

Children's Centre

**Working with
children's centres
to include
disabled children**

bulletin

Special Issue:

**Contact a Family
Directory – the essential
guide to medical
conditions, disabilities
and support**

Contact a Family is the only UK voluntary organisation providing information and support to parents of children aged 0-19 with any kind of disability or medical need. The purpose of these bulletins is to illustrate how Contact a Family can work with children's centres in supporting these families.

Funding from DH and DCSF makes our work with children's centres possible.

You can find out more by visiting our website:

www.cafamily.org.uk

How the directory can help you support families

There are thousands of different medical conditions and disabilities affecting children, some very rare.

It is impossible for children's centre staff to know about all these different conditions. Yet it is useful for people working with families to have some understanding of the child's support needs.

Families say they appreciate it when people find out about their child's condition as it helps them feel more understood and less isolated.

The Contact a Family Directory contains a summary of over 1200 medical conditions and disabilities.

It provides information about physical symptoms, psychological and behavioural characteristics as well as details of UK support groups for parents.

This bulletin illustrates how different professionals working with children will find the directory useful in their work.

Thanks to funding from the Department of Health children's centres can register for free online access to the directory until 2010 by simply sending an e-mail to ccsubs@cafamily.org.uk

Please ensure staff and families are aware of this valuable source of information.



Conditions can affect children in different ways

Some conditions affect a child's physical mobility and coordination, making it harder for them to stand, walk or handle small objects such as toys, spoons or buttons.

If blind, partially sighted or deaf, the child will find it harder to learn about the world and how to communicate with others.

A child with a learning disability can find it harder to acquire skills not only at school but also at home, for example feeding, toileting or crossing the road.

Particular types of behaviour can be associated with certain conditions, including poor concentration, finding it difficult to wait, or becoming anxious in unfamiliar settings. It helps if those around a child understand what is likely to trigger bad behaviour and use strategies that promote good behaviour, for example having a clear routine so the child knows what to expect.

Certain medical conditions and disabilities cause symptoms which though not very visible can be extremely disabling, for example tiredness, pain, incontinence, seizures or diarrhoea.

How severely a child is affected by a particular condition can vary considerably.

How a child is affected can impact on the whole family, for example employment, social isolation, sleep, time spent with siblings and relationships. Understanding a child's needs can help children's centres signpost families to appropriate support and other types of information, for example benefits.



How the directory has helped professionals

"Her mother was really pleased we had looked up her daughter's condition and knew what Rett syndrome involved. She said she got tired of having to explain the same thing every time she met someone new."

Nursery staff

Rett syndrome

'Is a complex, genetic, neurological condition which affects far more girls than boys. Although signs may not be initially obvious, it is present at birth. It usually becomes more evident during the second year. People with Rett syndrome are almost always profoundly and multiply disabled and totally dependent on others for all their needs throughout their lives but severity may vary considerably.'

Medical text written February 2002 by Dr Orlee Udwin, Consultant Clinical Psychologist, and Dr Alison Kerr. Last updated August 2005 by Dr Alison Kerr, Consultant Paediatrician and Professor Angus Clarke, Professor in Medical Genetics.

"I was asked to visit the home of a child recently diagnosed with Batten Disease. By referring to the Contact a Family Directory I was aware it was a terminal condition."

Family support worker

Batten Disease

'Symptoms include loss of vision, epilepsy and loss of abilities including walking, eating and talking... At present there is no cure or treatment that makes a significant impact on the progressive decline in bodily functions and inevitable early death.'

Medical text written January 2008, Batten Disease Family Association. Approved January 2008 by Dr Ruth Williams, Consultant Paediatric Neurologist, and Sara Mole, Reader in Molecular Cell Biology.

"I had not worked with a child with autism before and wondered why he would not interact with me. Once I read about the condition I knew to avoid eye contact, to only give instructions one at a time and keep them simple."

Play leader

Autism

'Affected children have difficulties in making sense of the social world and the subtleties of verbal and non verbal communication. They have difficulty understanding the feelings and emotions of other people and present with a restricted range of interests often with stereotyped repetitive behaviours.'

Medical text written August 2006 by Dr C Dover, Specialist Registrar in Learning Disability Psychiatry, Dr C Grayson, Consultant Paediatrician and Professor A Le Couteur, Professor of Child and Adolescent Psychiatry.

"I was puzzled because his verbal skills were OK but he struggled in other ways. I found out about the Dyspraxia Foundation in Contact a Family's Directory. Their publications gave me a much clearer idea of how best to support him."

Teacher

Dyspraxia

'The child shows ability by having good oral skills but is unable to achieve literacy or recording skills at the same level. Poor concentration and attention control and physical restlessness or over activity may be an additional problem. It is not uncommon for such children to be described by teachers as lazy or poorly motivated.'

Medical text written June 2001 by Dr D Keen. Last reviewed October 2005 by Dr D Keen, Consultant Paediatrician, St George's Hospital, London, UK.



"After reading about Duchenne muscular dystrophy I had a better understanding of what questions to ask when carrying out my assessment of their support needs."

Social worker

Duchenne muscular dystrophy

'The weakness, however, is progressive and children with DMD will lose ambulation by the age of thirteen years; the mean age being approximately nine years. This is due to a combination of weakness and contractures affecting the ankles, knees and hips.'

Medical text written June 2000 by Professor F Muntoni. Last updated December 2004 by Professor F Muntoni, Professor and Consultant in Paediatric Neurology.

"I had not come across this metabolic disease before. The information in the Directory helped me understand how it might affect the child and indeed the whole family."

Health visitor

Purine & Pyrimidine metabolic diseases

'Particular problems include kidney stones and renal disease (see entry, Kidney disease), recurrent infections and severe immune deficiency, severe recurrent anaemia (anemia - US), muscle cramps and wasting, arthritis, neurological problems such as developmental delay, autism and seizures (see entry, Epilepsy).'

Medical text written October 2002 by Dr M Champion. Last reviewed September 2007 Dr M Champion, Consultant in Paediatric Metabolic Medicine.

Contact a Family Directory – the essential guide to medical conditions, disabilities and support

Reliable and continually updated

All medical texts appearing in The Contact a Family Directory have been written by, or approved by, a leading medical expert on the disorder with details of the authorship and date of last update shown at the end of each entry. It complies with the Health on the Net Foundation's (HONcode) standard for trustworthy health information.

Details of UK support organisations where available

Many disabilities and medical conditions that affect children (including some very rare ones) have a national support group, usually run by parents of a child with the condition. They can be an invaluable source of support and advice for families, especially when it feels as if nobody else understands what they are going through.

Families without a firm diagnosis can also use these groups as they can offer support around some of the symptoms a child is showing.

If there is no condition specific support organisation, our family linking officer can help parents make contact with other families whose child is affected by the same condition.

MakingContact.org is our free online linking service for families with disabled children and parents can also find us on Facebook. Hundreds have already joined up and are sharing their experiences with other parents.

Medical conditions and disabilities not in the directory

Contact a Family may also be able to help with information and contacts for conditions not listed. Please call the Contact a Family Helpline on Tel: 0808 808 3555 (Mon-Fri, 10am-4pm & Mon, 5.30-7.30pm).

Accessing the Contact a Family Directory

The Contact a Family Directory is available online at Web: <http://www.cafamily.org.uk/medicalinformation> and is also printed annually. It is free online to people who only need limited access to a few conditions. However frequent users need to pay.

Thanks to funding from the Department of Health, children's centres can register for free online access until 2010. If you want to register for free access, please e-mail: ccsubs@cafamily.org.uk

Buy the Contact a Family Directory in paperback and get a free copy of the Disability Rights Handbook



The Contact a Family Directory is available as a paperback book for just £40.

Order now and we'll send you a free copy of the Disability Rights Handbook 2008* - that's a saving of £21.

For more information and to order visit our website Web: <http://www.cafamily.org.uk/shop>

Get in contact...

Contact a Family

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Website: www.cafamily.org.uk

How is your centre supporting families with disabled children?

Please let us know so we can share with others.

We also welcome your ideas and suggestions of topics for future issues.

Contact the children's centre team on:

Tel: **020 7608 8742**
e-mail: ccsubs@cafamily.org.uk

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