First impressions

Emotional and practical support for families of a young child with a learning disability
Introduction

“Don’t be afraid to ask for help – don’t slip through the net.”

Finding out that your child has a learning disability or developmental delay is likely to be a significant turning point in your life. It will mean that a whole new, unexpected and possibly challenging world opens up. It can take some adjusting to, both practically and emotionally, for all the family.

So it’s important to know what support is out there to make life easier. And to find the right support for your child and family that ensures you are more in control of your situation. This will enable your child and all the family, to enjoy their childhood.

There are a lot of services out there. But finding your way through the range of information, specialists, therapists and support organisations can be confusing. That’s why we’ve written this guide to emotional and practical support. It’s based on what families of young children with learning disabilities have told us was helpful to them. The quotes throughout First Impressions are their words; others are from an article by Kathy Evans which appeared in the Guardian in 2004. The author of First Impressions is also the parent of a son with a learning disability.

Not all the information here will be relevant now. But you may want to keep this booklet handy to refer to whenever you need it. Getting the right emotional and practical support from the beginning can make the difference to all the family.
Finding out – the diagnosis

For most parents the moment of receiving the news of their child’s diagnosis is life-changing. The diagnosis may be clear at birth or it may come after weeks or months of concern by parents or professionals. For some children there may never be a clear diagnosis.

“We loved this tiny boy and could only do our best for him and his brother.”

Everyone’s first reaction to the news is personal. For parents who have pressed for a diagnosis, knowing the facts may come as a relief. But reactions vary, and may include one or more of the following: shock, numbness, disbelief, hurt, anger, anxiety, fear, feeling vulnerable and isolated. Some may feel joy and overwhelming love for their child, often there is a mixture of emotions. It takes time to take in the news and find out what it all means.

For some parents the sense of loss for the child they had anticipated can be overwhelming. It may be difficult to accept the diagnosis. It’s natural to feel sad. Some parents will have concerns about what the future will bring for their son or daughter. Others say they never really come to terms with the diagnosis but they learn to live with it.

You may want to talk to professionals, or other parents who’ve been there, about what to expect and how to encourage high but realistic expectations for your child. It may help to talk things over with a counsellor – you can ask your GP to refer you.

“It took me two weeks to really get control over the whole news – everything, because you have expectations of your child... we didn’t know what had happened.”

Essential information

The way the news is given and how well professionals listen to families’ concerns can set the scene for the way everyone works together for the child in the future. It will be hard to take everything in the first time so a follow up appointment including the same professional should always be arranged.

“In the beginning I wanted information about how it would affect Amy – I didn’t know anything about it and I’m sure it’s true for most people.”

Relevant, timely and sensitive information helps to make sense of the news. Too much information can be overwhelming. Too little can mean missing out on important facts about the child’s condition or support opportunities. The internet should be used with caution as it can be unreliable and misleading. What’s important is knowing where to get the information you need at each stage and always asking lots of questions of the professionals working with you and your child.
What is a learning disability?
Having a learning disability (some people also use the terms learning difficulties, developmental delay or special needs) means that a child finds it harder than others of the same age to learn things such as basic life skills. The cause is often unknown but it is a lifelong condition. A learning disability may be the result of a chromosomal or genetic abnormality (such as Down’s syndrome, Rett syndrome, Fragile X or Cri du chat), or be caused by injury or physical trauma, for example.

Who does what?
- **GP or family doctor** – the first person to speak to if you have concerns about your child’s development. If necessary they will refer your child to a paediatrician or other child specialist, many of which are listed below.
- **Health visitor** - advises on any child health care or development issues.
- **Specialist health visitor** (not in all areas) – have specialist knowledge about children with special needs and the services for them.
- **Paediatrician** – a doctor specialising in child health and development.
- **Child Development Centre or Children’s Centre** – this is a multi-agency centre, usually in or near a health setting, including a team of different children’s specialists who work as team to assess, diagnose and offer treatment or therapies.
- **Children’s Trusts** – by 2006 most areas in England will have a Children’s Trust which combines local education, social care, some health services for children and young people and other local partners within one organisation.
- **Early Years and Childcare Partnership** – part of the local council that deals with services for pre-school children.
- **Local Education Authority (LEA)** – part of the local council responsible for schools and youth services.
- **Speech and language therapist** – specialises in assessing and diagnosing communication, swallowing, eating and drinking difficulties and developing a programme to maximise a child’s communication.

Useful resources
*Contact a Family* is a particularly helpful source of family-friendly information. Their aim is to empower parents of disabled children to obtain the best possible care for their children and families. They have a telephone helpline, website, internet discussion groups and some excellent publications. They have a free booklet for families called *When Your Child Has Additional Needs* and for detailed information about learning disabilities look at the *Contact a Family* directory at your local library or online.

Families have told us that the most useful information provided by local professionals, voluntary organisations and national specialist organisations is:

- ✓ about the child’s condition, given face-to-face and backed up with written leaflets, books or websites
- ✓ to help families adjust to the diagnosis
- ✓ who to ask locally for help, information and support
- ✓ who to talk to locally for emotional support
- ✓ for partners, brothers and sisters, grandparents and the extended family
- ✓ early years opportunities and education such as home learning services (including Portage in England and Wales)
- ✓ benefits and other financial help
- ✓ how everyone – professionals and the family – will work together.

If it’s not offered you should ask for this and any other information you need. Later sections of this booklet tell you where to get the information.

At the end of the booklet is a comprehensive list of useful organisations you may want to contact in due course.
Family matters: Looking after the well being of all the family

Being well informed about support

Being well informed is the key to being in control and getting the support you need and choose. The support that suits you and your family best may, for example, come from:

- family members and friends
- other families in a similar situation
- services such as a specialist health visitor, social worker, Portage or other home educational visitor
- your faith or community group.

“Our key worker is always there for us. She’s always willing to sort things out which is brilliant. It saves me having to make endless phone calls.”

Helping your child

Children with learning disabilities are children first and have the same need for love, care, security, play and communication as any others. Stages in your child’s development such as learning to listen, giving eye contact or feeding may have to be broken down into small steps and achieved through play.

Families who have access to supportive pre-school or early years services say they get good advice, information and support. If these services are not offered don’t delay in asking your health visitor, local Child Development Centre or Children’s Centre. Time is valuable for a young child’s development so the sooner you get good support the better.

“We want people to realise that our sons and daughters are children first.”

- Occupational therapist – supports children in learning to do daily activities including self care and getting enjoyment out of life. Advises on adaptive equipment.
- Physiotherapist – a professional trained in the role of movement in health and well being, including gross motor skills such as crawling and walking; and fine motor skills such as picking things up between thumb and forefinger.
- Social services department or community services or a social worker – helps you get the support you need.
- Clinical psychologist – works with children and their families to offer help with any developmental or behaviour problems.
- Educational psychologist – works with children, their parents and teachers on the assessment of the educational and psychological needs of children with a learning disability.
- Key worker – see page 17.
- Portage or other home educational and support services – see page 21 for further details.

OCCUPATIONAL THERAPIST – supports children in learning to do daily activities including self care and getting enjoyment out of life. Advises on adaptive equipment.

PHYSIOTHERAPIST – a professional trained in the role of movement in health and well being, including gross motor skills such as crawling and walking; and fine motor skills such as picking things up between thumb and forefinger.

SOCIAL SERVICES DEPARTMENT OR COMMUNITY SERVICES OR A SOCIAL WORKER – helps you get the support you need.

CLINICAL PSYCHOLOGIST – works with children and their families to offer help with any developmental or behaviour problems.

EDUCATIONAL PSYCHOLOGIST – works with children, their parents and teachers on the assessment of the educational and psychological needs of children with a learning disability.

KEY WORKER – see page 17.

PORTAGE OR OTHER HOME EDUCATIONAL AND SUPPORT SERVICES – see page 21 for further details.
Children with learning disabilities can enjoy the same activities as other children including playgroups, swimming, gym and lots more. This may be particularly helpful if it means that brothers and sisters can do things together, provided they don’t always have to take responsibility for their sibling.

Activities to do with your child
The home visitor from your pre-school educational service will give you lots of suggestions for activities. You might also get some good ideas from:

- Your local toy library – contact the National Association of Toy and Leisure Libraries for details.
- If there is one, the national organisation that deals with your child’s condition.
- Useful books that may be available from your local library, voluntary organisation or Portage scheme, include:
  - *Play Talks* – useful resource pack for families from Scope. Fun ways to promote communication through play for children under 5 who have additional needs.
- Websites: Many organisations have a ‘kids’ area on their website, for example, Scope Early Years.

Ideas from other parents to make life easier
“If you need a special trolley at the supermarket, check in advance that it will be available. If necessary, ask them to open a till to avoid queuing.”

- Use Disability Living Allowance (see page 26) to pay for a family helper, babysitter or to pay for housework.
- Involve brothers and sisters in pre-school learning activities.
- Work with your child at their speed.
- Ask your health visitor to use a different milestone chart such as the one for children with Down’s syndrome.
Looking after your own well being

Adjusting to different expectations for your child as well as coping with the day-to-day caring of all the family can place a lot of demands on physical and emotional energy. Taking one day at a time is often an essential way of coping.

Like anything in life, the way families cope emotionally with their child’s disability will be personal to them. Having a supportive partner, family and friends will always be helpful. But partners may find they cope with the news at different times and in different ways. One partner may find the child’s difficulties harder to accept. So it may be important that you and your partner have an opportunity to talk about your feelings to someone else – such as a trusted family member, close friend, professional or organisation such as Relate.

Caring for a child with a learning disability may be particularly challenging for lone parents. One Parent Families is an organisation that gives lone parents a voice. They offer advice and information and have a comprehensive guide book called The Lone Parent Handbook.

“Life revolves around the child with a disability and can take the emphasis off the other children in the family.”

If you’re feeling stressed, getting help with personal assistance for your child may give you some breathing space. Ask your health visitor, social worker or other professional to help organise this, possibly using direct payments (see page 29).

Families may find it’s difficult to do things as a family group. It may be especially hard for parents to share their attention between all the children in the family. Each family member is equally important – a whole family approach to support and information helps everyone including brothers and sisters, grandparents and extended family and friends.

Support for all the family

Partners

The reactions of mothers and fathers to having a disabled child may be different. Also, depending on their work patterns, partners may be involved in different ways with the care and support of their child. In the study some parents said their partners found it hard to know what to say to work colleagues and other people about their child’s disability.

Useful information for fathers includes:

- **Contact a Family** factsheet for fathers.
- Fathers’ zone on the Contact a Family website.
- **Sure Start** – some schemes have projects especially for fathers.
- www.face2facenetwork.org.uk is a website discussion room for parents.
Brothers and sisters
“I don’t know what it would be like to have an ordinary sister, I think I’d rather have Jane.”

Family relationships with brothers and sisters are likely to be the longest lasting for children with learning disabilities. Having a brother or sister can be hard for all children at times, but having a sibling with a learning disability can bring complex and mixed feelings. It may mean being jealous of all the time and attention needed by the disabled child or having to cope with teasing at school. It’s important for all children in the family to feel equally valued. But through their personal experience brothers and sisters often show great empathy and sensitivity towards other people.

Useful resources for brothers and sisters include:
- Local siblings or young carers groups – ask your health visitor or social worker, local library, voluntary organisation or support group.
- Contact a Family factsheet.
- Sibs – an organisation for people who grow up with a brother or sister with special needs or a disability.
- Views from our Shoes: Growing up with a brother or sister with special needs edited by Donald J. Meyer, 1997, published by Woodbine House.

Other family members and friends
Reactions amongst family and friends may be mixed - some will be very supportive; others may feel they don’t understand the child’s difficulties and don’t know how to react or what to say. In some families grandparents provide welcome practical and emotional support. Contact a Family have a useful factsheet for grandparents.

“…People seemed different, too. They did not know how to respond to the new me, so some chose not to respond at all.” Kathy Evans
Getting good support from services and facilities

Support from social services, health and voluntary organisations varies throughout the UK as do the guidelines saying who is entitled to statutory services. There are many national and local organisations offering helplines, practical and emotional support. Some help with information on issues such as education, play or specific conditions (for example, *Down’s Syndrome Association*). If your child does not have a diagnosis *Contact a Family* is a good starting place.

Support groups

Some families find it helpful to get together with others with similar experiences for mutual support. Ask other families or any of the professionals working with you for details of local support groups. Or phone *Contact a Family* for details of organisations and support groups dealing with specific conditions including rare syndromes.

“It’s great having other parents to talk to who know what it’s like. We sit and chat and have a laugh but most of all we understand each other.”
Key workers
Some areas now have key worker schemes run by a multi-agency service. A key worker is someone who co-ordinates services, appointments and other support for you and your child. They should get to know you and your family well and work closely with you.

Ask at your local Child Development Centre, Children’s Centre or social services department if you can have a key worker. The Care Co-ordination Network UK promotes key working or care co-ordination for disabled children and their families throughout the UK. Membership is free to parents.

“There wasn’t much support between birth and access to pre-school opportunities, just friends and family, so some constant professional support would be useful.”

Home Start (in some areas only)
Home Start offers support, friendship and practical help to parents with young children throughout the UK. Trained volunteers, usually parents themselves, visit families at home to offer informal and confidential support. Your Health Visitor or the Children’s Information Service at your council’s Early Years Department can let you know if there is a Home Start in your area.

Sure Start (in some areas only)
Sure Start is the government’s programme in each of the four UK countries to improve the health and well being of families with children from birth until they start school. Some schemes have projects specifically for disabled children. Your Health Visitor or the Children’s Information Service at your council’s Early Years Department can let you know if there is a Sure Start in your area.

What services and support may be available locally
Some or all of these may be available in your area:
- Child Development Centre or Children’s Centre (see page 5)
- Portage or other home educational and support services
- Key worker
- Homestart
- Sure Start
- Counselling
- Early Support Programme (England)
- Training for parents/families
- Social services children’s disability team
  - Carers assessments
  - Sitting schemes
  - Short term care schemes
- Siblings and young carers groups
- Children’s Information Service at your council’s Early Years Department
- Childminders - contact your local Children’s Information Service or the National Childminding Association for local details. Ask if there are childminders specially trained to work with disabled children in your area.

“The Portage worker encouraged me to start attending the Play and Development Centre – I was unsure at first but she encouraged me to try one session. I like to talk to other parents.”
**Early Support Programme**

The **Early Support Programme** is a major new government policy initiative in England that recognises the importance of early support for disabled children under three and their families. It encourages different services to work together with the child’s needs at the centre, including the promotion of the key worker role.

As part of the programme an Early Support Family Pack is available to any family in England with a child with additional needs. You should receive a pack from one of the professionals working with you. You can also download it from the internet at www.espp.org.uk or order it from **Department for Education and skills Publications**.

For equivalent information in Northern Ireland, Scotland and Wales see the Early Years Support useful organisations section on page 32.

**Having a break**

Caring for a child with learning disabilities can be exhausting. One way to ease the stress is to ensure you have a break from time-to-time. This can benefit the whole family – allowing you to share more time with your other children or partner – as well as giving your disabled child a chance to make new friends and do new things.

Some social services departments and voluntary organisations have family-based schemes which link families with a disabled child to families offering short term breaks. Residential short term breaks can be offered but these are rare for children under five years.

**Going on holiday**

A break from day-to-day routine may be a welcome change for some families. Planning ahead about any equipment or other special needs is always advisable. The **Holiday Care Service** offers information and advice for families going on holiday with a disabled child. The **Family Fund** can give grants for holidays or day outings for families who meet their general criteria.

Holiday grants are also available through the Carer’s Grant which is administered by local authority social services departments along with local carers’ organisations.

**Getting around**

Just getting around can be a source of stress if you don’t have your own transport. At three years of age the higher rate mobility component of Disability Living Allowance may be payable to some children with mobility difficulties. The lower rate is payable to other children who meet the criteria at five years of age. See also page 26.

The **Family Fund** can help with modest transport costs and driving lessons for the child’s main carer for families who meet their general criteria.
**Education**

**Pre-school learning and school for very young children**
Like any others, young children with learning disabilities learn best through play. Depending on where you live, specialist services are likely to be available from birth to help your child’s development.

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<thead>
<tr>
<th>All children aged 3-5 years are entitled to a free part-time pre-school place in pre-school education or early years settings. This may include:</th>
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<tr>
<td>■ State nursery schools</td>
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<tr>
<td>■ Nursery classes in state primary schools</td>
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<tr>
<td>■ Nursery classes in a special school</td>
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<tr>
<td>■ Playgroups or pre-schools</td>
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<tr>
<td>■ Opportunity groups for under five’s with additional needs</td>
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<tr>
<td>■ Private nurseries or nursery schools</td>
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<tr>
<td>■ Day nurseries</td>
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<td>■ Reception classes in state primary schools</td>
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For details of local choices contact your Local Education Authority Early Years Development and Childcare Partnership or the local Parent Partnership Service through the local education authority. They can provide information and advice on your child’s special educational needs to help you make informed decisions. They can also put you in touch with an Independent Parental Supporter.

**Home-based learning services**
Most areas will have a home learning service – ask your health visitor, Local Education Authority, Children’s Centre or social services department.

Services that may be offered in your own home include:

- Portage (England and Wales) or other home learning services (see below)
- Specialist teachers from the local authority if your child has a visual or hearing impairment or has multi-sensory impairment

Portage is a home visiting educational service for pre-school children with additional support needs and their families. It will provide a trained Portage worker who will work in partnership with parents. They will work in a fun way to develop the child’s learning, play, communication and activities of everyday living, building on what the child can do. Contact the National Portage Association or the Local Education Authority for more information.

“Portage coming to see you at home is great. There’s a better chance of listening to what they are saying in your own home.”
Inclusion and Special Educational Needs (SEN)

Children who need more help with learning than other children are described by education services as having ‘special educational needs’ (SEN). As far as possible children with special educational needs should be supported in their local playgroups, nurseries and schools.

Parents for Inclusion is a national parent-led organisation who can advise parents about issues relating to their children’s inclusion in school. They have a free telephone helpline staffed by parents. They run workshops and support groups for parents.

The SEN Code of Practice explains in detail how support should be provided for children with special educational needs including your rights as a parent. A free parent’s guide called Special Educational Needs (SEN): A guide for parents and carers is available from Department for Education and Skills Publications. The different levels of support for children’s learning in pre-school and school settings are listed below:

<table>
<thead>
<tr>
<th>Early Years Action</th>
<th>Early Years Action Plus</th>
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<tr>
<td>Is additional help that is arranged by your child’s pre-school.</td>
<td>If your child needs more help than the school can arrange, the next level of support is ‘Early Years Action Plus’ involving outside specialists to help your child’s teachers support your child.</td>
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<tr>
<th>Statement of special educational needs</th>
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<tr>
<td>If the Local Education Authority (LEA) and you as parents agree that a lot of support may be needed for your child to learn, or to access school facilities, the LEA will first carry out a ‘statutory assessment’. The outcome from this will describe your child’s difficulties, the extra support and help they will need and how this will be provided. This is called a ‘statement of special educational needs’. Children do not automatically receive a ‘statement’ so it is really important to make sure that you have as much information as possible to make a strong case for your child.</td>
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<tr>
<th>People to talk to about your child’s learning, pre-school and school</th>
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<tr>
<td>Portage, home learning visitor or specialist teacher</td>
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<tr>
<td>Special Educational Needs Co-ordinator (SENCO) based in all pre-schools and schools</td>
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<tr>
<td>Parent Partnership Service (see page 20)</td>
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<tr>
<td>Children’s Information Service – ask at your local council or see <a href="http://www.childcarelink.gov.uk">www.childcarelink.gov.uk</a></td>
</tr>
<tr>
<td>Your key worker if you have one</td>
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<tr>
<td>One of the national organisations listed on page 32</td>
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<tr>
<td>Parents for Inclusion</td>
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What financial help is there?

Bringing up a child with learning disabilities involves more expense than with most other children. So it's important to make sure you're getting all the financial help you're entitled to. Some benefits are based on your child's needs and are available to anyone regardless of income. Others depend on your income and savings.

Many of the benefits listed in this section can be obtained by contacting the Benefit Enquiry Line on 0800 882200. Don't be afraid to ask for help when completing the forms as they can be quite time consuming. Your health visitor, staff from the child development center or organisations such as the citizens advice bureau, the local Mencap or Carers UK branches can give support.

Looking forward to school

Most children with a learning disability will go to mainstream school, often with additional support. However there are special schools or specialist units attached to mainstream schools in many areas.

When thinking about which pre-school or school your child will go to it's important to:
- think and plan ahead
- get as much information as possible about the available choices
- talk to the professionals who know your child best
- talk to other parents about their experiences
- visit any potential pre-school settings or schools before making a decision.

[Image of children and adults talking and reading]
Disability Living Allowance (DLA)
This is made up of two parts:
- **Care component** for children who need extra attention or supervision.
  This is paid at three different rates depending on how much help the child needs.
- **Mobility component** for children who need help with getting around.
  This is payable at two different rates depending on the nature of the mobility problem. The higher rate can be paid from age three and the lower rate from age five.

Your child may qualify for either or both of these components.
Give as much information as possible about the care and support you give your child. It will also help if your doctor gives information to support your claim.

Carer’s Allowance
You may be eligible for the Carer’s Allowance if your child gets the care component of DLA at the middle or higher rate and any earnings are within the current limits.

Disabled Child Premium and Carer Premium with Income Support
Income Support is a means-tested benefit to help individuals or families on a low income and with savings below the current limit. If you get Income Support and your child gets Disability Living Allowance you will get an additional Disabled Child Premium with your Income Support. If you get Carer’s Allowance you will get an additional weekly Carer Premium paid with your Income Support.

Transport costs to visit your child in hospital
You may be entitled to a Community Care Grant (see below) to pay for fares to visit your child in hospital.

Transport costs to hospital for treatment
If you are on Income Support or income-based Job Seeker’s Allowance, you can claim help with travel costs to and from hospital for NHS treatment when escorting your child. You can get a refund of your fares directly from the hospital if you can prove you are in receipt of benefits.

If you are on a low income you may still be able to get help. Ask at the hospital.

Community Care Grant or loan if you get Income Support
You may be entitled to a Community Care Grant from the Social Fund if you need help to pay for something you can’t afford from your weekly benefit, such as fares to visit your child in hospital, bedding, clothing, laundry or safety items. Some of these payments are discretionary which means you are not automatically entitled to them. You may be offered a budgeting loan instead of a grant, which you will have to pay back over an agreed time.
Tax credits
If you or your partner go out to work you may be eligible for Child Tax Credit and/or Working Tax Credit. Both have extra payments for a child who gets Disability Living Allowance.

Other government funds

Family Fund
The Family Fund, funded by the four UK governments, gives grants to families with a severely disabled or seriously ill child who comes within their disability and income criteria. Ask for anything that will help to make life easier as long as it is related to your child’s care needs; for example, washing machine, tumble dryer, holidays, outings, driving lessons, clothing, bedding, play equipment and so on. For more information contact the Family Fund.

Road Tax Exemption (Vehicle Excise Duty)
If your child gets the higher rate Disability Living Allowance mobility component, you should have been sent a Vehicle Excise Duty (VED) exemption form by the Department of Work and Pensions. You just need to fill it in and return it to the address on the form. Or write to: Disability Living Allowance Unit (VED), Warbreck House, Warbreck Hill, Blackpool FY2 0YE.

Your local authority

Direct payments
Direct payments are a way of giving parents money to organise and pay for services their child has been assessed as needing, instead of the local authority arranging them on their behalf.

Direct payment schemes can advise about employing personal assistants or arranging other services with direct payments. Ask at your local social services office. There is also a useful, free booklet called A parent’s guide to direct payments available from Department of Health Publications.

Council Tax disability reduction
This is money off your council tax (rates in Northern Ireland) you may get if your home is specially adapted for your disabled son or daughter. For example, if your child needs a ground floor bedroom or bathroom, or an extra room for wheelchair accessibility. Ask for details at your local council office.

Disabled Facilities Grants
These grants are available towards the costs of adaptations to housing to make it suitable for a disabled person. It could include improving access, or adapting a bathroom, for example. Ask at your social services or housing department for details. Your child’s occupational therapist will be able to advise you.
Health service

Free nappies
Free nappies and other continence equipment are available through the health service, from around age three years, although this varies throughout the UK. Ask your health visitor or GP about what help there is locally.

Other

Funderfinder
Funderfinder is a database of charitable trusts that give grants to individuals (for equipment for example) and organisations. Ask at your local library or Citizens Advice Bureau.

Blue Badge Parking Scheme
The Blue Badge Scheme provides parking concessions for people with severe walking difficulties who travel either as drivers or passengers. You can get a Blue Badge from your local social services department if your child receives the higher rate of DLA mobility (see page 26). The Scheme does not operate in some central London boroughs. Further details from the Department for Transport website at www.dft.gov.uk or phone 020 7944 2914.

Who to contact for more information
The benefits system is complicated so always get advice about claiming if you are unsure. The following organisations can help:

- Benefit Enquiry Line – 0800 88 22 00 or Minicom: 0800 24 33 55
- Department of Works and Pensions – 020 7712 2171
- Contact a Family Helpline – ask for their factsheet ‘Benefits, Tax Credits and other financial assistance’
- Citizens Advice Bureau
- Local welfare rights adviser – ask at your local council offices
- Disability Alliance Rights Advice Line – 020 7247 8763.

Parents usually have both dreams and concerns for their young children. Getting the right support and information can help work towards the dreams and manage the concerns. It can help if everyone focuses on nurturing the child’s gifts and abilities.

“Socially, she is streets ahead and possesses a remarkable knack of engaging people.” Kathy Evans
## Useful organisations

### Brothers and sisters
- **Sibs**
  - Tel: 01535 645453 or 01904 550029
  - www.sibs.org.uk

### Childcare
- **National Childminding Association**
  - Tel Information line: 0800 169 4486
  - www.ncma.org.uk

### Communication
- **I CAN**
  - Tel: 0845 123 2303
  - www.enquire.org.uk
  - Provides independent advice and information to families of children with disabilities who need extra help at school.

### Early Years Support
- **Early Support Programme (England only)**
  - Tel: 0870 000 2288
  - www.surestart.gov.uk

### Department for Education
- **Northern Ireland Parents’ Special Educational Needs website**
  - www.deni.gov.uk/parents/special_ed_needs/guide_parents/d_under.htm

### Parentzone website (Scotland)
- www.parentzonescotland.gov.uk/specialneeds/index.asp

### Enquire (Scotland)
- Tel: 0845 123 2303
- www.enquire.org.uk
- Provides independent advice and information to families of children with disabilities who need extra help at school.

### Parentsnet website (Wales)
- www.learning.wales.gov.uk/parents

### Home Start
- Free information line: 0800 68 63 68
- www.home-start.org.uk

### Sure Start
- Tel: 0870 000 2288
- www.surestart.gov.uk

### Equipment
- **Disabled Living Foundation**
  - Helpline: 0845 130 9177
  - Minicom: 020 7432 8009
  - www.dlf.org.uk

### Disabled Living Centres Council
- Tel: 0161 834 1044 or 0870 770 2866
- www.dlcc.org.uk/

### General
- **Carers UK**
  - Tel: 0808 808 7777
  - www.carersuk.org

### Contact a Family
- Free Helpline: 0808 808 3555
- www.cafamily.org.uk

### Council for Disabled Children
- Tel: 020 7843 1900
- www.ncb.org.uk

### Disability Rights Commission
- Helpline: 08457 622 633
- Minicom: 08457 622 644
- www.drc.gov.uk

### One Parent Families
- Helpline: 0800 018 5026
- www.oneparentfamilies.org.uk

### Holidays
- **Holiday Care**
  - Information line: 0845 124 9971
  - Minicom: 0845 124 9976
  - www.holidaycare.org.uk

### Information
- **Citizens Advice Bureau (CAB)**
  - NACAB (National Association of Citizens Advice Bureaux)
  - Tel: 020 7833 2181
  - www.nacab.org.uk

### Department of Education and Skills Publications
- Tel: 0845 60 222 60
- Email: dfes@prolog.uk.com

### Department of Health Publications
- Tel: 08701 555455
- Email: doh@prolog.uk.com

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**Holidays**

- **Holiday Care**
  - Information line: 0845 124 9971
  - Minicom: 0845 124 9976
  - [www.holidaycare.org.uk](http://www.holidaycare.org.uk)

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**Department of Education and Skills Publications**

- Tel: 0845 60 222 60
- Email: dfes@prolog.uk.com

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**Department of Health Publications**

- Tel: 08701 555455
- Email: doh@prolog.uk.com
National Electronic Library for Health
www.nelh.nhs.uk
Is an excellent source of the most up-to-date information resources on child health

Key working and early support
Care Co-ordination Network UK UK
Tel: 01904 321959
www.york.ac.uk/inst/spru/ccnuk.htm

Money
Benefit Enquiry Line for People with Disabilities: 0800 88 22 00
Minicom: 0800 24 33 55
In Northern Ireland: 0800 22 06 74
Minicom: 0800 24 37 87

Disability Alliance
Tel/Minicom: 020 7247 8776
www.disabilityalliance.org

Family Fund
Tel: 0845 130 45 42
www.familyfund.org.uk

National organisations
BILD (British Institute of Learning Disabilities)
Tel: 01562 723010
www.bild.org.uk

Capability Scotland
Tel: 0131 313 5510
www.capability-scotland.org.uk
Scotland’s leading disability organisation.

Cedar Foundation (Northern Ireland)
Tel: 028 9066 6188
www.cedar-foundation.org
Provides support to people with disabilities to be fully included in their communities.

Down’s Syndrome Association
Tel: 0845 230 0372
www.downs-syndrome.org.uk

Down’s Heart Group
Tel: 0845 166 8061
www.dhg.org.uk
Offers support and information to families who have a member with Down’s Syndrome and congenital heart defects

Enable (Scotland)
Tel: 0141 226 4541
www.enable.org.uk
Scotland’s leading learning disability charity.

Foundation for People with Learning Disabilities
Tel: 020 7802 0300
www.learningdisabilities.org.uk

The Fragile X Society
Tel: 01371 875100
www.fragilex.org.uk

Mencap
Free Learning Disability Helpline: 0808 808 1111
Minicom: 0808 808 8181
www.mencap.org.uk

National Autistic Society
Helpline: 0845 070 4004
www.nas.org.uk

Rett Syndrome Association
Tel: 0870 770 3266
www.rettsyndrome.org.uk

Scope Early Years
(England and Wales)
Tel: 01432 370860
www.scope.org.uk/earlyyears

Scope National Office
(England and Wales)
CP Helpline: 0808 800 3333
www.scope.org.uk

Unique
Tel: 01883 330766
www.rarechromo.org
A rare chromosome disorder support group.

Parents with Disabilities Change
Tel: 0113 243 0202
www.changepeople.co.uk
Supports the rights of parents with learning disabilities to be parents

Circles Network
Tel: 0117 373 7010
www.circlesnetwork.org.uk/crowley_house
The Crowley House Project supports disabled parents at risk of social exclusion

Play
Action for Leisure
Tel: 01926 650195
www.actionforleisure.org.uk
Promoting play and leisure with and for disabled children and adults.

National Association of Toy and Leisure Libraries
Tel: 020 7255 4600
www.natll.org.uk
Pre school learning
and Education
Advisory Centre for Education
(ACE)
Advice line: 0808 800 5793
www.ace-ed.org.uk

IPSEA (Independent Panel for
Special Education Advice)
Tel: England and Wales
0800 0184 016,
N.Ireland 0232 705654,
Scotland 0131 665 4396
www.ipsea.org.uk

Enquire (Scotland)
Advice line: 0845 123 2303
www.childreninscotland.org.uk

National Portage Association
Tel: 01935 471 641
www.portage.org.uk

Network 81
Helpline: 0870 770 3306
www.network81.co.uk
A national network of parents
working towards properly
resourced inclusive education for
children with special needs

Parents for Inclusion
Helpline: 0800 652 3145
www.parentsforinclusion.org

National Parent Partnership
Network
Tel: 0207 843 6058
www.parentpartnership.org.uk

Pre-school Learning Alliance
Tel: 01954 232327
www.pre-school.org.uk

Working
Working Families
Tel: 020 7253 7243
www.workingfamilies.org.uk

www.ace-ed.org.uk

www.ipsea.org.uk

www.childreninscotland.org.uk

www.portage.org.uk

www.network81.co.uk

www.parentsforinclusion.org

www.pre-school.org.uk

www.workingfamilies.org.uk
We use research and projects to promote the rights of people with learning disabilities and their families.

We do this by:

- Identifying work that is needed to overcome barriers to social inclusion and full citizenship.
- Communicating our knowledge to a wide range of people.
- Turning research into practical solutions that make a real difference to people’s lives now and in the future.

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Email: fpld@fpld.org.uk
www.learningdisabilities.org.uk

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