# HEALTH SERVICES FOR DISABLED CHILDREN & YOUNG PEOPLE



INFORMATION FOR HEALTH PROFESSIONALS



# Every child has the right to the best possible health.

UN Convention on the Rights of the Child, Article 24

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### INTRODUCTION

#### This guide has been written for:

- Health practitioners and commissioners, to increase their understanding of the specialist services that disabled children access.
- GPs, to help coordinate care for disabled children, young people and their families.

The guide will also help parents to understand how health professionals can support their child on issues commonly affecting disabled children.

Families with disabled children can face a complex web of interdependent systems and pressures, leading to what families often describe as a 'constant battle for services' and feeling unable to cope. People providing high levels of care, such as parents of disabled children, are twice as likely to suffer from poor health as those without caring responsibilities. Various reviews have found major problems in the provision of health services for disabled children.

'Children and young people have the right to a good and meaningful everyday life. This means being part of a well-supported loving family, having friends, trying new things and having fun.'

Developing support and services for children and young people with a learning disability, autism or both (NHS England, 2017)

### CHILD DEVELOPMENT TEAMS

Child development teams are led by paediatricians working closely with physiotherapists, occupational therapists and speech and language therapists to assess and review a child's needs and devise treatment programmes to encourage and support their development. They also require input from psychologists, either as part of the team or from the Child and Adolescent Mental Health Services (CAMHS). The paediatrician leads and liaises with other services from community, acute and tertiary settings involved in the child's care.

Disabled children often need assistance from all of these practitioners to support more than one area of their development. For example:

- a speech and language therapist might give input to help with safe eating, drinking and swallowing, so the child can self-feed
- a physiotherapist may devise exercises for the child to develop movements to assist with feeding themselves and advise on the best sitting position
- an occupational therapist may provide advice on seating, equipment
- a dietician may provide advice on food the child can manage to swallow and make sure they are receiving sufficient nutrition.

This is why disabled children benefit from the involvement of a multidisciplinary team working as a 'team around the child'. They can carry out joint assessments and work together to consider all the different areas of development the child needs support for, agree priorities and devise treatment programmes to best meet the needs of the individual child and their family.

### SPECIALIST NURSES

#### **HEALTH VISITORS**

Have an important role, working in partnership with other early years staff, to raise awareness and understanding of children's health and development needs and encouraging referral to other services if they or the parents are concerned about a child's development. Health visitors can also provide additional care programmes related to the child's disability or to address issues which can arise in any family but are more likely where a child has special needs – maternal, parental mental health, feeding, weaning, toilet training, play etc. Having a specialist health visitor for children with disabilities in the area is particularly useful for supporting families, training generic health visitors and coordinating the Early Support programme, Common Assessment Framework and local integrated pathways.

#### **COMMUNITY CHILDREN'S NURSES**

Play a pivotal role in supporting disabled children at home and within community settings. This includes technology dependency such as tube feeding and gastrostomy care. They also play an important role in making sure a child's health needs are supported safely in nursery or school.

#### LEARNING DISABILITY NURSES

Help parents develop skills to support their child's development. They can also be invaluable in providing advice to GP practices and local hospitals on working with children with learning disabilities, and what reasonable adjustments are needed to make services more accessible and less stressful for people with learning disabilities.

### COMMUNITY PAEDIATRIC TEAMS

In some areas, child development teams only see children aged o-5 and older children are seen by community paediatricians who are specialist children's doctors with a particular expertise in looking after children with long term health problems. In some areas, school age children are referred to the Child and Adolescent Mental Health Service (CAMHS) for assessments for certain conditions, such as ADHD and autism spectrum disorders (ASD).

#### **CAMHS**

CAMHS stands for child and adolescent mental health services. They are usually NHS services and offer assessment and treatment for families where children and young people have emotional, behavioural or mental health difficulties. They are sometimes known as 'specialist CAMHS', because they also provide other services that can help children and young people with their mental health, such as youth counselling and school counselling.

Children, young people and their families can be offered support by CAMHS if they are experiencing difficulties with their behaviour or emotions, or they are finding it hard to cope with life in the family, at school or in the wider world.

CAMHS may also diagnose and offer support with conditions such as ASD and ADHD, but this differs from area to area, so ask your GP for advice about this.



MindED is a free online educational resource for professionals and families on children and young peoples' mental health: www.minded.org.uk

#### PALLIATIVE CARE

Palliative care is not just for end of life. It should be offered as soon as there is a diagnosis of a life-limiting condition or recognition that curative treatment for a life-threatening condition is not an option. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the whole family.



**Together for Short Lives** is a national charity that supports families with seriously ill children: www.togetherforshortlives.org.uk

#### **COORDINATION OF CARE**

Care for disabled children can involve several healthcare disciplines and other agencies. This is usually provided by a multi-disciplinary team, with a paediatrician and other services (see diagram overleaf). When a large number of professionals are seeing a child, there is increased risk of fragmentation of care. It is important for professionals to keep detailed, up to date records during each contact with a child and promote accurate sharing of information between professionals. Of particular importance is information sharing with the GP, where a child's medical record is kept.

What is clear is that if professionals find the system a challenge, then it is almost impossible for families to navigate. Professionals talked throughout of the need for a "navigator", a "keyworker", a "lead clinician" to stop the child from being lost in the systems.

Lenehan Review, These are our children (2017)

### KEY WORKING

Families of children who are seen by a large number of professionals will require a key worker to:

- act as a single point of contact for the family
- coordinate the delivery of services from all agencies involved in the care and support of the child and family
- ensure the family has access to appropriate services.

Key working support may come from health, social care, education or the voluntary or private sector. General practice teams might be able to offer key working to some families but where there are complex needs, arrangements would need to be made through a GP referral and multidisciplinary needs assessment and discussion. Key working support differs in many areas; some areas have 'Early Support Co-ordinators' whereas others may have a more informal approach to key working.

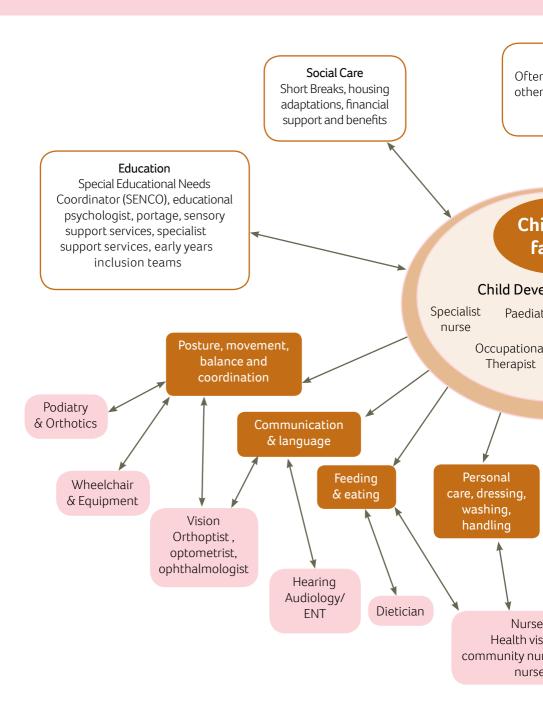


**Disability Matters** has an e-learning module with advice on the importance of building relationships and coordination of care. Search for 'Building relationships matters' at **www.disabilitymatters.org.uk** 

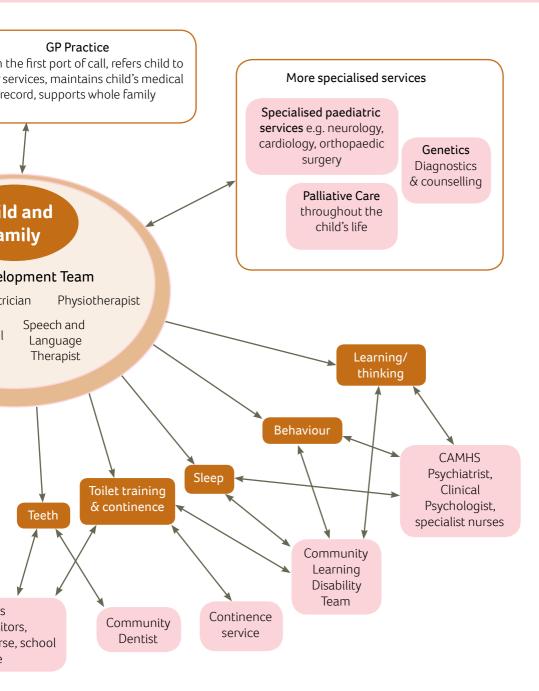
Equal access to healthcare is absolutely vital to the health and wellbeing of all disabled people. When services are designed and delivered by compassionate, caring staff with a flexible approach to access, communication and outcomes are improved.

Disability Matters in Britain (2016)





#### SERVICES ACCESSED BY DISABLED CHILDREN



### COMMONLY PRESENTING ISSUES

This section provides information about issues disabled children might present with. It explains the roles of different health professionals who may be able to help and provides details of patient information for health practitioners to give to parents. It has sections on:

- developmental delay
- · feeding and eating
- speech and communication
- · movement and coordination
- learning
- dental care
- toilet training and continence
- behaviour
- · sleep.

Disabled children are likely to require support in many if not all of these areas. Children with more complex needs will require input from a multi-disciplinary team of health professionals on most, if not all, of these. Having a multi-disciplinary team approach is more cost effective, reduces the number of appointments a family needs and provides a more holistic, integrated service.

'Specialist equipment, including wheelchairs, seats, communication aids, beds and postural support systems play a vital role in protecting the health of disabled children and those who care for them.'

Failing Disabled Children across the UK. Making the right decisions British Healthcare Trades Association (2016)



### DEVELOPMENTAL DELAY

Some children are diagnosed shortly after birth as having a condition likely to cause developmental delay. For example, Down's syndrome and other genetic disorders may present in infancy with feeding problems or low muscle tone. For others, the first indication that the child has additional needs may be picked up at their 8 week,  $2^{1/2}$  year and pre-school developmental checks.

This can be a very worrying and difficult time for parents looking for answers and explanations. The term 'developmental delay' can lead parents to expect their children to catch up with their development later. This will be true for some children but not for others. Communicating this to parents requires careful and sensitive handling. When considering whether a child's development is delayed, it is useful to ask a parent how they feel their child is developing compared to other children of the same age. This will help to get an idea of their concerns and start to piece together an overall picture of the child and their development.

## THE FOUR MAIN AREAS OF LEARNING & DEVELOPMENT Personal, Social and Emotional

Such as copying facial expressions, responding to what parents say, becoming a conversational partner, forming close attachments, playing with others, showing affection and concern for others, learning to wait or take turns.

#### Communication and Language

Such as smiling, listening, responding to words, pointing to objects, talking, reading and writing and expressing needs, thoughts and feelings.

#### **Physical**

Such as holding and handling objects, sitting up, crawling, walking, using the toilet, dressing themselves, and becoming agile and exploratory.

#### Cognition

Such as showing interest in toys, engaging in pretend play, completing simple puzzles, drawing people with a head and some features.

When there are concerns about a child's development, GPs and health visitors are often the parent's first point of contact.

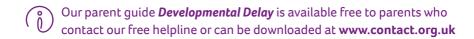
### WHY EARLY IDENTIFICATION & THERAPEUTIC INTERVENTION IS IMPORTANT

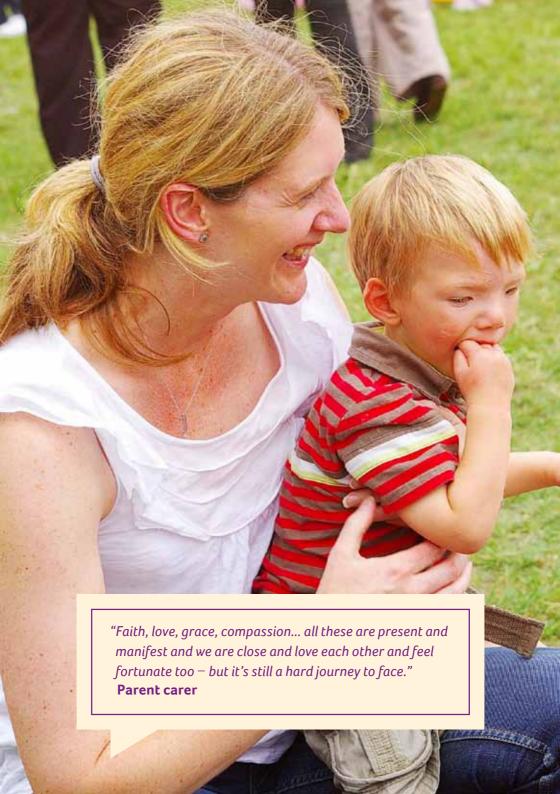
Therapists play an important part in assessing a child with developmental delay and identifying approaches that will promote development.

These can be most effective in the first few years while the brain is still developing. For this reason, therapists like to see children when developmental delay is first suspected or diagnosed. Children with developmental delay can benefit from expert input well before they go to school. These early interventions maximise the chance of the child achieving their best by the time they reach school and growing up being able to be more independent and having a better quality of life.

Children and young people with developmental delay may benefit from the involvement of a multi-disciplinary team such as a child development team, who can carry out joint assessments and work together to devise treatment programmes to best meet the needs of the individual child and their family.

- Health Visitor or GP are likely to be the first point of contact for the parent and they can suggest activities to support their child's development.
- Paediatrician provides support to identify and understand the cause of the developmental delay. They may order tests for specific conditions that could be causing the delay in their development.
- Physiotherapist provides advice and/or treatment designed to enable children to achieve their own level of functional motor skills. They develop programmes which become part of the child's daily activities and parents and/or education professionals are shown the best way to assist the child during day to day care and play.
- Speech and language therapist provides support to help develop speech, language and communication, or help with chewing food, drinking or swallowing.
- Occupational therapist provides support to help with developing physical skills or to manage everyday tasks, for example in feeding, dressing or playing.
- **Educational psychologist** provides support to help with learning and with benefiting from a learning setting.
- **Clinical psychologist** provides support for emotional or behavioural difficulties.





### FEEDING & EATING

Children with neuromuscular conditions can find it difficult to chew and swallow food. Children with a learning disability or autism spectrum disorder can have difficulties that may relate to overeating, under eating or being very selective about what they will eat. Supporting these issues can require input from a number of health professionals working together.

- **Speech and language therapist** provides help where there are physical issues with eating, drinking and safe swallowing.
- Dietician provides advice on food, diet and nutrition.
- Physiotherapist devises programmes to encourage appropriate movements and advise on the best sitting position for feeding/eating.
- Occupational therapist provides advice on equipment and aids to assist with feeding/eating. They can also advise parents on strategies for managing meal times.
- Community nursing team provides support to families whose child requires tube feeding.
- Clinical psychologist or psychiatrists help implement cognitive and behaviour strategies for children with behavioural issues around feeding/eating.

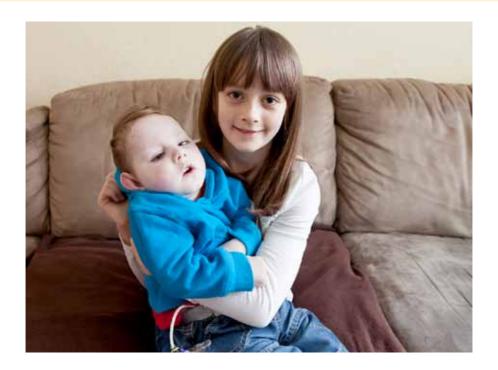


### MOVEMENT & COORDINATION

A child may find it difficult to learn to sit, walk and develop fine motor skills. This may be due to loss of movement, sensation, balance or co-ordination. Supporting this can require input from a number of health professionals working together.

- Occupational therapists assess children in all areas of development including hand—eye coordination. They advise on toys and games to encourage the development of the child's motor skills. They also advise on equipment to help mobility, like tricycles and trolleys, and equipment and aids that could help the child with everyday activities, like eating.
- Podiatry or orthotic services provide orthopaedic soles and splints when needed.
- Wheelchair and equipment services support the child in home and at school. Wheelchairs need regular reviewing to monitor the child's growth and make sure they are providing good postural support.
   Poorly fitting wheelchairs not only cause pain and discomfort but can also cause other medical problems to develop.
- Our parent guide Aids, equipment and adaptations is available to parents who contact our free helpline or download it at www.contact.org.uk

  Chartered Society of Physiotherapy has information on how physiotherapy can help with cerebral palsy. Look for 'cerebral palsy' at www.csp.org.uk



### SPEECH & COMMUNICATION

A child might be delayed in responding to sounds, simple requests or beginning to talk compared to the typically developing child. Supporting this can require input from a number of health professionals working together.

- Audiologists have special tests to measure the hearing of children who
  cannot respond consistently to sound. The audiologist can work with
  other specialists to improve the child's hearing and arrange for hearing
  aids to be fitted.
- Speech and language therapists can work with parents to develop communication skills. If a child cannot talk they can help them explore other ways to communicate such as Makaton signing.

- Physiotherapists can provide advice around supporting the child to be able to sit upright so they have more frequent face contact with their parents.
- Occupational therapists can provide advice on aids to support sitting upright.
- Portage is a pre-school education home visiting service that works with families of children with additional needs. They help the family support the child's development of communication and pre-school learning skills.

#### **FURTHER RESOURCES**

**Royal College of Speech and Language Therapists** has factsheets about speech and language therapy at **www.rcslt.org** 

**Afasic** helps children with speech, language and communication impairments and has a range of information for parents and professionals at **www.afasic.org.uk** 

**Communication Matters** supports people with little or no clear speech where augmentative and alternative communication (AAC) may be helpful. AAC can be anything from symbols and letter boards to complex communication devices

www.communicationmatters.org.uk

**The Communication Trust** has resources for professionals and parents to encourage listening, understanding, interaction and play **www.thecommunicationtrust.org.uk** 

**Talking Point** – resources for parents and practitioners www.talkingpoint.org.uk

### LEARNING

Children with a learning disability find it harder than others to learn, understand or communicate. A learning disability can be mild, moderate or severe. Supporting this can require input from a number of health professionals working together.

- Paediatricians assess the child's learning disability and/or monitor their health and progress.
- Learning disability nurses work with children and adults with a learning disability and their families. Clinical psychologists help children with specific problems, learning new skills and help them overcome behavioural difficulties.
- Educational psychologists assess the child's learning disability and provide advice to parents and education staff on appropriate interventions to support learning and improve behaviour.
- Speech and language therapists offer support and advice to parents
  of children with any type of communication problem and help children
  develop their communication, language and speech. They also provide
  advice and appropriate programmes of intervention for education staff
  working with the child.
- Portage is a home visiting educational service for pre-school children and their families who need extra support.
- Special Educational Needs Coordinators (SENCOs) are teachers in schools or members of staff in education settings who are responsible for coordinating special educational needs provision. Provision is always additional or different to that provided for other children of the same age.



Our Education Advice Service helpline **0808 808 3555** can help parents **or** see our information at **www.contact.org.uk/the-senprocess Royal College of Psychiatrists** has information about children with learning disabilities at **www.rcpsych.ac.uk** 

### DENTAL CARE

Maintaining oral hygiene and dental health in disabled children can be challenging, leaving these children more at risk of suffering from dental conditions.

Children with learning disabilities or autism can find being examined by a dentist frightening and some will not tolerate treatment. Children with a physical disability can find it difficult to brush their teeth or access a dental surgery. Children with certain genetic conditions are more prone to misaligned or differently positioned teeth because of their cranio-facial structure. Dental hygiene is particularly important for this group.

Some disabled children never receive dental checkups and later on require hospital treatment for tooth decay.

Prevention of dental conditions can save unnecessary pain, anxiety and expensive hospital treatment later on.

Community dental services provide treatment for people who may not
otherwise receive dental care, such as disabled children, individuals
with learning disabilities, mental health needs or other conditions
which may prevent them from visiting a local dental practice. Very
often parents are not told about this service.



**National Autistic Society** has tips on developing oral hygiene routines and preparing children for visits to the dentist. Search for it at **www.autism.org.uk** 

**Scope** – information for people with cerebral palsy. Search 'Dental care' at www.scope.org.uk

### TOILET TRAINING & CONTINENCE

Disabled children might not be ready to start toilet training until they are older than other children. It can take a longer time for them to learn to use the potty or toilet. It can be much more challenging to toilet train a disabled child and parents of disabled children are more likely to need advice to help them toilet train their child. The NHS provides nappies and incontinence equipment to children who require nappies. The age at which they are eligible can vary locally but usually starts around the age of three or four.

- **Paediatricians** will check for medical reasons if a child finds it difficult to become toilet trained.
- Health visitors, community nurses and learning disability nurses can give parents advice on toilet training. In some areas they are also able to prescribe continence products.
- Occupational therapists can advise on equipment to help the child be comfortable sitting on a potty/toilet.
- **Clinical psychologists** can give advice on how to encourage the child to use the toilet.
- **Continence services** can give advice and practical help and help with products and equipment.
  - Our parent guide *Potty/toilet training* is available to parents who contact our free helpline or can be downloaded at www.contact.org.uk

    ERIC information and support on childhood bed wetting, daytime wetting, constipation and soiling www.eric.org.uk

    Bladder & Bowel UK has information resources for professionals including guidance for the provision of continence products to children and young people at www.bbuk.org.uk



### BEHAVIOUR

Disabled children are more likely to have problems with their behaviour than non-disabled children.

Some behavioural difficulties are more likely in children with particular medical conditions or disabilities for example, attention deficit hyperactivity disorder (ADHD) and autism spectrum disorder (ASD). Children with learning, sensory or physical disabilities may have delayed or no speech and need alternative ways to communicate. If they are helped to express choices, they are less likely to become frustrated and may have more control over their behaviour. Children with certain genetic conditions may be more prone to obsessive thoughts, anxiety, overeating, poor sleep or self-injurious behaviour.

Any changes in behaviour may represent a new medical problem or psychological distress. Causes should be considered in light of the child's physical wellbeing and social circumstances and not be purely attributed to a child's underlying disability.

Challenging behaviour in children can be extremely stressful and affect the whole family. Research shows that providing parents of disabled children with strategies to help them manage their child's behaviour improves the physical and mental wellbeing of the family.

In some areas parenting courses are available which can equip parents of disabled children with strategies to help them manage their child's behaviour.

A range of different professionals might need to be involved, depending on the cause of the behaviour. Children are usually initially referred to the child development team who will work closely with Child and Adolescent Mental Health Services (CAMHS) and community learning disability

teams. Paediatricians may offer advice on how to deal with behaviour or refer on to any of the other professionals on this list.

- Speech and language therapists can offer strategies around communication that may help to improve the child's interpretation of some situations.
- Occupational therapists can provide advice on practical issues for children whose challenging behaviour may be linked to a physical cause, either in coordination or mobility.
- **Paediatric nurses** often come across different behaviours and have experience of working with children who are ill or disabled. They can have a wide range of knowledge and suggestions to help.
- **Physiotherapists** help children who mobility issues which may be at the centre of their frustration and behaviour problems.
- Clinical psychologists will look at the child's behaviour, assess its cause and discuss practical strategies parents can use.



- **Psychiatrists** may be able to help children whose behaviour is linked with mental health issues.
- Educational psychologists challenging behaviour may occur in different settings, including nurseries or school. Children can be referred by the parents, health professional, nursery or school to an educational psychologist to look at setting up strategies to help the child.
- Child and Adolescent Mental Health Service (CAMHS) and Learning
  Disability Teams are available in some areas and specialise in meeting
  the psychological and emotional needs of children and young people
  with a learning disability.
- Community Learning Disabilities Team (CLDT) help plan and arrange care and support for people (across the age ranges) with learning disabilities and their carers. The team may be made up of staff from health and social care and can include social workers, community nurses, psychiatrists, psychologists and a range of therapists.
   Composition of these teams will vary between localities.



**Challenging Behaviour Foundation** – for parents and professionals caring for people with severe learning disabilities whose behaviour challenges: www.challengingbehaviour.org.uk

**National Autistic Society** – support programmes for parents with strategies for helping young autistic children, including mental health. Search for 'EarlyBird' at **www.autism.org.uk** 

**Cerebra** – charity for children with brain-related conditions. Information on self-injurious behaviour for parents. Look under the 'Research' tab at www.cerebra.org.uk

### SLEEP

Researchers estimate that between 40% and 80% of children with additional needs have difficulties settling and sleeping patterns. There are sometimes medical reasons why a child may not be able to sleep. If a child struggles to communicate this may hinder the establishment of appropriate routines for settling and staying asleep.

Disordered settling and sleeping patterns can have a number of effects on the child and family. For parents, they are associated with high levels of stress and irritability and increase parents' needs for other services such as respite or short breaks. Siblings can be affected, as well as the child. Being sleep deprived can affect concentration and memory, making it difficult to function during the day.

Only a minority of families who have a disabled child with disordered settling and sleeping patterns receive any help in dealing with the problem.

Workshops to provide parents with strategies to develop good bedtime routines early on has proved to be extremely beneficial. In some areas, health visitors have been trained to provide a one-to-one sleep counselling service to parents of disabled children. Melatonin treatment may be initiated by a specialist and then prescribed by GPs under local shared care arrangements to help with sleep difficulties for children who do not respond to behavioural approaches on their own.

- **Paediatricians** will be able to decide whether further investigations are required and may signpost on for additional support.
- **Health visitors** may be able to help parents to develop and establish a bedtime routine.

- Occupational therapists can advise on sensory issues. They may suggest for example that a child would benefit from a weighted blanket. Weighted blankets can help children with sensory issues feel calmer and safer at bedtime.
- **Physiotherapists** can assess whether there are any physical issues that may be interfering with the child's sleep.

#### **FURTHER RESOURCES**

Our guide *Helping your child sleep* is available to parents who contact our free helpline or can be downloaded at www.contact.org.uk

**Research Autism** has resources and research for encouraging good sleep in children with autism, see

www.researchautism.net/guidance-sleep

#### **SLEEP SERVICES & PRACTITIONER TRAINING**

**Cerebra Sleep Service** – charity for children with brain-related conditions. Has a team of practitioners who can offer help and advice on overcoming sleep problems at **www.cerebra.org.uk** 

The Children's Sleep Charity offers a number of different training packages around sleep and train both parents and professionals – www.thechildrenssleepcharity.org.uk

**Sleep Scotland** provides training to professionals in England wanting to develop a sleep service: **www.sleepscotland.org** 



# GP LEARNING DISABILITY REGISTERS & ANNUAL HEALTH CHECKS

Reducing health inequalities for people with a learning disability is one of the key priorities in the NHS Long-Term Plan. Since 2014/15, all children and young people with a learning disability should be included on GP learning disability registers, and young people aged 14 and over should be offered an Annual Health Check.

Some children or young people may need significant preparation before having clinical interventions or even just to attend the surgery, and research by Contact showed that 75 percent of parent carers of disabled children said they did not take their child to see their GP.¹Many parents say they find it easier to take their disabled child to A&E.

This means that many children or young people may not be well known to their GP. When the child moves to adult services, the GP often becomes the lead professional responsible for coordinating care, yet has not seen the child for years so is not familiar with the medical condition or history.

Discussing the Learning Disability Register and Annual Health Checks with parent carers and encouraging them to contact their GP and ensure their child is on it will enable practice staff to understand the child or young person's support needs, and any reasonable adjustments that may need to be considered, and help reduce the health equalities these children and young people face.



Our factsheet for parents explains how children and young people can access an annual health check at www.contact.org.uk/health-checks

<sup>1</sup> GP involvement in disabled children's care (2011)

# HOW CONTACT CAN HELP HEALTH PROFESSIONALS

Contact is a UK charity that provides support and information to families with disabled children, whatever the condition or disability.

#### **GUIDES FOR GPS**

Our guide *Making GP practices more welcoming* contains information to assist GPs in encouraging families into their practice. You can also order free leaflets about how Contact can help parents, credit-card sized helpline cards and posters for your surgery.

020 7608 8700 info@contact.org.uk

#### RESEARCH

Our research can help you understand the difficulties families experience in accessing services and support, and the stigma and discrimination families face.

www.contact.org.uk/research

#### **OUR HELPLINE**

Health professionals can signpost families of disabled children to our freephone helpline for support on any aspect of raising a disabled child, including help with finances, education, emotional and practical support.

0808 808 3555 helpline@contact.org.uk

#### RARE CONDITIONS

Our medical directory has reliable, medically verified information on more than 400 medical conditions, including rare syndromes, and also has details of UK condition specific support groups parents can go to for support about their child's specific condition.

www.contact.org.uk/medical-information

### GET IN CONTACT

Our helpline advisers can support you with any issue about raising your disabled child: help in the early years, diagnosis, benefits, education and local support.

- ② 0808 808 3555
- info@contact.org.uk
- (h) www.contact.org.uk
- (y) twitter.com/contactfamilies
- (f) facebook.com/contactfamilies
- youtube.com/contactfamilies

Contact Head Office 209–211 City Road London EC1V 1JN



We are Contact, the charity for families with disabled children.

We support families with the best possible guidance and information

We bring families together to support each other.

We help families to campaign, volunteer and fundraise to improve life for themselves and others.

