

UNDERSTANDING YOUR CHILD'S BEHAVIOUR - UK

contact a family
for families with disabled children
incorporating
The Lady Hoare Trust



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 **Lãnguagê Liñè**



Introduction

Being the parent of a child who presents with behaviour problems can be an enormous challenge. This factsheet makes suggestions about some of the ways your child can be helped, along with information about the professional and voluntary organisations you can approach for further guidance and support.

Some conditions are associated with certain types of behaviour. For example, children with a learning disability may have more difficulty with communication than other children, which may lead to frustration; children with a physical

disability will face other issues and they too may experience the same feelings of frustration and anger, but for different reasons.

All children are different and there is no single answer to the problems that may arise. However, there are many different people who could become involved in helping change the behaviours that are causing concern.

Some parents may feel guilty, others frustrated, when their child displays behaviour that is unacceptable or difficult to understand - especially

when they have tried to help their child overcome the problems for a period of time. However, there are often complex reasons behind the behaviour patterns and it is rarely anyone's 'fault'. It is important to remember that all behaviours are a form of communication. Part of the challenge for parents is to work out what their children are trying to communicate through their actions and to help them find another more acceptable way to do this.

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What do we mean by challenging behaviour?

The term 'challenging behaviour' can be used to cover a whole variety of behaviours. It can range across:

Kicking, spitting, hair-pulling, and other aggressive outbursts

In some cases, a child with learning disabilities may display extreme behaviour patterns such as prolonged tantrums. This might include kicking, hair pulling, aggressive outbursts, self-harming, tearing clothes or destroying property. Behaviour like this can cause physical harm to the child or other people around the child and it may well result in the child being denied access to ordinary community facilities.

Smearing faeces

Some children and young people with behaviour problems smear faeces - this behaviour has an impact not only on the child, but on the whole family, and can be very hard to deal with, not only because of the physical consequences

(extra washing, disinfecting, etc.) but also because of the added pressure it puts on both the parents and child. They may become exhausted and anxious about the behaviour and the endless explanations that they may feel they have to make to other people.

When help is needed

If you are dealing with severe behaviour on a day to day basis, a huge strain can be placed on the whole family. It can sometimes feel impossible to get the right services to help and you may need to explore many different strategies to address the needs of your child. Where the problems continue over the long term, you may be feeling very isolated, tired, worried, helpless and at a loss. Guides like this may be helpful, but for families in these circumstances it will usually be essential to access support from the kinds of services as outlined later on in this factsheet.

Sleep problems

Many children exhibit problems around sleep and bed-time, for example where the child doesn't settle in bed until late or gets up in the night, insisting on sleeping in the parents' bed, or making noise in the night and waking up the household. These issues may not seem so urgent, but prolonged periods of poor sleeping can have a huge effect on both the child and the parents. If you are exhausted, it will only make it harder to cope with the child and other members of the family.

Shouting, swearing, refusing to cooperate

There are lots of other behaviours which might, over time or in the extreme, cause difficulties for the family such as swearing and shouting, or non cooperation in tasks like getting dressed, or undressed. There may be inappropriate reactions to situations, for example laughing when someone is hurt or angry, or crying for an unexplained reason. One of the

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most common areas where families face difficulties is in the toilet training of disabled children which may take much longer and involve several different strategies.



General guidelines in dealing with challenging behaviour







There is no single answer to dealing with challenging behaviour, but there are some common approaches which may have some effect. Here are a few approaches to consider, if you haven't already.


Recognising triggers


Recognising the cause of anxieties which may trigger behaviours is a skill that is also an ongoing learning experience. It is helpful, if you can, to avoid situations which are known to provoke the child and lead to raising the levels of anxiety. Some children will be more able to cope if they know in advance what is going to happen. Where possible, establish a clear routine with the child so that they know what to expect. Use a communication system suitable for your child's needs to inform them of what is happening – this may be by using simple language, PECS (Picture Exchange Communication Systems) symbols, makaton signs (a visual


communication aid), photographs, other familiar pictures or objects e.g. their coat to indicate that it is time to go out.

If the child does start to display behaviour which indicates a rise in anxiety, try to work out the cause and address it. Examples include:

-  Does the child understand what is being asked?
-  Is the task too difficult?
-  Is the child familiar with the person working with him/her?
-  Is the child hungry?
-  Is the child thirsty?
-  Is the child in pain?

 Is the child tired?

 Is it too noisy in the room?

 Is it too hot or too cold in the room?

Devise strategies which remove or reduce the effect of triggers

All of the above can be addressed in an appropriate way. However, it is natural and common for anyone caring for a child to respond to the behaviour without first identifying what has triggered it. This can mean that your first strategies might not always work - it takes time and practice for parents to work out what might be causing a particular behaviour and what helps reassure the child, removing or reducing the effect of the trigger. It will help you, other family members and those working with your child – particularly those who are new to working with your

child - if you make a list of what kinds of triggers can lead to your child exhibiting challenging behaviour and include details of strategies you have found which help with each.

For example:

'My child hates too much noise

– he will only tolerate it for about two minutes before he becomes agitated and aggressive. Move him somewhere quieter or ensure the noise level is reduced.' Or,

'My child does not understand complicated verbal requests,

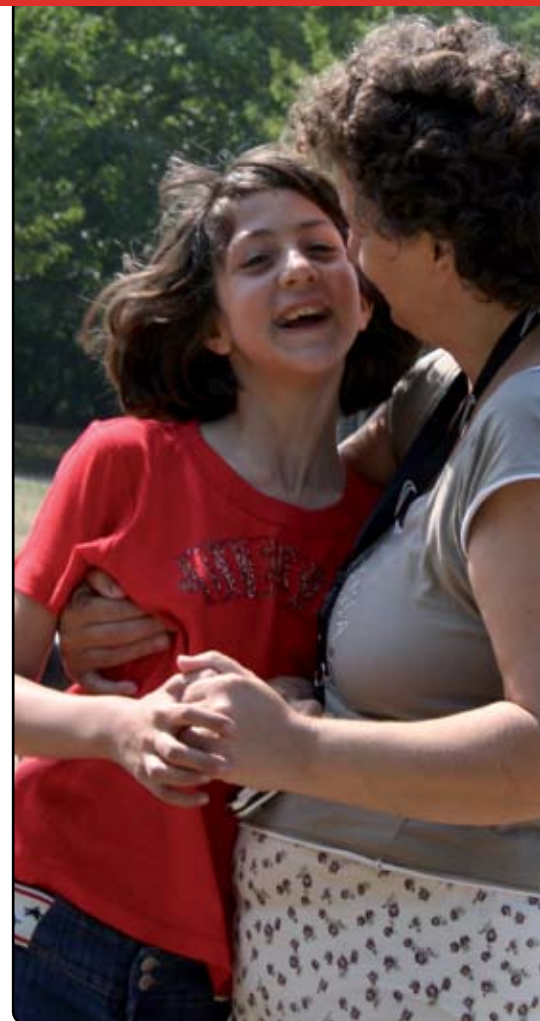
please speak to him in simple and brief sentences – 'Dinner is on the table.' not, 'Come along and get your dinner – it is your favourite, roast beef, come and sit down on your chair at the table and enjoy it!' – Too much information will confuse him.'

Dealing with unavoidable triggers

It will not always be possible to avoid certain triggers. An example could be a child who loves going out for walks in the

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park, but is really frightened of dogs and may run out of the park into the road, or may display his fear by biting the carer, if a dog approaches. Strategies will have to be put in place to reassure the child and gain his/her confidence in these situations. It is likely that you will learn what works best for your child. For example, you may learn that telling a particular story, or using a favourite toy or singing a favourite song will help to calm your child. Professionals and other parents may be able to offer suggestions.





Routine, routine, routine...

Setting up simple routines is acknowledged to help many disabled children cooperate in day to day situations. By putting a structure in place, and outlining clear boundaries, children can become familiar with what is expected of them, and even those with profound communication difficulties may respond in a positive way. Giving children time to absorb what you have said is important. Behaving consistently yourself (and asking other family members and paid carers to do the same) is crucial.

Minimising risks around the child

It is also important to minimise the risks present in the child's environment. The Challenging Behaviour Foundation produces a range of information sheets including one on different aspects about safety equipment and the Contact a Family factsheet 'Aids, Equipment and Adaptations' explains how to obtain grants to adapt your home.

Communicating with your child

Many children with a learning disability have a problem with communicating their

When difficult behaviours occur, it is generally helpful to –

Give time, stay calm and neutral

Give reassurance in a way the child is able to understand

Make yourself appear less threatening, for example by sitting down

Keep language simple, give clear messages and describe the behaviour you want

Remove other adults and children from the situation

Look and sound confident – even if you're not feeling confident

Intervene quickly, e.g. divert or distract your child

It is generally less helpful to-

Look angry or upset

Lose your temper

Intimidate

Talk a lot

Confuse the child

Have other people chip in

Look nervous

Do nothing

Re-ignite the situation

Be negative, saying 'naughty', 'bad', 'no' or 'don't'

// Many children with a learning disability have a problem with communicating their needs and wishes to others. //

Getting help for a child who self harms

Watching a child with a behaviour that includes self harm is one of the most difficult issues some parents have to face.

The behaviour can vary from biting the back of their own hand, picking at areas of skin, constant scratching of one particular area on their body, head banging, pulling their hair out or eating inappropriate objects. Parents can try to prevent the behaviour by working out what is causing the episodes to occur, but such behaviours will almost certainly need to be referred to experts. Specialist consultants in the condition, psychologists or other parents may be able to offer support around these behaviours.

needs and wishes to others – this is often a trigger for difficult behaviour. Try as many communication strategies as possible to enable the child to make their needs understood. If the child is non verbal, then s/he may respond to a visual system using signs or photographs, or s/he may

need a real object to demonstrate what is happening next e.g. a towel to show it is time for a bath. Professionals such as portage workers, speech and language therapists and psychologists can help look at systems to help the child make his/her feelings known in an appropriate way.

Conditions which affect a child's behaviour

There are some specific conditions which may affect a child's behaviour: this is called a 'behavioural phenotype'.

What is a behavioural phenotype?

This is a medical term which describes behaviour associated with specific disorders, particularly those which include learning disabilities. These disorders may result from a genetic or other biological cause.

Some syndromes result in the child having higher verbal IQ scores or difficulties with language. In some cases, a pattern of behaviour can help in the process of diagnosis, as it may suggest an underlying genetic cause.

Some conditions may be associated with a tendency to self injure, for example **Lesch Nyhan syndrome** and **Smith Magenis syndrome**.

Children with **Prader-Willi syndrome** are often described as easy-going, friendly and affectionate, but behavioural difficulties can become increasingly apparent and severe with age. These are often related to the insatiable desire to obtain food, which develops between one and four years of age and is accompanied by excessive or rapid weight gain, and is physically, emotionally and socially debilitating. Excessive intake of food may cause life-threatening obesity and often involves stealing and hoarding food. Research shows that people with Prader-Willi syndrome think a lot more about food than other people, and may continue to eat at a steady rate as long as food is available.

Children with **Fragile X syndrome** may have mild to moderate learning disabilities. There can be difficulties with the social use of language, with continuing speech anomalies, repetitive behaviour, attention deficits and overactivity,

autistic-like features such as poor eye contact, hand flapping, social anxiety and an insistence on routine.

Down's syndrome is a common cause of learning disability, but the range of learning disability is wide, as is the range of behaviours a child with Down's syndrome may show. Each person is an individual, but often their social skills are better than their intellectual ability.

People with **Williams syndrome** may have behaviour problems: Hyperactivity, short attention span and obsessional behaviour. Peculiar to the syndrome is an increased verbal ability in comparison to other cognitive skills. This can lead to them becoming inappropriately over friendly with people.

Children with **Autistic Spectrum disorder**, including **Asperger's syndrome**, often show challenging behaviour. The 'triad of impairment'

used to identify the disorder looks at problems with social communication skills (difficulty with verbal and non verbal communication), lack of imagination (difficulty in the development of play and imagination) and social interaction (difficulty with social relationships). In addition to the triad, repetitive behaviour patterns and a resistance to change in routine are common.

Support groups for specific conditions can help...

If your child has a diagnosis of a specific condition, the support group for that condition will almost certainly have information about coping with behaviours common in that condition, developed by parents with experience of bringing up an affected child. See page 18 for information about getting in touch with a support group.



Professionals who may be able to help when dealing with different behaviours

There is a huge array of professionals who can be involved in supporting you and your child. Here is a list of some of the main ones who can offer further support and guidance.

Health visitor – the child's health visitor may have had face to face contact with you and the child in your home for a period of time and may well have some experience of certain behaviours.

GP – the child's doctor may have some useful advice to offer, but if the child has a rare disorder, they may refer on to a professional with more specialist knowledge.

Paediatrician – the child's paediatrician may have seen the child over a period of time, so should be able to offer advice on how to deal with the behaviour. However, they may also refer on to any of the other

professionals on this list.

Paediatric nurses – these are children's nurses who have often come across different behaviours and have experience of working hands on with children who are ill or disabled. They may have a wide range of knowledge and suggestions to help.

Portage workers – as part of a team that visits the child at home, the portage workers may well have witnessed the behaviours that are causing concern in the home setting and may be able to give some suggestions on how to manage the situations that arise at home.

Earlybird programme - for children on the autistic spectrum there may be a local Earlybird training scheme for parents. This is a six week course run by trained professionals and is for parents of young

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children who have had a recent diagnosis of autism. It covers many issues including some of the specific behaviours that may arise.

Speech and Language therapists – if your child has been referred for speech and language therapy, the therapist who is working with them will have some direct knowledge of how s/he behaves. They may also offer some strategies around communication which may help to improve the child's interpretation of some situations.



Music therapists – if your child receives music therapy, this can often be a way of communicating with a child and allowing the child to express feelings and emotions through music.

Occupational therapist – for children whose challenging behaviour may be linked to a physical limitation, either in coordination or mobility, an occupational therapist might be a good source of advice on practical issues.

Physiotherapist – for children who require support in the physical aspects of

their life, and who experience limitations in their mobility which may be at the centre of their behaviour problems.

Clinical Psychologists - children with behaviours that are more challenging for parents may need to see a clinical psychologist who will look at the sort of behaviours, assess whether the pattern of behaviour is associated with a specific condition and discuss practical strategies with parents.

Educational psychologists – behaviours may often occur in different settings,

including schools. Children may be referred by the school to an educational psychologist to look at setting up strategies to help the child. Such strategies need to be shared between school and home to ensure consistency.

Psychiatrists – for behaviours which are linked with mental health issues, it may be necessary to see a psychiatrist; he or she may also have an interest in 'behavioural phenotypes'.

Dealing with professionals

At one time or another, many parents have come away from meetings with professionals concerned with their child's care feeling dissatisfied, unsupported or with questions still unanswered. Here are a few tips to help you get the most out of meetings:

Take a partner or friend with you if you can – it makes it easier when there are two people listening to the advice.

It's helpful if the professional you are meeting has met your child before. If this has not been possible and you have to take the child with you, then it might be helpful for an extra person to be on hand to take the child into a separate room whilst you discuss the behaviours that are causing problems – it is very difficult to concentrate at a meeting if your child is not comfortable and is displaying the sort of behaviour you are trying to address. This might make it easier for you to be honest about the situation and your feelings.

Puberty and beyond...

Puberty and teenage years are times of change for all children and young people. Disabled children are no different and are usually subject to the same hormonal changes as everyone else. These times can bring about many issues and concerns for families, not least the realisation that your disabled child is becoming a disabled adult. With most families it is a difficult period of adjustment - both for parents and young people alike.

Sexuality and sexualised behaviour can provide one of the biggest challenges for families, including where some disabled young people find it difficult to distinguish between situations where they can express their sexuality and where it is inappropriate. Parents, young people and their advocates need access to good information. It is important to remember that professionals are often familiar with the sorts of behaviours that can occur, so it should be possible to have honest and open discussions without being embarrassed by the nature

of the problem. Contact a Family has produced three separate booklets on young disabled people and growing up, sex and relationships – one is aimed at young people, another for parents and a third for professionals working with young disabled people. You can obtain a free copy of these guides from the helpline.

You, or the professionals working with your child, may also notice other behaviour changes – mental health issues may become increasingly apparent, and there may be a referral to the local Child and Adolescent Mental Health Service (CAMHS). CAMHS is a comprehensive range of services available within local communities, towns or cities, which provide help and treatment to children and young people who are experiencing emotional or behavioural difficulties, or mental health problems, disorders and illnesses. Further information about mental health issues is available from **YoungMinds** – see page 19.

If your son or daughter is in trouble with the police

Sometimes a young person with challenging behaviour may come into contact with the police. A young person



may not realise it is inappropriate to touch a stranger, or someone with learning disabilities may take something from a shop, not realising the item must be paid for. There are many scenarios where young people can be misunderstood by other people, including the police.

Children under ten years cannot usually be held legally responsible for a crime and it would be up to social services to deal with a young child who has committed an offence. Social services will assess whether the behaviour is a risk and should work closely with the family. As a last resort, children can be made subject to a child safety order which puts them under the supervision of a social worker or youth offending team. Alternatively, a care order

may be considered. It is important to emphasise that usually social services work very successfully with families without any need for 'legal orders' to be considered.

Children aged ten years or older can be held responsible for a crime. Parents must be informed if a child has been arrested and the parent or another 'appropriate adult' (for example, a social worker) must be present if they are questioned. They have the same right to a solicitor as an adult. It is important that parents make the solicitor aware of any disability or illness and what this means for the child – for example any link with challenging behaviour, and the degree to which they can understand what is being communicated to them.

Practical and financial help

Looking after a child with behaviour problems puts constant demands on the parent and can have a knock-on effect on the rest of the family. Parents often experience substantial stress, exhaustion, sleep deprivation, and difficulties finding any time for themselves and the rest of their family.

Getting help from social services

It is very important that you look after your own health and make the most of any opportunities that may arise to have short breaks from caring.

The law says that the local authority (usually the social services department) must carry out an assessment of parents' and carers' needs if they have a disabled child. If you are assessed as needing a short break from caring, then this must be supplied by the local authority. The break could happen in a number of ways – your disabled child could go to stay with another family for a short while (family

based respite), or to a residential facility which may be nearby or some distance away. It may be that a sitter could come into the home to look after your child while the rest of the family has a break.

It can be difficult to find a suitable short break option for children with behaviour problems, but it is important not to give up. Contact a Family publishes the factsheets, 'A guide to assessments and services in England and Wales' and 'A guide to assessment and services in Scotland' which explain entitlements and how to use the law to get a break.

The law also makes provision for vouchers and Direct Payments to be provided to parents of disabled children where they have been assessed as needing services. You can use vouchers, which you trade in for short breaks, instead of having to speak to social services everytime that a break is needed. Direct Payments allow you to receive the cash instead of services so you can arrange your own help, which

means you might be able to employ a care worker who can then be trained to meet your child's needs.

Benefits and other financial help

Other financial help available to parents of children with behaviour problems includes Disability Living Allowance (DLA) which would be payable if your child needs significantly more care or supervision than other children of the same age because of a disability. DLA has two components and both - the care and the mobility component - may be payable as a result of behaviour problems including hyperactivity, lacking a sense of danger or because of how behaviour might make it more difficult in getting around outdoors.

Other financial help may be needed to pay for new furniture, bedding or clothing if, for example, your child tears fabric or damages furniture. Help may be provided from the Social Fund if you

are on Income Support, income-based Jobseeker's Allowance or Pension Credit. Children with challenging behaviour should be given additional priority for grants.

The Family Fund

Unit 4 Alpha Court, Monks Cross Drive,
Huntingdon, York YO32 9WN

Tel: **0845 1304542**

e-mail: **info@familyfund.org.uk**

The Family Fund gives grants to families caring for disabled children under 16 years of age, under certain income levels.

The Contact a Family helpline has information on many other sources of grants from charitable funds and can advise you to make sure you are claiming all your entitlements. We also publish a factsheet: 'Benefits, Tax Credits and other financial assistance'.



Further information and useful contacts

The Web

Many parents search the internet for information. It is essential to know whether the information is relevant to the child's condition and that it is reliable and up to date. Contact a Family have produced a leaflet, which is also available on our web site, 'Finding medical information on the internet' which offers simple to follow advice about the suitability of websites etc. It can be read at:

<http://tinyurl.com/nokzg>

More about behavioural phenotypes

You can read more about behavioural phenotypes in 'An introduction to behavioural phenotypes' by Prof. Jeremy Turk, Professor in Developmental Psychiatry at St. George's Medical School
Web: <http://tinyurl.com/fyogd>

Information about conditions

Information on a range of specific conditions can be found in the Contact

a Family Directory of Specific Disorders and UK Family Support Groups:

<http://www.cafamily.org.uk/dirworks.html>

Contact a Family Helpline

Freephone: **0808 808 3555**

Mon-Fri 10.00-16.00, Mon 17.30-19.30

Textphone: **0808 808 3556**

e-mail: helpline@cafamily.org.uk

Contact a Family has a team of parent advisers who can put parents in touch with support groups for the disorder affecting the child, advise about rights and entitlements and offer a listening ear. Where a condition is very rare and there is no support group, we will try to link individual families through a web-based service at www.makingcontact.org or over the telephone. Many parents report that the best advice is often from another parent who has had a similar experience. It is also comforting to know that you are not alone and that other parents are there to support you when you need help.

Contact a Family produces a range of free factsheets which can be found at www.cafamily.org.uk/factsheets.html or by ringing the Contact a Family helpline or writing to: Contact a Family, 209-211 City Road, London EC1V 1JN.

Challenging Behaviour Foundation Family Support Network

C/o Friends Meeting House, Northgate, Rochester, Kent, ME1 1LS

Tel: **01634 838739**

e-mail: info@thecbf.org.uk

Web: <http://www.thecbf.org.uk>

This network is for families caring for, or individuals with, severe learning disabilities (both children and adults) who typically display behaviour which may put themselves or others at risk or which may prevent the use of ordinary community facilities. The Challenging Behaviour Foundation produces a range of factsheets on this topic. While there are many local and national support groups for specific syndromes, individuals are affected differently by different disorders and you may feel you are alone in trying to cope with your son or daughter's aggression, self injury or disruptive and

// The Challenging Behaviour Family Linking Scheme will try to link you with another family who are experiencing or who have experienced some of the same issues as yourself. //

destructive behaviours. If that is the case, then the Challenging Behaviour Family Support Network may be helpful.

The Challenging Behaviour Family Linking Scheme will try to link you with another family who are experiencing or who have experienced some of the same issues as yourself. While it may not be possible to link you with another family in your area, you may find that it helps to chat on the phone or via email with another family. The Challenging Behaviour Foundation also operate a parents' email network which enables you to be in touch with a number of families and issues they are dealing with, without any obligation to reply or to identify yourself.

Other contacts

National Autistic Society (NAS)

393 City Road, London EC1V 1NG

Tel: **020 7833 2299**

Fax: **020 7833 9666**

Helpline: **0845 070 4004**

Mon-Fri 10.00am – 4.00pm

Web: **<http://www.nas.org.uk>**

The NAS offers advice and support to families, professionals and people who have autistic spectrum disorder including those with Asperger's syndrome.

Parentline Plus

Helpline: **0808 800 2222**

Web: **<http://www.parentlineplus.org.uk>**

This is a 24 hour helpline on all aspects of parenting.

Royal College of Psychiatrists

External Affairs Department,
17 Belgrave Square, London SW1X 8PG

Tel: **020 7235 2351**

Fax: **020 7245 1231**

e-mail: **rcpsych@rcpsych.ac.uk**

Web: **<http://www.rcpsych.ac.uk>**

Has a range of useful leaflets and information for families.

Society for the Study of Behavioural Phenotypes

2nd floor, Douglas House,

18b Trumpington Road,

Cambridge CB2 2AH

Tel: **01223 746100**

Fax: **01223 746 122**

email: **ssbpRobbie@aol.com**

Web: **<http://www.ssbp.co.uk>**

A useful contact for professionals.

Young Minds

48-50 St John Street, London EC1M 4DG

Tel: **0800 018 2138**

Fax: **020 7336 8446**

email: **enquiries@youngminds.org.uk**

Web: **<http://www.youngminds.org.uk>**

YoungMinds provides information to parents and professionals. It produces leaflets on various topics, a directory of child guidance, psychiatric and psychological services and a newsletter.

0808 808 3555

Freephone helpline -

Open Mon - Fri 10am - 4pm and Monday 5.30pm - 7.30pm

www.cafamily.org.uk

WWW.makingcontact.org

This factsheet is one of a series produced for parents and groups concerned with the care of disabled children. A selected list can be seen to the right. A full list of Contact a Family publications is available on request.



A Genetic Condition in the Family

A brief introduction to genetics.



Aids, Equipment and Adaptations

Information on where to obtain special equipment.



Living without a Diagnosis

Answers some of the common questions parents have.



Holidays, play and leisure

Provides for people special planning a holiday.



Relationships and caring for a disabled child

Comments from parents.



Working and caring for a disabled child

For parents planning to return to work or who are in employment.



Transition

Identifies the main areas that parents and young people need to think about.



Finding and Paying for Childcare

Advises on access to quality childcare.

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Printed by: MWL Print Group

Although great care has been taken in the compilation and preparation of this factsheet to ensure accuracy, Contact a Family cannot take any responsibility for any errors or omissions.

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Web www.cafamily.org.uk Reg. Charity No. 284912

Helpline 0808 808 3555 Freephone for parents and families (10am-4pm, Mon-Fri and Mon 5.30pm - 7.30pm)

Chief Executive Francine Bates

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Insert for Understanding your child's behaviour guide – Page 17

The Family Fund is a grant giving organisation that can help families caring for a disabled child. In England and Wales the age limit of children and young people they can help is 17 years of age or under (providing the application is received before the 18th birthday).

In Northern Ireland and Scotland the age limit of children and young people they can help is 16 years of age or under (providing the application is received before the 17th birthday).

Eligible families must have a gross income of no more than £23,000 pa (£25,000 in Wales) and savings of £18,000 or less.