

Children's Centre

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

bulletin

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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

Welcome to the winter edition of the **Contact a Family bulletin**.

Although the bulletin is written for children's centres, other professionals such as those working for local information services or in schools might find it useful. Parents might also enjoy reading about the experiences of others and find the practical advice given helpful.

Families with disabled children and professionals working with them will need to have some understanding of the child's medical condition and how it affects the child. Finding reliable medical information can be difficult and stressful, especially if the condition is less common. The Contact a Family Directory is a unique resource containing information on over 1000 long term medical conditions and rare disorders including details of UK family support groups where available. Information in the directory is written and endorsed by leading medical experts to ensure it is up to date and accurate.

Funding from the Department of Health means we can offer FREE unlimited access to our online medical directory to children's centres. If you would like to register for this please e-mail: ccsubs@cafamily.org.uk or Tel: 020 7608 8776.





A parent's story

Chrissie from London talks about her feelings on hearing her son's diagnosis.

When Ernie was born I was naturally over the moon, a healthy, beautiful baby boy. I couldn't be happier and life just couldn't be better. When Ernie, (pictured above), had his eight-week hearing test, the results were difficult to read due to him having a bad cold. He was referred for a further test. The unforgettable day came on 18th August 2006 at 9.30 am. I found out Ernie was profoundly deaf in both ears. He was then twelve weeks old. It was not what I expected to learn.

After they told me, the whole world as I knew it, turned upside down. I couldn't believe it or take it all in. It felt like someone had just slapped me hard around the face. I had so many questions going around my head and felt as if I didn't know what my own son needed. From a baby I knew, to a baby I didn't, and in such a short space of time. Everything I had said to him since he had been born, he just hadn't heard.

I was in a daze for many days and I grieved for his hearing for a long while and most probably still do. I found out on a Thursday and was told someone would contact me. I didn't know when or how long to wait, I felt scared and isolated as I really didn't know how to treat my baby or what steps to take. I couldn't reassure him verbally, this felt strange and unnatural. Eventually, a teacher of the deaf visited me on the following Wednesday. She explained so much, gave solid advice and positive reassurance. I really felt as though I wanted to speak with another mother in a similar situation. I had so many feelings that I found hard to understand.

I was given a 'suitcase' full of information called Early Support. I didn't know where to start with all this information; I was still struggling to understand that I had a 'disabled' child. It sat unopened in the corner of the room for many days.

How we can help

Each bulletin will focus on a common scenario and how we might be able to help.

This issue: around diagnosis

In Chrissie's story opposite her son's diagnosis came out of the blue but it can sometimes be a more drawn out process, with the condition not being finally diagnosed until long after concerns are initially raised about some aspect of a child's development.

Though each parent's experience of diagnosis is unique, certain responses are common. Parents are often in shock and also very anxious about how they will manage. How families are supported around the time of diagnosis can impact on how well they cope and adjust to their situation.

Many families will want to find out more about the condition and how they can best support their child. Condition support groups are not only sources of detailed information about the child's condition but their newsletters often provide positive stories of other families managing, which helps parents feel more confident that they too will cope.

If a condition support group does not exist, the Contact a Family linking officer can help put families whose children have the same condition in touch with one another. Families can also use Web: <http://www.makingcontact.org> an online resource for linking families.

In some areas there are schemes such as the Scope Face 2 Face initiative see – Web: <http://www.face2facenetwork.org.uk> and Home-Start, Web: <http://www.home-start.org.uk>. These can be very helpful to families in the first few months following diagnosis.

In the parent's story, Chrissie mentions being given a suitcase of information from Early Support. Their information material is very useful - see Web: <http://www.earlysupport.org.uk> but is not meant to be delivered in this way. Giving parents masses of information at the time of diagnosis can be overwhelming. It is more helpful to let them know briefly what help is available, and where they can go for more detailed information should they need to.

How children's centres can help

- put families in touch with condition support groups such as those listed in the Contact a Family Directory and other sources of local support;
- provide short written information outlining the different types of support available, such as the Contact a Family's guide, 'When your child has additional needs';
- make sure families know they can come back to the centre anytime in the future, for more detailed information or help in accessing support for their child or themselves.

Contact a Family casebook

Notes from Penny, parent adviser on our freephone helpline.

Friday 10am

Elizabeth and her husband are moving to a new area and therefore have a new local authority. Their son has a statement of special educational needs and will be changing schools because of the move. They have been told his statement will be reviewed. Elizabeth is concerned about what will happen to his statement?

Penny's advice

Your son's statement automatically transfers from the old local authority to the new local authority when you move and the new local authority becomes responsible for maintaining your son's statement and for the provision specified in it. Before changing the specified provision, the new authority must review the statement or make a statutory assessment. However, as the move means your son must attend a different school, the new local authority may arrange for him to temporarily attend an appropriate school until it is possible to review and amend his statement.

Within six weeks of the date of transfer, the new local authority must write to you to tell you that the statement has been transferred and if they plan to make an assessment or review the statement. If they review the statement, it will be a similar process to the annual reviews you've experienced before. You should be asked to provide written evidence and attend the review meeting. Other professionals may also be involved.

If, after the review, the local authority decides to amend that statement, they must inform you, the headteacher and other appropriate professionals of the proposed amendments. If you are unhappy with these, you can write to the local authority within 15 days of receiving the amendment notice. You can also meet with the local authority to discuss the proposed amendments.

If you are still unhappy with the amendments, you can appeal to SENDIST (Special Educational Needs and Disability Tribunal) within two months of the local authority's decision to amend the statement. If you feel that the provision in the new authority is different or that a fresh assessment by new people would be useful, you can write to the new local authority and request a reassessment of your son's needs.

You may want to contact your new Parent Partnership Service for support during this process and you may find it useful to read our factsheet 'Special Educational Needs - England'. This contains information about statutory assessments, reviews of statements and appealing to the SENDIST.



**Contact a Family
freephone helpline**

0808 808 3555

Open to parents and professionals
Monday to Friday, 10am-4pm
Monday evening, 5.30pm-7.30pm

Textphone: 0808 808 3556
e-mail: helpline@cafamily.org.uk

Telephone interpreter service
available

**Think
about...**

The casebook example illustrates the detailed advice the Contact a Family helpline adviser can give parents.

Children's centres can help parents by:

- telling parents about our helpline or have copies of our education factsheet at hand to give to families;
- having an understanding of the education assessment process and how the local parent partnership can help – see Web: <http://www.parentpartnership.org.uk>;
- being able to provide information about local organisations that can support families through the process, such as advocacy services.

A children's centre story

In each issue of the bulletin we will feature a children's centre which is making special efforts to include disabled children and their parents.

In this issue: Sara Houghton, Extended Services Manager at Wade Hall Children's Centre in Lancashire, describes the steps they took to help parents with disabled children use the mainstream activities available at their centre.

Sara writes: *Wade Hall Children's Centre is a brand new building, physical access for those using a wheelchair is not a problem but as a mainstream service we were concerned that families with disabled children more used to accessing specialist services would not use our facilities. The local Child Development Centre (CDC) shared our concerns so they suggested we attend an existing parent group to get to know some families and discuss their needs. We asked parents what their expectations would be from a children's centre and their experiences of attending mainstream activities.*

We were then approached by our local Home-Start scheme, one of their volunteers was in contact with a lot of parents with disabled children who were meeting up together in each other's houses, with very little space and resources. We now run a weekly parent support group in partnership with Home-Start, in our children's centre.

The parents benefit from the resources available at the centre and also have input from the centre teacher Amanda Spavin who provides structure and guidance to the group. The parents at the group also benefit from the good multi agency working we have at the centre; they can access a range of organisations depending on the query or issue.

Once the families become established and settled at the children's centre we introduce them to other sessions and activities available to all families.

Hints and tips...

Attracting parents with disabled children to your centre takes time. Families are more likely to attend an event based around a particular theme they are interested in, for example, a drop-in session aimed at helping parents manage toilet training. An alternative could be an information day about local support services where representatives from a range of local organisations are invited. This could be advertised through professionals working with families. It helps to keep the day informal so parents can meet and find out what each organisation can offer over a cup of tea. A private room might also be available if a parent wanted to speak confidentially to any of the agencies.



Get in contact...

Contact a Family

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Fax: 020 7608 8701

Textphone: 020 7608 8702

e-mail: info@cafamily.org.uk

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** or **020 7608 8773**

e-mail: csubs@cafamily.org.uk

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