

Aids, equipment and adaptations

A guide for families in England, Northern Ireland, Scotland and Wales



Introduction

Caring for a disabled child can sometimes be made easier with the use of certain aids, equipment and adaptations. Getting the right equipment early will help your child's development and confidence. And having the right equipment is essential for a child to become more independent as they grow up.

This guide has information on how to get equipment your child may be legally entitled to, and where to go for further advice.

You will also find information on equipment for play and leisure, borrowing equipment, buying second-hand equipment, financial help, VAT relief, help adapting your home, and useful contacts for specialist support and information.

Contents

Who provides equipment?	3
Communication	9
Computers and information technology	10
Continence	12
Clothing and aids for daily living	14
Mobility	15
Education	20
Play, leisure and child development	22
Adapting your home	25
Second-hand equipment	31
Financial help	32
Value Added Tax (VAT)	34
Commercial suppliers	36
Consumer rights	37
Further sources of help and advice	38
Frequently asked questions	41

! Information in this guide

Although great care has been taken in producing this guide to ensure accuracy, Contact a Family cannot take any responsibility for any errors or omissions. Listing of other organisations and companies is for information purposes only and does not mean that Contact a Family endorses any product or service.



Who provides equipment?

In general, local authority social service departments are responsible for providing equipment for your child's social care needs.

Social care is a general term that describes all types of personal care (like help getting in and out of bed) and practical help for daily living that your child needs to help their independence.

This includes aids and equipment to help with lifting and transferring your child, eating, bathing and washing. It also includes help with arranging adaptations to your home, or any additional facilities for your child's greater safety, comfort and convenience.

In **England** and **Wales**, local authorities services for children are usually provided by a department called 'children's services'.

In **Scotland**, the department is usually called 'social work', and in **Northern Ireland**, the Health and Social Services Trust. In this guide, we use the term 'local authority', or 'social services' for short to describe social care services.

The health authority is responsible for providing equipment to meet nursing or medical needs, including wheelchair services. Equipment can be supplied through the NHS on a free loan basis, with certain items being prescribed by the GP or a consultant. This might include special beds and bed equipment, hoists, incontinence aids, feeding aids, mobility aids and hearing aids.

Throughout this guide, we refer to the 'health service'. In your area, this might also be known as the Clinical Commissioning Group (CCG) in England, Local Health Board (LHB) in Wales, or Health and Social Services Trust in Northern Ireland.

The school or local authority may arrange equipment to help a child access the curriculum. See page 20. Our education advice service can give you further information about your child's rights to equipment in school. Call our freephone helpline on 0808 808 3555.

What are my child's rights to getting aids and equipment?

Local authorities (LAs) have a legal duty to provide practical help, including equipment and additional facilities for the greater safety, comfort or convenience of children and young people who are assessed as needing them under Section 2 of the Chronically Sick and Disabled Persons Act 1970 (England and Wales). There are equivalent laws for Scotland and Northern Ireland. In your area, there may be a local agreement which says who is responsible for different types of equipment.

In England, local authorities must publish information about aids and equipment on their website as part of their 'local offer' of support for families with disabled children.

The NHS was set up under the National Health Service Act England and Wales 1946 (and equivalent legislation for Scotland in 1947 and Northern Ireland in 1948) to provide universal healthcare services for all, based on a clinical need and not on an individual's ability to pay.

Our freephone helpline can give you more information about your child's rights to equipment.

Items which must be provided free

In the UK, medical aids and equipment needed for health reasons are services for children are often provided free of charge from the health service.

If you live in England, certain aids and equipment provided by the local authority can't be charged for. These include equipment for daily living such as a shower chair, or minor adaptations costing £1,000 or less.

If you live in Northern Ireland, your local trust decides whether they will fund the equipment or minor adaptation or whether you'll have to pay for it yourself.

If you live in Scotland, your local council will normally provide essential equipment or adaptations costing under £1,500 free of charge.

If you live in Wales, you may have to pay towards disability equipment and minor adaptations, but the amount you're asked to pay must be reasonable and based on your financial circumstances.



Getting the right equipment

Your local authority and the NHS should work together to support your child. They will usually assess your child to find out what the most appropriate equipment is to meet their needs.

Who to contact

Contact your social worker if you have one, social services (social work department in Scotland), or your GP, and tell them about the kind of help you're looking for.

You can also contact healthcare or personal care professionals, such as a district nurse, physiotherapist or school nurse.

Assessing you and your child's needs

An occupational therapist (OT) or social worker will usually visit you in your home to discuss your child's needs and carry out the assessment. An OT is a professional who can tell you about equipment for daily living and managing more easily in the home.

When the OT or social worker visit you, make sure you tell them about your needs as a carer, and the needs of other family members. For example, you might not be able to get your child in and out of the bath safely, or getting them in and out of bed is giving you a back injury. Tell them about any health and safety concerns for you and your child.

If your child needs equipment to help with medical or health needs, a joint assessment should be carried out and the social worker or OT may contact the community nursing service or your GP.

Once your child has been assessed as needing help to manage more easily at home, the social worker or OT must consider how these needs will be met. They may give you practical advice about doing things differently, provide aids and equipment, and/or advice about alterations to the house. See 'Adapting your home' on page 25.

There may be waiting lists to receive equipment. If you have been waiting a long time, then it might be worth contacting charities listed in this guide to see if they can lend your child a wheelchair, for example.

Ask for a carer's assessment

If there is more than one carer providing regular care in your household, you are both entitled to an assessment. For more information, see our guide *Getting social care services when your child has additional needs – England*, or call our helpline.



If you're unhappy with the outcome of a social services assessment

If you're unhappy with the result of the assessment, talk to the person responsible. If this doesn't work, then you can make a complaint using the local authority's complaints procedure. It can be useful to get help to make a complaint from a local disability or carers' organisation.

Call our freephone helpline for more advice. We can give you more information about the complaints process in your area and tell you about local organisations that can help.

If you're unhappy with the health service

If there is any aspect of health provision that you're unhappy with, including wheelchair services, then you should raise this with the person responsible.

If you are still not happy then you can make a formal complaint. It is often best to get help with making a complaint.

Families in England can also ask their local patient advice and liaison service (PALS) or Healthwatch. See our guide, *The NHS and caring for a disabled child* for more information.

Community health councils in Wales can offer support and guidance on how to make a complaint.

Families in Scotland can make a complaint with the help of their local health council.

Families in Northern Ireland can make a complaint with the help of the Patient and Client Council. www.patientclientcouncil.hscni.net

If your complaint is not successful then seek legal advice. Call our freephone helpline for more information on 0808 808 3555.

Making an effective complaint to a Public Body by the Public Law Project

This short guide aims to help with making an effective complaint to a public body, though many of the tips could also be used in making a complaint to a commercial or non-profit body. You can download it free from their resources library.

 www.publiclawproject.org.uk/resources

Hearing

Your GP can make a referral to an audiologist for an examination and hearing test. If a hearing aid is necessary, another referral is made to a hearing aid department where the hearing aid will be fitted. NHS hearing aids are serviced, maintained and supplied with batteries free of charge. Hearing aids can also be bought privately. For more information, you can contact the organisations below:

> NDCS (The National Deaf Children's Society)

Provides information and advice to families with a deaf child.

☎ Helpline: 0808 800 8880

☎ Textphone: 0808 800 8880

🌐 www.ndcs.org.uk

> Action on Hearing Loss

Offer information advice and support on any aspect of deafness, hearing loss or tinnitus.

☎ Freephone helpline: 0808 808 0123

🌐 www.actiononhearingloss.org.uk



Vision impairment

Low-vision aids such as hand and stand magnifiers can be prescribed under the NHS through the hospital eye service, along with more complex appliances. The RNIB can provide further information on aids for visually impaired children:

> RNIB (Royal National Institute for the Blind)

Offers information, support and advice to people with sight loss.

☎ Helpline: 0303 1239 9999

🌐 www.rnib.org.uk

Communication

If you are concerned about your child's communication, talk to your GP or the SENCO in your child's school and ask them to refer you to a speech and language therapist. Therapists are usually based in hospitals or clinics. After an assessment of your child's needs, the therapist may be able to lend you any required equipment.

Speech and language therapy for children is often an educational provision. This means that funding for it can be provided by the local authority as well as by a health trust. The following organisations can also provide further information:

> Afasic

A parent-led charity that helps children and young people with speech and language impairments. Also provides information and training for parents and professionals.

☎ Helpline: 0845 355 5577

🌐 www.afasic.org.uk

> Caudwell children

Caudwell may provide sensory equipment for eligible children who have autism to help promote communication, cognition and wellbeing. Annual family income (not including benefits) must currently be less than £45,000.

🌐 www.caudwellchildren.com

> I CAN

I CAN supports the development of speech, language and communication skills in children.

☎ 0845 225 4071

🌐 www.ican.org.uk



In England, Education, Health and Care plans started to replace statements of special educational needs from 1 September 2014. Speech and language therapy should be identified in your child's statement of special educational needs or Education, Health and Care plan or co-ordinated support plan if you live in Scotland. Please call our freephone helpline for information on 0808 808 3555.

Augmentative and alternative communication

Alternative and augmentative communication, also known as alternative and assistive communication (AAC) is used to describe all the different ways that help people with disabilities communicate. AAC aids range from printed picture symbols, to high-tech tools, such as voice recognition equipment.

> Communication Matters

Communication Matters is a UK-wide organisation supporting people of all ages who find communication difficult because they have little or no clear speech. You will find information on methods of augmentative and alternative communication (AAC) to supplement the more usual methods of speech and writing.

📍 www.communicationmatters.org.uk

> AAC Scotland

The AAC Scotland website, commissioned by NHS Education for Scotland and created by CALL Scotland, has a range of practical AAC resources.

📍 www.aacscotland.org.uk/Home

Computers and information technology

Access to the internet can open up a wealth of information for education development and fun.

There is a wide variety of websites, applications (known as 'apps'), and products such as laptops and tablets available to families with disabled children. These can help in everyday life and leisure as well as help with your child's development, communication and learning.

Equipment and packages can help with sound and vision and difficulties with operating a computer. Solutions may include voice recognition or eye-tracking systems, touch screens or replacing the mouse with a trackball.



This kind of equipment may be available from your local authority if you're assessed as needing it and you meet the criteria. Help may also be available from charitable trusts. Call our freephone helpline on 0808 808 3555 for information about grant-giving organisations.

i Because of the volume of information and products available, it is important to get specialist advice. The following organisations can provide further information:

> Aidis Trust

A charity that specialises in computer technology to help disabled people.

 Freephone helpline: 0808 800 0009

 www.aidis.org

> The LiveNet assistive technology loan scheme, (Northern Ireland)

Provides an opportunity for people to preview a variety of items of software or hardware that have been specially designed to help improve access to a computer. The loan scheme is available to any member of the learning disability community free of charge.

 www.livenet.org.uk

> Accessibility Wales

The Accessibility Wales website has an online forum to find ways to support disabled people to take advantage of the benefits of digital technology and the internet.

 www.eaccessibilitywales.org.uk

> The Sequal Trust

Supplies adapted computers and communication aids to disabled people of all ages across the UK.

 01691 624 222

 www.thesequaltrust.org.uk

Other organisation that can help include:

- Ability Net (see page 40)
- Disabled Living Foundation (see page 38)
- Meru (see page 39)
- ACE Centre (see page 38)



Continence

You can ask for advice on continence from health visitors, district nurses, learning disability nurses, community nurses, or social workers. Most health authorities will also have a continence adviser.

Once your child is no longer an infant, continence aids can be supplied by your local health authority, provided your child's difficulties with continence are due to a disability. In most cases, free pads will not be given before a child is four, but flexibility should be allowed for special cases, such as children with multiple disabilities. Continence aids may be charged for, or free, depending on where you live. Aids such as bedding protection, disposable nappies, catheters, pants and odour controls may be provided by the health authority, or can be bought privately (see clothing for daily living on page 14).

The Department of Health report on *Good Practice in Continence Services*, (published in 2000), says that, 'In most cases it will not be appropriate to provide free pads before the age of four, but flexibility should be allowed for special cases such as children with multiple handicaps and decisions should be made in liaison with the designated paediatrician.' This document also says that 'Pads (nappies) should be provided in quantities appropriate to the individual's continence'.

The following organisations provide practical information and advice on continence issues:

➤ ERIC (Education and Resources for Improving Childhood Continence)

Provides information, support and resources to children and young people, their families and health professionals.

☎ **Helpline: 0845 370 8008**

🌐 www.eric.org.uk

➤ The Bladder and Bowel Foundation

This foundation gives information and support for all types of bladder and bowel related problems. There is a specialist helpline, providing clinical support for patients and carers as well as a general enquiry line.

☎ **01536 533255**

☎ **Nurse helpline: 0845 345 0165**

🌐 www.bladderandbowelfoundation.org

Water charges and washing machines

Help might also be available with water charges. If your water supply is metered, then you may be able to get your bill capped. Please contact our freephone helpline for advice. Other help for families dealing with continence difficulties is the laundry service, although not all local authorities offer this. Where available, it is usually attached to the home help service of the social services department. In other areas, it is operated by the NHS.

Families with severely disabled children can apply for help with washing, such as a washing machine, from the Family Fund. See 'Financial help' on page 32.

You may live in an area where you can get a donated or recycled machine.

➤ The Furniture Re-use Network

National co-ordinating body for 400 furniture and appliance re-use and recycling organisations in the UK. They collect a wide range of household items to pass onto people in need.

🌐 www.frn.org.uk

➤ Freecycle and Freegle

Networks of online recycling groups, each moderated by local volunteers. Membership is free and you can give away and ask for all sorts of free, second-hand household items including washing machines.

🌐 www.freecycle.org

🌐 www.ilovefreegle.org/groups

Clothing and aids for daily living

Parents' lives can be made easier, and their children and young people can achieve more independence and confidence by having:

- specialist clothing
- adapted implements for eating and drinking
- environmental controls to operating certain appliances such as light switches, TV, phone, or opening doors, for example.

Your child may have the opportunity to borrow a piece of equipment or particular application to try it out. Extra help may also be available if your child has a statement of special educational needs, or from 1 September 2014 Education, Health and Care (EHC) plan. This could lead to the provision of specialist equipment to help with learning (see 'Education' on page 20).

> Disabled Living Foundation – Living made easy

Information and advice for parents or carers of a disabled child, and professional about daily living equipment and clothing.

✦ www.livingmadeeasy.org.uk/children

> Fledglings

Fledglings is a national charity that sells products that improve the lives of disabled children and their families.

✦ www.fledglings.org.uk

> Rackety's

Rackety's is a company that supplies clothing for disabled adults and children.

✦ www.disabled-clothing.co.uk

> Togs4specialsprogs

Togs 4 special sprogs is a company that makes custom-made clothing and accessories for babies, children and young people with additional needs.

✦ www.togs4specialsprogs.com

Seating, beds and toughened furniture

> Independent Living

Independent living has a list of suppliers for all kinds of specially designed products to help disabled children achieve greater levels of comfort, security and independence at home. Products include toughened furniture, and specially designed beds and seating

✦ www.independentliving.co.uk/category/children-category

Mobility

If you're concerned about your child's mobility, talk to your GP. They can make a referral to the physiotherapist at your local hospital, who will assess your child's needs. Your local hospital or community health service can lend you basic walking aids if the physiotherapist recommends this.

Your local NHS wheelchair service will assess your child for a wheelchair (powered or manual) and provide them with one. Children's buggies can also be supplied through the wheelchair service.

Wheelchairs are supplied to someone who needs a chair permanently.

Children in the UK have to be 30 months old (two and a half) before they can be assessed for an NHS wheelchair. Generally, there is no NHS funding for powered wheelchairs for children under five. See page 17 for charities that help with powered wheelchairs, including for children under five.

In theory, any wheelchair can be supplied by the NHS wheelchair service. This can, however, depend on local criteria, resources, and individual circumstances. In Scotland, though, there are national criteria for the provision of powered wheelchairs.

The service should help you to choose a wheelchair that meets your child's needs. This includes extras such as cushions, armrests or trays. The service will also be responsible for its maintenance, provided any problems are not caused by misuse or neglect. You should be given the number for a local approved repairer who will be responsible for repairs.

Your GP, local health centre, physiotherapist or occupational therapist should be able to tell you where your local wheelchair service is.

NHS England also links to all the wheelchair services in the UK - search for 'Wheelchair services' at www.nhs.uk



Parents in England, Northern Ireland and Scotland can call NHS Direct 111. Families in Wales can call NHS Direct Wales on 0845 4647. Alternatively, visit the wheelchair services section of the NHS website at <http://preview.tinyurl.com/cu7hyo4>

If you want more than a standard wheelchair

In many cases, eligibility criteria and the limited budgets of local NHS wheelchair services mean that many children are not given a wheelchair or buggy. Usually, you have to buy outdoor electric wheelchairs, scooters or specialist sports chairs.

If you're unhappy with the choice available and need something other than a standard chair, then you could consider the wheelchair voucher scheme (England only). This allows you to pay the difference between the costs of a basic manual wheelchair, provided by the wheelchair service, to a more expensive wheelchair of your choice. Before you take this option, ask the wheelchair service to explain in writing who would be responsible for paying for repairs. In some areas of the country, services say that you would be responsible for repair bills if you take a wheelchair voucher.

☹ If you're unhappy with the wheelchair service

Unfortunately, things can go wrong. If you feel unhappy with the wheelchair service, you can try to resolve this by letting the service know you are unhappy. If this doesn't work, you can make a complaint. Ask the wheelchair service for a copy of their complaints procedure, which will explain how to make an official complaint.

You can find details of who can help you with making a complaint in any of the four nations of the UK in the 'Health' section on page 7.



i Additional sources of help with wheelchairs

> Whizz-Kidz

Whizz-Kidz can provide a wide variety of mobility equipment for children up to 18 that is not available from the NHS. Families may need to contribute to the cost. Also provide wheelchair skills training and a loan scheme for children under seven years old.

☎ 020 7233 6600

🌐 www.whizz-kidz.org.uk

> Designability – Wizzybug powered wheelchairs for children under five years old in the UK

The Wizzybug is a powered indoor/outdoor wheelchair providing a fun first experience of independent mobility for children aged 18 months to 5 years. The scheme is managed by an occupational therapist, who works with families and referring therapists to see if the Wizzybug is suitable for their child. Wizzybugs are lent to families, free of charge. Families pay a £200 security deposit, returned to them at the end of the loan.

🌐 www.designability.org.uk/product/wizzybug

> Meru

This charity has a range of off-the-shelf and custom-made products including the Bugzi. The Bugzi is a powered indoor wheelchair for children aged one to six to experience independent mobility. MERU lend Bugzi wheelchairs free of charge. Qualifying criteria apply.

🌐 meru.org.uk/what-we-do/bugzi

> Tiny Trax

This Ipowered wheelchair is for children from two to 12 years old. Available in over 50 designs and colours, the chair can be easily taken apart, so there is no need for specialist vehicles. See the website for details of help with funding.

🌐 www.tinytrax.com

> Caudwell Children

Caudwell Children's mobility equipment service includes multi-purpose wheelchairs and therapy cycles as well as specialised car seats and mobility buggies. Annual family income (not including benefits) must currently be under £45,000.

🌐 www.caudwellchildren.com/

> Go Kids Go! (Association of Wheelchair Children)

This charity enables young wheelchair-users throughout the UK to become independently mobile. They provide wheelchair skills training to young wheelchair-users and their families. Also provide disability awareness training in schools.

☎ 01482 887163

🌐 www.wheelchairchildren.org.uk

> The Mobility Trust

This charity provides powered wheelchairs and scooters for severely disabled children and adults who cannot get them through statutory sources or afford the equipment themselves.

🌐 www.mobilitytrust.org.uk

Mobility schemes

If your child receives either the higher rate mobility component of Disability Living Allowance (DLA) or the enhanced rate of the mobility component of Personal Independence Payment (PIP) and has at least twelve months award length remaining, you can join the Motability scheme. The scheme can help disabled people hire or buy a car, or a powered wheelchair, or a buggy. You can only be on the car scheme or the wheelchair and scooter scheme, not both at the same time. For more information, contact Motability operations on 0800 953 3060, or visit www.motability.co.uk

Other mobility services

> Forum of Mobility Centres

This is a network of 17 independent organisations covering England, Scotland, Wales and Northern Ireland. They offer information, advice and assessment to individuals who have a medical condition or are recovering from an accident or injury which may affect their ability to drive, access or exit a motor vehicle.

 0800 559 3636

 www.mobility-centres.org.uk

The Blue Badge scheme

The Blue Badge scheme allows some parking concessions for those on DLA mobility component at the higher rate and others with severe walking problems who are aged two or above. You may also qualify if your child is under three and has a condition which means they either need to be accompanied by bulky equipment or kept near a vehicle at all times.

Disabled adults on PIP also qualify for a Blue Badge if they score eight points or more under the PIP activity of 'moving around'.

In Scotland and Wales, entitlement has also been extended to adults who score 12 points or more in the Personal Independence Payment activity of 'planning and following a journey'. There are other small differences in the Blue Badge scheme rules in the four nations.

Call our freephone helpline or your local authority for more information.

Road tax for your car

You can get a 100 per cent rebate if you qualify for, or have a child aged three or over who qualifies for either Disability Living Allowance mobility component at the higher rate or PIP mobility component at the enhanced rate. A 50 per cent rebate is made where someone qualifies for PIP mobility component at the standard rate.

Grants for driving lessons

If you need help with driving lessons, see the Disability Grants website www.disability-grants.org/funding-for-driving-lessons.html

As a result of a carer's assessment, you may be able to get Direct Payments to help with the costs of driving lessons.



> Family Fund Driving Ambition grants for young people

Family Fund has a grant to help eligible young people aged 16 and 17 take the first steps in learning how to drive. The Driving Ambitions grant supports the young person to get started by funding a combination of:

- provisional licence
- theory test
- learning materials, such as the Highway Code or theory test book or DVD
- first taster lesson.

This is only available for the eligible young person who has not yet had any driving tuition. Family Fund cannot provide support for ongoing driving lessons.

Unfortunately, Family Fund does not provide help with driving lessons for parents or carers of disabled or seriously ill children.

☎ 01904 621115

🌐 www.familyfund.org.uk

Education

Aids and equipment that a child or young person needs for education may be supplied by your local authority and your child's school or college.

The school may arrange for an occupational therapist to assess your child and may provide aids for use in school and at home. Contact the head teacher or special educational needs coordinator (SENCO) for more information.

If your child has a statement of special educational needs or Education, Health and Care plan (coordinated support plan in Scotland), details of specific equipment your child needs to help them at school should be included on it. If you have concerns about your child's needs, talk to the school.

Contact a Family's guides, *Special educational needs Wales*, and *Additional support for learning Scotland* have more advice about your rights and relevant organisations for more help. In England, the system for supporting children with special educational needs changed in September 2014. See our factsheets in the Education section of our website. Families in Northern Ireland and the rest of the UK can call our freephone helpline and speak to our Education Advice Service about any aspect of their child's education, including help with aids and adaptations.



☹️ If you're unhappy with your child's equipment in education

If you think your child is not getting the right equipment, talk to the person responsible. If this is not successful, then you can get help to make a formal complaint from a local law centre, welfare advice centre or carers' centre. If this does not resolve the issue, then take legal advice. Parents and young people must try to resolve any issues they have with a school or college before going to a tribunal or court.

Further and higher education

For young disabled people in further and higher education, additional help may be available. This can be in the form of specialist aids and equipment or allowances to help pay for equipment or practical help. Young disabled people will need an assessment to decide what help they need.

These organisations can help:

England

Disability Rights UK

Disabled students freephone helpline:

 0800 328 5050

 www.disabilityrightsuk.org

Scotland

Lead Scotland

 Freephone helpline 0800 999 2568

 www.lead.org.uk

Northern Ireland

Disability Action

Disability Action offer support in work and training

 www.disabilityaction.org/services-and-projects/support-in-work/

NI Direct Careers Service

Provides careers information, advice and guidance service, to help young people and adults make informed choices about their future career paths.

 0300 200 7820

 www.nidirect.gov.uk/careers-service

Family Fund

For families on a low income, the Family Fund can give grants to 16 and 17 year olds around the UK for equipment such as laptops, tablets and equipment for college.

 01904 621 115

 www.familyfund.org.uk

Wales

Careers Wales

 Freephone helpline

0800 028 4844

 From a mobile call 029 2090 6800 and you will be called back for free

 www.careerswales.com



Play, leisure and child development

Play has an important role in a child's development. Play can help develop speech, sensory skills, imagination, independence and social skills. Toys and play can be fun as well as educational and therapeutic. All children have the right to play, have fun and take part in recreational activities. All children, whatever their abilities, must be given opportunities to play and access leisure facilities.

Toys, play and development

For advice on suitable toys, you can speak to a paediatric occupational therapist. Through activity and play, the therapist works with children to help them attain the highest possible quality of life. The therapist can work in a variety of settings including the NHS, social services, educational or charitable organisations.

There may be also be a local play scheme or parent support group in your area where toys and ideas can be shared or exchanged. Call our freephone helpline for local information. We also have a guide, *Holidays, play and leisure*, that includes lots of ideas for play, leisure and sport. Our guide is available free for parents from our freephone helpline.

Toy libraries

Local toy libraries are usually free for children who access local services, (such as portage, or speech and language therapy), or who receive DLA or are on the local children's services register.

You can borrow a range of sensory toys and equipment. The toy librarian can help you choose toys for fun and development. Good quality toys and sensory equipment are often expensive to buy for children with additional needs, so being able to borrow these is useful. Toy librarians can also signpost you to local play and leisure services and, in some areas, run their own play sessions.

The following organisations can provide further specialist information:

> Disabled Living Foundation

☎ 0845 130 9177

🌐 www.dlf.org.uk

> Listening Books

Provide audio books for leisure and learning on MP3, CD, and via internet streaming for anyone who has difficulty reading.

☎ 020 7407 9417

🌐 www.listening-books.org.uk

> Smart Play Network (Scotland)

Run a range of play projects and offer services directly to children and families. Also, help and support toy libraries and play projects in Scotland to deliver quality services for children and families.

☎ 0131 664 2746

🌐 www.smartplaynetwork.org

> Charlotte's Tandems

Charlotte's Tandems is a charity with lots of tandems and trailer bikes for free hire throughout the UK for disabled people. You can also find information of other borrowing and cycling schemes, and where to buy adapted cycles and trikes.

🌐 www.charlottestandems.co.uk/index.html

Buying sensory toys and equipment

Sensory toys and equipment can be expensive but can be bought on a budget. Below are just a few online companies

> The Sensory Toy Warehouse

Online shop selling sensory toys from pocket-money prices upwards.

📞 www.sensorytoywarehouse.com

> Cheap Disability Aids

Online shop with sensory toys and equipment.

📞 www.cheapdisabilityaids.co.uk

> Glow

Sells a range of products, including sensory toys and lighting.

📞 www.glow.co.uk

> TFH Special Needs Toys

A range of products, including strong swings for children, young people and adults, and squeeze vests.

📞 www.specialneedstoys.com/uk

> Bag Books

Design and produce multi-sensory story packs for people with learning disabilities.

📞 020 7627 0444

📞 www.bagbooks.org



In our magazine *Connected* in Spring/summer 2014, (on page 23), we had an article on how to make a DIY sensory room. Parents can call our freephone helpline and ask for a free copy or download a copy from our website.

www.cafamily.org.uk

Adapting your home

If you need to adapt your home to make it easier for you or your child to manage, you may be entitled to a Disabled Facilities Grant (or Home Improvement Grant if you live in Scotland). If you are considering applying for a grant, please seek further help and advice as the system can be quite complex.

Disabled Facilities Grants in England and Wales

The housing department of your local authority usually pays disabled Facilities Grants (DFGs). To be eligible you must be an owner-occupier, a tenant (private, local authority or housing association) or a landlord with a disabled tenant.

A DFG can help with the cost of, for example:

- building a safe play area
- installing a stair-lift
- adapting a lighting or heating system
- building suitable kitchen or bathroom facilities, or
- to enable access to a garden, and other works.

A DFG is a mandatory grant. This means you must be given a grant if your local authority is satisfied that the work to your home is both 'necessary and appropriate' to meet your disabled child's needs, and 'reasonable and practicable', taking into account the age and condition of the property.

When your child is under 19 years of age, your financial circumstances should not be taken into account for a grant to meet their needs. The exception is when a young person is getting certain means-tested benefits in their own right or is in advanced education.



Your local authority must decide if you are entitled to a DFG within six months of receiving your valid application.

An application for a DFG is only valid if you have given all the following information:

- details of the property
- details of the work needed
- at least two estimates of the cost from two different contractors, (unless the local authority says otherwise)
- details of other services and charges needed, for example, supervising the work, disconnecting electricity, water or other utilities.



Most local authorities will ask for an assessment from an occupational therapist (OT) or social services to help them decide if the work is 'necessary and appropriate' to meet your disabled child's needs. However, nowhere in the legislation does it say that an OT assessment is required for a valid application.

It is important to remember that just contacting social services or an OT to ask for an assessment is not the same as making a formal application, and some families have long delays before their formal application is submitted. This is because there are no time limits on how long you may have to wait to see an OT.

To minimise delays, make a formal application for a grant as soon as you can, so you can get a decision within the six-month time limit. You can do this even if you are still waiting for an OT to visit to do an assessment.

You can make a formal application on a form available from the local authority, or by letter. Your local authority can't refuse to allow you to make a formal application, or refuse to give you a grant application form. Call our freephone helpline if they do refuse, or if you are experiencing long delays in the grant process.

To help them decide if your request is 'reasonable and practicable' your local authority will also ask for an assessment from an environmental health officer or a building surveyor (local authorities tend to use members of their own staff where possible).

You may also need to get approval for building regulations, planning, listed buildings or conservation areas purposes. Your local authority has the right to ask for these but it should not use them to go over the six-month time limit for assessing a claim.

It is important to remember that you can't get a grant for work that you have already started.

How much can I get?

Currently, the maximum grant is £30,000 in England and £36,000 in Wales. However, if costs are over this limit, the local authority has the discretion to give a further grant to cover the whole cost of the mandatory works. Local authorities can also use their discretion to give financial and other assistance for improvements or repairs to your home. This can be a grant, loan, labour, relocation expenses, materials or advice. Contact your local housing authority to find out how this applies in your area.

When does the work have to be carried out?

If your application is successful, the grant will usually only be paid if the work is carried out within 12 months of the date the application is approved.

If your application isn't approved you can make a complaint. If you can't get enough financial help from your local council, you could apply to charitable trusts for help. Call our freephone helpline for more information.

Disabled Facilities Grants in Northern Ireland

The system for getting help with adaptations in Northern Ireland is similar to England and Wales. An OT will need to recommend that adaptations are 'necessary and appropriate' for your disabled child. The rules only apply to homeowners or people renting in the private sector. There are different rules for people in public sector housing, housing executive or housing association tenants.

You can get a grant of up to £25,000 and in some circumstances more than this, subject to senior management approval.

Contact your local Health and Social Services Trust in the first instance. See the Northern Ireland Housing Executive website for more information at www.nihe.gov.uk

Grants for improvements and adaptations in Scotland

Each local authority in Scotland must have a 'Scheme of Assistance' statement, which explains how they support homeowners and tenants in their area who have to carry out repairs, improvements and maintenance to their houses. Under the scheme of assistance, local authorities must give grants to adapt a home so a disabled child has access to standard amenities. These are:

- a toilet
- bath or shower
- wash hand basin and sink (in each case with hot and cold water supply).

Local authorities must also give grants for other work that is seen as 'essential' to meet your disabled child's needs. Your local authority will decide whether an adaptation is essential when they assess your disabled child's needs.

A grant can't be made for an extension that gives you extra living space. If an extension gives you a standard amenity (for example, a downstairs bathroom) as well as extra living space, a grant is only awarded for the part of the work that gives you the standard amenity. If the extension only makes space for a standard amenity and no extra living space is created, you should get a grant to cover the whole cost.

The minimum amount of grant for your child's 'essential' needs is 80 per cent of the eligible cost. A local authority can pay more than 80 per cent of the costs. When it does so this should be included in the local authority's statement of assistance. If you get certain means-tested benefits, the grant should cover 100 per cent of the cost.

If you need help with an extension, your local authority should give you advice and information to help you fund the work, such as information about loans, or a referral to another agency that may be able to provide financial help.

If you are refused a grant, for example, because you need an extension that doesn't qualify, ask your local authority about a discretionary grant. The local authority can offer a discretionary grant if your application meets the conditions set out in its Scheme of Assistance statement.

Your local authority can't apply an upper limit on the cost of a grant for adaptations for your child. If your child is assessed as needing the adaptations, they must legally be given a grant, regardless of the cost.

The local authority will usually refuse an application for a grant if you've already started the work, unless there was good reason why it was started before you made an application.

You can usually only get a grant if you are owner-occupier or a private tenant. The Scottish government has produced a leaflet called *Help with Adaptations To Your Home*, which can be found on their website at www.scotland.gov.uk.

If you rent from a council or housing association, ask your landlord about financial and other help that's available for adaptations.



☹ If you're unhappy about the outcome of an application for a grant

If you're unhappy about the outcome of an application for a grant, or the length of time it has taken to reach a decision, get advice. You can challenge a decision by talking to your local authority, complaining using the local authority complaints procedure, or asking the local government ombudsman to investigate. A local citizen's advice bureau or home improvement agency may be able to give additional advice.

i Getting further help and advice

Home improvement agencies, sometimes known as 'Care and Repair' or 'Staying Put' agencies, are local organisations that help vulnerable home owners improve their living conditions. They can give technical and financial advice. They can also help you apply for a grant and help you through the grants process. If you are looking for a handyman to help you make any adaptations you can search their 'Trusted Tradespeople' database to find government-endorsed trusted trades people in your area. They may also be able to identify other sources of financial help if the grant isn't enough.

England - to find your local agency contact

> Foundations

☎ 0845 864 5210

🌐 www.foundations.uk.com

In Scotland

> Care and Repair Scotland

 0141 221 9879

 www.careandrepairsotland.co.uk

Families in Scotland can also find more detailed information in the Scottish government's guidance for local authorities, *Guidance on the provision of equipment and adaptations*, see www.sehd.scot.nhs.uk/publications/CC2009_05.pdf

You can also contact our Scotland office on 0131 659 2930, or email us at scotland.office@cafamilly.org.uk

In Wales

A local disability advice project or citizens advice bureau should be able to help. -

> Citizens Advice

 Helpline 03444 77 20 20

 www.adviceguide.org.uk/wales.htm

You can also contact our office in Cymru/Wales on 02920 396 624 or email cymru@cafamilly.org.uk

In Northern Ireland

A local disability advice project or Citizens Advice Bureau should be able to help. To find your local agency see

 www.adviceguide.org.uk/nireland.htm

You can also visit the website of the Northern Ireland Housing Executive at

 www.nihe.gov.uk/index/advice/disability

You can also contact our office in Northern Ireland on 028 9262 7552 or email: nireland.office@cafamilly.org.uk

People in England and Wales can find further information in the good practice guide, *Delivering Housing Adaptations, for Disabled People*, at www.gov.uk/government/publications/delivering-housing-adaptations-for-disabled-people

Second-hand equipment

Below are a few suggestions for sources of second-hand equipment.

> Newlifeable equipment service

Newlife's project, Newlifeable, has some new and clinically refurbished and certified equipment, all available through a grant for 'priority delivery' at no cost. The service is for significantly disabled children and young people up to the age of 19 across the UK. Equipment includes specialist seating, manual wheelchairs, buggies, walking frames and assisted living aids like height adjustable tables. Newlife can in some cases help with fundraising for essential equipment.

📍 www.newlifeable.co.uk

> Spinal Injuries Association

Has helpful factsheets on buying and selling second-hand equipment. This includes details of publications to advertise in and helpful organisations. Information from the Spinal Injuries Association also lists dealers in second-hand wheelchairs and adapted vehicles.

📞 0800 980 0501

📍 www.spinal.co.uk

> Disabled Living Foundation

Has a useful factsheet on buying second-hand equipment.

📍 www.dlf.org.uk/factsheets/sources_of_second_hand_equipment.pdf

> Disability Equipment Register

A not-for-profit organisation providing a service for disabled people and their families to enable them to buy and sell items of used disability equipment on a direct basis.

📞 01454 318 818

📍 www.disabilityequipment.org.uk

> Mobility Market

A website where you can buy or sell used mobility aids and equipment.

📍 www.themobilitymarket.co.uk



Financial help

There are a number of benefits and financial help for families with disabled children. To make sure you're claiming everything you're entitled to, call our freephone helpline on 0808 808 3555 for a full benefits check. You can also ask for a copy of our free guides on benefits. *Money Matters – a checklist for parents when your child has additional needs* (England, Scotland and Wales), and *Checklist for parents – Northern Ireland*, have brief summaries of financial help you might be entitled to. Our helpline can also give you information on grant-making trusts you may be able to apply to.

Using direct payments to buy equipment

Families in the UK can use direct payments to buy equipment. Our guide *Getting direct payments to buy social care your disabled child in England and Wales* look at how to ask for them and how they work in practice. For a copy and more information about direct payments, call our freephone helpline. Families in Northern Ireland and Scotland can contact our helpline for advice.

Charities and benevolent funds

> Caudwell Children

The charity's services include:

- mobility equipment including bespoke multi-purpose wheelchairs and therapy cycles as well as specialised car seats and mobility buggies
- sensory equipment for children who have autism to help promote communication, cognition and wellbeing.

📍 www.caudwellchildren.com

> Family Fund

Gives grants to low-income families across the UK to meet the extra costs of caring for a severely disabled child aged 17 years old and under. You will be asked some details of your household income and any benefits being received – see their website for eligibility criteria. Young people aged 16 and 17 can apply for items that are relevant to their age group – for example laptops, tablets and equipment for college. The Fund will not help with costs that are the responsibility of the local authority or health services.

☎ 01904 621 115

📍 www.familyfund.org.uk

> Newlife

Provides grants for essential equipment such as: pain relieving beds, wheelchairs, communication aids, and much more. It also has a 'just can't wait' loan service for terminally-ill children and lends sets of developmental and therapeutic specialist toys.

📍 www.newlifecharity.co.uk

> Turn2us

This online service allows you to search for information on benefits and grant-making trusts from statutory and voluntary organisations in the UK.

☎ Freephone: 0808 802 2000

📍 www.turn2us.org.uk

Value Added Tax (VAT)

You don't have to pay any VAT when you buy certain aids and equipment for the personal use of your disabled child.

You don't pay VAT on:

- adjustable beds, chair lifts, hoists and sanitary devices
- auditory training aids, like hearing aids and equipment
- low-vision aids
- certain medical and surgical appliances
- emergency alarm call systems
- motor vehicles and boats adapted to meet your disabled child's condition. Not every vehicle or adaptation will qualify, so seek further advice from our freephone helpline
- any other equipment or appliance designed solely to be used by your disabled child. It is not enough to show that a piece of equipment is one that is often used by disabled people – it must be specifically designed for your child's use. For example, you would pay VAT on an orthopaedic bed because they are designed to be used by disabled and non-disabled people. Ultimately, it is the designer or manufacturer of a product who decides whether VAT needs to be paid.

You also don't have to pay VAT on any charges made for the installation, repair and maintenance of these aids and adaptations, or for any spare parts or accessories they need.

You don't pay VAT on certain building work. This includes work on:

- ramps
- widening doorways and passages,
- extending or adapting bathrooms, shower rooms, wash rooms and toilets
- installing and repairing a lift.
- any general purpose goods adapted for a disabled child's use. The extra you pay for the adaptation should be VAT free, although not the actual goods themselves.

However, if you employ an architect, surveyor or consultant you will have to pay VAT on their services, even if they are providing services in connection with building work that does qualify.



If you import equipment from abroad to meet your disabled child's needs, there are specific rules allowing VAT exemptions in certain circumstances. See below.

How to make sure you do not pay VAT

To avoid paying VAT, you need to put down in writing, to the supplier, that you are entitled to buy the goods and services without paying VAT. A parent can do this on behalf of their disabled child. There is no official form for this, but Her Majesty's Revenue and Customs (HMRC) has suggested wording you can use in *VAT Notice 701/7 – VAT reliefs for people with disabilities* at www.hmrc.gov.uk/vat/sectors/consumers/disabled.htm. This web page also has information on what items you do or don't have to pay VAT on.

It is the supplier's responsibility to check that you don't have to pay VAT. If you have been wrongly charged VAT, your supplier may be able to adjust their VAT records and refund you the money. You can't get a refund of VAT from HMRC.

 For further advice about paying VAT, call our freephone helpline or contact HMRC on 0300 200 3700.

Commercial suppliers

Many companies that sell aids and equipment also have a mail order service. Because of the vast range available, it is important to seek independent advice.

➤ Disabled Living Foundation

Has a list of suppliers of a range of children's equipment on their website.

✦ www.dlf.org.uk

➤ The Challenging Behaviour Foundation

Supplies information about specialist equipment and safety adaptations. This includes suppliers of items such as toughened furniture, special flooring, beds and bedding.

✦ 0845 602 7885

✦ www.thecbf.org.uk



Consumer rights

When you buy goods and services, you have a right to expect certain standards. This applies when you buy in person or by mail order. If something goes wrong and/or you're not satisfied with the service or goods, try contacting the supplier first. If you're unhappy with the outcome, seek further specialist advice. It is important to do this as soon as possible as your rights may depend on when the transaction took place, otherwise you could find that you're out of time.

If you need to make a complaint

Your local citizens advice service or local trading standards service can give you more advice and help you make a complaint.

Local trading standards office

England Scotland and Wales

To find your local office and for information on your rights

 **Trading Standards Central helpline 03454 04 05 06**

 **www.tradingstandards.gov.uk**

Northern Ireland - ConsumerLine

Northern Ireland's consumer advice line and website

 **0300 123 62 62**

 **www.consumerline.org**

Citizen's Advice Service

UK-wide consumer rights advice and where to find your local citizen's advice bureau.

 **www.adviceguide.org.uk/consumer**

 **People living in England can call 03444 111 444**

In Wales call 03444 77 20 20

Further sources of help and advice

There are numerous suppliers of disability equipment, mobility products and daily living aids in the UK. Below is a small number. Again, please note that their appearance on this list should not be seen as an endorsement by Contact a Family of their products.

> Ace Centre

Work alongside young people with communication difficulties to design software that enables, rather than restricts, the user.

 0161 358 0151

 www.ace-centre.org.uk

> Disabled Living Foundation (DLF)

Produces a comprehensive range of fact sheets on choosing daily living equipment. This includes advice on equipment for children who need help to dress, personal care (toileting, bathing, washing) as well as information on beds and bed accessories. The factsheets can be downloaded from their website or you can ring the equipment helpline where up-to-date product and supplier information can be given.

The DLF also has a website SARA (Self-Assessment, Rapid Access) you can visit at www.asksara.org.uk for information on products that may help. Assist UK leads a UK-wide network of Disabled Living Centres. Each centre includes a permanent exhibition of products and equipment that give people opportunities to see and try products.

 0845 130 9177

 www.dlf.org.uk

> Assist UK

Assist UK leads a UK-wide network of disabled living centres. Most centres include an exhibition of products and equipment to try out. You can also get information and advice from staff about suitable products.

 0161 832 9757

 www.assist-uk.org

> LiveNet (Northern Ireland)

The LiveNet assistive technology loan scheme provides an opportunity for people in Northern Ireland to preview a variety of items of software or hardware that have been specially designed to help improve access to a computer.

The loan scheme is available to any member of the learning disability community free of charge. This includes:

- children, young people or adults with a learning disability (under 18s must get a responsible adult to sign the agreement)
- family carers
- staff or volunteers who support people with a learning disability.

📞 028 9049 4907

🌐 www.livenet.org.uk

> MERU

MERU aims to improve life for children and young people with disabilities by designing custom-made specialist equipment when no ready-made solution exists to meet a child or young person's needs. MERU also has an information and advice service for parents and therapists worldwide.

📞 01372 725203

🌐 www.meru.org.uk

> Remap

Design, manufacture and supply appliances to meet the individual needs of disabled people where they cannot be sourced commercially.

📞 0845 130 0456

🌐 www.remap.org.uk

> Ricability (Research Institute for Consumer Affairs)

Ricability is an independent research charity that provides consumer information for disabled and older people. Guides are available on request or through their website.

📞 020 7427 2460

🌐 www.ricability.org.uk

> Abilitynet

Offer advice and information on information and communications technology (ICT). Also supply a range of factsheets and skill sheets (available on their website) that give detailed information on a wide range of assistive technology.

☎ 0800 269 545

🌐 www.abilitynet.co.uk

> British Red Cross

Has a volunteer-led medical equipment service that provides wheelchair hire and short-term loans of equipment in almost 1,000 outlets in the UK.

☎ 0844 412 2804

🌐 www.redcross.org.uk

> Youreable

A community-based website that has information on products and services for disabled people.

🌐 www.youreable.com

> Independent Living

A site providing news, views and product information designed to assist with living independently.

🌐 www.independentliving.co.uk

Frequently asked questions

"I bought a trike for my disabled son and was told by the supplier that I have to claim back the VAT. How can I do this?"

First, you need to establish whether you should pay VAT on the trike (see 'Value Added Tax (VAT)' on page 34). VAT relief doesn't apply to general purpose goods for disabled people. Unless the trike has been solely designed to be used by your disabled son, you will have to pay VAT. You should also be aware that Her Majesty's Revenue and Customs don't refund VAT to customers. Instead, it is the responsibility of the supplier to determine whether the item in question is subject to VAT. If you have been charged VAT incorrectly, your supplier may be able to adjust their VAT records and refund you the VAT.

"With help from the Disabled Facilities Grants Scheme I've just turned one of my reception rooms into a special playroom for my disabled child. I've been told I can get some help with the Council Tax because of this. Is this true?"

This is possible under the Disability Reduction Scheme. When a property has been altered in a certain way to accommodate the needs of a disabled person, then the 'band' for your property can be lowered. The lower the band, the smaller the bill. In your case, you qualify because you have a room which is needed by and predominantly used by your disabled son. It is worth noting that if the dwelling is in band 'A', then you can get a reduction of one-sixth of your bill. And also that the reduction can be fully backdated. Properties in the lowest band already, (A), only have the right to backdate to 1 April 2000.

I bought a second hand wheelchair from a trader, but I've been told I don't have the same rights as if I'd bought it brand new, and I can't return it if there's a fault. Is this true?

No, you have the same rights as if you'd bought a new one, and the trader is also obliged to point out any faults before you pay for it. If any faults have been pointed out, then this may affect your rights. Contact your nearest advice service or trading standards office for further advice. See 'Consumer rights' on page 37.

I've just enquired about applying for a Disabled Facilities Grant and I've been told by the occupational therapist (OT) that there's a waiting list for the assessment. It could be months before I'm seen by the OT and two years before I get a grant. What are my rights?

The assessment by the OT is a crucial part of the grants process. Following on from the OT's recommendations, a formal application is often submitted to the housing authority. But you can still make a formal application to the housing authority for the grant before the OT's assessment. This can help speed up the process as the authority must then make a decision within six months of receiving the application. Within that time, the OT will hopefully visit your home to carry out the assessment.

If you don't get a decision within the time limit, you should write to them asking why you haven't heard anything and asking for a decision to be made. If there is still no decision, then seek advice on other possible remedies, such as making a complaint using the local authority's complaints procedure or the local government ombudsman. See 'Adapting your home' on page 25 for more information.

Support Contact a Family

Help us continue to provide information, advice and support to all families with disabled children in the UK.

From cake sales, to running the London Marathon, or signing up to be a regular giver – there are many ways you can help. Find out more on our website, and get in touch with our fundraising team:

📍 www.cafamily.org.uk/fundraising

☎ 020 7608 8786

✉ fundraising@cafamily.org.uk

And why not get involved in our campaign work across the UK?

📍 www.cafamily.org.uk/takeaction



Written by Nathalie de Broglio, Karin Beeler and John Ball.

contact a family
for families with disabled children

Get in contact with us

209–211 City Road, London EC1V 1JN

 020 7608 8700

 info@cafamily.org.uk

 www.cafamily.org.uk

 www.facebook.com/contactafamily

 www.twitter.com/contactafamily

 www.youtube.com/cafamily

Free helpline for parents and families:

 **0808 808 3555** (Mon–Fri, 9.30am–5pm)

 helpline@cafamily.org.uk (Access to over 200 languages)

Our free family linking service

 www.makingcontact.org



Charities Evaluation Services



Registered Charity Number: 284912 Charity registered in Scotland No. SC039169.
Company limited by guarantee. Registered in England and Wales No. 1633333. VAT
Registration No. GB 749 3846 82. ® Contact a Family is a registered trade mark.

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

The photographs in this guide do not relate to any personal accounts.

© Contact a Family, March 2015

Order code i30