

# Briefing paper

## Information for families

### Why families struggle for information and support

Having a disabled child can have a huge impact on family life. Without support families find it difficult to take part in normal daily activities and can become very isolated and feel unable to cope. This can affect the well being of the whole family.

There is a wide range of support available for families but much of it is delivered by different agencies and organisations. Families often do not find out about available support because:

- they don't know it exists, so don't know to look for it or where to look for it
- the professional's working with them assume someone else is giving them the information
- they're overwhelmed by masses of information, much of which is not relevant to them, making it harder for them to find the information they need

The information families need changes as the child grows older, their condition deteriorates or family circumstances change.

### What information families of disabled children might need

**Assessments:** how to get one, what's involved, how to access support including direct payments

**Childcare:** help in finding and funding childcare which can support their child's specific needs

**Education:** how to get help for their child's learning, before as well as at school

**Employment:** such as carer entitlements, training schemes to help them return to work

**Equipment and adaptations:** help getting equipment at home, in school, or at childcare

**Family issues:** support for siblings, fathers, grandparents and parental relationships

**Finance and benefits:** sources of financial support, to help them meet additional expenses

**Health services:** including therapists, continence services, community dentists

**Leisure activities:** that their disabled child can access, so important for social development

**Medical information:** information on their child's condition, getting a diagnosis or living without one

**Parenting support:** to help them support their child's learning, manage challenging behaviour,

**Short breaks (Respite):** local schemes which gives parents a break from caring

**Survival Strategies:** help with sleep (for child and parent), feeding and toileting

**Support groups:** including condition support groups, parent groups and carers organisations

**Transport and mobility:** including Blue Badge scheme, wheelchair services, transport to school.

**Transition:** information on transition planning and process adult services

### How can children's centres/family information services help?

- make sure families of disabled children know they can come to you for information
- help families find the specific information they need, and tell them about other support they might need but not be aware of
- invite other people, such as disability advice organisations, in to provide information and advice at your centre
- ask professionals working with disabled children to tell families about how you can help.

### Contact a Family can provide:

- Our '**Promoting Self Care Leaflet**' informs staff about the different types of information families might need with details of organisations who can provide support.
- Our **Resource Pack** contains 25 different information factsheets covering a wide range of topics including finance, education, parenting, behaviour and employment.
- Our **Medical Directory** provides information on over 1000 medical conditions and has details of over 350 UK national condition support groups, regularly updated – see [www.cafamily.org.uk/home.html](http://www.cafamily.org.uk/home.html)

**Key people for children's centres and family information services to link up with:**

<b>Contacts</b>	<b>What can be offered</b>
<b>Child development teams</b>  <a href="http://www.bacdis.org.uk">www.bacdis.org.uk</a> or ask local PCT	Child development teams assess and support disabled children where input is needed from more than one health professional. They are likely to know about sources of support, such as parent groups, specialist playgroups and carers organisations. They might help you reach out to families with disabled children living in your area
<b>Parent partnership schemes</b> Tel 020 7843 6058 <a href="http://www.parentpartnership.org.uk">www.parentpartnership.org.uk</a>	A local statutory services offering information, advice and support for parents of children and young people with additional needs to help them access educational support
<b>Social services– children with disabilities team</b>	Provide information on activities for disabled children as well as details of local support organisations
<b>National Association of Councils for Voluntary services</b> <a href="http://www.navca.org.uk">www.navca.org.uk</a>	Your local council can provide details of organisations supporting families with disabled children in your area
<b>Contact a Family Helpline</b>  Tel: 0808 808 3555 <a href="http://www.cafamily.org.uk/cafiya">www.cafamily.org.uk/cafiya</a>	Provides information and advice for families and professionals on any aspect of caring for a disabled child and sends out leaflets and factsheets. They can provide details of national and local support groups. Telephone interpreter service is available
<b>Contact a Family local support</b>  Tel: 0808 808 3555 <a href="http://www.cafamily.org.uk/cafiya">www.cafamily.org.uk/cafiya</a>	Contact a Family have offices, family support workers and volunteer parent representatives <b>in some areas of the UK</b> . They can provide a listening ear and signpost families to other local support including parent groups.

**How family information services can help:**

1. Collate information on all the support available locally for families with disabled children.
2. Avoid duplication by making sure this information is updated regularly by one source and made widely available to professionals, statutory agencies, voluntary organisations as well as families.
3. Present the information in a way that is easy to navigate, which explains the different types of help available and signposts to sources of more detailed information. An example of this can be seen at [www.sendsutton.info](http://www.sendsutton.info)
4. Ask parents of disabled children how useful and accessible they find the information. If possible involve parents early on, to assist in developing really comprehensive and 'parent friendly' information. Contact a Family's Parent Participation guide gives advice on how to do this.

This is one of a series of briefing papers to help children's centres and family information services begin to support families of disabled children on specific issues. You can browse all of these at <http://www.cafamily.org.uk/childcentres.html>

**To find out more about how the children's centre team at Contact can help please contact:**

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