



GP practice guide: supporting disabled children and young people

Information for Health Professionals

Introduction

This guide has been written for GPs and clinical commissioning groups to increase their understanding of the specialist services that disabled children access. This guide will also assist GPs to coordinate care for disabled children, young people and their families.

It includes sections on:

- the health professionals who work with disabled children and young people and the specialised services they access
- why early identification of and intervention for developmental delay is important
- issues that disabled children frequently present with, who can support them and patient information that GPs can provide to families.

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.

Recent reviews found major problems in the provision of health services for disabled children.

'Children with disabilities or those in situations that make them vulnerable, do not always get the attention and care from healthcare services that they need.'

Healthcare Commission 2008

'Despite the high number of children coming into their surgeries, many GPs have little or no experience of paediatrics as part of their professional training. This means that, technical competence notwithstanding, many GPs lack the confidence to assess and treat children effectively.'

Sir Ian Kennedy 2010, Getting it right for children and young people

GPs are often the first port of call when families experience illness or disability. Carers say getting early advice and information from their GP can transform their experiences of caring by allowing them to access support from the outset. Parents of disabled children were asked how GP care could be improved.

'66% want GPs to have a better understanding of their child's condition, 61% want better support for parent carers and the wider family from GPs. 62% want to see improved joint working of GPs with other professionals'

Contact a Family 2011, Report into the extent of GPs involvement in disabled children's care



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Services accessed by Disabled Children

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, to help the child to self-feed the child might need input from a speech and language therapist to help with safe eating, drinking and swallowing, a physiotherapist to devise exercises for the child to develop movements to assist with feeding themselves and advise on the best sitting position, an occupational therapist to provide advice on seating,

equipment and a dietician to 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 multi-disciplinary 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.



'Disabled children and young people receive child-centred multi-agency co-ordinated services from the point of referral through identification and assessment to delivery.'

**National Services Framework for Children and Young People
Standard 8: for Disabled Children and those with Complex Health Needs**

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, secondary and tertiary services

The care for disabled children can involve several healthcare disciplines (at primary, secondary and tertiary level involvement) and other agencies (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.

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

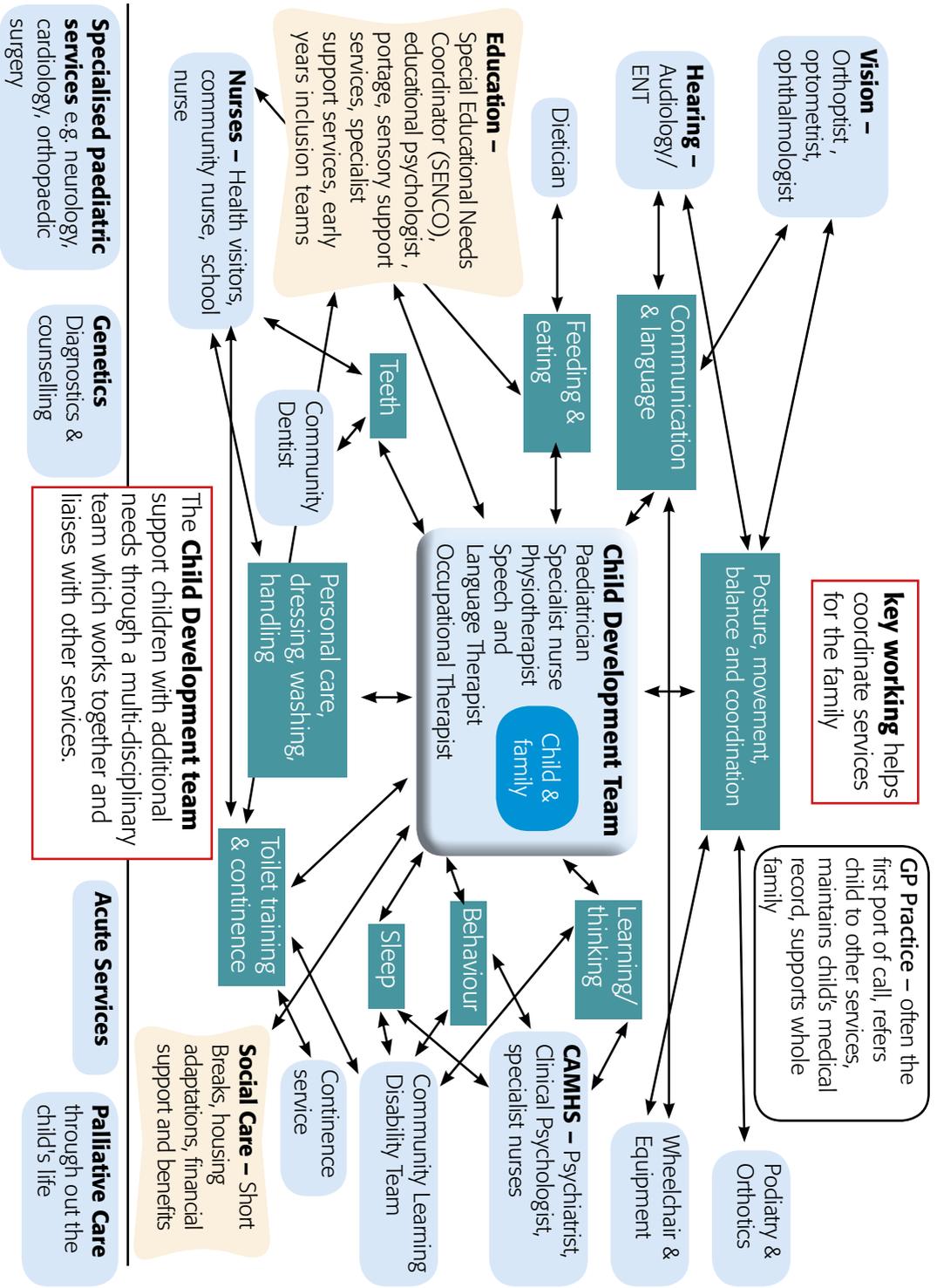


for a life-threatening condition is not an option. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person, and support for the whole family.

'Families of disabled children have contact with an average of 10 different professionals'

'Disabled children often attend the same hospital two or three times in the same week; this can affect the family's wider health needs and be disruptive to family, school and working life'

**National Services Framework for Children and Young People
Standard 8: for Disabled Children and those with Complex Health Needs**



Coordination of care and 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 multi-disciplinary needs assessment and discussion.



For more information about key working, and how it improves outcomes see <http://ncb.org.uk/early-support/key-working>

'Parents of severely disabled children or those with high levels of need require a single point of contact with services and an effective, trusted and informed named person (a 'key worker' or Care Manager) to help them obtain the services they require.'

'Studies of key workers consistently report positive effects on relationships with services, fewer unmet needs and greater family well-being.'
National Services Framework for Children and Young People Standard 8: for Disabled Children and those with Complex Health Needs

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, 2½ 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 and development are:

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 parents' first point of contact.

Why early identification and 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 have 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.

Commonly presenting issues

This section provides information about issues disabled children might present with in primary care. It explains the roles of different health professionals who may be able to help and provides details of patient information for GPs to give to parents.

It has sections on:

- 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.

Each section describes the roles different health professionals can take in providing support on each issue. This might vary across different local areas.

Some children will only require input on a few of these issues from one or two health professionals. Children with more complex needs will require input from a multi-discipline 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.

'Interventions support optimal physical, cognitive and social development are provided as early as possible with minimum waiting times.'

'Assessments include parents' needs for support with caring for a child with, for example, sleep, behavioural or emotional problems, breathing difficulties or fits.'

National Services Framework for Children and Young People Standard 8: for Disabled Children and those with Complex Health Needs



Feeding and eating

Children with neuromuscular conditions can find it difficult to chew and swallow food.

Children with learning disability or autism spectrum disorders (ASDs) 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 can provide advice on food, diet and nutrition.

Physiotherapist can devise programs to encourage appropriate movements and advise on the best sitting position for feeding/eating.

Occupational therapist can help by providing advice on equipment and aids to assist with feeding/eating. They can also advise parents on strategies for managing meal times.

Community nursing team is needed to support families whose child requires tube feeding.



Clinical psychologist or psychiatrists might be needed to help implement cognitive and behaviour strategies for children with behavioural issues around feeding/eating.

Parent information

Contact a Family Parent Guide
Feeding and Eating: www.cafamily.org.uk/parent-guide:feeding-eating

Scope – Food Talks – Practical tips to include children with eating difficulties:
www.scope.org.uk/sites/default/files/Scope_Food_Talks.pdf

National Autistic Society – *Dietary management for children and adolescents with ASDs*: restricted diet:
www.autism.org.uk

Speech and 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 work with families of children with additional needs. They help the family support the child's development of communication and pre-school learning skills.



Parent information

Royal College of Speech and Language Therapists : *Help your child to talk*:

www.rcslt.org/docs/free-pub/helpyourchildtotalk.pdf

Early Support Information for parents: *Speech, language and communication needs*:

www.ncb.org.uk/early-support/resources

Afasic helps children with speech, language and communication impairments. They have a range of printed information for parents:

www.afasicengland.org.uk/parents

Makaton is a language programme using signs and symbols to help people to communicate:

www.makaton.org

Movement and 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.

Physiotherapists can provide 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 their child during day to day care and play.



Occupational therapists can assess children in all areas of development including hand eye coordination. They can advise on toys and games to encourage the development of the child's motor skills. They can 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 may be needed to support the child in home and at school. Wheelchairs need regular reviewing to monitor the child's growth and make sure it is providing good postural support. Poorly fitting wheelchairs not only cause pain and discomfort but can also cause other medical problems to develop.

Parent information

Chartered Society of Physiotherapy – *How can physiotherapy help with cerebral palsy?*

www.csp.org.uk/your-health/conditions/cerebral-palsy

Contact a Family Parent Guide: *Aids, equipment and adaptations:*

www.cafamily.org.uk/parent-guide-aids-equipment-adaptations

Learning

Children with learning disabilities 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 behavior.

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 an early education setting who have responsibility for coordinating SEN provision within that establishment. Provision is always additional or different provision to that provided for other children of the same age. The SENCOs role is found in England, Wales and Northern Ireland.

Parent Information

Royal College of Psychiatrists –
learning disability:

www.rcpsych.ac.uk/mentalhealthinfo/mentalhealthandgrowingup/learningdisability.aspx

Early Support – *does your child have a learning disability?*

www.ncb.org.uk/early-support/resources/publications



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.**



Parent information

National Autistic Society: *Oral health for children with Autism*

Tips for parents on developing oral hygiene routines and preparing them for visits to the dentist:

www.autism.org.uk/living-with-autism/at-home/oral-health-for-children.aspx

Scope: *Dental care for people with cerebral palsy:*

www.scope.org.uk/help-and-information/cerebral-palsy/dental-care

Toilet training and 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 be 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.

Parent Information

Contact a Family Parent Guide: *Toilet Training*:

www.cafamily.org.uk/parent-guide:toilet-trainin

ERIC – Information and support on childhood bedwetting, daytime wetting, constipation and soiling to children, young people, parents and professionals:

www.eric.org.uk



Behaviour

Disabled children are more likely to have problems with their behaviour than typically developing 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's physical and mental wellbeing. 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 whole 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 co-ordination 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 require support in the physical aspects of their lives and who experience limitations in their mobility 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.

Parent information

Early Support: *Information for parents: behaviour:*

www.ncb.org.uk/early-support/resources

Contact a Family Parents Guide: *Understanding your child's behaviour:*

www.cafamily.org.uk/parent-guide:behaviour

The Challenging Behaviour Foundation:

www.challengingbehaviour.org.uk/

Parent training

National Autistic Society – Early Bird and Early Bird Plus – a three-month programme aimed at the parents of

children under 5 years with a diagnosis of autism. Early Bird Plus is aimed at parents of children aged 4–8 who receive a later diagnosis of autism:
www.autism.org.uk

Cerebra – a charity set up to help improve the lives of children with brain related conditions:
www.cerebra.org.uk



Sleep

Researchers estimate that between 40% and 80% of children with additional needs have disordered settling and sleep 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 services 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.

Parent information

Early Support *Information for parents: Sleep*

<http://www.ncb.org.uk/early-support/resources>

Contact a Family Parent Guide: *Helping your child's sleep*

www.cafamily.org.uk/parent-guide:sleep

Research Autism – *Encouraging good sleep in children with learning disabilities:*

www.researchautism.net/pages/research_autism_projects_studies/research_autism_project_016

Sleep services and Practitioner Training

Cerebra Sleep service has a team of sleep practitioners who can offer help and advice on overcoming sleep problems:

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.thechildrensleepcharity.org.uk

Sleep Scotland provides training to professionals in England wanting to develop a sleep service:

www.sleepscotland.org/index.php



About Contact a Family

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

Through a national helpline and family support service, we provide advice on any aspect of raising a disabled child, including help with finances, education and getting the right support for your child and your family.

How Contact a Family can help GPs

Our **medical directory** – See www.cafamily.org.uk – provides reliable information on many medical conditions, including rare syndromes, and also provides details of UK condition support groups

Our guide '**Making GP practices more welcoming**' explains how GPs can make their practices more friendly and accessible to families of disabled children

We provide parent guides on a range of topics, including '*Concerned about your child*' which explains the role of the different health professionals and how they support disabled children

GP practices can signpost families of disabled children to our freephone helpline on **0808 808 3555** for support on a wide range of topics.

We manage the Annette Chumley library which holds a range of information, reports and resources relevant to disabled children, their carers and the professionals who support them.

You can send the library and information team an enquiry
Email: library.team@cafamily.org.uk

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The British Academy of Childhood Disabilities
<http://www.bacdis.org.uk/>

Carrie Britton – National Network of Parent Carer Forums
www.nnpccf.org.uk

Local contacts

Child Development team

Name Tel

Address

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..... Email

Child and Adolescent Mental Health Service (CAMHS)

Name Tel

Address

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Community dentist

Name Tel

Address

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Continence service (children)

Name Tel

Address

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Learning Disabilities Team (children)

Name Tel

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Local contacts

Nurses/health visitors/community nurses

Name Tel

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Name Tel

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Occupational Therapy (children)

Name Tel

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Physiotherapy (children)

Name Tel

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Local contacts

Speech and Language Therapy (children)

Name Tel

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Wheelchair & Equipment services (children)

Name Tel

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Other local support organisations

Name Tel

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Getting in contact with us

Free helpline for parents and families
0808 808 3555

Open Mon–Fri, 9.30am–5pm

Access to over 170 languages

www.cafamily.org.uk
www.makingcontact.org

Contact a Family Head Office:
209–211 City Road, London EC1V 1JN
Tel **020 7608 8700**
Fax **020 7608 8701**
Email **info@cafamily.org.uk**
Web **www.cafamily.org.uk**



Other information booklets available

Contact a Family provides guides for parents of disabled children on a range of topics.

The following guides might be of particular interest to health professionals. Most have been translated into six community languages:

- *Concerned about your child*
- *Helping your child's sleep*
- *Toilet Training*
- *Feeding and eating*
- *Understanding your child's behaviour (English only)*

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