

Chapter 9

Children with neurodevelopmental disabilities

Chapter authors

Clare Blackburn,¹ Janet Read,² Nick Spencer³

1 Associate Professor, Division of Mental Health and Wellbeing, Warwick Medical School, University of Warwick

2 Reader, Division of Mental Health and Wellbeing, Warwick Medical School, University of Warwick

3 Professor Emeritus, Division of Mental Health and Wellbeing, Warwick Medical School, University of Warwick

Key statistics

- There are 0.8 million disabled children and young people aged 0–18 in the UK, 6% of all children.¹
- Children with neurodevelopmental impairments and conditions are the largest group of disabled children and young people. The estimated prevalence of neurodevelopmental impairments and conditions is around 3–4% of children in England.²
- Attention deficit hyperactivity disorder (ADHD) is the most common neurodevelopmental condition in the UK and is estimated to affect 1–2% of children and young people, if the narrower criteria of International Classification of Diseases-10 are used.³
- Autism is thought to occur in at least 1% of children and young people in the UK.⁴
- The most common functional limitations reported for disabled children and young people concern mobility (18%), communication (22%) and memory, concentration or learning (24%).¹
- The household income for a household with a disabled child has been shown to be around 13% lower than for those with non-disabled children.⁵
- Children in socio-economically disadvantaged households in early childhood are twice as likely than the least disadvantaged children to develop a disabling condition in later childhood.⁶
- Some 32% of disabled children and young people live with a lone parent compared with 22% of their non-disabled peers.⁵
- Almost half of disabled children and young people, as compared with a fifth of non-disabled children and young people, live with a parent who is also disabled.⁵
- Some 28% of disabled children and young people experience barriers to education, leisure or play. Barriers include unsuitable environments, lack of money and the attitudes of others.⁷

Overview

Childhood disability continues to be a significant public health issue in England and across the world. **While disabled children and young people can lead full and fulfilling lives, for many, disability is associated with limited development and social participation, and with poor educational, health and employment outcomes.**⁸ It can create difficulties and sometimes pain for the children and young people concerned and, indeed, for their families. This chapter focuses particularly on children and young children with neurodevelopmental disorders, sometimes referred to as neurodisabilities. This group of conditions (which includes autism, intellectual and developmental conditions) is of particular importance because the children and young people affected frequently have other conditions and complex medical and support needs.

The chapter begins by discussing how we understand childhood disability generally. It then examines the percentage of disabled children with specific impairments/conditions and functional difficulties before outlining the broad range of risk factors associated with neurodevelopmental disability. After a brief discussion of how disability can impact on the daily lives of children and families, it examines key approaches to improving outcomes for children and young people with neurodevelopmental health problems.

What is childhood disability?

The ways we define and measure disability determine how we understand the nature and causes of any difficulties disabled children and young people face and what we regard as effective interventions aimed at enabling them to lead as fulfilling lives as their peers who do not live with disability.

The past three decades have seen substantial changes in ways of understanding and defining disability. Crucially there has been a challenge to the notion that a child's impairment or medical condition is primarily responsible for any restrictions that they face and a much greater emphasis has been placed on the disabling role of contextual factors. It is now widely accepted that disability results from the interaction of individuals' impairments and conditions with the context in which they live.⁹ This way of understanding childhood disability is reflected in international human rights conventions¹⁰ and the World Health Organization's approach to classifying health and disability.¹¹ One implication of this approach is that any attempt to improve the situation for disabled children and their families through service provision and other means needs to be based on an understanding of children's individual conditions, the environment in which they live and on the dynamic relationship between the two.

How many disabled children and young people are there?

Information on the prevalence of and trends in childhood disability is important for the development of effective

policies and interventions to reduce it and improve disabled children's outcomes. There is a variety of sources of information on the numbers of disabled children that measure disability in different ways for various purposes. Robust quantitative sources of information on child disability, however, are more limited than those on adults and, as yet, do not reflect the understandings of disability discussed above.⁸

According to the UK Equality Act 2010, a person is disabled if they have a physical or mental impairment that has a substantial and long-term effect on their ability to carry out normal day-to-day activities. **In total there are 0.8 million disabled children and young people, aged 0–18 (6%) in the UK.**¹ The estimated percentage has remained relatively stable over the past decade.¹ The population estimates for all-cause childhood disability in the UK fall in the middle of the range of estimates for other high-income countries (1.5 to 10%).¹³

A wide range of impairments and conditions is associated with child disability, with neurodevelopmental conditions forming the largest group. Unlike the USA, the UK does not have a single survey or administrative source that can provide data on the number of children and young children with specific neurodevelopmental impairments/conditions across the 0–18 age range. A range of sources has been used here, therefore, to provide prevalence estimates (see Table 9.1). The estimated prevalence of neurodevelopmental disorders in England is around 3–4% of children.² ADHD, impairments affecting speech, language and communication, and specific and moderate learning difficulties are the most commonly reported primary disorders or diagnoses. **Many children and young people with neurodevelopmental conditions, however, experience a number of impairments and co-morbidities which, in conjunction with restrictions and barriers to participation, result in complex medical, educational and social support needs.**

Prevalence estimates for some impairments and conditions associated with childhood disability appear to be rising. Information on trends for specific conditions, however, is limited. **ADHD, the most common behaviour disorder in the UK, is one such condition.** Estimates of prevalence appear to have risen over time, although this increase is, at least in part, associated with increased recognition and diagnostic practices.¹⁴ Estimates of prevalence also vary depending on the diagnostic criteria used. **Using the broader Diagnostic and Statistical Manual of Mental Disorders IV diagnostic criteria, it is estimated to affect 3–9% of school-aged children and young people. The narrower criteria of ICD-10 suggest a prevalence of 1–2%.**¹⁵

Autism is another condition for which prevalence appears to have increased over the last two decades. Although it is thought to have a genetic component, little is known about risk factors for autism. It occurs in at least 1% of children.³ Some of the reported increase, however, is likely to be attributable to increased awareness, new administrative

classifications and diagnostic practices.⁴ Increased identification of some conditions has resulted in increasing demand for diagnostic and support services, and welfare benefits for children, young people and their families. For example, **the number of children in receipt of Disability Living Allowance diagnosed with autism, ADHD or learning disabilities has increased from around 50,000 in 1995 to around 210,000 in 2012.**¹⁶

Table 9.1 Percentage of children and young people with specific neurodevelopmental impairments, conditions or needs

Impairment/condition	Disabled children %
Any neurodevelopmental disorder ²	3.0–4.0
ADHD: ¹⁷	
<i>DSM IV</i>	3.0–9.0
<i>ICD10</i>	1.0–2.0
Cerebral palsy ¹⁸	0.2
Epilepsy ¹⁹	0.3
Autism:	
<i>All children</i> ³	1.0
<i>School-aged children</i> ²⁰	0.9
Specific learning difficulties ²⁰	1.0
Moderate learning difficulties ²⁰	2.0
Severe learning difficulties ²⁰	0.4
Profound learning difficulties ²⁰	0.1
Speech, language and communication needs ²⁰	1.7
Hearing impairment ²⁰	0.2
Visual impairment ²⁰	0.1
Multi-sensory impairment ²⁰	0.01
Physical disability ²⁰	0.4
Other (unspecified) ²⁰	0.4

In addition to information on children's impairments and conditions, information on functional difficulties is also important. **The most commonly reported functional difficulties are with memory/concentration/learning, communication, mobility and physical co-ordination** (see Table 9.2).

Table 9.2 Functional impairments experienced by disabled children and young people aged 0–18 years

Functional impairment type	All disabled children %	Boys %	Girls %
Mobility	18	17	20
Lifting, carrying	8	7	9
Manual dexterity	10	11	8
Continence	12	12	12
Communication	22	25	19
Memory/concentration/learning	24	29	17
Recognising when in danger	18	22	13
Physical co-ordination	15	17	12
Other	28	29	27

Source: Family Resources Survey 2010/11

Factors associated with neurodevelopmental disability

The causes of childhood disability are not always clear, but **many conditions result from social and genetic factors coming together in complex ways, often across generations.**²¹ Impairments/conditions resulting from purely genetic or purely social/environmental factors are rare.⁶ Common factors include birth weight, age, sex, ethnicity, socio-economic status, parental behaviours, communicable diseases and unintentional injuries.

Pregnancy outcomes

Birth weight, influenced by both genetic and social factors, is associated with a number of impairments/conditions, including cerebral palsy, reduced cognitive function and epilepsy.^{22–25} Using cerebral palsy as an example, a child's risk of cerebral palsy decreases with increasing birth weight up to a weight of 4.5 kilograms, before rising slightly among babies with birth weights above 4.5 kilograms.²³

In England and Wales in 2010, 7.1% of babies were born prematurely. Children born extremely prematurely are at greater risk of poor health outcomes and developing neurodevelopmental disabilities than those born at term.²⁶ Improvements to neonatal care in England between 1995 and 2006 appear to be associated with increased survival rates for preterm births. The EPICure 2 study of children born very preterm in

2006 suggests that more children are surviving disability-free; however, there does not appear to have been any reduction in the proportion of children at age 3 years with moderate or severe impairments/conditions.²⁷ **The EPICure 1 study of children born very preterm in 1995 showed that at age 11 years more than half of premature birth children have no or only minor impairments or health problems; however, this means approximately 45% have a moderate or severe impairment or condition by the time they reach this age.**²⁸

Sex

The prevalence of all-cause childhood disability is higher among boys than girls in the early years, although by late teens the prevalence rate among girls is similar to that of boys.²⁹ Neurodevelopmental conditions appear to be more common among boys than girls. Understandings of why this is the case, however, are incomplete but may be associated with genetic differences between sexes, or under-identification in females due to diagnostic criteria based on male characteristics.³⁰

Ethnicity

Limited evidence suggests there may be an association between some impairments/conditions and ethnicity. Studies that have taken account of the association between deprivation and ethnicity have found an increased risk of all-cause disability among children and young children of mixed ethnicity and black African/Caribbean origin only.³¹ For intellectual and developmental disabilities, the pattern is complex. Emerson² reported that among children and young people aged 7–15 years in England, rates of identification were lower in children from minority ethnic groups overall. Notable exceptions were higher rates of less severe forms of intellectual disability among Gypsy/Romany and Traveller children of Irish heritage, and more severe forms of intellectual disability among children of Pakistani and Bangladeshi heritage.

Socio-economic disadvantage

The prevalence of child disability increases as socio-economic status decreases.²⁹ **Intellectual and developmental disabilities are strongly associated with socio-economic disadvantage.**^{6,18} A systematic review³¹ indicated that for children and young people in low socio-economic status households, the odds of being reported to have any intellectual disability or a mild, moderate/severe intellectual disability were over two times greater when compared with others. Exposure to socio-economic disadvantage in early childhood has been shown to be a predisposing factor for the onset of disabling conditions in later childhood: **for children in the most socio-economically disadvantaged households, the odds of developing such conditions are twice those for children in the least disadvantaged households.**³²

The likely explanations for this association include the fact that children and young people in socially disadvantaged

households are frequently more exposed to social and environmental risk factors in the prenatal and early childhood periods that may result in the later onset of activity-limiting conditions.^{6,33} These include poverty, poor nutrition, unsafe housing, environmental pollutants and hazards, infections, unintentional injuries, and some negative parental behaviours.

Parental behaviours

Some impairments/conditions may be associated with some parental behaviours. Parental **smoking**, particularly maternal smoking, is associated with low birth weight and preterm birth, and is thought to play a role in the development of a number of neurodevelopmental disorders including autism.⁶ Various child health outcomes, including growth before and after birth, preterm birth and fetal alcohol syndrome have been associated with mothers' alcohol intake.³⁴ **Unsupportive and unstimulating parenting** has been linked with some intellectual **disabilities and conduct disorders.**³³ Many parental behaviours associated with poor health outcomes, however, are more common in socio-economically disadvantaged households and linked to poor personal and household resources.

Communicable diseases

Communicable diseases such as German measles (rubella) and other infections acquired during pregnancy can lead to disabling conditions in childhood. Although relatively rare, complications of communicable diseases such as measles and mumps acquired later can also lead to child disability. Some groups of children and young people, for example those not registered with a GP, those from some minority ethnic groups or non-English-speaking families, and looked-after children, are at greater risk of contracting preventable communicable diseases because they are less likely to be fully immunised.³⁵

Unintentional injuries

These become increasingly important causes of disability as children get older. Infants and toddlers are most at risk of injuries in the home while road traffic accidents dominate as children get older. At all ages, children and young people in poorer households and neighbourhoods are at greater risk of injury. This partly results from living in accommodation near busy roads and in poor quality housing.³⁶

The circumstances of disabled children and their families

As in any other group, disabled children's circumstances vary. The evidence, however, indicates that, in general, **children and young people with neurodevelopmental and other conditions are at greater risk of adversity than others.**

Household composition

The majority of disabled children and young people are brought up in their families of origin. Disabled children are more likely than non-disabled children to live in lone-parent

households (32% compared with 22%).⁵ They are also more likely than their non-disabled peers to live with other disabled adults (47% compared with 21%) and one or more siblings who are also disabled.⁵ While further research is needed to explain this, it is crucial to recognise the additional needs and difficulties that may arise when parents and children in the same household are disabled.

Household living standards

Households with disabled children and young people are more likely to have poverty-level incomes than those with non-disabled children. The household income for a household with a disabled child has been shown to be around 13% lower than for those with non-disabled children.⁵ The lowest incomes are to be found among lone parents, black and minority ethnic families and those with disabled parents and disabled children in the same household.⁵ **At the same time, such families incur higher rates of expenditure associated with disability.**³⁷ Caring for a disabled child appears to have a negative effect on



Wipe that Smile... (from an installation by a young person expressing her past)

Source: Kids Company

parental employment. The strongest impact is on mothers, particularly lone mothers.⁵²

Households with disabled children and young people are more likely than those with non-disabled children to report one or more debts and not being able to afford items and activities generally seen as important for all children and young people, and those caring for them.⁵ **Many also live in poor or unsuitable housing which is more likely to be rented and have fewer rooms than the households of non-disabled peers.**^{35,37}

Social participation

Disabled children and young people are more likely to experience barriers to social participation than their peers. These include barriers to participation in sport, education, leisure and using public transport, and in personal relationships.^{7,39} Commonly reported barriers are lack of money, unsuitable physical environments and the attitudes of others.¹⁶ The type and severity of impairment can also be associated with levels of participation, with those experiencing pain and more severely impaired mobility, fine motor skills, communication and intellectual abilities experiencing lower levels of participation.⁷

Violence and abuse

Children with neurodevelopmental impairments/conditions appear to be at higher risk than their non-disabled peers of all forms of violence, including abuse and neglect by parents/carers, peers and others.^{41,42}

There is limited information on prevalence rates of violence and abuse of disabled children in England and little is known about the effectiveness of safeguarding services for this important group. In addition, concern has been raised about professional responses to violence and abuse in relation to disabled children.⁴²

Accessing key services and support

Many disabled children, young people and their families experience considerable difficulties accessing appropriate health, education and social care services.^{43–45} **Of particular concern is the absence of essential co-ordination of provision within and between services.**⁴³ There is evidence of geographical variation in support provided to children and their carers, and inequitable provision, for example, of short-term breaks and direct payments.^{46,47} Young people with learning disabilities are at an increased risk of mental health or behavioural problems. However, it is widely recognised that there is a serious lack of appropriate mental health provision to meet these needs.⁴⁸

Improving outcomes for disabled children

Improving outcomes for disabled children requires a range of approaches: primary prevention, early identification and interventions to maximise disabled children's and young people's life chances.

Primary prevention

Reducing the incidence of preventable impairments/conditions is important because, for children and young people, these may be associated with pain and restriction. While gene markers and gene therapies may offer a way forward for a small number of conditions, for most common childhood conditions, in most cases, primary prevention is likely to be best achieved through public policies to reduce exposure to social and environmental hazards.⁶ See Box 9.1 for key elements of a primary preventive approach.

Box 9.1 Key elements of a primary preventive approach

Strategic interventions at national and local level to:

- **Reduce socio-economic disadvantage** across the life course through 'living wages' and employment, and adequate welfare benefits.
- **Improve material environments** such as safe and healthy housing, schools and workplaces.
- **Reduce exposure to environmental hazards** including air pollutants, and environmental and industrial pollutants, especially lead.
- **Reduce exposure to parental and other sources of environmental tobacco smoke** in utero, infancy and childhood.
- **Promote safe alcohol consumption** in pregnancy.
- **Ensure adequate dietary intake of key nutrients, including folic acid and other vitamins and minerals**, among women of childbearing age, to protect against neural tube conditions and other consequences of vitamin deficiencies. Vulnerable groups may require supplementation around the time of conception.
- **Achieve population coverage of immunisation against common communicable diseases**, notably rubella, sufficient to ensure herd immunity to protect both the fetus from pregnancy-acquired infection and children from complications of these diseases.

Box 9.2 Nationally approved population screening programmes recommended by Public Health England

Antenatal and newborn

- NHS Fetal Anomaly Screening Programme
- NHS Infectious Diseases in Pregnancy Screening Programme (hepatitis B, HIV, syphilis, susceptibility to rubella)
- NHS Linked Antenatal and Newborn Sickle Cell and Thalassaemia Screening Programme
- NHS Newborn and Infant Physical Examination Screening Programme (developmental dysplasia of the hip, eye disease and congenital heart disease)
- NHS Newborn Blood Spot Screening Programme (phenylketonuria, congenital hypothyroidism, medium-chain acyl-CoA dehydrogenase deficiency)
- NHS Newborn Hearing Screening Programme

Childhood

- Vision screening for 4–5 year olds
- NHS Diabetic Eye Screening Programme (age 12 years+)

Early identification

Early identification of impairments and conditions may allow children to receive specialist care services at an early stage, improving outcomes and preventing severe disability and sometimes death.⁴⁹ Box 9.2 lists approved systematic population screening programmes in pregnancy and early childhood of direct relevance to early detection of impairments/conditions associated with disability. Screening can raise complex questions for parents; thus it is important they receive adequate, unbiased information and support to make choices about taking up screening opportunities and accessing appropriate services. In addition to screening, impairments and conditions may also be identified early through the parents coming into contact with well-trained healthcare practitioners when services are accessible.

Case study

Breathe Magic: magic in rehabilitation

A research programme developed by Dr Dido Green, Oxford Brookes University, and the team at Breathe Arts Health Research, explored the feasibility of using a magical theme in intensive bimanual occupational therapy programmes for children. Specially scaled and adapted magic tricks and theatrical skills, using a group therapy model, were incorporated into a 2-week summer day camp to address children's motor and psychosocial difficulties. For the camp finale, the children put on a magic show in a professional theatre, reflecting both their new magical abilities and bimanual developments.

Research evidence shows significant motor skills gains and increased positiveness and self-esteem for children with mild to severe movement restrictions (Green et al., 2013; Green, 2013; Weinstein et al., 2013). Furthermore, parents report a reduction in the hours needed to support their children from an average of 8 to 4 hours per day, corresponding with the child's increased independence in daily skills (Green, 2013). Costs compare favourably with those of current procedures, such as botulinum toxin A injections, but achieve more functional skills for the child. This research has been translated into an evidence-based clinical service run by Breathe Arts Health Research and funded as a clinical commission from Lambeth Clinical Commissioning Group.

This innovative therapy programme delivered gains for the children and their families. It showed that a fun, engaging, effective and efficient means to provide intensive, task focused therapy for children could be developed.

Occupational therapists, working collaboratively with researchers, artists and social entrepreneurs, achieved this and evaluated the methodology.

'This is the first time I am going back to school and can show my friends something they can't do, it is always the other way around' – Breathe Magic camp attendee.

'It has helped our whole family. We have seen huge improvements in T – he can do things now he could never do before, such as eating independently, and because of that his self-esteem has improved dramatically. He has even been moved up two reading groups in school, as he now believes that he is capable of more. Breathe Magic has helped him across all areas of his life and we are eternally grateful. The summer camp model has also allowed us to spend some much needed time with his brother, who usually gets significantly less of our time due to T's disability' – mother of Breathe Magic camp attendee.

Meeting the needs of disabled children, young people and their families

The aim of services for children and young people with neurodevelopmental disabilities and their families should be to enable them to maximise their health, wellbeing and life chances and to promote opportunities for social participation. Some of this may be achieved by ensuring that universal services, environments and facilities are designed to include them and safeguard their interests – an approach enshrined in both domestic law and international conventions.⁵⁰ A substantial amount of legislation and good practice guidance also governs assessment and service provision for individual disabled children and those close to them to support them to achieve their fullest potential.⁵⁰

As the new legislation comes into place shortly, it will be important to ensure that the needs of those no longer covered by the definition of disability are being adequately managed, as there is a risk that targeting might mean that the very children who could benefit the most will miss out.

It is considered important that:

- children, young people and their families should have **personal** health, education and social care planning with provision that matches their individual needs and reflects **their preferences**^{51,52}
- services develop care pathways with children, young people and their families that reflect the above principles and apply them in timely and consistent ways
- while children's, young people's and their carers' needs are intimately connected, the **needs of each** are addressed in their own right
- children, young people and their carers should have **timely and accessible information** about the services to which they are entitled⁵²
- service providers recognise that children with neurodevelopmental disabilities may have complex needs and co-morbidities which all require skilled attention and may need innovative practice approaches; for example, the lack of appropriate mental health services for children and young people with learning disabilities has given rise to concern⁴⁸
- there are robust measures in place to ensure that **services are joined up**
- the particular needs of households with both **disabled children and disabled adults** are recognised and that there is a co-ordinated approach to service provision
- **periods of transition from children's to adults' services** require particular attention as they have been shown to be hazardous for young people and their carers¹³
- **poverty and the substantial additional costs** to families are recognised and reduced

Case study

Aiming High for Disabled Children – Sunderland Adaptive Snowsports

Of approximately 11 million disabled individuals in the UK, less than 20% take part in sport. In Sunderland, a pilot site for the national Aiming High for Disabled Children project, an inter-agency project board was established including the health, education and social care services, the voluntary sector and parent carers. Parent carers' and children's and young people's participation officers were appointed.

Consultation work with disabled children and young people revealed that they wanted to go on ski trips like their friends, but were unable to do so because their disabilities were a barrier to participation.

Using Aiming High for Disabled Children money to get it going, Sunderland Adaptive Snowsports was established, led by Mike Stansfield, head of the specialist support team from Sunderland Education, and Karen Parry, project officer for Aiming High for Disabled Children Sunderland, supported by the project board.

An appropriate venue in the South of France was risk assessed and Sunderland Adaptive Snowsports instructors were recruited. Young people were identified from the Aiming High for Disabled Children's inter-agency database, most of whom had never previously been away from home or the care of their parents because of their disabilities. Activities were planned around the specific needs of each individual.

Three highly successful annual ski trips have now taken place, benefitting the children and young people enormously. The young people themselves, their families and the team of professionals who worked with them describe the experience as life changing, improving independence and enhancing confidence, drive, caring and nurturing of others as well as providing a social experience.

One young person with unilateral cerebral palsy feared a life of unemployment. His experience with Sunderland Adaptive Snowsports has inspired him to train as a ski instructor himself.

Another young person is working towards training with the Paralympic junior development squad. Parent's remarks include;

'Before she became involved with the Snowsports group, my daughter, who is a wheelchair user with cerebral palsy, talked unconfidently about eventually leaving home, now she talks confidently about when she is going to leave the country!'

'Being away with kids of all disabilities made him appreciate his limitations and not see them as a bad thing or restrictive. It made him almost happy to NOT be 'normal'. He is so much happier and coping better. It has changed his outlook on life.'

- service commissioners have access to **robust data** about the population of disabled children and young people in order to plan and commission appropriate services; this includes data on technology-dependent children and children experiencing violence and abuse and the effectiveness of support and safeguarding services
- the **attitudinal, social, environmental and financial barriers** that impede the development and participation of children and young people with neurodevelopmental conditions and other disabilities are reduced
- children with neurodevelopmental and other disabilities are provided with the resources to enable them to live an **ordinary life** (see, for example, the case study on the variation in aspects of healthcare for children and young people with cerebral palsies living in northern England).

Conclusion

In considering the situation of disabled children and their families, there needs to be two basic approaches. Many would accept that reducing the prevalence of preventable disabling conditions is desirable in order to limit the number of children whose health and wellbeing are likely to be adversely affected. This requires a multidimensional strategy that addresses the factors associated with rates of impairment, discussed earlier. At the same time, for the existing population of disabled children and their families, there needs to be a range of measures to reduce barriers to participation and to ensure that individual needs are met.

Case study

Variation in aspects of healthcare for children and young people with cerebral palsies living in northern England

Mortality rates for children and young people in the UK are among the worst in Europe. One potential contributor to this is the quality of health services they receive. There is a dearth of literature about this, especially for disabled children and young people, as population-based data are not routinely collected. A well-established population-based register, the North of England Collaborative Cerebral Palsy Survey (NECCPS), was used to underpin an audit of evidence-based aspects of healthcare for children and young people with cerebral palsies to explore any local variations in healthcare.

A facilitated consultation event involving children and young people with cerebral palsies and their families and key stakeholders across agencies and the voluntary sector, including national and international experts in the field, considered the existing care pathway for children and young people with cerebral palsies and an aspirational care pathway.

A retrospective medical record review was undertaken of 389 children and young people with cerebral palsies registered on the NECCPS, born between 1 January 1995 and 31 December 2002, with subsequent data validation by paediatricians and physiotherapists. Data were collected on magnetic resonance brain imaging as a marker of aetiological assessment, hip and spine status, pain and its management, feeding and nutritional status. The Townsend deprivation index, derived from maternal residential postcode and divided into quintiles, was used as a proxy for socio-economic status.

The audit confirmed that there is variation in aspects of healthcare between districts in the north of England, for children and young people with cerebral palsy. A new care pathway has been agreed across the north of England with funding from the Health Quality Improvement Programme, and the main NECCPS database has been extended to capture the new indicators to facilitate ongoing quality assurance. These data will assist with working towards more equitable healthcare and thus more equal opportunities for the best health outcomes. The new care pathway has been incorporated into the care pathway for children and young people with cerebral palsies that has been published by the British Academy of Childhood Disability (www.bacdis.org.uk/policy/guidelines.htm).

What we still need to find out

While there is a growing body of research, there is still a great deal we do not know and need to understand about the causes of neurodevelopmental disability in children and the most effective way of meeting their needs. We need to know more about the following.

- **The trends in the prevalence of specific neurodevelopmental conditions across the whole of the 0–18 age range** (such as is available in the USA), particularly those conditions where prevalence appears to be increasing. Research will be needed to investigate and design the most appropriate ways of collecting such data. Currently, there is a lack of sufficiently detailed nationally representative data on prevalence and trends.
- **The ways of improving the nature and quality of data on the numbers, characteristics, needs and circumstances of disabled children and their families at the local level.** This needs to be done in consultation with service users and providers. Only limited data are available to local service commissioners.
- **The causes of and risk factors for neurodevelopmental conditions**, as these are not always clear. More research is needed to investigate how a range of genetic and social/environmental factors interacts across the life course to increase the risk of neurodevelopmental conditions.
- **How to meet the needs of particular groups of children and young people for whom provision has been very unsatisfactory.** This includes children and young people who have learning disabilities and mental health issues, including challenging behaviour. A programme of research is urgently required, **designed with children, young people and their families**, to identify effective provision that would meet these needs.

Key messages for policy

- As there continues to be a lack of robust data, particularly at local health service and local authority level, on the numbers, characteristics and circumstances of disabled children, there is an urgent need to improve the quality of data available to service commissioners.
- The lack of sufficiently detailed nationally representative data sources to provide information on the trends in prevalence of **specific conditions** across the whole 0–18 age range should be addressed.
- Environmental risk factors and hazards, including airborne and other pollutants and environments unsafe for children, need to be tackled at a public health level.
- As many neurodevelopmental disabilities are associated with socio-economic disadvantage, it is important to target preventive efforts to reduce socio-economic disadvantage in order to improve maternal health and wellbeing, as well as that of children and young people across the life course.
- Because of the evidence of increased poverty among households with disabled children and the impact this has on their social participation and life chances, it is important that they have adequate incomes, whether through wages or welfare benefits, that offset the additional costs of disabled living.
- There should be evidenced-based programmes to support parents to change behaviours associated with increased risk of disability.
- At local and national levels, there need to be action plans to address the specific attitudinal and environmental barriers to full participation and life chances identified in the recent cross-government report, *Fulfilling potential. Building a deeper understanding of disability in the UK today*.¹
- Services at national, local and individual levels should be shaped by the needs, wishes and aspirations of both children and their families.
- All services for disabled children should be underpinned by their legal rights and aim to maximise their health, wellbeing and life chances. Services should promote opportunities for social participation and the chance to lead an ordinary life.
- The recommendations of the Care Quality Commission on practical ways to improve local healthcare services for disabled children should be implemented.
- There should be robust measures in place to ensure co-ordination within and between services for children and their families.
- As transition from children's to adults' services too frequently causes disruption and stress, and results in unmet needs, appropriate transition arrangements should be a priority for all services.
- Careful attention needs to be paid to the effect of the new Children and Families Bill and how the redefinition of disability affects outcomes.
- Care providers should extend the use of rehabilitation prescriptions more widely to all children with neurodisabilities, to ensure that children and young people are helped to reach their best possible function and quality of life.

References

1. Department for Work and Pensions (2012) Family Resources Survey 2010/11.
2. Emerson, E. (2012) Deprivation, ethnicity and the prevalence of intellectual and developmental disabilities. *Journal of Epidemiology and Community Health*; 66: 218–244.
3. NICE (2011) Autism diagnosis in children and young people. Recognition, referral and diagnosis of children and young people on the autism spectrum. NICE clinical guideline 128. <http://publications.nice.org.uk/autism-diagnosis-in-children-and-young-people-cg128> (accessed 20 May 2013).
4. Levy, S., Mandell, D., Schultz, R. (2009). Autism. *The Lancet*; 374: 1627–1638.
5. Woolley, M. (2004) Income and Expenditure of Families with a Severely Disabled Child. York: Family Fund.
6. Sørensen, HT., Sabroe, S., Olson, J., Rothman, KJ., Gillman, MW., Fischer, P. (1997) Birth weight and cognitive function in young adult life: historical cohort study. *BMJ*; 315: 401–403.
7. Jones, L., Bellis, M., Wood, S., Hughes, K., McCoy, E., Eckley, L., Bates, G., Mikton, C., Shakespeare, T., Officer, A. (2012) *The Lancet*; 380 (9845): 899–907.
8. Department for Work and Pensions (2013) Fulfilling potential. Building a deeper understanding of disability in the UK today.
9. Leonardi, M., Bickenbach, J., Ustun, TB., Kostenjsek, N., Chatterji, S., MHADIE Consortium (2006) The definition of disability. What's in the name? *The Lancet*, 368, 1219–1221.
10. United Nations (2008) Convention on the Rights of Persons with Disabilities and Optional Protocol. www.un.org/disabilities/documents/convention/convoptprot-e.pdf
11. World Health Organization (2007) International Classification of Functioning Disability and Health – Children and Young People. Geneva: WHO.
12. Read, J., Blackburn, C., Spencer, N. (2009) Disabled children in the UK: a quality assessment of the quantitative data sources. *Child: Care, Health and Development*; 36: 130–141.
13. OECD. OECD Family Database: CO1.9 Child Disability 2012. www.oecd.org/els/family/CO1%209%20Child%20disability%20FINAL.pdf (accessed 4 June 2013).
14. Taylor, E. (2009) Developing ADHD. *Journal of Child Psychology and Psychiatry*; 50: 126–132.
15. NICE (2013) Attention deficit hyperactivity disorder: diagnosis and management of ADHD in children, young people and adults. NICE clinical guideline 72. <http://publications.nice.org.uk/attention-deficit-hyperactivity-disorder-cg72> (accessed 20 May 2013).
16. School age children in UK. Source: NICE (2013) Attention deficit hyperactivity disorder: diagnosis and management of ADHD in children, young people and adults.
17. Dolk, H. et al (2010) Socio-economic inequalities in cerebral palsy prevalence in the United Kingdom: a register-based study. *Paediatric and Perinatal Epidemiology*; 24: 149–155.
18. Children age 0-17 years with a diagnosis of epilepsy and receiving anti-epileptic drugs in England. Source: NICE (2013) Diagnosis and management of the epilepsies in adults, children and young people.
19. Children and young people, by primary type of SEN, in state-funded schools and colleges (including nursery, special schools, academies). Source: Department for Education (2012) Special Educational Needs in England, January 2012.
20. Hjern, A., Weitoft, G., Lindblad, F. (2010) Social adversity predicts ADHD-medication in school children – a national cohort study. *Acta Paediatrica*; 99: 920–924.
21. Rauch, S., Lamphear, B. (2012) Prevention of disability in children: elevating the role of the environment. *The Futures of Children*; 22: 193–217.
22. Sun, Y., Vestergaard, M., Pedersen, C., Christensen, J., Basso, O., Olsen, J. (2008) Gestational Age, Birth Weight, Intrauterine Growth and Risk for Epilepsy. *American Journal of Epidemiology*; 167: 262–270.
23. Spencer, N. (2003) Weighing the Evidence: How is Birthweight Determined? Abingdon: Radcliffe.
24. Dolk, H., Pattenden, S., Johnson, A. (2001) Cerebral palsy, low birthweight and socio-economic deprivation: inequalities in a major cause of childhood disability. *Paediatric and Perinatal Epidemiology*; 15: 359–363.
25. Moore, T., Hennessy, E., Myles, J., Johnson, S., Draper, E., Costeloe, K., Marlow, N. (2012) Neurological and developmental outcome in extremely preterm children born in England in 1995 and 2006: the EPICure studies. *BMJ*; 345: e7961.
26. Costeloe K., Hennessy E., Haider S., Stacey F., Marlow N., Draper E. (2012) Short term outcomes after extreme preterm birth in England: comparison of two birth cohorts in 1995 and 2006 (the EPICure studies). *BMJ*; 345: e7976.
27. Johnson, S., Fawke, J., Thomas, S., Wolke, D., Marlow, N. (2009) Neurodevelopmental disability through 11 years of age in children born before 26 weeks gestation. *Pediatrics*; 124: e249–e257.
28. Spencer, N., Blackburn, C., Read, J. (2010) 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. *Child: Health, Care and Development*; 36: 566–573.
29. Gould, J., Ashton-Smith, J. (2011) Missed diagnosis or misdiagnosis: girls and women on the autism spectrum. *Good Autism Practice*; 12: 34–41.
30. Blackburn, C., Spencer, N., Read, J. (2013) ESRC End of Award Report RES-062-23-2883: Childhood limiting long-

- term illness/disability and socioeconomic disadvantage in the UK: predictors, trends and causal directions. www.esrc.ac.uk/my-esrc/grants/RES-062-23-2883/outputs/Read/9fbdb0ff-fd9a-4d5d-ae6f-6c8c8a2ec935
31. Blackburn, C., Spencer, N., Read, J. (2013) Is the onset of disabling chronic conditions in later childhood associated with exposure to social disadvantage in earlier childhood? A prospective cohort study using the ONS Longitudinal Study for England and Wales. *BMC Pediatrics*; 13: 101. www.biomedcentral.com/1471-2431/13/101
 32. Kalff, A., Kroes, M., Vles, S., Hendriksen, J., Feron, F., Steyaert, et al. (2001) Neighbourhood level and individual level SES effects on child problem behaviour: a multilevel analysis. *Journal of Epidemiology and Community Health*; 55: 246–50.
 33. Royal College of Obstetricians and Gynaecologists (2006) Alcohol consumptions and outcomes pregnancy (RCOG statement no. 5). London: RCOG.
 34. NICE (2009) Reducing differences in the uptake of immunisations. NICE Public Health Guidance 21. <http://publications.nice.org.uk/reducing-differences-in-the-uptake-of-immunisations-ph21> (accessed 30 May 2013).
 35. NICE (2010) Strategies to prevent unintentional injuries among the under-15s: Public Health Guidance 29. www.nice.org.uk/nicemedia/live/13272/51621/51621.pdf (accessed 30 May 2013).
 36. Blackburn, C., Spencer, N., Read, J. (2010) Prevalence of child disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey. *BMC Pediatrics*; 10: 21.
 37. Beresford, B. and Rhodes, D. (2008) Housing and Disabled Children. York: Joseph Rowntree Foundation.
 38. Department for Culture, Media and Sport (2012) Taking Part: The National Survey of Culture, Leisure and Sport Adult and Child Report 2011/12: Statistical Release.
 39. Sport England (2001) Young People with a Disability and Sport. London: Sport England.
 40. Fauconnier, J., Dickinson, H., Beckung, E., Marcelli, M., McManus, V., Michelsen, S., Parkes, J., Parkinson, K., Thyen, U., Arnaud, C., Colver, A. (2009) Participation in life situations of 8-12 year old children with cerebral palsy: cross sectional European study. *BMJ*; 338: b1458.
 41. Stalker, K., McArthur, K. (2012) Child abuse, child protection and disabled children: a review of recent literature. *Child Abuse Review*; 21: 24–40.
 42. Care Quality Commission (2012) Special Review. Health Care for Disabled Children and Young People.
 43. Department for Children, Schools and Families (2009) Special Educational Needs and Parental Confidence. The Lamb Inquiry.
 44. Brawn, E. and Rogers, C. (2012) Keep Us Close. London: Scope.
 45. Forsyth, R., McNally, R., James, P., Crossland, K., Woolley, M., Colver, A. (2010) Variation at local level in the support for families of severely disabled children and the factors that affect it. *Developmental Medicine and Child Neurology*; 52: e259-e266.
 46. Welch, V., Hatton, C., Welch, V., Collins, M., Langer, S., Robertson, J., Emerson, E. (2010) The impact of short breaks on families with a disabled child: report one of the quantitative phase. Department for Education. www.gov.uk/government/uploads/system/uploads/attachment_data/file/181959/DFE-RR063.pdf (accessed 14 June 2013).
 47. Bernard, S., Turk, J. (eds) Developing Mental Health Services for Children and Adolescents with Learning Disabilities: A Tool Kit for Clinicians. RCPsych Publications in collaboration with the National CAMHS Support Service.
 48. UK National Screening Committee (2013) Screening in England 2011/12.
 49. Broach, S., Clemments, L. and Read, J. (2010) Disabled Children. A legal handbook. London: Legal Action Group Education and Services Trust.
 50. Department of Health (2012) The Mandate: A mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015.
 51. Department for Children, Schools and Families (2008) Aiming High for Disabled Children. London: DCSF.
 52. McKay, S. and Atkinson, A. (2007) Disability and Caring Among Families with Children: Family Employment and Poverty Characteristics. Research Report No. 460. Department for Work and Pensions.