

Chapter 6: The child with a disability

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Disabled children and young people should enjoy the same rights and opportunities as other children, and should be fully included in every part of society.

Council for Disabled Children, 2008¹

6.1 Definition of disability

The Disability Discrimination Act (DDA)^a define a disabled person as a person with 'a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities'.² The important point about this definition is that it makes no reference to the origin of these difficulties, nor any attempt to exclude particular classes of condition.^b Children with Asperger's syndrome, or with anorexia nervosa, or with cystic fibrosis are, therefore, all disabled (although may not define themselves as such), and have a right to protection under the Act. This chapter will adopt the DDA definition, as it reflects accurately the medical consensus that disability is a broad category, not limited to what have traditionally been regarded as 'disabled children', ie those with physical and/or cognitive limitations of a developmental nature.

The DDA definition does not have universal acceptance: most prominently, the social model of disability regards disability as a social construct, existing only as a result of the broader society's failure to accommodate difference. This academic debate has generated much heat, but sheds little light. Our purpose in defining disability is, after all, the identification of a population in need of additional assistance, in order to make precisely the kind of accommodation that social theorists advocate.

6.2 The disabled child population

A 2010 study by Blackburn et al examined the prevalence of childhood disability as identified on the FRS.³ A rate for disability of 7.3 per cent was found, indicating that 952,741 children in the UK suffer from a disability (as defined by the DDA). The study classifies disability by difficulty in classes of activity, not diagnosis. The findings are summarised in **Table 6.1**.

a Please note, the DDA has been superseded by the Equality Act 2010.

b Some conditions are specifically excluded from being covered by the disability definition, such as a tendency to set fires or addictions to non-prescribed substances.

Table 6.1: Proportions of children with a DDA-defined disability reported as experiencing particular difficulties

Difficulty/ problem experienced	% [95% confidence intervals] of population (weighted)		% [95% confidence intervals] of disabled children (non-weighted)				
	All	Male	Female	P			
Mobility	193,950	1.5 [1.3,1.7]	150	20.7 [17.9,23.8]	98	21.1 [17.8,25.3]	0.940
Lifting and carrying	84,759	0.7 [0.6,0.8]	66	9.1 [7.2,11.4]	44	9.5 [7.1,12.5]	0.921
Manual dexterity	107,798	0.8 [0.7,1.0]	93	12.8 [10.6,15.5]	41	8.8 [6.6,11.7]	0.040
Continence	88,748	0.7 [0.6,0.8]	66	9.1 [7.2,11.4]	48	10.3 [7.9,13.4]	0.556
Communication	255,534	2.0 [1.8,2.2]	210	29.0 [25.8,32.4]	106	22.8 [19.2,26.8]	0.022
Memory, concentration, learning	288,203	2.2 [2.0,2.4]	260	35.9 [32.5,39.5]	96	20.6 [17.2,24.6]	<0.001
Recognising physical danger	171,352	1.3 [1.1,1.5]	154	21.3 [18.5,24.4]	55	11.8 [9.2,15.1]	<0.001
Physical coordination	167,585	1.3 [1.1,1.5]	151	20.9 [18.1,24.0]	64	13.8 [10.9,17.2]	0.002
Other	268,427	2.1 [1.9,2.3]	214	29.6 [26.4,33.3]	135	29.0 [25.1,33.3]	0.846
Difficulty if didn't take medication	247,898	1.9 [1.7,2.1]	160	22.1 [19.2,25.3]	141	30.0 [26.3,34.7]	0.452

Numbers add up to more than 7.3 per cent due to multiple impairments.

Source: Blackburn CM, Spencer NJ & Read JM (2010) Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey. *BioMed Central Pediatrics* **10**: 21. Reproduced with the permission of BioMed Central Pediatrics.

The last category will include children with well-controlled chronic disease, who strictly qualify as disabled, even if not experiencing any ongoing impairment (although arguably ongoing medical care does impair their quality of life). Unfortunately, it is not clear how many qualify as having a disability purely on this basis. At least 5 per cent of children in the UK are experiencing impairment of the type described above, and this group will be our subject.

These categories do not give a comprehensive picture of the level and patterns of need. It is, however, important to note that the most prevalent needs are learning (broadly)

and communication. This is supported by studies of the prevalence of disability by diagnosis. No one study, however, collects data across the spectrum of disability in a way that matches UK diagnostic practice. **Table 6.2** offers a summary:

Table 6.2: Prevalence of disability by diagnosis

Condition	Prevalence/1,000
Language disorders	30-50
Severe learning disability	3
Moderate learning disability	20
Dyspraxia/developmental coordination disorders (DCD)	50
ADHD	10-20
Autistic spectrum disorders (ASD)	10
Fetal alcohol syndrome (FAS)	0.3
Syndromes	3 (approximately)
Physical disability (apart from DCD)	1 (approximately)
Profound and multiple learning difficulties	1

Source: Blackburn CM, Spencer NJ & Read JM (2010) Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the family resources survey. *BioMed Central Pediatrics* **10**: 21. Reproduced with the permission of BioMed Central Pediatrics.

There is an obvious disparity between the 5 per cent figure, given above, and the sum of the prevalence figures given in **Table 6.2**. This may be explained by two factors. Firstly, many children have more than one diagnosis, and secondly, for many of the more common conditions (eg DCD), only a more severe presentation would be likely to fulfil the definition of disability. If only severe ADHD were counted, for example, the prevalence would be around 7/1,000. The condition-specific figures are, therefore, compatible with the Blackburn study.

Table 6.2 provides a picture of a large number of children with relatively 'mild' disability, and a much smaller group of children with profound disability. This is also the case within the diagnostic categories: much of the recent increase in ASD diagnosis has occurred in the higher-functioning population. We have a picture of the pattern of need: a large number of children requiring ongoing help, guidance and support, and a smaller group requiring more intensive intervention. For all groups, such help needs to be coordinated not just within health but also within education and social care.

The variation and overlap within and between diagnoses, require assessment and intervention to be broad and personalised. All aspects of the child need to be examined and addressed, be they physical, cognitive, communicative, emotional or behavioural. Such a requirement, for a group as large as the childhood disability population, places an obvious burden on services.

This burden has increased since 1999, owing to changes in the nature of the population. There is a sharply increasing group with intensive medical needs.⁴ This is primarily a result of improved survival rates of premature neonates. Equally, there is an increasing recognition of the prevalence of ADHD, for example, and disabling problems with coordination and motor planning. Given these factors, it is easy to see how demand for child disability services has exploded in the last decade.

6.3 Services: outcomes and shortfalls

In order to examine the question of how services measure up to expectations and standards, and what can be done to improve them, it is necessary to ask the following inter-connected questions:

- what do children and families want from child disability services?
- what are the professional standards that disability services should aspire to?
- how do we measure quality and outcomes in disability?
- how do we organise and commission disability services to achieve quality?
- what are the socioeconomic barriers for families?
- what are the educational barriers encountered by children?
- how do we engage families and stakeholders in change?

6.4 Child disability services

Within child disability services, unlike in other aspects of healthcare, the healthcare professional is very often not treating the condition itself, but making a holistic effort at improving the child's function and quality of life. The problems encountered are very often common to all disability, for example, behaviour, sleep and feeding problems for the child, financial problems in the family, and educational failure in schools. Secondly, the care of disabled children and families is complex, requiring contributions from health, social care and education. Even within health, very often children see a variety of professionals, in primary, secondary and tertiary care, and across community, hospital and mental health settings.

In 2011, the Every Disabled Child Matters (EDCM) campaign published a report⁵ compiled from the views of families with disabled children. The report called for:

- efficient services coordinated and communicating with each other
- integrated services, through which families can be guided by key workers
- information about services at a local and national level

- transparency of process when deciding on what can be offered locally
- early identification of difficulties and intervention at an early age.

The extent to which these requirements are being fulfilled will be discussed in further detail in the following paragraphs.

6.5 Professional standards

This area has, in some ways, shown great progress since 1999. The NSF⁶ for children was published in 2004, and included a section on disabled children; this followed the original Kennedy Inquiry,⁷ and Lord Laming's 2003 report.⁸ In 2010, Sir Ian Kennedy⁹ published his review of the services provided by the NHS England to children and young people. The review has uncovered many cultural barriers standing in the way of improving services for children and young people. These were created, and operate, at a number of levels, from Whitehall, through regional and local organisations, to contacts between individual professionals, and with children, young people and those looking after them. Sir Ian makes several recommendations for improvement. It is difficult to disagree with Sir Al Aynsley-Green (former Children's Commissioner) when he comments that the UK has 'the world's best-defined standards of health care'.¹⁰

There is a recurrent feeling of déjà vu whenever a report on children's services is produced. Comparing the 2004 NSF and Kennedy's 2010 report, inter-agency care pathways, multi-agency transition groups, pooled budgets, and urgently improved access to mental health services are recommended by both. We know what ought to happen, but it is apparent, from the available data, that we are not there yet. In contrast, following introduction of the NSF for CHD, there was a rapid and sustained improvement in outcomes in this area.¹¹ It is reasonable to infer a link with the fact that the recommendations of the NSF for CHD were made compulsory, and money provided to back them up. By contrast, the children's NSF is merely aspirational, with no additional resources attached.

The current NHS funding situation creates the risk of a disproportionate loss of funding to children's services, as the NSF-led adult services have to cope with increased demand and fixed standards. Risk for children with disability is likely to be especially high, as elements of their core care (eg short breaks) extend beyond the health sector to social care and education, where funding is decreasing. There is no easy answer to this difficult situation. The economic situation precludes appeals for increased overall funding, and so given increasing demand, some services will need to be prioritised for funding over others. A clear children and young people's health budget, at both a national and local level, will allow for the balancing of adult and child health priorities to take place in an open and honest manner.

The second factor limiting the implementation of these reports and recommendations may lie in the very nature of the work itself. The cross-cutting multi-agency nature of child disability work may have the side-effect of making the responsibility for delivery of standards unclear. There is no consensus regarding responsibility for the management of behavioural problems in ASD, and professionals from child health, mental health, social care and education all contribute without, in many instances, any one agency taking ownership of the problem. The 2012 *Report of the Children and Young People's Health Outcomes Forum*, highlighted the failures in child health in the UK.¹² It noted that too many health outcomes for children and young people are poor and that, despite important improvements, more children and young people are dying in this country than in other countries in northern and western Europe. The report calls for integration of care around the needs of children, young people and their families. This is fundamental to improving their health outcomes. It also reduces duplication and waste and saves significant sums of public money that can be spent on service improvement. It is particularly important for children and young people with disabilities or at risk of developing disabilities, with long term conditions, with complex needs or with mental health disorders. The most effective commissioning for disabled children, according to the Children and Young People's Health Outcomes Forum, integrates specialist healthcare, community services like NHS therapists and local authority educational support services, special schools and children's social care services.

The need for clarity in relation to 'standards for care' has become much more pressing with the introduction of the Children and Families Bill.¹³ This covers children with special educational needs (SEN) or disability, and requires 'local authorities to publish a "local offer" showing the support available to disabled children and young people and those with SEN, and their families'.¹⁴ This would go some way towards satisfying the need for transparency and information, recommended in the EDCM report, although what evidence should be consulted when deriving a 'local offer' is not yet clear.

Clear practical professional guidance and standards will be essential to allow families and professionals to make the 'local offers' consistent, effective and fair. Most progress in this area has been in specific conditions; for example, the NICE guidance on the diagnosis of ASD.¹⁵ Children do not present with diagnoses, but problems, which may not point to a specific condition until quite careful assessment has been performed. To further complicate matters, these conditions overlap, have features and complications in common, and generally confound diagnostic boundaries.

Pre-diagnosis guidance on recognition and assessment of childhood disability, and guidance regarding the types of common but often severe problems that are common to most disabilities, such as sleep, feeding and behavioural disturbance, is essential. Guidance should be evidence based, incorporating research recommendations and setting out quality indicators that can be audited. Similar guidance has been produced

by NICE for many clinical situations, and NICE is the obvious body to take on this work, in association with professional groups. The process of producing the guidance would inevitably uncover countless unanswered research questions, acting as a spur to the underdeveloped academic aspects of child disability assessment, and encouraging cross-fertilisation of research across disciplines.

6.6 Quality and outcomes

Child disability services are staffed by dedicated professionals with children's best interests at heart. But this dedication does not always translate into quality of services.

A good-quality service should provide:

- early identification of difficulties and timely multidisciplinary assessment
- access to necessary services for emergent difficulties, untrammelled by organisational boundaries
- coordinated care, minimising disruption to family life
- clear protocols and pathways for the management of particular difficulties
- effective information sharing.

The responsibility for early identification and initial management of difficulties falls to professionals at the 'primary level', for example, health visitors, teachers, and GPs. It is often nursery staff, for example, who first spot speech and language problems and take the initial steps towards remediation. These professionals often lack knowledge, training and support from specialist services. Attention has moved towards inter-agency training and liaison, the HCP is an example of this work,¹⁶ although currently this is limited to the health sector. Given the advantages of early identification and intervention in childhood disability, there seems to be a strong argument for a review of child development content in the curriculum of all professions working with children. Specifically, it is surprising to find that there is no child development in the curriculum of teacher training courses.

Children should have access to the lengthy multidisciplinary assessments offered in tertiary centres, receiving a comprehensive 'gold-standard' assessment of all aspects of their health and development. Given the current funding situation, it seems sensible to open a debate about the balance between spending on assessment and on intervention. To take an example, in some areas, services have introduced a 'consultation' model by which primary-level staff are trained by specialists in basic identification of need and first-line intervention, with only children experiencing continuing difficulties referred on for specialist assessment. This model has been found to be beneficial in DCD.¹⁷ The important point here is that assessment should not be an end in itself, but serve as available and effective intervention.

In relation to access to services, once a diagnosis or formulation of difficulties is established, a management plan is made. This phase of a family's experience of services

can be problematic in several ways. Firstly, the management plan is often made without consultation with the family. This may be because services feel they are simply offering what is indicated and available. As the evidence base improves and more protocols become available, there will be pressure on clinicians to manage difficulties 'as per protocol'. Families are then often referred to other agencies both within health and in other sectors, for services that may not be available. Referral is essentially a process by which one professional makes a 'bid' for the services of another, in the hope that this second professional will be able to help the patient. This process is very time-consuming, stressful and too often futile; all of these difficulties increase with 'organisational distance', and most problems occur when referring to external agencies.

Services are frequently poorly coordinated. For children with complex needs, the number of appointments soon adds up and can create considerable disruption. Since the pioneering work of Mary Sheridan in setting up child development centres, there has been a recognition that joint or coordinated appointments are desirable. The EDCM report, however, makes it clear that they are not being achieved. Simply exhorting professionals to coordinate better has not been effective. This is an area deserving more study, but a few suggestions can be made at this point:

- when implementing the new commissioning arrangements set out in the Health and Social Care Act, and implementing payment by results (PbR), joint working should be incentivised
- telemedicine should be harnessed when the opinion of a geographically distant specialist is required
- for children with complex health needs, some follow-up should be delegated from the specialist hospital level to secondary practitioners such as community paediatricians.

The formation of a comprehensive and robust local multi-agency protocol covering a diagnosis or pattern of difficulties can reduce the stress and uncertainty of being referred. A system where a professional is informed by a colleague of the child and family's need for a service, established by robust assessment against agreed norms and criteria, would be better. There might be an agreement, for example, that every child with ASD receives input from speech and language, paediatric follow-up until the age of five years, and an assessment of need by social care. The introduction of 'local offers' may help these protocols to emerge.

Good information sharing between services can prevent the situation, condemned by Kennedy, by which families 'go to multiple appointments to tell the same story'.¹⁸ The barriers to information sharing are multiple for example, a lack of interoperability between IT systems. In her 2012 review of Information Governance, 'Information: to share or not to share?', Dame Fiona Caldicott has highlighted a number of cultural barriers to sharing, for example because healthcare professionals are anxious about compliance with data protection rules. The findings of the Caldicott Review will be

published in Spring 2013 and will include recommendations to support and enable appropriate information sharing.

Child disability lacks an orderly, quantitative outcome such as survival rates or complication rates. When we examine outcomes, there are several approaches. The first, outlined by Kennedy, revolves around satisfaction with the process and outcomes of care.⁹ He recommends, radically, that this be the sole criterion for measuring the quality of children's services: satisfaction of the family with the process, and satisfaction of the relevant quality indicators, as ensured by professionals. The idea has great potential for simplifying a potentially highly complex and confusing area. Paediatric professional bodies would play a leading role, along with other professional groups, in developing national measures of family satisfaction. This would need explicit support from the DH.

The second approach looks more broadly at the overall quality of life, either of the individual or the family unit, as a whole. An improvement in the quality of the patient's life is the *sine qua non* of medical treatment. The factors underlying quality of life estimation in disability are complex, and the causal chain between high-quality healthcare and resulting improvement may be long, both in the complexity of the process and the time course. In this context, the outcome of the Children's Outcome Measurement Study (CHUMS trial),¹⁹ looking at patient reported outcome measurements (PROMs) in children with disability, will be important in determining the future direction of work in this area.

6.7 Commissioning and organisation of disability services

Given the devolution of political control of the NHS to the individual nations of the UK, it is difficult to give a comprehensive picture of the current organisation of health services for disabled children. The child development centre mode inspired by the work of Mary Sheridan among others, is widely adopted. In this (ideal) model, child development professionals share a building, information system and organisational structure, and work together to deliver the seamless multidisciplinary assessment and management of childhood disability. They are (ideally) joined by professionals from mental health, education and social care, to ensure that management of a child's difficulties can proceed untrammelled by organisational boundaries, towards optimal function for the child. The British Association for Community Child Health (BACCH) has produced a manifesto for community child services, currently in draft, which can be accessed via their website.²⁰

As Kennedy made clear in 2010, services are not always designed with children in mind, or with the involvement of children and families.⁹ Care is typically commissioned by block contract to services, split along organisational lines which reflect the history of the organisations rather than local need or ease of access.

The Children and Families Bill will in several ways help with the formation of clear 'local offers' and pathways. The Bill makes provision for joint commissioning for children with SEN, which should result in the integrated multi-agency care that children with disability need.

It is not clear to what extent joint commissioning will be supported by organisational integration between services. A 2012 article detailed the barriers and benefits to integration.²¹ The article concluded that the large-scale pilot of integrated care services was showing early signs of success for patients and staff, but this is often despite NHS processes not because of them. It is unclear how the changes to commissioning in England will help or hinder this drive to integration. While there has been verbal assurance from Government that integration of care remains a priority, the financial tariff structures and outcome frameworks created by the Bill do not seem to encourage integration, and EU competition law will still apply to a reformed NHS. There are still many unknowns regarding the details of the Health and Social Care Act, including the role and powers of the local health and wellbeing boards.

While most commissioning will be done locally by CCGs, there is provision in the Act for national specialist commissioning. Unfortunately, the early indicators are that these services will be based on diagnosis (eg vein of Galen malformation services) rather than need (eg technology-dependent children), thus creating a 'molecular lottery'. At the time of writing, discussion is ongoing as to how to refine this approach.

The long-awaited application of PbR to disability services (which will need to be funded on a per-patient rather than episodic basis) will provide a spur to the formalising of pathways, as patients can then be funded 'by pathway'. This in turn may lead to the breakdown of organisational barriers, and may also lead to financial incentives towards joint working and fewer appointments for families. How the 'consultation model', mentioned above, fits into this system is unclear and it may be that disability services need to be funded by a hybrid of block contracts and PbR. This is under discussion at the DH at the time of writing, but the 'year of care' currently under trial for adults with long-term-care (LTC) holds greatest promise for funding services for children with disability.

6.8 Socioeconomic barriers

The 2010 paper by Blackburn et al demonstrates the socioeconomic trap that disability sets for families.³ Having a child with a disability is estimated to increase the family expenditure by 10 to 18 per cent. Median household income, however, was found to be 13 per cent lower in children with a disability. This situation is likely to worsen, given the reduction in tax credits effective from 2011 and the restrictions on Disability Living Allowance (DLA) under the Welfare Reform Act.²² These are the headlines, but Blackburn digs behind these to the impact on family life and finances. Not only do

these families live more impoverished lives, but they are also significantly more indebted than the rest of the population. They are less likely to own their own home, and thus hold no capital with which to decrease the cost of borrowing. Given the long-established link between low socioeconomic status and poor health outcomes, it is easy to see how families become trapped by disability into a cycle of poverty and worsening health. A 2012 report by Contact a Family,²³ made the situation vividly clear: one in six families with disabled children are going without food, and one in five without heating, owing to financial pressures. At this extremity, poverty is unarguably a menace to health, and therefore a concern for the health sector.

As with the problems of poverty generally, there are no easy solutions to this. Action can be taken at individual, local and national levels. Clinicians have a responsibility, as part of a commitment to children's wellbeing, to ensure that families are aware of their eligibility for benefits. Local authorities have a duty to provide easy-to-access benefit advice that is not dependent on meeting any particular threshold, and national bodies, such as the BMA, can demonstrate to Government the false economy of cutting benefits to vulnerable families, whose worsening resultant health will increase the drain on NHS resources.

6.9 Educational outcomes

Three-quarters of children with disability have SEN, and this figure grows with increasing severity of disability. The recent green paper on SEN was highly relevant. It begins by painting a bleak picture of the current educational outcomes for children with SEN. Compared to the general population, more than twice the number young people who have had a statement of SEN are not in education, employment or training at 18, and pupils at school action plus (extra help but no statement) have 20 times the risk of a permanent exclusion from school.

It is not clear that this issue has been addressed by recent developments. The SEN green paper published in 2011, proposed that schools remain financially responsible for excluded pupils, and that they be required to perform a multi-agency assessment prior to exclusion. This requirement has disappeared from the final bill. The Ofsted inspection regime is focused on achievement and good order, not inclusion and welfare.²⁴ The disproportionate exclusion of pupils with SEN is likely to be unaffected by the Children and Families Bill.

The Bill does seek to address the bureaucratic and frustrating process of obtaining support. The 'local offer' is discussed above. Another major initiative is the replacement of statements of SEN with Education, Health and Care (EHC) plans.²⁵ These will be introduced for children who would currently receive a statement of SEN. The introduction of these plans will do nothing for those not currently protected by statements, and it is not clear how health and social care budgets will be mobilised under the new plans.

The other challenge for the EHC plans is how to ensure efficient input from the various agencies involved in assessment, so that the change is not merely 'rebranding'. The obvious solution is to integrate the plans with the existing CAF. This system is not mentioned in the Bill, so it seems that the two are to run alongside each other (with inevitable duplication). The practicalities and challenges of delivering such a system will emerge from pathfinder exercises in the coming months.

6.10 Engagement of children, young people and families

There is no area where the dangers of noble words without action are more apparent than in the often-stated commitment to engage 'service users' in service improvement. None of the recommendations of this chapter will be achievable without the views of the families involved, either being consulted or actively advocating on behalf of children with disability. It would be absurd to produce a 'local offer' without the involvement of the families. The views of families will provide insight into difficult problems, such as whether to measure satisfaction with one episode of care, or with the overall process of assessment and management. We would also, by doing so, be respecting Article 12 of the UNCRC.²⁶

The move towards requiring public involvement in commissioning is welcome. Commissioners should require that any tender or contract has significant family involvement in its formation. Such an approach may encounter the danger of tokenism, with public involvement a 'box to be ticked'. A more fundamental change may therefore be required.

Kennedy provides us with a useful structure.⁹ The key feature of his local service partnerships is that they contain a mixture of professionals, politicians and members of the public, and hold the local children's budget as a whole, independent of organisational boundaries. This is helpful in two ways. It makes 'special interest' groups less influential, and, by mixing professions, it tends to prevent members of the public from feeling 'outranked' by any one group. The idea needs to be explored in more detail, and the CCGs should be implemented with these principles in mind.

6.11 Recommendations

Government should:

- revisit the Kennedy report in the light of the changes planned in the Health and Social Care Act and consider Local Service Partnerships as a vehicle for change, supported by local children's budgets and simplified outcome measures
- ensure that the benefits of the new systems envisaged for the Children and Families Bill are shared by all children with disability
- implement PbR, bearing in mind the chronic nature of difficulties and the benefits of a consultation model

- put child development on the curricula of teaching training courses
- review the impact of Ofsted's assessment framework on inclusion and welfare for children with SEN.

Professional bodies should:

- campaign for awareness regarding the impact of benefit cuts on families of disabled children
- collaborate to produce professional guidance and standards on pre-diagnosis assessment and generic problems, in order to inform the development of local offers
- produce and evaluate outcome measures for childhood disability.

Local authorities and health commissioners should:

- establish local need and work on an offer for childhood disability
- set up local service partnerships to guide the formation of care pathways in disability.

Clinicians in a leadership role should:

- collaborate with local partners to produce care pathways and 'offers' for local disability services
- get involved with local CCGs to ensure appropriate commissioning
- get involved in national work.

All clinicians should:

- ensure that the families they work with understand what services are available, and feel empowered to make their voices heard
- ensure that the families they work with are in receipt of all relevant benefits.

Carers of disabled children should:

- get involved in service improvement.

See **Appendix 6** for a list of websites that are useful for keeping up to date on this complex and rapidly evolving subject.

