

contact a family
for families with disabled children

in contact



The newsletter of Contact a Family Northern Ireland
www.cafamily.org.uk/nireland

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ADVICE • INFORMATION • LINKING

NEW INFORMATION TO HELP FAMILIES WITH DISABLED CHILDREN MANAGE DEBT

Average incomes for families with disabled children are almost one quarter below the UK average, and yet it costs up to three times as much to bring up a disabled child, compared to other children. Unsurprisingly, says charity Contact a Family Northern Ireland, many of these families struggle to make ends meet, and often find themselves in debt.

It's to help these families that, thanks to funding from Inland Revenue, the charity has produced a brand new factsheet, entitled "**Dealing with Debt – Northern Ireland**".

Clear and easy to use, the factsheet sets out the practical steps families can take to tackle their debts.

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Firstly, it explains, you should list everything you owe, next, sort your debts into priority debts i.e. those with serious consequences like having your home repossessed, and non-priority debts, and then work out what you can afford to repay each week or month. A handy income and expenditure chart is included to help with this stage of the process.

Other sections explain the consequences of not repaying various types of debt, set out what steps creditors can take to enforce repayment, and outline the legal process.

The factsheet also suggests ways of increasing household income, for instance, ensuring you claim for all benefits associated with caring for a disabled child.

A benefits check from Contact a Family's helpline can help with this.

Finally, the factsheet recommends that, if possible, people seek the help of a money adviser. Not only will an adviser help you draw up a repayment plan, but they can negotiate with creditors on your behalf. A list of organisations providing this free and impartial service is included.

For a copy of the "**Dealing with Debt – Northern Ireland**" factsheet, telephone Contact a Family Northern Ireland on 028 9262 7552.

AN OVERVIEW OF THE SPECIAL EDUCATIONAL NEEDS AND DISABILITY ORDER (NI) 2005

A new law relating to disability discrimination in education came into effect on the 1st September 2005. The new law is called the Special Educational Needs and Disability (Northern Ireland) Order 2005 (also known as SENDO). The new law applies to schools, education and library boards, universities and colleges including teacher training and agricultural colleges.

SEUDO aims to

- Introduce disability discrimination law to the education sector in Northern Ireland
- Strengthen the rights of children with Special Educational Needs to be educated in mainstream education.

The legal responsibility for ensuring that discrimination does not take place lies with the **'Responsible Body'**

- Responsible Bodies in the school sector include Boards of Governors/Trustees or the owner of the school and Education and Library Boards.
- Responsible Bodies in the Further and Higher Education sector include governing and managing bodies and in certain circumstances the Department of Employment and Learning/Department of Agriculture and Rural Development.

Disability Discrimination under SENDO

SEUDO places new duties on bodies responsible for the provision of education and associated services, admissions and expulsions. The new duties include:

- Not to treat disabled pupils/students and prospective pupils/students **less favourably** (for a reason relating to their disability) than it treats, or would treat, a person to whom that reason does not or would not apply (unless justified).
- To make **'reasonable adjustments'** to all policies, procedures and practices to ensure that a disabled pupil/student is not placed at a substantial disadvantage compared to pupils/students who are not disabled.
- This duty is both an anticipatory duty and a reactive duty. This means that educational institutions make changes, where reasonable, to how education is delivered both in response to the individual needs of students and proactively for disabled students generally.



PARENT PARTICIPATION SURVEY

Many thanks to all the parents who returned the completed survey questionnaires.

Out of the 500 sent out there were 87 returned completed.

We are now in the process of analysing the information and will hopefully have the full report completed by summer 2006.

There are a few questions that have arisen out of the survey so if you are a parent who has participated in child health services in any way, living in the Southern Health & Social Services Board area we would love to expand on some of the information, so please give us a phone!

Many thanks also to Sainsbury's PLC who were kind enough to supply vouchers to the first 20 parents who returned their questionnaires.

REVIEW OF PUBLIC ADMINISTRATION

On 22 November 2005, Minister for Health Shaun Woodward announced the reorganisation of Northern Ireland's Health and Social Services (HPSS), as part of the Review of Public Administration (RPA).

He said: "The current organisation of health and social services is too cumbersome, too bureaucratic, and inefficient. The case for reform is very strong. Faster and better treatment. Efficiency in the service. Greater patient safety. Removing inequality.

"Why do we need 19 Trusts? Why four Boards? The total management cost of running existing bodies, including Boards and Trusts, is £155 million every year. If I could take just one million out of that, I could put every MS patient now on a waiting list for drugs-off that list."

To find out more about the reform of Northern Ireland's HPSS view the press release entitled: [Woodward Reforms Health Service Structure to Put Patients First.](#)

HOW DO I GET HELP?

Carers Northern Ireland have produced a very informative booklet for all carers entitled 'How do I get help?' It will give you straight forward information on community care assessments, carers assessments, direct payments, the Independent Living Fund and how to make a complaint if you are not happy with the way social services have dealt with you.

To get a booklet contact Carers Northern Ireland Tel 028 9043 9843.



Guide for claiming Disability Living Allowance

Could you be claiming Disability Living Allowance (DLA) for a child under 16 years of age? Your child doesn't have to be disabled to claim DLA. If, because of a brain related condition, they have greater difficulty with everyday activities than other children of the same age then they may be eligible. So, if you've never made a claim or you've been turned down in the past, please take the Two Minute Test to find out if your child could be eligible for DLA.

Cerebra have produced a 68 page, step-by-step guide to claiming DLA for children under 16 years of age who have a brain related condition. The guide takes readers through the claim pack, box-by-box, and contains lots of useful hints and tips on: preparing for a medical visit; obtaining supporting evidence; keeping a DLA diary and much more.

You can download a copy of the DLA guide from the link below. It is currently available as a .pdf file. The .pdf file is quite small and relatively quick to download, but you will need software called Adobe Acrobat to open it. If you don't already have Adobe Acrobat, you can download a free copy by clicking on the link below. Please remember that it may take a while to transfer and your screen may go blank for some time whilst it is downloading.

Download a copy of the DLA for children guide in .pdf format (330KB) - [DLA Guide](#)

Alternatively, copies of the guide are available free from the Cerebra office. (One copy per person). Phone the freephone helpline 0800 32 81 159

Send us an email info@cerebra.org.uk to request a copy, giving your UK postal address.

Cerebra Postal Lending Library

The Postal Lending Library has around 1,500 books. The available specialist books cover a huge variety of conditions including cerebral palsy, Down syndrome, ADHD, autism & autistic spectrum disorders, such as Asperger syndrome. There are also other resources such as videos and sensory equipment.

Parent members in the UK can request two books/resources at a time. These are issued for 28 days and can be renewed for a further 28 days, This can be done via email or telephone, as long as no other members are waiting to borrow the item(s).

They only loan out one piece of multi-sensory equipment at a time for a 3 month period. Delivery and collection is arranged with a courier on a convenient day – please telephone/email for further details.

When you have finished, you can return the item to the FREEPOST Cerebra address, which is:

Cerebra Postal Lending Library
FREEPOST SWC3360
Carmarthen
SA31 1ZY

Cerebra are always adding new titles and would be pleased to send you a paper library list or a list relating to a particular subject. They also welcome feedback on the items you have borrowed from them and also any other you have read/used and would like to recommend.

Two recent additions to the library include:

Managing Stress for Carers, by Ann Edworthy. ISBN 0954743342.

Free to parents and carers. Phone 0800 32 81 159 for your copy.

This is Cerebra's first published book. This is a very practical book. The first half discusses the research that informed the book, information that many parents will identify with. The second half gives advice on how to deal with services. Many of the solutions are to do with finding and using information, welfare benefits and education services.

Hidden Tears and Happy Smiles (Living with Andrew and other special children) By Rachel Cooper ISBN 1 873942 63 X.

A compelling and realistic portrayal of caring for a child with a disability. This book is filled with some laughs, some tears and a lot of practical down to earth humanity, advice and understanding

If you have any questions or feedback, please contact us on 0800 32 81 159 or email info@cerebra.org.uk

Cerebra's Grant Scheme

Cerebra has increased their budget this year to give more grants to help children who have disabilities because of a brain related condition or injury. The condition may be of a physical nature or a learning difficulty or both.

The equipment or resource requested must improve the child's quality of life and not be available from statutory agencies like social services or the NHS. The child also must be aged 16 or under.

Some examples of grants made are touch screen computers, holidays, approved therapies, power wheelchairs, and sensory toys.

Parents and carers can request an application form by calling 0800 328 1159 or by e-mail at debbieg@cerebra.org.uk. It can also be downloaded at www.cerebra.org.uk. Decisions on completed applications are made weekly.



New Rare Eye Conditions Directory

Contact a Family is very pleased to announce the new Contact a Family Rare Eye Conditions Directory. This long awaited publication contains descriptions of over 60 specific eye conditions or syndromes which have eye involvement

The new Directory is modelled on the highly respected main Contact a Family Directory which now has over 400 entries. All condition descriptions are written by expert doctors or when drafted by Contact a Family carefully checked by experts. Contact a Family places great importance on the provision of up to date accurate information for individuals, families, carers and professional advisers, and on signposts to effective support organisations.

As well as the alphabetical entries with the descriptions of conditions and contact details for support groups, the directory contains sections on:

Patterns of Inheritance – many of the entries are heritable;

Contact details for the UK's Regional Genetics Centres;

Dictionaries and glossaries – both specific to eye conditions and general information;

Benefits and other forms of financial help for people with visual impairment or sight loss;

Extensive details of General Visual Impairment and Other Helpful Organisations;

How to find up to date details of Local Visual Impairment Organisations.

It is only available in printed format. To order your copy please visit the Contact a Family Shop at www.cafamily.org.uk



Learning Disability and the Mobility Component of DLA

Contact a Family Northern Ireland receive many enquiries from parents whose children are turned down for higher rate mobility as they are deemed as not meeting the criteria. However, some people who are autistic, deaf/blind, or have a learning disability may qualify for higher rate mobility component on the basis of 'virtual inability to walk'.

'Virtually unable to walk'?

The need for help to get from one point to another and the purpose of walking are totally irrelevant to the 'virtually unable to walk' test. Instead, this test is tied to physical limitations on a person's ability to put one foot in front of the other and to continue to make progress on foot. These physical limitations can include behavioural problems if they are a reaction to or a result of the person's physical disablement (e.g. genetic damage in the case of Down's Syndrome).

The virtual inability to walk test looks at interruptions in the ability to make progress on foot. These interruptions have been referred to as 'temporary paralysis' (as far as walking is concerned). The interruptions must be accepted as physical in origin, and as part of your accepted disablement rather than under your direct and conscious control. Thus, being able to put one foot in front of the other does not stop you passing the virtual inability test.

You must, however, be able to show that:

Your behavioural problems, which may sometimes include a failure to exercise your powers of walking, stem from a physical disability and

Your walking difficulties, including interruptions in your ability to make progress on foot, happen often enough so that your walking is **'so limited, that (you are) virtually unable to walk'**.

What can you do?

Provide evidence (from GP, consultant, etc) to show that:

The learning disability has a physical cause (e.g. brain damage);

All the behavioural problems which interrupt outdoor walking stem directly from that physical cause.

You can also provide evidence (from GP etc) to show that it is not appropriate to talk of the person concerned as being able to exercise deliberate and self-conscious choices in the sense of making a 'deliberate election' to walk or not to walk. The key thing is to get evidence to show that the interruptions in the ability to make progress on foot outdoors are reactions to various stimuli. Those reactions are a result of the brain damage or the genetic damage that caused the learning disability, and prevent or interfere with the normal co-ordination of mind and body.

Finally, you need to be able to give the decision maker a clear picture of the person's normal walking difficulties and the frequency of interruptions in their ability to make independent progress on foot. The idea is to present an objective picture of how the person normally makes, or doesn't make, progress on foot outdoors, without active help from another person.

For more information phone our free helpline on **0808 808 3555** and talk to a Parent Advisor.

OVERPAYMENT OF TAX CREDITS

Recently, there has been a lot of media attention surrounding overpayment of tax credits. If you have been overpaid tax credits, the Revenue will normally seek to recover the excess paid by reducing your tax credit payments.

The Revenue should not recover an overpayment that arose as a result of 'official error' so long as you could not have been reasonably expected to realise you were being overpaid.

In addition the Revenue have the discretion not to recover an overpayment if you can show that this will cause you hardship.

Seek further advice if you are told by the Revenue that you have been overpaid or that you are likely to be overpaid. If you dispute that an overpayment has occurred or dispute the amount of the overpayment you can lodge an appeal. However, if you accept that you have been overpaid, there is no right of appeal against a Revenue decision to recover that money. Instead you can ask them to use their discretion not to recover. If they insist on recovery you can challenge this via the Revenue's complaint procedure.

Contact a Family produce a short guide to Tax Credit Overpayments covering these issues in much more detail. This is available free from the helpline **0808 808 3555**.

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