

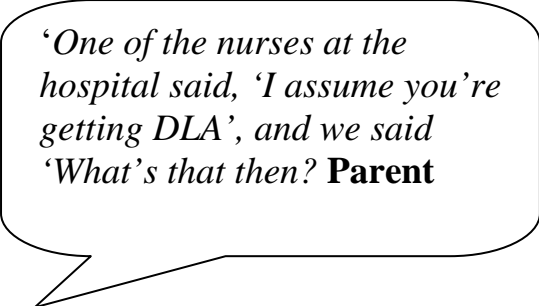
Information for families of disabled children: Checklist

This checklist has been developed to assist local areas in providing information to families of disabled children about services and support in their local area.

Families of disabled children often need a range of services and support provided by different agencies and organisations. They need to be told about what help is available and how to access it. Parents continually say they struggle for information, and often hear about support they are entitled to years after they first needed them.

In England local authority areas have a duty to provide information to families of disabled children. In many areas the Family Information Service is responsible for this, but some local authorities fund other organisations to provide this service.

Only parents can say whether the information being provided is meeting their needs. This information checklist has been developed to help local information providers work with parents to find out whether the information currently provided is meeting family's needs, identify any gaps in information and develop an action plan to improve the way information is provided.



*'One of the nurses at the hospital said, 'I assume you're getting DLA', and we said 'What's that then?' **Parent***

Parents forums can provide parents from a range of disabilities to assist with this. Contact details of local parent forums can be found at [for contact details](#).

Other useful information on involving parents in shaping services can be found in the 'How to Guide on Parent Participation' (TDC, March 2010) available at:

<http://www.togetherfdc.org/SupportDocuments/HowToGuideParentParticipation.pdf>

Contact a Family is often described as a one stop shop of information for families of disabled children. They provide information to families across the UK on a wide range of topics. The checklist draws on this expertise.

Parents can request further information and free copies of any of the Contact a Family guides mentioned in this checklist by contacting their free phone helpline, open Monday-Friday 9.30am-5.00pm

Contact a Family Help Line - Tel 0808 808 3555 or send an email to helpline@cafamily.org.uk

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NB Names given to services do vary across England. We have tried to use the names most commonly used. We would welcome peoples comments on how helpful this checklist has been and how it could be improved. These comments will be incorporated into later versions . Please Email Sheila.Davies@cafamily.org.uk

Together for Disabled Children is a partnership between Serco and Contact a Family

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About this checklist

Together for Disabled Children has developed this checklist to help local authorities improve the way they provide information to families of disabled children.

This checklist has been designed to help local areas:

- identify the different types of information that should be provided and who is responsible for keeping this up to date
- check whether the information provided is kept up to date and meets parents' needs
- consider how information is being disseminated to families and how this could improve
- increase the number of services and practitioners signposting families to information about support services other than their own
- identify particular groups of families who might struggle for information and make plans to address this

Who this checklist is for

This checklist assumes that different teams will be responsible for maintaining different information but that one organisation has overall responsibility for coordinating the provision of information for the local authority area. Very often this will be the Family Information Service. Most of the checklist will be completed by the responsible individual in the lead organisation, but it has been designed so separate sections can be sent to different teams to be filled in and returned.

It is not expected that any local area will be able to implement all of this immediately but that it will help local areas identify what is already in place, plan what needs to be done and monitor progress in improving information provision to families of disabled children.

It is provided in Microsoft Word so people can adapt it to reflect their own local area structures.

Why providing this information is necessary and complex

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. Parents often do not find out about available support because they do not know it exists, so don't know to look for it.

In 2000 research carried out by the Social Policy unit in York showed that parents struggle for information and that they wanted a short summary telling them what support is available and where to go for more detail. The Childcare Act 2006 introduced a new duty on local areas to provide information for families of disabled children. The disabled children's service indicator introduced in 2009 measures how information is provided through a survey of families of disabled carried out on an annual basis. The 2009 survey shows that families still struggle for information and support.

Families can need very different information about support depending on the nature of their child's disability. Providing families with too much information can be overwhelming, especially if much of it is not relevant to them. Families' information needs change as the child grows older, their condition deteriorates or family circumstances change. There is a wide range of support available for families but much of it is delivered by different agencies and organisations.

Managing the way a local area provides information for families of disabled children is therefore complex and requires planning and coordination.

Good practice in providing information

Parents of disabled children frequently say they do not know where to go to get information about support local to where they live. Some parents are given information but it is written in jargon using words they struggle to understand. Parents frequently tell us of being given a long list of organisations who might help and their frustration when after contacting all of them they find not can provide the support they need.. This is extremely time consuming and demoralising for them.

To avoid this always

- Write using simple and friendly language and ask a few parents to highlight words or phrases others might not understand.

- Break information under separate heading, so parents can quickly find what is relevant to them
- Provide a brief description of what the organisation /service provides and how to access it
- Explain who it is for e.g. age group , types of disability, eligibility criteria and any costs involved
- Provide contact details so parents can talk to someone about their child's support needs.

Supporting individual need

Many people still think of the word 'disabled' to mean a physical disability and think of a child in a wheelchair. This means families of children with more 'hidden disabilities' such as learning disabilities and challenging behaviour often get overlooked.

Disabled children need different types of support, depending on the nature of their disability. A child with a physical disability might need help with access, feeding and going to the toilet. A child with speech and language difficulties might need someone who can communicate with them using the method the child uses e.g. signing, Makaton, picture communication symbols. A child with a learning disability might need additional support to carry out instructions, go to the toilet or someone there simply to make sure they stay safe. A baby changing table is not suitable for an eight year old who is not continent.

*'The database said there was a swimming session on Wednesday for disabled children. I rang up to book a place only to find out it meant the pool had a hoist. They said the session was not suitable' for my son who has a learning disability – he was very disappointed; **Parent***

If parents are to be confident in using a service for their child, they need to first check whether child's needs can be supported. For people to support disabled children and young people, they need to learn from the family what the child's support needs are. There needs to be a process in place to allow this dialogue to happen and parents need to be told about it.

Involving parents

The best way to make sure information meets parents needs is by involving them when developing information and getting feedback from parents to find out if existing information is helpful. This checklist has been designed for the organisation responsible for providing local information to families of disabled children to fill in with input from parents.

In most areas there is a parents forum, whose membership welcome opportunities to improve services. They can be useful in helping local areas make sure that the information they are providing to families is helpful. More guidance on writing information for families can be found in the TDC How To Guide on Parent Participation.

Who coordinates information and who keeps it up to date?

Who is responsible for collating and coordinating information for families of disabled children across all services?	
Name	
Organisation	
Telephone	
Email	
Address	

Who is responsible for keeping the following information up to date ?	
Childcare: help in finding and funding childcare to support a child's specific needs	Name: Organisation: Tel: Email :
Disability specific services: including wheelchair, continence, community dentists (most funded through health)	Name: Organisation: Tel: Email
Education: how to get help for a child's learning, before as well as at school	Name: Organisation: Tel: Email
Employment: helping parents back to work –e.g. carer entitlements, training schemes	Name: Organisation: Tel: Email
Family and emotional support: relationships, support for siblings, managing sleep and challenging	Name: Organisation:

behaviour, contact with other families

Tel:
Email

<p>Finance and benefits: sources of financial support, to help families meet additional expenses</p>	<p>Name: Organisation: Tel: Email</p>
<p>Leisure activities: support for a disabled child to access social/leisure activities including holiday schemes</p>	<p>Name: Organisation: Tel: Email</p>
<p>Parent participation and parent forums; information about how parent can get involved in improving services</p>	<p>Name: Organisation: Tel: Email</p>
<p>Social care; e.g. short breaks, direct payments, equipment and adaptations to the home</p>	<p>Name: Organisation: Tel: Email</p>
<p>Transition: moving from children to adults services in health, education and social care</p>	<p>Name: Organisation: Tel: Email</p>
<p>Transport and mobility: including Blue Badge scheme, wheelchair services, transport to school</p>	<p>Name: Organisation: Tel: Email</p>

What sources of information have you for families?

What resources have you in place to alert families to the different types of support available? How confident are you that it is kept up to date and that parents find the content helpful?

Parents (and professionals) often do not know what is available or how to access a particular service. Families require different information depending upon nature of their child's disability. Providing parents with lots of information much of which is not relevant to them can be overwhelming to parents as well as expensive to keep up to date. Parents of disabled children continually say they want a one stop shop of information.

Have you?	Who is responsible for	Last updated	Positive feedback from parents?
A short leaflet describing the different types of support and where to go to find out more detail			
A local directory briefly describing all services and available support and where to go to find out more detail			
A webpage/website describing the types of support available with links of where to go for more detail			
A 'telephone' one stop shop for information describing all services and support available and where to go to find out more			
A 'face to face' one stop shop for information which can advise families people about the types of support available and give them more detail			
Other? Please feel free to add			

Where are families provided with information?

Leaflets/directory: Where can families pick up leaflets, newsletters and ,if you have a directory, be able to read it?

	Who keeps up to date?	Last sent updates?
Child development centre		
Special schools		
Libraries		
Local carers centres		
Children centres		
Nurseries.schools		
Specialist services e.g therapies, wheelchair		
Other : please add		
Web page/website describing the types of support available Do you have links to/from		Date links last checked
Children's services website		
Family information service website		
Parent Partnership website		
Parent Forum		
Other – please add		

How are families kept up to date?

What resources have you to make sure families hear about new services, changes to existing ones and events and how confident are you that parents find the content/service helpful?

	Frequency of newsletter	Positive feedback from parents?	Working with parents to develop /improve
Do you have a newsletter?			
If Yes does it include updates about:			
• Leisure activities/holiday events			
• Social care support e.g. short breaks, direct payments			
• Educational support			
• Community health services			
• Events/workshops for parents			
How do people find out about the newsletter?			
Register of disabled children			
Children's services			
Parent Partnership			
Web site			
Other			
Do you have other ways of keeping parents up to date e.g. texting service, Facebook, information event ? Please add details below			

Which services/practitioners signpost families to information about other services?

Which agencies are signposting families to other services and how confident are you that the information they provide is up to date?

		Providing information?	Date material last updated?
Universal services	Family Information Service		
	Children Centres		
	Libraries		
	Schools		
	GPs		
Specialist Services			
Education	Special Educational Needs Coordinators		
	Portage service		
	Parent Partnership service		
Social care	Social workers		
	Family support workers		
	Short break providers		
Disability specific	Child & Adolescent Mental Health (CAMHS)		
	Child Development Centre		
	Community Dentist		
	Community Equipment		
	Continence		
	Dietician		
	Genetic counsellor		
Health Information			

	Occupational therapy		
	Orthotics (splints)		
	Physiotherapy		
	Sensory support services (hearing and visual impaired)		
	Speech and language service		
	Wheelchair service		

Who provides initial information to families about support when	
The child is diagnosed around the time of birth	
Early years: A child is assessed for developmental delay	
A child or young person becomes disabled from an emerging health condition	
A child or young person becomes disabled as a result of an accident	
A child or young person becomes disabled through mental health problems	

Information for families from minority ethnic communities

Families from minority ethnic communities who are caring for a disabled child face the same difficulties as other parents, but these problems are often compounded by additional factors such as lack of information and culturally appropriate services.

These communities might include people from Africa and the Caribbean, South Asia, Latin America, Eastern European countries. It might include white minority ethnic communities such as gypsies and travellers, asylum seekers and refugees, some religious groups.

Leaflets in languages other than English are important for enabling greater access to services. However before translating check whether it is needed. Many families are multi-lingual and can read information in English. Others find translated audio material more useful than written. Local community organisations can advise on what is going to be most helpful as well as assist in disseminating information out to these communities. Written information cannot replace a sympathetic, knowledgeable person who can offer advice on the range of services available.

Community	Local organisation	Translated material needed?	Translated material last updated?
<i>e.g. Somalia</i>	<i>e.g. Tower Hamlets Somalia Organisation and Nnetwork</i>		

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Other Information

	Date last updated	Checked with local community
Information about local interpreter services		
Information about language lines		

Useful Information

You can find out about the ethnicity and religion of the population on your local authority is available from the Census website - see www.statistics.gov.uk

Contact a Family Help line - Tel 0808 808 3555. The helpline has access to interpreters in over 170 languages.

Diversity matters - Good practice in services for disabled children and their families from black and other ethnic minority communities can be downloaded from Council for Disabled Children website see <http://www.ncb.org.uk/cdc/home.aspx>

Specific Topics

The following pages contain separate sections on childcare, education, employment, family and emotional support, finance and benefits, specialist disability services, leisure activities, parent participation and forums, social care, transition, transport and mobility.

Each section could be sent out to the different teams /agencies responsible for maintaining this information to complete and then returned to the lead individual responsible for collating and coordinating information for families of disabled children

Childcare

Help in finding and funding childcare to support a child's additional needs

Despite the increase in childcare places over the past ten years, parents of disabled children tell us

- they are not provided with information telling them who can help them find suitable childcare
- they do not know how to get childcare which will support their child's needs e.g. medical needs, challenging behaviour
- childcare is scarce and patchy particularly in the school holidays and for older children
- childcare is too expensive as parents are often asked to pay a premium to cover additional support costs
- parents find childcare is not appropriate to their needs and/or is rationed where available.
- transport arrangements after school are inflexible and prevents them from accessing childcare

Are you providing information to families of disabled children about...?	Date last updated?	Positive feedback from parents?	Working with parents to develop /improve
Crèche and childcare taster sessions to build parents confidence in leaving their child			
Brokerage service to assist families in finding suitable childcare including older children aged 5-19			
Specialist provision and funding streams to support inclusion in child care setting			
Support for disabled children to access holiday play schemes and after school activities			

Useful resources

Contact a Family - Finding and paying for childcare', see <http://www.cafamily.org.uk/families/rightsandentitlements/childcare.html>

Early Support background information factsheet on childcare describes the different types of childcare and support for disabled children aged 0-5. see <http://www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/earlysupport/home/>

Day Care Trust provide a guide for parents of disabled children which sets out what should be available and the different childcare options. see <http://www.daycaretrust.org.uk>

Disability specific e.g. speech and language, continence services, community dentists

Most of these are provided by the NHS, though some are provided by the local authority.

Disabled children can be slower developing in some areas as a result of their condition. Getting help early on can make a real difference in outcomes for the child. However parent are often unaware of what help is available and how to access it. .

Are you providing families of disabled children information about these services...?	Date last updated?	Positive feedback from parents?	Working with parents to develop /improve
Child & Adolescent Mental Health (CAMHS): Can offer advice on behavioural difficulties. Parents may also find it helpful to talk to them about how their child’s difficulties impact on the daily life of the whole family.			
Child Development Centre assesses and provides support to children showing developmental delay and /or a diagnosed disability. This service is usually led by a paediatrician with a team of other specialist including health visitors, therapists and educational psychologists			
Community Dentist provides advice on diet and planning for healthy teeth and provides dental services to children who find it difficult to access mainstream dental services.			
Community equipment (might include wheelchair services) provides medical aids and equipment needed for health reasons and to assist with daily living e.g. lifting and transfer, eating, bathing, washing. They also provide equipment needed by a child at school.			
Continence Can provide advice and practical help if a child is incontinent. When the child reaches a certain age they can provide help with getting nappies or incontinence aids.			
Dietician Can advise on food, diet and nutrition where a child is reluctant to eat, needs to be on a special diet or has difficulties in chewing and/or swallowing.			

<p>Genetic counsellor provides information about the likelihood of a genetic condition happening in a family.</p>			
<p>Health Information provide Information about the child’s medical condition, how it will impact on their life, how to manage symptoms and minimise the risk of it worsening.</p>			
<p>Occupational Therapy Can can advise and provide suitable aids, or assist with the child gain new skills, to maximise the childs independence. to help with everyday activities such as feeding, dressing, toileting, bathing and play in younger children and writing skills in older children.</p>			
<p>Orthotics (often called splints) supply and fitting of aids and equipment to help improve mobility or provide support This might be provided by occupational therapists, physiotherapists, orthotists or orthotic technicians. If a child needs special shoes they might be seen by a podiatrist.</p>			
<p>Physiotherapy helps in the management and development of movement skills. This may include exercises to strengthen weak muscles and games to improve co-ordination and motor skills.</p>			
<p>Sensory support services (might be separate hearing and visual impairment services) .provide support to families of children with hearing and /or visual impairments. The support can be in the family home, at nurseries and playgroups or in a range of school settings. They also offer advice and support to nurseries, playgroups, schools and colleges that teach deaf children , .<i>*This service is provided by the local authority.</i></p>			
<p>Speech and language service helps children learn to communicate, either through speech or other methods. They can also help if there are problems with eating, drinking and swallowing. They are usually run by the health service.</p>			

<p>Wheelchair services carry out assessment and provide wheelchairs and buggies to meet a child's needs, including extras such as cushions, armrests and trays.</p>			
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Useful resources

Contact a Family medical Directory can provide information on over 1200 disabilities and conditions, and associated support groups as well as leaflet describing the roles of different health professionals. see <http://www.cafamily.org.uk/medicalinformation/index.html>

They also have guides on a range of other topics including aids and equipment , behaviour and about diagnosis.

Early Support – provide information about some conditions including autism, cerebral palsy, down syndrome, sensory impairment, speech and language difficulties see <http://www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/earlysupport/resources/esresources/>

AFASIC support these children and their parents, enabling them to overcome their speech and language difficulties.. <http://www.afasic.org.uk>

ERIC - provides information and support on childhood bedwetting, daytime wetting, constipation and soiling to children, young people, parents and professionals <http://www.eric.org.uk/>

ICAN ICAN's mission is to make sure that everyone in contact with children knows how important communication is, what a communication difficulty looks like and what they can do to help. <http://www.ican.org.uk/>

National Autistic Society information and support for people with autism (including Asperger syndrome) and their families. <http://www.autism.org.uk/>

Scope – information and support for parents of children with cerebral palsy. <http://www.scope.org.uk>

Whizz Kidz – provide advice on getting the right wheelchair for a disabled child and what training is available to them. <http://www.whizz-kidz.org.uk/>

Education

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

Some common areas parents encounter difficulties with are:

- knowing who to approach if they think their child needs additional support
- understanding the admission process for children with special needs
- being unhappy with the support their child is receiving at school and not knowing what to do next
- going through the process of requesting a statutory assessment or being refused a statutory assessment
- accessing support at school for their child's medical needs or personal care
- being excluded from school activities (disability discrimination)
- exclusion from school because of challenging behaviour
- home to school transport, particularly when the disabled child attends a different school to siblings
- home tuition if their child has medical needs and is unable to attend school

Are you providing information to families of disabled children about...?	Date last updated?	Positive feedback from parents?	Working with parents to develop /improve
Support for disabled children pre-school e.g. including in Early Years settings, Portage service			
School admission process for children with additional needs			
The process for accessing additional support including the role of Special Education Needs Coordinators(SENCO)			
Parent Partnership service – what they do and contact details			
Inclusion support for school activities, including after school clubs and Disability Equality Duty/inclusion policy			
Support around managing challenging behaviour including help from an educational psychologist			

Getting support for a child's medical needs at school			
Bullying: What to do if your child is being bullied			
Transport: Accessing home to school transport			
Home and hospital schools service			
Support in selecting and moving school			

Useful resources

The Advisory Centre for Education (ACE) - provides advice and information to parents and carers on a wide range of school based issues including exclusion, admissions, special education needs, bullying and attendance. see <http://www.ace-ed.org.uk>

Contact a Family can provide families with a guide on special educational needs and one on Bullying see see <http://www.cafamily.org.uk/families/rightsandentitlements/education.html> and www.cafamily.org.uk/pdfs/bullying.pdf

Early Support :background information fact sheet on education explains the different types of support for a child's learning in the Early Years see <http://www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/earlysupport/home/>

Employment

Helping parents back to work –e.g. carer entitlements, training schemes

Although some parents of disabled children actively make the choice to stay at home to care for their child, for the vast majority of parents this is not a choice, but a situation forced upon them. Parents highlight the following barriers:

- demands of caring leaves them with limited time or too exhausted to work
- earning enough to cover costs, including loss of benefits
- lack of opportunity for part-time or term-time employment and availability of training courses
- lack of information, support and guidance on returning to work and their rights in relation to work
- unreliable transport services and help in emergencies
- a lack of awareness and access to carers assessments that consider their right to work, study and leisure opportunities

Are you giving families of disabled children information about...?	Date last updated?	Positive feedback from parents?	Working with parents to develop /improve
Training and schemes aimed at helping parents getting back to work, including volunteering opportunities			
Whether going back to work is likely to affect their benefits and help them get a 'Better off welfare benefits calculation'			
Parents rights whilst at work and what options are available if parents are thinking about leaving work			
Parents' right to a carers' assessment and direct payments			
Parents' rights to attend hospital appointments with their children			
How local Jobcentre Plus supports parents with disabled children.			

Useful resources

Carers UK Provides a range of fact sheets, research and guide on combining work and caring. See <http://www.carersuk.org/Home>

Contact a Family provide guides on Working and 'Getting direct payments - see www.cafamily.org.uk/pdfs/working_factsheet.pdf and www.cafamily.org.uk/families/.../directpayments.html

They have an online benefits calculator see <http://www.cafamily.org.uk/cashcounts> so parent can calculate the impact on benefits of going out to work. Their telephone helpline can provide individual advice to families about the impact on benefits for parents going back to work.

Family and emotional support e.g. relationships, siblings, sleep, challenging behaviour, contact with other families

The pressures of raising a disabled child and lack of time parents have for one another means they are at a greater risk of relationship breakdown. It can also be difficult for parents to find time for other siblings or take part in ordinary activities most families take for granted. Disabled children often have disturbed sleep patterns; e.g. children with autism often only need four hours sleep a night, children with cerebral palsy can need turning during the night. This can leave parents exhausted, unable to think clearly and struggling to cope with their daily activities. Being the parent of a child who presents with behaviour problems can be an enormous challenge for the whole family. Parents often receive no information or advice on managing their child's sleep and/or challenging behaviour. Meeting other families can relieve isolation, help parents find solutions to common problems and provide them with new networks of support.

Are you giving families of disabled children information about...?	Date last updated?	Positive feedback from parents?	Working with parents to develop /improve
Local babysitter/carer services for children with medical/additional needs			
Information about workshops supporting parents at time of diagnosis e.g .Early Support			
Information about where to go for help with their child's sleep, including parent workshops			
Information about where to go for help with their child's challenging behaviour, including parent workshops			
Information about drop ins – where they can meet other parents and receive information			
Details of local parent support groups			
Details of local counselling services			

Useful resources

Contact a Family provides a range of guides including ones on Relationships, Siblings Sleep and Challenging behaviour They can also help families get in touch with other families, including those with rare conditions see www.cafamily.org.uk

Early Support – have produced fact sheets on sleep and behaviour
see <http://www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/earlysupport/resources/esresources/>

Relate - Relate offers advice and relationship counselling - see <http://www.relate.org.uk/home/index.html> for details of local Relate centres

Scope provide support for parents of disabled children around time of diagnosis and can provide sleep counsellors and workshops for parents to help them manage their child sleep in some areas – see <http://www.face2facenetwork.org.uk/>

National Autistic Society - provide practical information and tips on ways of dealing with challenging behaviour
<http://www.autism.org.uk/> Nas

The Challenging Behaviour Foundation – supports families of children with severe learning disabilities, such as those with no speech or limited communication, a significantly reduced ability to learn and requiring support with daily living skills such as dressing and eating. See <http://www.thecbf.org.uk/>

Finance and Benefits

Sources of financial support to help families meet additional expenses

It costs on average three times more to raise a disabled child than a non-disabled child. Many parents have reduced earnings because they find it difficult to combine paid work and caring. There are many different sources of financial help and benefits that might be claimed. Many families with disabled children are not claiming the benefits they are entitled to and are missing out on vital extra income. This can be because parents:

- don't know where to go for information, and find out about benefits in an adhoc way
- have difficulty understanding benefits information, as eligibility for one benefit is often dependent upon eligibility for another
- find application forms long and unwieldy to fill in as well as very demoralising, as they focus on what the child cannot do.

Advising families on financial benefits is complex and should only be carried out by properly trained staff. There are voluntary groups in most local areas providing specialist support to families claiming benefits. Before signposting families to organisations for financial advice, first find out what services they offer e.g. information, help filling in forms, represent families at appeal tribunals?

Are you giving families of disabled children information about...?	Date last updated?	Positive feedback from parents?	Working with parents to develop /improve
The different financial support available to disabled children and their families			
Local organisations qualified to provide benefits advice to families of disabled children			
Organisations providing face to face support in helping families in fill in benefits forms			
The Family Fund who can sometimes can provide funding to help families with one-off expenses like washing machines and holidays			
Dealing with Debt - organisations supporting people in debt . Families looking after a child with a disability often struggle financially and can be particularly vulnerable to debt problems			

Useful resources

Contact a Family: provide a range of guides on finance and benefits have qualified benefits advisors who can be contacted through their helpline.. They also have a guide on managing debt. see <http://www.cafamily.org.uk/families/rightsandentitlements/benefitstaxcredits/index.html>:

Citizens Advice Bureaux - Citizens Advice Bureaux provide free, confidential and independent advice around debt and benefits in over 3000 locations - see . <http://www.citizensadvice.org.uk/index/getadvice.htm>

Disability Advice Network A network of approximately 130 local disability information and advice services run by and for disabled people. See www.dialuk.info

The Princess Royal Trust for Carers network of over 130 independently managed Carers' Centres which provide information and Advice See www.carers.org

Leisure activities:

Support for a disabled child to access social/leisure activities including holiday schemes

Disabled children and young people consistently say that leisure and play, after school, in the holidays and at weekends, is the most important missing element in their lives. Parents strive to make opportunities for these but often find many unnecessary barriers, including a basic lack of information about what's available. Parents will want to know what activities are on offer, what support is available for their child and whether their child will be able to mix with other children and young people.

Are you giving families of disabled children information about...?	Date last updated?	Positive feedback from parents?	Working with parents to develop /improve
Universal services			
Support for inclusion in after school activities			
Support for inclusion in sport, leisure and social activities			
Specialist provision			
Toy libraries			
Play groups for children with additional needs			
Sport activities,clubs for disabled children			
Social/youth clubs specifically for disabled children			
Days out – local places to go and details of facilities supporting disabled children			
Specialist holiday play schemes			

Useful resources

Contact a Family: can provide a guide on holidays, play and leisure - see <http://www.cafamily.org.uk/families/holidays.pdf>

Extending Inclusion: This guide is designed to support the inclusion of disabled children in children's centres and extended schools. See http://www.ncb.org.uk/cdc/publications/extending_inclusion.aspx

Parent participation and forums

Information about how parent can get involved in improving services

Parent participation enables parents to get involved in service planning and decision making so that services better meet the needs of families with disabled children. They can do this by giving feedback about the services they receive, inputting to consultations or by getting more actively involved and working with professionals to improve particular services or becoming a representative on a strategic decision making board committee.

Are you giving families of disabled children information about...?	Date last updated?	Positive feedback from parents?	Working with parents to develop /improve
How they can get involved			
How to provide feedback on services they receive.			
Details of consultations they might want to input to			
Details of their local parents forum			
Reports from previous consultations			
Outcomes of parents getting involved in shaping services (You said- We did)			
How to make a complaint			

Useful resources

TDC website, parent participation pages - contains contact details of parent forums and material to support the development of parent participation.

Social care e.g. short breaks, direct payments, equipment and adaptations to the home

Families often do not find out about support they need and are entitled to. Local authorities provide certain services to disabled children. This can include practical assistance in the home, help accessing facilities outside the home and short breaks (once called respite). Short breaks provide the disabled child with an enjoyable activity that suits their individual needs whilst giving their carer a break from caring. The first step to accessing this is for the parent to ask for an assessment to find out if they are eligible. This is often carried out by a social worker from the children with disabilities team. The assessment should focus on the circumstances of both the child and the rest of the family. Local authorities can offer direct payments to parents wanting to buy in the services they have been assessed as needing if they want to manage their own social care needs

Are you giving families of disabled children information about...?	Date last updated?	Positive feedback from parents?	Working with parents to develop /improve
A description of the types of services provided by children services to families of disabled children including short breaks			
Information about who is eligible for these services			
Information about how to get an assessment			
Information about direct payments and support for families in managing these.			

Useful resources

Contact a Family provides a fact sheet for parents about disabled children services and direct payments and information about getting help with adaptations is included in their Aids and equipment guide see

<http://www.cafamily.org.uk/families/rightsandentitlements/disabledchildrenservices/index.html> .

Transition

Moving from children to adults services in health, education and social care

.Between the ages of 14 to 25 young people usually have to make important decisions about their education; leave home; get a job and start having relationships. For disabled young people it can be a confusing and complicated time, as the support they received from a number of different agencies changes as they move into adult services. Planning should start well in advance of leaving school and be centred around the young persons aspirations, so that their needs and choices are fully explored.

NB The education section includes transition when starting and moving school

Are you giving families of disabled children information about...?	Date last updated?	Positive feedback from young people?	Working with young people to develop /improve
Transition plans (normally starts around 14)			
Details of organisations providing advice and advocacy to support young people through transition			
Details of educational opportunities for disabled young people			
Information about support for young disabled people to live independently of their parents			
Information about support for young disabled people to access employment			
Information about support for young disabled people to access social activities			
Information to young people look after their own health including information on sex and relationships			
Information about changes to benefits and finances			

Useful resources

Contact a Family provides a two guides for parents about transition, one on preparing for adult life and another on changes to financial benefits when your child reaches 16. see www.cafamily.org.uk/pdfs/preparing_for_adult_life_web.pdf and www.cafamily.org.uk/pdfs/money_when_your_child_reaches_16.pdf

The **Transition Information Network** is a website for parents, carers and people who work with and for disabled young people in transition to adulthood. See <http://www.transitioninfonet.org.uk/view/>

Transport and mobility: including Blue Badge scheme, Dial a Ride schemes, transport to school

Getting around can be difficult for families of disabled children. This is not solely restricted to families of children in wheel chairs or those with health problems who cannot walk far. It can be difficult for families of children with challenging behaviour to travel by public transport, or even walk down the road. If a disabled child is in a different school to their siblings, parents are faced with the problem of getting their children to two separate schools. LAs must publish their home to school transport policy on an annual basis. They should have a clear policy on transport for children with special educational needs.

Are you giving families of disabled children information about...?	Date last updated?	Positive feedback from parent?	Working with parents to develop /improve
Blue Badge schemes			
Local transports supporting disabled people e.g. Dial a Ride			
School transport			
Help with travel costs to and from hospital			
Help with bus /tram/train/taxi travel			

Useful resources

Contact a Family has a checklist for parents which lists all the different benefits they might be entitled to including help with transport. see www.cafamily.org.uk/pdfs/ChecklistNI.pdf

Their education guide also includes a section about school transport see www.cafamily.org.uk/families/.../education/englandwales.html