psychiatry and Psychology*, pp126–132.
- 47 Department for Education. *National statistics: Special educational needs in England: January 2018*.
- 48 G Russell, S Collishaw, J Golding, SE Kelly and T Ford, 2015, ‘Changes in diagnosis rates and behavioural traits of autism spectrum disorder over time’, *BJPsych Open*, 1(2), pp110–115.
- 49 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.
- 50 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; E Emerson. *The determinants of health inequities experienced by children with learning disabilities*. 2015; London: Public Health England.
- 51 Department for Work and Pensions, *Family Resources Survey, 2012/2013*; 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.

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,⁵² but 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 related to the child's disability.⁵³ Lone parenthood has considerable implications for the children and families concerned, as these families typically experience increased levels of poverty together with restricted access to essential goods and services.

1.30 Research has also pointed to the co-existence of childhood and adult disability within households.⁵⁴ A 2010 study reported that almost half of disabled children, compared with about a fifth of non-disabled children, live with a disabled parent. In addition, around a quarter of disabled children live with one or more siblings who are also disabled.⁵⁵ While further research is needed to understand more about these families, it is crucial to recognise the nature and scale of the supports families may require when parents and children in the same household are disabled.

- 52 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.
- 53 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.
- 54 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.
- 55 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.

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 to and increase the risk of poor health, additional impairment and social exclusion.⁵⁶ In other words, the well-being, choices and life chances of many disabled children and their families are eroded by living for substantial periods without the resources that would allow them to flourish.
- 1.32 The occurrence of most childhood disabilities is socially patterned, with the highest prevalence found among children whose parents are the least well off.⁵⁷ As a group, disabled children in the UK and elsewhere are in substantially more disadvantaged financial and material circumstances than non-disabled children.⁵⁸ The reasons for this are not fully understood.⁵⁹
- 1.33 Family disadvantage can make the emergence of some childhood chronic disabling conditions more likely.⁶⁰ Growing up with disability and caring for a disabled child also involves the need for substan-

56 Department for Work and Pensions, *Fulfilling potential. Building a deeper understanding of disability in the UK Today*, 2013.

57 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. N Spencer, C Blackburn and J Read, 'Disabling chronic conditions in childhood and socioeconomic disadvantage: a systematic review and meta-analysis of observational studies' *BMJ Open*, 2015;5:e007062, doi: 10.1136/bmjopen-2014-007062.

58 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.

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

60 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.

tial additional expenditure,⁶¹ estimated to be between £56 and £79 per week, which is not matched by state disability benefits.⁶² Simultaneously, the demands of caring in the absence of sufficient support reduce the options available to the adults in the family, particularly mothers, to bring in income through paid employment.⁶³

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 other households with children. There are variations between some groups, however, and the lowest incomes are to be found among lone parents, black and minority ethnic (BAME) families and those with disabled parents and disabled children in the same household.⁶⁴

1.35 The combination of all these factors means that overall, living standards in families with disabled children are lower across the board than those of their 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

- 61 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; S Baldwin, *The costs of caring: Families with disabled children*, Routledge, 2015.
- 62 M Melnychuk, F Solmi, and S Morris, 'Using compensating variation to measure the costs of child disability in the UK'. *The European Journal of Health Economics*, 2018, 19(3), pp419–433; F Solmi, M Melnychuk and S Morris, 'The cost of mental and physical health disability in childhood and adolescence to families in the UK: findings from a repeated cross-sectional survey using propensity score matching', *BMJ Open*, 2018, 8(2), p.e018729.
- 63 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.
- 64 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.

buying some basic toys.^{65,66} 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.⁶⁷ 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.⁶⁸

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.⁶⁹ Research commissioned by the Equality and Human Rights Commission (EHRC) has assessed the cumulative impact of government changes to public expenditure, taxation and benefits on specific groups within the whole population between May 2010 and January 2018. 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 incomes, with the hardest-hit again being households where there is both a disabled child and a disabled adult.⁷⁰

65 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. In some surveys, substantial numbers of families report being unable to afford adequate food and heating.

66 Contact, *Counting the Cost: research into the finances of more than 2,700 families across the UK in 2018*, 2018; LJ Buckner and S Yeandle, *Caring More Than Most: A profile of UK families caring for disabled children*, Contact, 2017.

67 Contact a Family, *Counting the Cost*, 2014; LJ Buckner and S Yeandle, *Caring More Than Most: A profile of UK families caring for disabled children*, Contact, 2017.

68 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.

69 Contact, *Counting the Cost: research into the finances of more than 2,700 families across the UK in 2018*, 2018; LJ Buckner and S Yeandle, *Caring More Than Most: A profile of UK families caring for disabled children*, London: Contact, 2017.

70 J Portes and H Reed, *The cumulative impact of tax and welfare reforms*, London: Equality and Human Rights Commission, Research report 112, 2018.

Housing problems

- 1.37 Restricted financial resources are also partly responsible for many disabled children and their families living in poor or unsuitable housing.⁷¹ 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.⁷² Some of the most severe housing difficulties are experienced by families with the lowest incomes, and those from black and minority ethnic groups. See further information in 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 support and care. Studies have recorded the ongoing and long-term nature of these caring commitments and have described the often high levels of personal and practical care being provided by

- 71 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.
- 72 B Beresford and D Rhodes, *Housing and disabled children: round-up: reviewing the evidence*, Joseph Rowntree Foundation, 2008; Equality and Human Rights Commission; *Housing and disabled people: Britain's hidden crisis*, London: EHRC, 2018.

parents to their disabled children of all ages.⁷³ The expertise and contribution to care parents make is not always valued and parents can feel unsupported.⁷⁴ While needs vary depending on the individual child, 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.

1.39 Getting out and about and doing things that other families regard as ordinary may need a great deal of planning and organisation. Going shopping, getting a haircut or having a day out can be made more difficult by a combination of such things as inaccessible transport and physical environments, a restricted budget and the need to transport bulky equipment.

1.40 Caring for a disabled child is undertaken in private, day after day, and for some children, during the night too.⁷⁵ Often it has to be accomplished by parents who are also attending 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 may also not as easily available as for other children because of the lack of affordable and accessible care. 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 sufficient and useful support from statutory services, less well off families often have only their own muscle-power, energy and ingenuity to fall back on.

73 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; GM Griffiths and RP 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.

74 J Smith, F Cheater and H Bekker, ‘Parents’ experiences of living with a child with a long-term condition: a rapid structured review of the literature’, *Health Expectations*, 2015, 18(4), pp452–474.

75 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.

1.41 The patterns of care in households with a disabled child tend to reflect childcare arrangements in families more generally, although employment patterns generally are changing. 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.⁷⁶ While employment rates for women in households with dependent children are increasing, with increasing employment rates for women as children become older, equivalent statistics for women in household with a disabled child have not been produced.⁷⁷ Mothers with disabled children are less likely than other mothers to be in paid work, and when working are less likely to be employed full-time.⁷⁸ While fathers' employment rates are less affected than mothers', both mothers and fathers of disabled children are less likely to be in high-income professional jobs.⁷⁹ In addition, studies point to the difficulties reported by employed parents in terms of work/family life balance.⁸⁰ (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.⁸¹ 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 issues. Childcare costs for disabled children also tend

76 N Coleman and L Lancelo, *Lone parent obligations: supporting the journey into work*, Department for Work and Pensions Research Report 736, 2011; Office for National Statistics, *Article: Families and the labour market, England: 2017*, London: Office for National Statistics, 2017.

77 Office for National Statistics, *Statistical bulletin: Working and workless households in the UK: April to June 2018*, 2018: London: Office for National Statistics.

78 LJ Buckner and S Yeandle, *Caring More Than Most: A profile of UK families caring for disabled children*, London: Contact, 2017.

79 LJ Buckner and S Yeandle, *Caring More Than Most: A profile of UK families caring for disabled children*, London: Contact, 2017.

80 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; T Brown and C Clark, 'Employed parents of children with disabilities and work family life balance: a literature review', *Child & Youth Care Forum*; 2017: 46(6); 857–876.

81 Department for Work and Pensions, *Fulfilling potential. Building a deeper understanding of disability in the UK Today*, 2013.

to be considerably higher than for those who are non-disabled.⁸² Disabled children can be more likely to experience authorised absences from school (typically for health-related reasons such as medical appointments) and both fixed-period and permanent school exclusions, which can make regular paid employment for parents more difficult.⁸³

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 by restricted opportunities. Parents tend to focus on the personal and practical arrangements which would enable their families to achieve a decent quality of life.⁸⁴ 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 towards them can be yet another problem to be dealt with.⁸⁵ Around a third of parents report that one of the main barriers their children face is the attitudes of others.⁸⁶ Disabled children and their families report that they often experience insensitive reactions by other people. Parents often feel that public spaces and arrangements that may suit the majority are not designed to include them.⁸⁷

82 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.

83 Department for Education. *SEN absences and exclusions: additional analysis*, London: Department for Education, 2016.

84 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.

85 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.

86 Department for Work and Pensions, *Fulfilling potential. Building a deeper understanding of disability in the UK Today*, 2013.

87 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.

- 1.44 Rates of reported bullying are higher for young disabled people than for other young people⁸⁸ and there has been a growing body of evidence that disabled children have an increased risk of exposure to violence⁸⁹ and abuse.⁹⁰ 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.⁹¹
- 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.⁹² For example, the government's Life Opportunities Survey can be used 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,

- 88 Department for Work and Pensions, *Fulfilling potential. Building a deeper understanding of disability in the UK Today*, 2013; S Chatzitheochari, S Parsons and L Platt, 'Doubly disadvantaged? Bullying experiences among disabled children and young people in England', *Sociology*, 2016, 50(4), pp695–713.
- 89 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.
- 90 K Stalker, and K McArthur, 'Child abuse, child protection and disabled children: a review of recent research', (2012) *Child Abuse Review*, pp24–40; A Franklin and E Smeaton, 'Listening to young people with learning disabilities who have experienced, or are at risk of, child sexual exploitation in the UK', *Children & Society*, 2018, 32(2), pp98–109.
- 91 National Working Group on Child Protection and Disability, '*It doesn't happen to disabled children*': *child protection and disabled children*, National Society for the Prevention of Cruelty to Children (NSPCC), 2003; S Chatzitheochari, S Parsons and L Platt, 'Doubly disadvantaged? Bullying experiences among disabled children and young people in England'. *Sociology*, 2016, 50(4), pp695–713.
- 92 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, Department for Education and Skills (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.

education, transport and leisure or play, with disabled children and young people being disadvantaged in all areas.⁹³ 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.⁹⁴ 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.⁹⁵

1.46 Parents may also express concern about the impact on their non-disabled children of the circumstances that can go along with living with disability.⁹⁶ In addition to research on the experience of parent carers, there has been growing recognition of the experiences of siblings. Siblings may provide help or assistance directly to their disabled sister or brother; at other times, they may support a parent who is undertaking most of the care. (See chapter 8 at paras 8.27–8.59 below for the law in relation to young carers.) Whether or not siblings are involved in care, there has been a recognition of the need to understand their experiences and to learn from their perspectives.⁹⁷ Studies that have consulted siblings directly report mixed reactions to their situations.⁹⁸ Many speak positively about their relationship with their disabled sister or brother. Others, as might be anticipated, do not get on so well. Some report being upset by the

93 Office for National Statistics, *Life Opportunities Survey. Interim Results 2009/2010*, 2010.

94 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 edn, Cambridge University Press, 2011; E Emerson, *The determinants of health inequities experienced by children with learning disabilities*, London: Public Health England, 2015.

95 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*, Department of Children and Family Services (DCSF) Publications, 2008; Daycare Trust, *Listening to parents of disabled children about childcare*, 2007.

96 Contact a Family, *Siblings*, 2011.

97 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.

98 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.

attitudes of other people towards their sister or brother, 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 and/or autism concludes that overall, the evidence indicates that neither the well-being of the majority nor their relationships with a disabled sister or brother 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, that we might do well to pay particular attention to this group. Research on siblings is limited in a number of respects, however, and this leaves gaps in our knowledge about this group of children and young people.⁹⁹

- 1.47 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.¹⁰⁰ Some studies have highlighted the impact on the emotional well-being of parents of any behavioural difficulties their children may have.¹⁰¹ Research has also suggested that the increased risk of poorer health and well-being may be attributed, in part at least, to the socio-economic disadvantage that is more likely to be experienced by families with a disabled child.¹⁰² Mothers also consistently report the stress of navigating services and of battling for resources to support their child as having a major impact on their mental health and well-being.¹⁰³

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

100 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; J Smith, F Cheater and H Bekker, 'Parents' experiences of living with a child with a long-term condition: a rapid structured review of the literature', *Health Expectations*, 2015, 18(4), pp452–474.

101 R Hastings, 'Parental stress and behavior problems of children with developmental disability', (2002) 27(3) *Journal of Intellectual and Developmental Disability*, pp149–160.

102 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; E Emerson, *The determinants of the health inequities experienced by children with learning disabilities*, 2015; London: Public Health England.

103 C Rogers, *Intellectual disability and being human: a care ethics model*, Routledge, 2016.

Dealing with services

1.48 In addition to the caring work and the practical and financial issues to be tackled at home, parents have to deal 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 that have explored parents' and children's experience as service users. These battles have led to parents taking on the role of advocate or even activist on behalf of their children.¹⁰⁴

1.49 There are increasingly high levels of unmet need for provision, with many finding that they are not eligible for services that would help them, that the things that are provided are not suitable, or that cuts result in families living in a state of worry about the future and a state of precarity that existing supports may be cut at any time. 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 also experience distress – are not well served. Many families report

104 S Ryan, K Runswick Cole, 'From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum', *Journal of Applied Research in Intellectual Disabilities*, 2009, 22(1), 43–53, doi.org/10.1111/j.1468-3148.2008.00438.x.

that they need to travel some distance to access services for their child.¹⁰⁵

1.50 Services are commissioned and delivered by specialists working in systems of baffling complexity that 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.¹⁰⁶ Some of the provisions of the CFA 2014 which are explained later in this handbook, represent relatively recent attempts on the part of government to address the problems of fragmented health, education and care services for disabled children and their families.¹⁰⁷

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 that should be accessible to all. Exclusionary practices and limited appreciation

105 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.

106 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.

107 Department for Education/Department of Health, *Special Educational Needs and Disability Code of Practice: 0 to 25 Years*, January 2015.

of theirs and their children's needs and rights can continue to create considerable difficulties.¹⁰⁸

- 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 parenting roles.¹⁰⁹ Their difficulties may often be exacerbated by the lack of effective collaboration between children's and adult social services. Given that research has highlighted a clustering of childhood and adult disability in a significant proportion of households,¹¹⁰ 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.¹¹¹ 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.¹¹² 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 'local offer' in every local area in England under the CFA 2014 is a legislative response to this problem.¹¹³

108 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.

109 Commission for Social Care Inspection, *Supporting disabled parents: a family or fragmented approach?*, 2009.

110 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.

111 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.

112 C Morris, S Blake, A Stimson, A Borek and K Maguire, 'Resources for parents raising a disabled child in the UK', *Paediatrics and Child Health*, 2016, 26(9), pp406–408.

113 CFA 2014 s30.

- 1.54 A number of studies have described what families regard as the key elements of effective information systems.¹¹⁴ 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 sharing information online.¹¹⁵ While this is undoubtedly making a positive difference to many, there was initially some concern about the position of families on low incomes on account of their having more limited internet access than others.¹¹⁶ It was argued that the 'digital divide' might actually exacerbate existing inequalities.¹¹⁷ 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 enable quicker and better access to services, improve communication and to make sure that they get what they and their children need.¹¹⁸

114 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; C Morris, S Blake, A Stimson, A Borek and K Maguire, 'Resources for parents raising a disabled child in the UK', *Paediatrics and Child Health*, 2016, 26(9), pp406–408.

115 See, for example, Special Educational Needs and Disability Regulations 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 CFA 2014 s30.

116 C Blackburn and J Read, 'Using the internet? The experiences of parents of disabled children', (2005) *Child: care health and development*, pp507–515.

117 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.

118 C Morris, S Blake, A Stimson, A Borek and K Maguire, 'Resources for parents raising a disabled child in the UK'. *Paediatrics and Child Health*, 2016, 26(9), pp406–408.

Critical transition stages

- 1.56 A time when information (among other things) is particularly crucial is when children and families find themselves at a critical transition stage – that is, 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. Many parents’ accounts of the process of finding out that they have a disabled child suggest that this experience can be exceptionally stressful.¹¹⁹ 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 come to modify or reject. It is not uncommon for people to describe feeling shocked and over-

¹¹⁹ 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.

whelmed.¹²⁰ 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. Personal reactions are diverse and complex but, as with any parent, love and positivity are the keystones of parents' relationships with their children.¹²¹

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.¹²² 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. However, some of these services have been lost as a result of the cuts to public spending over recent years. For example, local authority spending in England on Sure Start, children's centres and early years dropped by 35 per cent in absolute terms in four years, from 2012/13 to 2016/17.¹²³

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 issues in the early years include the stress involved in the process of getting a confirmed diagnosis of their child's impairment or condition. The way systems work means that a delay in diagnosis can result in: a delay in access to support;¹²⁴ 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; and exclusion from key mainstream and

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

121 RP Hastings, 'Do children with intellectual and developmental disabilities have a negative impact on other family members? The case for rejecting a negative narrative', *International Review of Research in Developmental Disabilities*, 2016, 50, 165–194.

122 The Parliamentary hearings on services for disabled children, October 2006.

123 Department for Education, Statistics: local authority and school finance: www.gov.uk/government/collections/statistics-local-authority-school-finance-data.

124 Care Quality Commission, *Special review. Healthcare for disabled children and young people*, 2012.

community service providers and facilities.¹²⁵ 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.¹²⁶

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 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.

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.¹²⁷

1.63 As families 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 in the absence of sufficient support can have an immediate impact, including decisions about parents' jobs. Suitable and affordable day care can be hard to come by, making the demands of caring and difficult to manage (see chapter 8 on carers' rights).

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

125 DfES, *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.

126 K Heer, J Rose and M Larkin, 'Understanding the experiences and needs of South Asian families caring for a child with learning disabilities in the United Kingdom: an experiential-contextual framework', *Disability & Society*, (2012) 27:7, 949–963, DOI, 10.1080/09687599.2012.699276.

127 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.

quality of life for children and their families, far too few are provided with effective, evidence-based early interventions.¹²⁸

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

1.66 The term 'special educational needs' was introduced into policy and law in the early 1980s following the Warnock report.¹²⁹ Children were deemed to have SEN 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 2018, 14.6 per cent of children in England were identified as having SEN and just under three per cent (2.9 per cent) had an Education, Health and Care (EHC) plan.¹³⁰ 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.¹³¹ Almost all children with SEN who do not have EHC plans (see paras 4.107–4.142 below) are educated in mainstream schools (99.7 per cent) while almost half (48.3 per cent) of those with an EHC plan are placed in special schools, a proportion that has increased since 2010. The Department for Education label 'autistic spectrum disorder' is the

128 Challenging Behaviour Foundation, *Early intervention for children with learning disabilities whose behaviours challenge*, Briefing Paper, 2014. NICE guideline NG11: *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges*, 2015: www.nice.org.uk/guidance/ng11.

129 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.

130 Department for Education, *Special Educational Needs in England: January 2018*, 2018.

131 Department for Education, *Special Educational Needs in England: January 2018*, 2018.

most common primary need reported for children with an EHC plan. Among pupils placed in special schools, the most frequent primary needs are identified as ‘autistic spectrum disorder’ (28.5 per cent) ‘severe learning difficulty’ (22.4 per cent), and ‘moderate learning difficulty’ (13.5 per cent).¹³²

1.67 Some children with SEN and disabilities and their parents undoubtedly have good experiences of well-managed, high quality education services,¹³³ and the majority of parents report that they are satisfied with their children’s educational provision as a whole.¹³⁴ In terms of educational attainment, in 2016/17 18 per cent of children with SEN achieved expected levels in reading, writing and maths at Key Stage 2, compared to 70 per cent of children without SEN. By the age of 19, 33 per cent of young people with SEN achieved Level 2 including English and maths, compared to 78 per cent of 19-year-olds without SEN.¹³⁵ Among adults aged 16–64 years, 51.2 per cent of disabled adults were in some form of paid employment compared to 81.2 per cent of other adults, a disability employment gap of 30 per cent that has been fairly consistent over time.¹³⁶

1.68 A range of research studies¹³⁷ and official reports¹³⁸ suggest that substantial numbers of children and their parents are not well-served

132 Department for Education, *Special Educational Needs in England: January 2018*, 2018.

133 Ofsted, *The Special Educational Needs and Disability Review 091221*, 2010; Lamb Inquiry, *Special educational needs and parental confidence*, DCSF, 2009.

134 Lamb Inquiry, *Special educational needs and parental confidence*, DCSF, 2009; L Adams, A Tindle, S Basran, S Dobie, D Thomson, D Robinson and C Shepherd, *Experiences of Education, Health and Care plans: a survey of parents and young people*, Department for Education, 2017: www.gov.uk/government/publications/education-health-and-care-plans-parents-and-young-people-survey.

135 Department for Education. *Special educational needs: an analysis and summary of data sources*, 2018.

136 Office for National Statistics. *Dataset A08: Labour market status of disabled people*, 2018.

137 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; 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; J Allen and D Youdell, ‘Ghostings, materialisations and flows in Britain’s special educational needs and disability assemblage’, *Discourse: Studies in the Cultural Politics of Education*, 38, 70–82, 2017.

138 Lamb Inquiry, *Special educational needs and parental confidence*, DCSF, 2009; Ofsted, *Special education needs and disability review*, 2010 and *House of Commons Education Committee, Special Educational Needs and Disabilities: First Report of Session 2019*.

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 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 ombudsman¹³⁹ identified six key main areas of concern:

- 1) delays in the process which can often lead to other problems, such as the loss of education;
- 2) inadequate assessment and review of statements of SEN;
- 3) poor planning of an individual's SEN support, particularly in three key transition phases;
- 4) failure to provide specific SEN support, such as qualified specialists;
- 5) unlawful exclusions, children wrongfully excluded from the educational system due to their SEN; and
- 6) 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.¹⁴⁰

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

139 Office of the Local Government Ombudsman, *Special Educational Needs: preparing for the futures*, 2014.

140 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.

established wisdom that it was both necessary and desirable for disabled children to be educated in separate schools from their non-disabled peers. By the mid-1990s, the inclusion of disabled children in mainstream schools had gained official support.¹⁴¹ Increasingly, law, policy and practice had assumed that mainstream schooling was the appropriate option for disabled children unless there is a particular reason why their needs cannot be met in this way. This has become more equivocal, with the 2010 Conservative manifesto stating, ‘We will end the bias towards the inclusion of children with special needs in mainstream schools’¹⁴² and increasing proportions of children with learning disabilities being educated in special schools since 2010.¹⁴³ 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.

1.70 Parents of disabled children have to make difficult choices about what is 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 UK government has argued that it introduced its 2014 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.¹⁴⁴ Statements have been 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 were 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.¹⁴⁵ There is no evidence that the reforms have offered a ‘quick fix’ in a system which has to attempt to meet the differentiated needs of a large and diverse population of disabled children within the resources that local and

141 Department for Education and Employment, *Excellence for all children, meeting special educational needs*, The Stationery Office, 1998.

142 Conservative Party. *Invitation to join the Government of Britain*. 2010.

143 C Hatton, G Glover and I Brown. *People with learning disabilities in England 2015*, Public Health England, 2016.

144 Department for Education, *Increasing options and improving provision for children with special educational needs (SEN)*, 2014.

145 Department for Education, *Support and aspiration: A new approach to special educational needs and disability*, 2011.

central government deem to be available. While government maintains that reforms are 'bedding in', critics have argued that the reforms have lacked ambition and are hindered by cuts to SEN and disability provision.¹⁴⁶

Transition to adulthood

- 1.72 The limited opportunities afforded to young disabled people during transition to adulthood and beyond, have long been cause for serious concern. Research and official reports consistently document 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 to refer to this period in their lives as 'the transition cliff'. For example, it is estimated that almost three-quarters of adults with learning disabilities are not recognised as such by health or social care services, despite them being likely to have been identified in education services.¹⁴⁷ 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 (although currently few young people keep their EHC plans up to the age of 25¹⁴⁸). Consistent themes emerge from the large number of official reports¹⁴⁹ and research studies¹⁵⁰ on the experience of transition.

146 House of Commons Education Select Committee, *Special educational needs and disability: first report of session 2019*. www.parliament.uk/business/committees/committees-a-z/commons-select/education-committee/news-parliament-2017/special-educational-needs-and-disability-launch-17-19/.

147 C Hatton, G Glover and I Brown, *People with learning disabilities in England 2015*. Public Health England, 2016.

148 J Hunter, *Plans that work: employment outcomes for people with learning disabilities*, IPPR North, 2019: www.ippr.org/research/publications/plans-that-work.

149 For example, HM Treasury and DfES, *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*.

150 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*, Personal Social Services Research Unit (PSSRU) Research Summary 48,

- 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 aspirations 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 co-ordination between services. There is variation in practice in different areas of the country, 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.

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; G Young-Southward, C Philo C and SA Cooper, 'What effect does transition have on health and well-being in young people with intellectual disabilities? A systematic review', *Journal of Applied Research in Intellectual Disabilities*, (2017) 30(5), 805–823.

- 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.¹⁵¹ 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.¹⁵² More recent data suggest that 29 per cent of disabled young adults aged 16–24 years were not in any form of education, employment or training, compared to nine per cent of other young adults.¹⁵³ In the UK, there are around 200,000 disabled young people age 16–24 in this category.¹⁵⁴
- 1.76 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.¹⁵⁵
- 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.¹⁵⁶ However, the government strategy to implement T-levels for technical education at ages 16–18 (with a potential 'transition' year) at a level equivalent to 'A' levels (Level 3) has clearly not been designed with students with learning disabilities in mind, and may replace some other education programmes currently accessed by

151 T Burchardt, *The education and employment of disabled young people*, Joseph Rowntree Foundation, 2005.

152 Ofsted, *Progression post-16 for learners with learning difficulties and/or disabilities*, 2011.

153 A Powell, *House of Commons Library Briefing Paper SN 06705: NEET: Young people not in education, employment or training*, House of Commons Library, 2018.

154 Department for Work and Pensions, *Fulfilling potential. Building a deeper understanding of disability in the UK today*, 2013.

155 Department for Work and Pensions, *Fulfilling potential. Building a deeper understanding of disability in the UK today*, 2013.

156 National Audit Office, *Oversight of Special Education for Young People age 16–25*, 2011.

students with learning disabilities.¹⁵⁷ Funding arrangements for further education (FE) have often been regarded as complex and difficult to manage.¹⁵⁸ The government's education inspectorate 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.¹⁵⁹ 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.¹⁶⁰

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 – in 2016/17 88 per cent of disabled people graduating from HE were in work or in further study compared to 91 per cent of other graduates.¹⁶¹ In 2016/17, over 70,000 disabled people qualified from HE courses. Those who receive a disabled student allowance (DSA) had been less likely to leave a course early than those who do not.¹⁶² The DSA is used to purchase equipment and other forms of

157 Department for Education, *Implementation of T Level programmes. Government consultation response: equalities analysis*, 2018; House of Commons Library, *T Levels: Reforms to Technical Education*, Briefing Paper 7951, 23 April 2019.

158 Department for Education, *Support and aspiration: A new approach to special educational needs and disability*, 2011.

159 Ofsted, *Progression post-16 for learners with learning difficulties and/or disabilities*, 2011.

160 Department for Education, *Preparing learners with high needs for adult life: research and analysis*: www.gov.uk/government/publications/preparing-learners-with-high-needs-for-adult-life

161 HESA, *Higher education leavers statistics: UK, 2016/17 – Leaver activities and characteristics*, 2018.

162 Department for Work and Pensions, *Fulfilling potential. Building a deeper understanding of disability in the UK today*, 2013.

study support to enable disabled students to participate fully as learners (see chapter 10, paras 10.99–10.101). The government made changes to the DSA in 2014, and further changes to the DSA funding model in 2015/16 and 2016/17, with the expectation that higher education providers will offset reductions in DSA by providing more reasonably adjusted education to disabled students.¹⁶³ An evaluation of the DSA scheme reported that only 40 per cent of disabled students had heard of DSA before they started their higher education course, with considerable confusion about eligibility for DSA and mixed experiences of the support received.¹⁶⁴

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 young people accessed as children are discontinued and are not replaced by age-appropriate provision for young adults. Local authority financial restrictions have had a substantial negative impact on adult social care¹⁶⁵ and as a consequence many disabled young adults have 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.¹⁶⁶

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 by the accommodation and supported living opportunities

163 C Johnson, H Rossiter, B Cartmell, M Domingos, S Svanaes, *IFF Research. Evaluation of disabled students' allowances: Research report*, Department for Education, January 2019: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/770546/Evaluation_of_DSAs_Report_IFF.pdf/.

164 C Johnson, H Rossiter, B Cartmell, M Domingos, S Svanaes, *IFF Research. Evaluation of disabled students' allowances: Research report*, Department for Education, January 2019: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/770546/Evaluation_of_DSAs_Report_IFF.pdf/.

165 ADASS, *Annual Budget Survey*, June 2018.

166 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; University of Bristol Norah Fry Centre for Disability Studies, *The Learning Disabilities Mortality Review (LeDeR) Programme Annual Report December 2017*, 2018: www.hqip.org.uk/wp-content/uploads/2018/05/LeDeR-annual-report-2016-2017-Final-6.pdf.

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. Evidence suggests, however, that choices are severely restricted for many young disabled adults. Long-term unemployment and reliance on benefits has a range of negative personal and financial consequences.¹⁶⁷

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. First, 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. Work following the revelations of abuse by staff at Winterbourne View hospital in 2011, has drawn attention to the limited community-based provision available to young people with learning disabilities with behaviours that challenge. Some may also have autism or mental health issues.¹⁶⁸ 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, reinforced by recent reports concerning the scale and fitness for purpose of residential special schools/colleges and inpatient units for young people.¹⁶⁹ As of March 2019, 11 per cent of all people in specialist inpatient units for people with learning disabilities or autistic people were under 18 years of age. Almost half of these young people (45 per cent) had not been formally sectioned, well over half (60 per cent) were girls, and over three-quarters (77 per cent)

167 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.

168 National Audit Office, *Care services for people with learning disabilities and challenging behaviour*, 2015; National Audit Office, *Local support for people with a learning disability*, 2017.

169 J Sunman, *A Local Experience of National Concern*, Oxfordshire Family Support Network, 2014; C Lenahan, *These are our children: A review commissioned by the Department of Health*, Council for Disabled Children, 2017; C Lenahan and M Geraghty, *Good intentions, good enough? A review of the experiences and outcomes of children and young people in residential special schools and colleges*. Council for Disabled Children, 2017.

were reported to be autistic without learning disabilities. A further 19 per cent of all people in these inpatient units were aged between 18 and 24 years old. Children with learning disabilities and/or autism in inpatient services were much more likely than other age groups to be subject to restrictive interventions such as physical restraint (including prone restraint), chemical restraint and seclusion.¹⁷⁰

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 likely to be regarded as ineligible for support services. They may find themselves in jeopardy as a result,¹⁷¹ including contact with the criminal justice system which can result in diversion to secure 'forensic' inpatient units.¹⁷²

1.83 The third group of young people is 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.¹⁷³

Children who live away from home

1.84 While most 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

170 NHS Digital, *Learning Disability Services Monthly Statistics – Provisional Statistics (AT: March 2019, MHSDS January 2019 Final)*, Leeds: NHS Digital; C Hatton (2019), 'Children and young people with learning disabilities and autistic children and young people in inpatient units – what do the statistics tell us?' Chris Hatton's blog; 18 March 2019.

171 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.

172 G Durcan, A Saunders, B Gadsby and A Hazard, *The Bradley Report five years on: An independent review of progress to date and priorities for further development*, 2014: London: Centre for Mental Health.

173 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.

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 4.187–4.191); some are in healthcare settings; and others are ‘looked after’ (see chapter 3 at paras 3.145–3.148) 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.¹⁷⁴ There has been some more recent attention given to this population of children and young people in research and official reports,¹⁷⁵ largely as a consequence of concerns about the potentially increasing number of young people in these places, the unsuitability of many of these places, and their high cost. However the 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.¹⁷⁶

1.86 Although statistics are not routinely available, a recent report revealed that there are just over 6,000 children and young people in

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

175 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 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. C Lenahan. *These are our children: A review commissioned by the Department of Health*, Council for Disabled Children, 2017; C Lenahan and M Geraghty, *Good intentions, good enough? A review of the experiences and outcomes of children and young people in residential special schools and colleges*. Council for Disabled Children, 2017.

176 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.

334 residential special schools and colleges, at an annual cost of approximately £500 million.¹⁷⁷ The number of places in residential special schools and colleges is decreasing over time.

1.87 Not all looked-after disabled children go to residential special schools, with eight per cent of all looked-after children with SEN in children's homes.¹⁷⁸

1.88 Again, it is widely recognised that the information we have about the looked-after disabled children is incomplete.¹⁷⁹ In 2016/17, over half of all children who had been looked after for at least 12 continuous months (56 per cent) were recorded as having a SEN. The most common type of SEN category reported among looked after children was 'social, emotional and mental health' (37.6 per cent of looked after children with an EHC plan).¹⁸⁰ 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.¹⁸¹

1.89 We do not know enough about the life trajectories and experiences of disabled children and young people placed in healthcare settings, although information on services is improving (see para 1.81 above). While these facilities are supposed to be mainly for short-term assessment and treatment, older analyses show that many do not operate in that way. A 2014 report which analysed additional unpublished data from the learning disability census on 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

177 C Lenahan and M Geraghty. *Good intentions, good enough? A review of the experiences and outcomes of children and young people in residential special schools and colleges*. 2017; London: Council for Disabled Children.

178 Department for Education, *Ad-hoc notice: Looked after children in residential care: analysis*, 2016.

179 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.

180 Department for Education. *Special educational needs: an analysis and summary of data sources*, 2018.

181 C Baker, *Permanence and stability for disabled looked after children*, Institute for Research and Innovation in Social Services, 2011.

or more.¹⁸² Twenty-nine per cent of the children were placed more than 100km from home. Frequency of the use of restrictive practices such as restraint and seclusion were issues of concern. Efforts to meet the formal government target of moving people from the assessment and treatment units to appropriate community-based provision have failed.¹⁸³

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. While 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,¹⁸⁴ more often a placement away from home appears to be a consequence of failures of local schools and services to properly support children and young people.¹⁸⁵

1.91 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.¹⁸⁶ 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.¹⁸⁷

182 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.

183 National Audit Office, *Care services for people with learning disabilities and challenging behaviour*, 2015; National Audit Office, *Local support for people with a learning disability*, 2017; J Sunman, *A local experience of national concern*, Oxfordshire Family Support Network and Healthwatch, 2014.

184 The Office of the Children's Commissioner, *The views and experiences of children in residential special schools: overview report*, 2014.

185 C Lenahan and M Geraghty. *Good intentions, good enough? A review of the experiences and outcomes of children and young people in residential special schools and colleges*, Council for Disabled Children, 2017.

186 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. C Lenahan. *These are our children: A review commissioned by the Department of Health*. 2017: London: Council for Disabled Children.

187 National Audit Office, *Care services for people with learning disabilities and challenging behavior*, 2015; C Lenahan, *These are our children: A review commissioned by the Department of Health*, Council for Disabled Children, 2017.

- 1.92 Lengthy out-of-area placements are likely to result in some children and young people becoming cut off from their families.¹⁸⁸ 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.¹⁸⁹ Despite this, maintaining contact can be particularly challenging for some, due, for example, to distance, transport arrangements and expense. This is a particularly important issue for families where their child is placed in a specialist inpatient unit, which can be a very long way from home.¹⁹⁰
- 1.93 While some children and young people may benefit overall from placements away from home, many 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 settings¹⁹¹. 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 after they have finished in residential school, making the maintenance of those personal links even more crucial.¹⁹²

188 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; C Lenahan and M Geraghty, *Good intentions, good enough? A review of the experiences and outcomes of children and young people in residential special schools and colleges*, Council for Disabled Children, 2017.

189 A Pinney, *Disabled children in residential placements*, DfES, 2005; C Lenahan and M Geraghty, *Good intentions, good enough? A review of the experiences and outcomes of children and young people in residential special schools and colleges.*, Council for Disabled Children, 2017.

190 C Lenahan, *These are our children: A review commissioned by the Department of Health*, Council for Disabled Children, 2017.

191 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.

192 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.

Services for disabled children and their families

1.94 At the beginning of this chapter we said that disabled children and those close to them are entitled to the same human rights as anyone else. These human rights may require additional supports and different arrangements to enable disabled children and their families to participate in experiences that are part and parcel of a full and fulfilling 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 public services are required by the reasonable adjustments duty in the Equality Act 2010 to make adjustments to improve their accessibility to disabled children.¹⁹³

1.95 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 a fulfilling 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.¹⁹⁴ It is also well-established that what is provided does not need to take the form of familiar traditional services, though sometimes it may. Some children and families, for example, may wish to access existing short break facilities because they find them beneficial, while recognising the diversity of short break services that families may find useful.¹⁹⁵ While some parents and their children

193 Equality Act 2010 ss20–22. See chapter 9 at paras 9.44–9.47.

194 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.

195 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.

may be clear about what would work best for them, others may find it helpful to gain 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.¹⁹⁶ 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.

1.96 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.¹⁹⁷ 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 support themselves.¹⁹⁸ To begin with, personal or individual budgets only applied to social care support funded by social services but they are 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,¹⁹⁹ although the take-up of

196 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; *Preparing for Adulthood*, www.preparingforadulthood.org.uk/.

197 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.

198 These were first made available by the Carers and Disabled Children Act 2000.

199 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.

personal budgets amongst families with a disabled child appears to be very low.²⁰⁰

- 1.97 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.²⁰¹ 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 additional stress on some families who are already overstretched, and also draw attention to the fact that the new system will not solve the problem of the shortfall of skilled support to meet some children's needs.²⁰² 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).

Conclusion

- 1.98 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 and material disadvantage 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 ongoing political, social and

200 Department for Education and NHS England, *Parent Carer Forum Survey 4: Implementation of the SEND Reforms*, Parent Carer Forum Survey Responses in February 2015; Department for Education, *Experiences of Education, Health and Care plans: a survey of parents and young people*, March 2017.

201 J Waters and C Hatton, *Measuring the outcomes of EHC plans and personal budgets*, Lancaster University and In Control, 2014.

202 For example, J Sunman, *A local experience of national concern*, Oxfordshire Family Support Network, 2014.

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.

