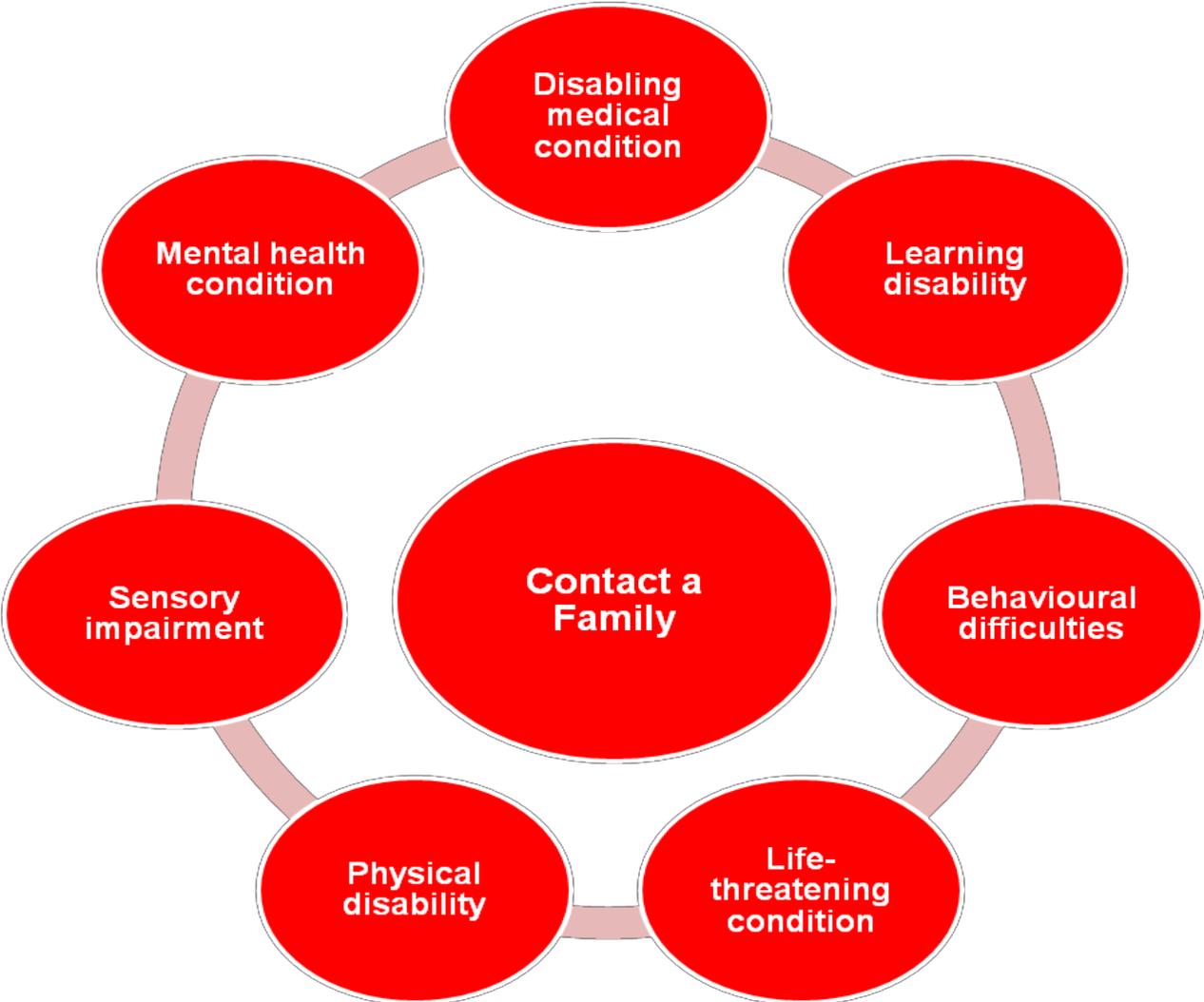


Resource pack for professionals who work with families with disabled children in England

- What do we mean by disability – the families we support 2
- Who’s who – professionals and parents who can help 3
- Information checklist – information parents/professionals need 6
- Top tips on providing information – quick guide to good information 11
- Contact a Family guides – publications for you and the parents you work with 13

We welcome your feedback or suggestions to improve this information.

Please send any feedback to library.team@cafamily.org.uk





Who's who for providing information?

Information, Advice and Support Services (IAS Services - formerly Parent Partnership Service)

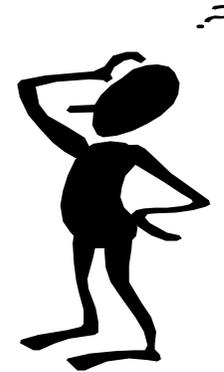
For special educational needs and issues around education, health and social care. Free confidential advice, information and support for parents, carers, and children and young people up to the age of 25. There is one in every local authority, although they may be called by a slightly different name. For example in Ealing the IAS service is called Ealing I SAID. They can also signpost parents to other local and national organisations for support. To find your local IAS service search here <http://www.iassnetwork.org.uk/find-your-iass/>

Parent carer forums

A parent carer forum is a group of parents and carers of disabled children who work with local authorities, education settings, health providers and other providers to make sure the services they plan and deliver meet the needs of disabled children and families. The forum usually provides parent representatives for strategic decision making committees who are able to represent the views of a wider range of parents. In England there are parent carer forums in almost all local authority areas. Find out more about parent participation at www.cafamily.org.uk/parentcarerparticipation

Local offer

The Children and Families Act requires all local authorities to publish and maintain a 'local offer'. A local offer is a wide range of information about all the support and facilities which families can expect to find in their area for children and young people who have special educational needs and disabilities. The information should cover education, health and social care support and services for children and young people aged between 0 and 25. The local offer is not a guarantee that a particular service will be available, but should be a useful guide to what parents can expect to find in their area, and how they can access that service. It's usually found on your local authority website.



Family Information Service (FIS)

The FIS acts as a central information point supporting parents and carers who need childcare, including those with children with disabilities. The FIS also holds up-to-date details of local childcare and early years' provision in the local area. The FIS provides a range of information on all services available to parents to help them support their children up to their twentieth birthday or up to 25 if their child has a disability. The local FIS will have close links with children's centres, Jobcentre Plus, schools, youth clubs and libraries. The following link gives information about local Family Information Services

<http://finder.familyandchildcaretrust.org/kb5/fct/childcarefinder/home.page>

Parent support groups

Parent support groups are local groups that provide support for families of children with additional needs/disabilities, in a specific town, geographical area or school. They can offer parents the chance to make friends, share experiences and learn about local services. National condition specific groups support families in the UK who have a child with a specific condition. Some of the larger groups offer local support (for example the National Autistic Society). They are a good way for parents to find out about their child's condition or disability, latest treatments and current thinking and are usually linked to expert medical professionals. To find out about local groups contact your local Information, Advice and Support Service, FIS or Contact a Family's freephone helpline on 0808 808 3555 (Mon–Fri).



Contact a Family

Contact a Family is the only UK-wide charity providing support, advice and information for families with disabled children, no matter what their condition or disability. We have a freephone helpline staffed by expert parent advisers. We also produce a wide range of publications with free parent guides covering issues such as benefits, education, aids and equipment and relationships. We have a range of newsletters, including a professionals newsletter – you can sign up here www.cafamily.org.uk/newsletter-signup/ Check out our website for more information at www.cafamily.org.uk

Information checklist for professionals

We've developed this checklist to help you plan and review how you support families with disabled children. We'd like to encourage you to:

- consider how you are reaching out to families with disabled children or children with special educational needs
- keep information about specialist services that families might need to access.

You probably won't be able to answer all the questions the first time you use the checklist. But we hope they will help you develop your information offered to families, no matter what their medical condition, additional need or disability.

1) What information is available for families in your setting, for example Information, Advice and Support Services, Family Information Service, regional and national support groups, local parent support groups, Contact a Family publications?	
	Action
2) Who is responsible for keeping this information up to date?	
	Action

3) Who is available in your setting to help families find information on local services?			
		Action	
4) Do you have information to help families to access the services listed below?			
Service type	Y/N	Name of service & contact information	How are families referred?
Benefits			
Child and Adolescent Mental Health (CAMHS)			
Child development centres (CDC)			
Childcare for children with SEN/disabilities			
Children's centres			
Community dentist			
Continence service			
Counselling			
Dietician			
Financial help/benefits advice			

Service type	Y/N	Name of service & contact information	How are families referred?
Family information service			
General health information/health centres			
Genetic counsellor			
Holidays/leisure activities			
Interpretation/translation services			
Occupational therapy/physiotherapy			
Orthotics (for example splints)			
Parenting advice/training			
Parent carer forum			
Parent carer support groups			
Personal budgets			
Portage (home visiting educational support service for pre-school children)			
Sensory support services, for example Braille/sign language			
Short breaks/respite			

Service type	Y/N	Name of service & contact information	How are families referred?
Social services disabled children's team			
Special educational needs			
Specialist aids and equipment, including repairs			
Speech and language therapy			
Support for challenging behaviour			
Support into work for young people			
Transition			
Transport			
Voluntary support organisations			
5) What information is available for families who have English as a second language or where parents have a learning disability?			
		Action	

6) What drop in sessions/parents groups, specifically for parents of children with additional needs/disabilities, take place in your area?

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Action

7) Do you know how the local Information, Advice and Support Services (IAS) and local parent carer forum can help families with children with additional needs/disabilities? Do you signpost families to the IAS and parent carer forum?

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Action

Top tips for providing information



Information should be:

- relevant
- easily accessible (including clear language and easy-to-read layout)
- widely available, for example through schools, GP surgeries, libraries
- in a variety of formats such as newsletters, internet, leaflets, booklets
- regularly kept up-to-date
- provided in bite size chunks, for example relevant information around the time of diagnosis
- delivered face-to-face where possible
- tailored to individual family needs
- available to a diverse range of groups, for example the travelling community, black and minority ethnic (BME) communities.
- available, where possible, in community languages reflecting the local area.





Parents need:

- to know where to go to get up-to-date information, as they need it
- to be able to access information in a variety of places
- to be able to access information in a variety of formats (for example print, online, audio)
- to know who to ask for the information they may need
- to be signposted to the right information source
- to be supported in finding information
- to not assume professionals know all about the information that is out there
- to link in with parent groups/forums as they are often good sources of information.

Professionals need:

- to be proactive in providing information
- to signpost families to relevant local services/organisations
- to link closely with other professionals
- to listen to parents and also the child where appropriate.



Contact a Family guides for families

Our parent guides and leaflets cover a range of subjects for parents and carers with disabled children.

All guides are free to download, and single copies are available free to families with disabled children.

To get a free copy parents can:

- call our freephone helpline on 0808 808 3555
- email helpline@cafamily.org.uk
- download free copies here <http://www.cafamily.org.uk/advice-and-support/resource-library/>

Examples of publications available for families with disabled children

Health:

- [Concerned about your child –health professionals who can help](#) – available in different community languages
- [NHS and caring for a disabled child – England](#)
- [Living with a rare condition](#)
- [Living without a diagnosis](#)
- [Developmental Delay](#)

Benefits and financial help:

- [Money matters: a checklist when your child has additional needs](#) – checklist of financial help available to families
- [Disability Living Allowance \(DLA\)](#) – a guide to claiming for children under 16
- [Personal Independence Payment and other benefits at 16](#)
- [The tax credits guide](#)
- [Help with council tax bills](#)
- [Help with fuel bills and keeping warm](#)

Education:

- [Special Educational needs in England](#) - a series of factsheets explaining the SEND reforms -

Family:

- [Fathers](#)
- [Siblings](#)
- [Grandparents](#)
- [Relationships and caring for a disabled child](#)
- [Holidays, play and leisure](#)

Practical help:

- [Getting social care services when your child has additional needs](#)
- [Aids, adaptations and equipment](#)
- [Understanding your child's behaviour](#)
- [Feeding and eating](#) – available in different community languages
- [Potty/toilet training](#) – available in different community languages
- [Helping your child's sleep](#) – available in different community languages
- [A guide to dealing with bullying](#)

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Freephone national helpline 0808 808 3555 www.cafamily.org.uk Contact a Family 209-211 City Road, London EC1V 1JN
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