



# **After diagnosis: What happens next? The Early Years**



**PLEASE USE THIS PAGE TO RECORD YOUR CHILD'S DETAILS  
FOR REFERENCE**

Name:

Date of Birth:

Diagnosis:

Array/karyotype result:

**Key phone numbers:**

Doctor:

Paediatrician:

Other:

**Notes:**

**This Unique guide has been written to help signpost families whose children have just been diagnosed with either global developmental delay and/or a rare chromosome disorder. The guide is aimed at parents whose children are 4 years and under (pre-school age). It could equally be of use to parents whose children have no recognised diagnosis other than that of developmental delay. This guide is provided as a basic information guide to services available to families with a young child with additional needs whether they be mildly, moderately or severely affected either mentally, physically or both.**



Diagnosed at 1 year

If your child has been diagnosed as having developmental delay, the first thing you will probably ask yourself is why? You will probably go through a whole range of emotions, like sadness, shock and a feeling of being very unsure. A diagnosis can be important as it may lead to you getting the right services for them, such as healthcare, therapies and education.

Most parents want a diagnosis for their child; at the very least it is an explanation of why your child isn't developing at the same rate as another child of the same age. You know that something isn't quite right, and you want to know why. In some cases, that

diagnosis helps you to know what problems your child is going to face in life and how to find help for your child. Leading up to diagnosis and getting the correct diagnosis for your child can be a very difficult time. This guide should help you to understand what happens after your child has been diagnosed with a developmental delay. We have included information regardless of whether your child is mildly, moderately or severely affected. So some information might not be relevant to all children.

### **Chromosome disorders**

Chromosome disorders can be so rare that many people won't have heard of them. This can lead to frustration when trying to explain about your child. Once a diagnosis has been received many families continue to feel isolated and lost. This can be because their child's disorder is made up of a series of numbers and letters that can be difficult for them to understand, let alone trying to explain them to other people. Many go through different emotions such as guilt, loss and sadness and coping with these emotions as well as trying to cope with your child's disorder and adjusting your own family life can be very hard. Every parent wants to do the very best they can for their child. Knowing where to start if your child has been diagnosed with developmental delay as a baby or young child can be difficult. If the diagnosis of a rare chromosome disorder comes later on in a child's life, it can be equally difficult.

## Questions

You will have lots of questions, some will easily come to mind, but you may ask yourself questions like these:

- \* How can I get help for my child?
- \* I have a job. Will I have to give up my career to look after my child?
- \* Will I be able to claim any benefits?
- \* Where will he/she go to school?

This guide has been designed to give you basic information on where you can obtain further advice on bringing up a young child with developmental delay. The early years are the really important ones. Getting the right support will help your child and your family to live as happy and fulfilling lives as possible. For answers relating to the questions above, please read on.

## Development - How can I get help for my child?

If you are worried about your child's development you should contact your family doctor (GP) or health visitor who will be able to talk to you about your concerns and if necessary refer your child to other services.

These services might include:

- \* Therapies: speech and language therapy, physiotherapy and occupational therapy
- \* Health visitors and community nurses
- \* Child and Adolescent Mental Health Services (CAMHS)
- \* Specialist continence services
- \* Eye and hearing services
- \* Specialist children's community nurses (covering specific health issues such as epilepsy, tube feeding and complex care needs)

**Child Development Centres** house a range of professionals who can assess and treat children with a wide variety of problems including physical disabilities, learning difficulties, developmental delay, health problems such as epilepsy and language and communication difficulties.

**Paediatric Occupational Therapists** work with children to make the most of their potential in specific areas and to increase their independence at home, school and in their recreational activities.

**Paediatric Physiotherapists** assess and treat children to improve their physical skills, including their posture and mobility.

**Paediatric Speech and Language Therapists** assess and treat children's speech and language, including the use of manual signs and symbols, and can also advise where children have chewing or swallowing difficulties.



Child development



Early support

**Early Support** - is for parents and carers of disabled children aged five and under. It brings together all the services and support available from different agencies. This makes it easier for families to co-ordinate their child's health, education and social care needs. Some families will have a key worker who provides advice and support and can help negotiate the system. A key worker may be needed more at some times than at others. Families can decide what works best for them. Early Support has developed a wide range of resources, training courses and workshops.

The government website [www.directgov.uk](http://www.directgov.uk) has a very useful early support family file that you can download and fill in. The early support family file allows parents and carers to share information about their child with the professionals they meet, without having to say the same things to every new person. You can also use the family file to write down important information and the names of professionals you meet.

### **Children's Centres**

Children's centres provide a variety of advice, information and support for parents and carers. You can locate your nearest Sure Start children's centre by contacting your local Family Information Service on 08002 346 346. A children's centre is different from a child development centre (health). Parents can self refer.

### **Children with Disabilities Team**

The Children with Disabilities Team (CDT) is a specialist service that aims to provide parents with support so that they can, whenever possible, bring up their child at home, leading as full and independent a life as possible. You can contact the Children with Disabilities Team directly by looking under Social and Caring Services in your phone directory or on your local/county council website. As a parent you have the right to ask for your child's needs to be assessed by the social services department. In Scotland this is known as the social work department and in Northern Ireland it is the health and social services trust. You also have the right to ask for an assessment for yourself. This is known as a carer's assessment. An assessment could lead to services for your disabled child being provided or services to help you as their carer. Assessments are the first stage in sorting out what help you need from social services. A social worker will carry out this assessment and organise any care and support that is agreed. The social worker will probably visit you at home to talk about what support and services you think you need.

**Disability Rights Handbook** Produced by the Disability Alliance. This handbook contains comprehensive and up-to-date information about benefits. Disability Alliance Fact Sheets include information and advice on benefits, tax credits, social care and other disability-related issues [www.disabilityalliance.org](http://www.disabilityalliance.org)

## Education - Where will he/she go to school?

### *Worries about your child's development*

Your child learns through being with other people and exploring the world around them. However, some children have more difficulties than most children of their age with:

- \* communication
- \* understanding and learning
- \* sensory and physical development
- \* behaviour or relating to other people.



Children with this type of learning difficulty or disability are said to have 'special educational needs'.

**Special Educational Needs (SEN)** the term 'special educational needs' (SEN) has a legal definition, referring to children who have learning difficulties or disabilities that make it harder for them to learn or access education than most children of the same age. Once a child aged three to five years has been identified as having special educational needs an individual educational plan (IEP) will be drawn up that includes activities to help them learn and progress. This first stage is called Early Years Action. The majority of pupils with special educational needs will have an IEP. The IEP is written by the school and records the key short-term targets and strategies. In some areas there may be special needs playgroups, often known as Opportunity groups, many of which are independently run, Contact your health visitor or local council to find out if there is one near you.

**Special Educational Needs: A guide for parents and carers** The 2009 edition is available free of charge from the Department for Education. Tel: 0845 60 222 60 or download a copy from [www.teachernet.gov.uk/docbank/index.cfm?id=3755](http://www.teachernet.gov.uk/docbank/index.cfm?id=3755) or [tinyurl.com/38qt2wf](http://tinyurl.com/38qt2wf)

**National Portage Association** is a free home-visiting educational service for pre-school children with additional support needs and their families. Parents can self refer. Tel: 0121 244 1807 [www.portage.org.uk](http://www.portage.org.uk)

**The Alliance for Inclusive Education** is a campaigning group promoting inclusive education for all children. Tel: 0207 737 6030 [www.allfie.org.uk/pages/about/index.html](http://www.allfie.org.uk/pages/about/index.html)

**The British Association for Early Childhood Education** provide useful resources and downloadable publications. Tel: 020 7539 5400 [www.early-education.org.uk](http://www.early-education.org.uk)

**Citizens Advice Bureau** England and Wales: [www.adviceguide.org.uk](http://www.adviceguide.org.uk)  
Northern Ireland: [www.citizensadvice.co.uk](http://www.citizensadvice.co.uk) Scotland: [www.cas.org.uk](http://www.cas.org.uk)

**Contact a Family** UK-wide charity providing advice, information and support to the parents of all disabled children. Helpline: 0808 808 3555 [www.cafamily.org.uk](http://www.cafamily.org.uk)

### **Work** - I have a job, Will I have to give up my career to look after my child?

Looking after a child with additional needs and working can be very difficult; it can put a huge strain on family life. You may have an arrangement with a family member to care for your child whilst you work, or you may have them looked after by a child minder or agency. If you feel you cannot work and you apply for Disability Living Allowance (DLA) for your child (see below) you could apply for Carer's Allowance. If you are aged 16+ and your child receives the middle or high rate care component of DLA and you are looking after your child for at least 35 hours a week, you will then qualify for Carer's Allowance. You cannot get Carer's Allowance if you are in full-time education with 21 hours or more a week of supervised study, or earn more than £100 a week after certain deductions have been made - for example Income Tax. Carer's allowance is not affected by any savings you may have. For more information visit [www.directgov.uk](http://www.directgov.uk) or look in the benefits section of this information guide for telephone numbers.

**Working Families** is the UK's leading work-life balance organisation. They help working parents and carers and their employers find a better balance between responsibilities at home and work. They have a free Legal Helpline which gives parents and carers legal and in-work benefits advice, as well as helping them to negotiate the flexible hours they want. They have information, videos and interactive guides for working mothers, fathers and carers on their employment rights, Tax credits and in-work benefits, maternity and paternity leave and flexible working options. This includes a section especially for parents of disabled children. Working Families has created *Waving not drowning* for parents of disabled children. This is a project for parents who work, or want to work and who have children with disabilities. It provides a network, a newsletter and a dedicated helpline on 020 7017 0072. The helpline is open on Wednesdays, Thursdays and Fridays 9.30am - 1.00pm and 2.00pm - 4.30pm. For free advice on tax credits, flexible working and rights at work, parents can also call a free helpline on 0800 013 0313 (Mon-Fri) [www.workingfamilies.org.uk](http://www.workingfamilies.org.uk)

### **Benefits** - Will I be able to claim any benefits?

The main benefit that you can claim for your child is Disability Living Allowance (DLA). DLA is in two parts - the care component which can be claimed before the age of 3 months (low, middle and high rate) and the mobility component (lower and higher rate). You may be able to get just one component or both depending on age and eligibility. The mobility component can be claimed from the age of 3 years if eligible. Your child must need a lot more help or supervision than other children of the same age. Call the Benefit Enquiry Line or check out the website for more information on eligibility. They can also arrange for someone to help you fill out the form if required. Tel: 0800 88 22 00. The Benefit Enquiry Line is open 8.30 am-6.30 pm Monday to Friday and 9.00 am-1.00 pm Saturday [tinyurl.com/cklyq4](http://tinyurl.com/cklyq4)

The main UK government website for benefits information and claim forms can be found at: [www.direct.gov.uk](http://www.direct.gov.uk)

**Cerebra guide to DLA** follow this link to a step-by-step guide to claiming Disability Living Allowance for children under 16 with brain-related conditions  
[www.cerebra.org.uk](http://www.cerebra.org.uk)

**The National Autistic Society** also produce guides to claiming DLA for children with a diagnosis of Autism Tel: 020 7833 2299 [www.autism.org.uk](http://www.autism.org.uk)

**Disability Living Allowance** helpline: 0845 712 3456

**Carer's allowance** is a taxable benefit for people who look after someone who is disabled. You do not have to be related to, or live with, the person that you care for. You may be eligible for the Carer's allowance if you are aged 16 or over and spend at least 35 hours a week caring for a disabled person. You can only get Carers allowance if your child is receiving middle or high rate care component of DLA. Carers allowance helpline: 01253 856123

A Carer's credit is available for carers to build up qualifying rights to a state pension. Benefit Enquiry Line: 0800 88 22 00

### Other useful benefits website links:

#### **Citizens Advice Bureau**

[www.adviceguide.org.uk/index/life/benefits.htm](http://www.adviceguide.org.uk/index/life/benefits.htm)

#### **Benefits and work**

[www.benefitsandwork.co.uk/home](http://www.benefitsandwork.co.uk/home)

**Turn2Us**, a website that helps you to calculate any tax credits, reductions in council tax, road tax exemption and benefits you may be entitled to

[www.entitledto.co.uk](http://www.entitledto.co.uk)



#### **Handy benefits calculator**

[www.entitledto.co.uk/default.aspx](http://www.entitledto.co.uk/default.aspx)

**Benefits Now**, a benefits and health information service, which allows you to assess yourself for various benefits [www.benefitsnow.co.uk](http://www.benefitsnow.co.uk)

**Disabled facilities grants (DFG)** This is a local council grant to help towards the cost of adapting your home to enable you to continue living there. Contact your local council for more information

Please note: at the time of writing this guide, government changes to the welfare system are possible. This guide will be updated occasionally, but between updates changes may occur. Please refer to the government website as mentioned above to check for any changes.

## Getting a break



**Short breaks** increase the quality of life for disabled children and their families by giving a break from caring for parents and carers or an activity for a child with his/her peers. They provide disabled children with opportunities to meet new people, make new friends and experience different activities. Many families will have extended family and friends that can help to look after your child so that you can have a break, but many will be less fortunate. You can either contact your local Child Disability Team direct, or ask your GP or paediatrician to refer you.

### Taking a break

**Sitting service** In some areas a sitting service might be provided. Contact your local council or carers' support service to see if there is one of these schemes near you.

**Crossroads for carers** is a charity providing 'in home care' and support to carers in the UK. They provide volunteer carers to give the regular carer time off to do things on their own and have a break. There is a scheme finder for people to find services in their area. Tel: 0845 450 0350 [www.crossroads.org.uk](http://www.crossroads.org.uk)

Scotland [www.crossroads-scotland.co.uk](http://www.crossroads-scotland.co.uk)

Northern Ireland [www.crossroadscare.co.uk](http://www.crossroadscare.co.uk)

**Direct payments** allow you to arrange care and services yourself instead of receiving them directly from your local council. They can be made to parents and carers aged 16 or over. This includes people with parental responsibility for a disabled child. Advice on all of the above including childcare can be obtained from your Social Service child disability team (CDT) or Sure Start children's centre.

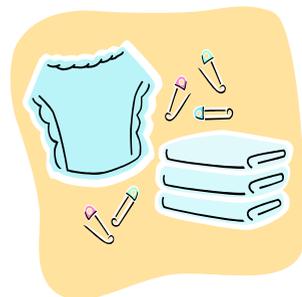
## Nappies

**Nappies and incontinence pads** If your child is not yet toilet-trained when he/she reaches a certain age, you will be eligible for free nappies/pads from your local Primary Care Trust. In most areas this is around the age of 4 but can vary.

Eligibility criteria in terms of age and number of pads/nappies allocated a day differ from trust to trust.

You can get a referral to your local PCT's continence service through your GP, health visitor, paediatrician or school nurse.

**PromoCon** offers information, publications and advice on continence products, Helpline: 0161 834 2001  
Mon-Fri 10am-3pm [www.promocon.co.uk](http://www.promocon.co.uk)



## Carers

A carer is someone of any age who provides unpaid support to family or friends who could not manage without this help. This could be caring for a child, partner, other relative or friend who is ill, frail, disabled or has mental health problems. To find out about your local carers' support service, contact: Carers UK [www.carersuk.org](http://www.carersuk.org) Carers Line: 0808 808 7777 or The Princess Royal Trust for carers [www.carers.org.uk](http://www.carers.org.uk) England Tel: 0844 800 4361 Wales Tel: 02920 221788 Scotland Tel: 0141 221 5066



**Blue badge** The Blue Badge Scheme provides a range of parking concessions for people with severe mobility problems over the age of 2 years, who have difficulty using public transport. The badge enables holders to park close to where they need to go. The scheme operates throughout the UK, and is administered by local authorities who deal with applications and issue badges. A parent of a child who is less than two years old may apply for a badge for their child if the child has a specific medical condition which means that they must always be accompanied by bulky medical equipment which cannot be carried around without great difficulty and/or need to be kept near a vehicle at all times, so that they can, if necessary, be treated in the vehicle, or quickly driven to a place where they can be treated, such as a hospital.



The Blue Badge advice line is provided by the Community Transport Association. The Blue Badge advice line can offer general information and advice, as well as details about using the Blue Badge abroad, toll concessions and more. Tel: 020 7944 2914 or 0161 367 0009 Email: [blue.badge@dft.gsi.gov.uk](mailto:blue.badge@dft.gsi.gov.uk) or contact your local or county council for an application form. You will need to provide two passport sized photographs, pay a small administration fee and ask your doctor to fill in part of the form.

**RADAR**, the disability network, is the UK's largest disability campaigning organisation. RADAR produces a wide range of publications and runs the National Key Scheme providing keys for disabled toilets around the country. Tel: 020 7250 3222 Email: [radar@radar.org.uk](mailto:radar@radar.org.uk) [www.radar.org.uk](http://www.radar.org.uk)



**The Changing Places Consortium** has launched its campaign on behalf of those people who cannot use standard accessible toilets. They need Changing Places toilets with enough space and the right equipment. For all enquiries in England, Wales and Northern Ireland Tel: 020 7696 6019 For all enquiries in Scotland contact Tel: 01382 385 154 [www.changing-places.org](http://www.changing-places.org)



## Other useful contacts:

**Family Fund** is an independent grant-giving organisation helping low income families who are caring for a severely disabled child. Grants are discretionary.

Tel: 0845 130 4542 [www.familyfund.org.uk](http://www.familyfund.org.uk)

**Cerebra** is a charity set up to help improve the lives of children with brain-related conditions through researching, educating and directly supporting children and their carers. They have a grant scheme, Speech and Language Therapy voucher scheme, Wills and Trusts Scheme, sleep service, stress helpline, an innovation centre and a postal lending library. They also offer e-learning courses to parents.

Parent support helpline: 0800 328 1159 [www.cerebra.org.uk](http://www.cerebra.org.uk)

**Fledglings** is a not-for-profit organisation, which helps parents and carers of a child with special needs of any kind to find simple, affordable solutions to practical problems. They offer a free product search service to locate toys, clothing, developmental aids and other items which may not be easily available, or those designed especially for children with special needs. Tel: 0845 458 1124 [www.fledglings.org.uk](http://www.fledglings.org.uk)

**Netbuddy** online forum and sharing of practical tips and ideas by parents, carers, teachers and therapists, people with everyday experience of learning disability  
[www.netbuddy.org.uk](http://www.netbuddy.org.uk)

**Motability** operates a scheme to help disabled people and their families become more mobile. (Conditions apply). Tel: 0845 456 4566 [www.motability.co.uk](http://www.motability.co.uk)

**Makaton Vocabulary Development Project** was developed in the 1970s to help people with learning disability to communicate. It is now widely used with a variety of children with communication difficulties. Tel: 01276 606760 [www.makaton.org.uk](http://www.makaton.org.uk)

**Pyramid Educational Consultants UK Ltd** is the source for PECS, the Picture Exchange Communication System: an alternative/augmentative communication system that teaches students to initiate spontaneous communication in a social context. Tel: 01273 609555 [www.pecs.org.uk](http://www.pecs.org.uk)

**Netmums** is a family of local websites for anyone involved in caring for young children. Netmums is a members' only site. Membership is free [www.netmums.com](http://www.netmums.com)

**Disabled Living Foundation** impartial advice, information and training about daily living aids. Helpline: 0845 130 9177 Mon-Fri 10am-4pm [www.dlf.org.uk](http://www.dlf.org.uk)

**Mencap** works exclusively with and for people with a learning disability, their families and carers. Tel: 020 7454 0454 [www.mencap.org.uk](http://www.mencap.org.uk)



## Support and Information

**Rare Chromosome Disorder  
Support Group,  
PO Box 2189,  
Caterham,  
Surrey CR3 5GN,  
UK**

Tel/Fax: **+44(0)1883 330766**  
info@rarechromo.org  
**www.rarechromo.org**

- ◆ *Unique* has a public fan page on Facebook [tinyurl.com/y9yrkoj](http://tinyurl.com/y9yrkoj)
- ◆ Unique chromosome network cafe (closed group for registered Unique members) <http://tinyurl.com/62hwvnb>

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