



Cerebra

Positively Different

Finding and appraising information and evidence on the Internet.

Introduction

Families of children with disabilities are often keen to look for more information about their child's condition, therapies and treatments, or other services that might be available, and the legal rights that they and their child have.

The Internet provides a huge amount of information, much of which is freely available and easy to access if you know how to search. Although there are many reputable websites that provide good quality, reliable information, there are also websites which are less reliable and should be treated with considerable caution. It can sometimes be difficult to tell whether information is trustworthy, but we present in this briefing some tips which can help.

This guide outlines some suggestions to help you search efficiently on the Internet, and to appraise whether the websites you find present reliable and unbiased information.

Before you begin any search it is important to think about what exactly it is that you are searching for. This guide begins with some ideas to help you think this through.

There are websites that are known to provide reliable, impartial information. This guide will list websites that we frequently use at PenCRU (Peninsula Cerebra Research Unit for Childhood Disability) and that provide trustworthy information. Using websites that are recommended will make your search quicker, and more importantly you will feel confident that you can trust the reliability of the information that you find.

This guide will also provide guidance about appraising information that you find. This is general guidance that can be applied to any health information for which you are searching. It is based on principles that we use in our every day work as researchers within an academic research unit.

Peninsula Cerebra Research
Unit for Childhood
Disability
(PenCRU)

Much of the information that you find through the Internet or elsewhere may be research evidence, particularly when you are looking for information about treatments and therapies. We offer some guidance about appraising research evidence, and a link to some useful checklists to assist with this.

Finally, it is clear that not everyone uses the Internet to find information, or that it is not the only source that people use. Following a brief survey of parent members of our Family Faculty, we look at other potential sources of information that may be useful to you.

Finding information on the Internet

Searching

1. Where possible use a website that has been recommended by a health professional, or that you know is a reliable source of information, such as those listed later in this section.
2. In some websites you can use the terms AND, OR and NOT, which are known technically as 'Boolean operators'.
 - If you use AND between each search word you will only get results that contain both words (so AND narrows the search).
 - If you use OR between each search word you will get results which contain either one word, or the other, or both (so OR broadens the search).
 - If you use NOT before a search word you will exclude results which contain this word.
3. Define your search terms before you start. It may help to think about what you are trying to find out in relation to the following:
 - The group you are interested in (e.g. children with Autistic Spectrum Disorder)
 - The specific intervention/treatment/therapy/service that you would like to know more about
 - Whether you want to know about this in comparison to any other treatment (for example the usual care that you would expect your child to receive)
 - Outcomes that you are interested in (i.e. what effect would you like the intervention/treatment/service to have).

The answers to these questions can be used as 'Key Words' which you can type into the search facility of a website, or a search engine.

Example:

If you wanted to know whether your 5 year old with cerebral palsy would sleep better following massage therapy you might search for: Cerebral palsy AND (Child

OR infant) AND massage AND sleep.

4. Brackets can be helpful, for example if you want to search for two descriptions of a condition and a therapy, e.g. (Autistic Spectrum OR ASD) AND Music Therapy.
5. Inverted commas can be used to search for an exact phrase, e.g. "Cranial Osteopathy".
6. Most databases will give you the option to limit your search to within a specific date range which can be helpful.
7. 'EVIDENCE' and 'GUIDELINE' can be good search terms to add in if you are looking for specific interventions, treatments or therapies.
8. You may want to add the term UK to find information relevant to the United Kingdom.
9. If you search using search engines such as Google or Yahoo then you will almost certainly come across websites that are based on an individual's personal experiences. This might be of interest to you but may not always provide a reliable source of information that is relevant to your child's condition. Even children with the same diagnosis may be affected in very different ways.

Websites providing reliable, impartial information

The websites listed here are known to provide reliable, impartial information. They are listed in sections in relation to specific reasons that people might look for information.

General search engines such as Google are also popular when searching for information on the Internet, and it is ok to use them as long as you bear the following in mind:

- Search engines trawl through the Internet and automatically create collections of sites with no regard for the quality of the information that they find.
- Be aware that many organisations pay so that their website appears at the top of the first page of results.
- Many search engines do not access the latest information that is available.
- Use the guidance in the 'Appraising Information' section of this guide to ask yourself questions about any information that you find through a search engine to ensure that it is a reliable and trustworthy source.

1. Information about the condition

At the point of diagnosis many families feel that they want to search for more information about the condition or diagnosis. A logical first step is to ask the professionals who know your child. They should be able to provide you with the latest information that is relevant to your child, and direct you to a reliable website for further information. At this stage it is strongly recommended to use websites that have been endorsed by a health professional.

Contact a Family

www.cafamily.org.uk

Contact a Family is often a good place to start if you are searching for information about a condition. They provide information on over 1200 disabilities and conditions, and also give details of relevant support groups. The information on each condition has been written or edited by a member of the Royal College of Paediatrics and Child Health.

NHS Choices

www.nhs.uk/Conditions

NHS Choices is the online 'front door' to the NHS. It is the country's biggest health website and provides an A-Z list of conditions with lots of details about symptoms, causes, diagnosis and treatments.

Health Talk Online

www.healthtalkonline.org

This is the website of the DIPEX charity, where you can read, watch or listen to more than 2000 people's experiences of over 60 health-related conditions, and find reliable information about specific conditions. The information is based on qualitative research (usually interviews) into health experiences, led by experts at the University of Oxford.

Charities for specific conditions

There are often charities associated with specific conditions and these can be useful sources of information about those conditions. Use the guidance about appraising the information you find to assess whether the charity website is a reliable source of information.

2. Information about treatments and therapies

When considering treatment options for a child it might be interesting to find out what treatment is likely to be available, and what treatments are known to be effective for the particular condition.

Choice of treatments, therapies and interventions:

NHS Choices

www.nhs.uk/Conditions/Pages/hub.aspx?tab=Condition

NHS Choices gives lots of information that might be helpful when you need to make choices about your child's health, including information about conditions and treatments that are likely to be available through the NHS.

Effectiveness of treatment, therapies and interventions:

NHS Evidence

www.evidence.nhs.uk

NHS Evidence is a website provided by the NHS which allows you to search by topic or condition for clinical and non-clinical evidence and best practice guidelines. Some areas of the website are unfortunately not available to the general public as they require an NHS Login.

The Cochrane Library

www.thecochranelibrary.com

The Cochrane Library is a database of systematic reviews. Systematic reviews summarise and interpret the results of high quality medical research. You can use this website to find the most up-to-date evidence about the effectiveness of a given intervention.

National Institute for Clinical Excellence (NICE) guidelines

www.nice.org.uk

NICE is an independent organisation responsible for providing national guidance to the NHS on promoting good health and preventing and treating ill health. You can use this website to search for guidance that has been produced on a particular topic, procedure or treatment.

TRIP Database

www.tripdatabase.com

The TRIP Database is a clinical database which allows you to search for the highest quality clinical evidence for clinical practice. The results are organised by the level of evidence.

PenCRU

www.pencru.org

The Peninsula Cerebra Research Unit for Childhood Disability (PenCRU) responds to questions from families about therapies and health services for children affected by disability. The website provides summaries of the available evidence in response to specific queries from families and information about research and what different terms mean.

3. Information about services

The local services that are available for a child will vary depending on geographical location. There will usually be a website linked to the local or county council which should provide information about services that are available.

Example:

In Devon there is an organisation called DISCplus which produces newsletters for families about services and events happening in the county. They can also be contacted for information and they have a website which can be used to search for services www.devon.gov.uk/discplus.

4. Information about rights/legal advice

Information about the legal rights of the child and families may be necessary; it is sensible to go to trustworthy organisations for this information.

Every Disabled Child Matters (EDCM)

www.ncb.org.uk/edcm/home.aspx

EDCM is a campaign to get rights and justice for every disabled child. The website has a resources section which provides useful information and documents about various policy briefings and disabled children's rights and the law.

Council for Disabled Children

www.ncb.org.uk/cdc

The Council for Disabled Children (CDC) works to influence national policy that impacts on children with disabilities and their families. The website provides a wide range of resources and information for families, including the publication 'Disabled Children: A Legal Handbook' which is an accessible guide to the legal rights of disabled children and their families in England and Wales.

Cerebra

www.cerebra.org.uk

Cerebra provide information on their website about 'Disability Rights and Legal Issues'. They have a particularly useful DLA (Disability Living Allowance) guide which takes you through the form step by step offering guidance about how to complete it.

Cerebra have recently teamed up with Cardiff Law School to develop a series of comprehensive guides on the rights and entitlements of children with neurodevelopmental conditions and their parents, as well as the various transition processes these children and young people may face. These guides are currently still being written but Cerebra believe that they will empower parents and carers and signpost them to valuable information and advice. For more information about

these guides you can contact Cerebra directly.

Citizens Advice Bureau

www.citizensadvice.org.uk

The Citizens Advice Bureau (CAB) provide free, independent and confidential advice about a range of issues, including Money, Family, Daily Life and Rights. There is lots of advice on the website, as well as information about their telephone service and how to find your local CAB office.

5. Information about support

Families may often seek out support from other families in similar positions or who have children with the same condition. There are a range of condition-specific support groups to choose from and many of them have websites with forums which can help families to stay in touch even if they do not live in the same area. Contact a Family have produced specific guidance about assessing support group websites, details are given in the 'Appraising Information' section of this guide.

Contact a Family – Making Contact

www.makingcontact.org/

Making Contact is a service provided by Contact a Family which provides a safe way to get in touch with other people facing similar circumstances without having to give out personal contact details.

Face2face

www.face2facenetwork.org.uk

Face 2 Face provides a national befriending scheme which operates across the UK and is affiliated with SCOPE. Parents whose child has been recognised as having a long-term disability can contact their local scheme for support. It is not necessary for a diagnosis of any condition to have been made. Face 2 Face also offers an email or telephone service which links parents with trained parent befrienders.

Special Kids in the UK

www.specialkidsintheuk.org

Special Kids in the UK is a registered charity whose main focus is an online parent support forum. Parents can post questions for others and share information.

NHS Choices

<http://www.nhs.uk/CarersDirect/guide/parent-carers/Pages/Parentsupportgroups.aspx>

NHS Choices is the online 'front door' to the NHS. It is the country's biggest health website and includes a section dedicated to parent support. There is information about where you can access

support, and links to other websites that might be of interest.

Appraising information

Once you have found relevant information, there are a few questions that you can ask yourself about the website or material that you have found. This will help you to decide whether it is reliable, useful and relevant for you. It is not always possible to answer all of these questions but they may help you to think about the purpose of a website and whether the information is likely to be biased in some way.

Who wrote the information?

- Does the site or piece of information that you are looking at have a named author?
- Is there any information about the author's qualifications or expertise in this area?
- Can you verify that this person exists, e.g. is contact information provided?
- Are there any references or links to an educational institute (e.g. a university) or another known reputable organisation?
- If the website is written by a charity, is there a registered charity number?

How accurate is the information?

- Can you verify the information?
- Does the website or written information give references for the sources that have been used?
- How does the information compare with what you already know, or what you have read from other sources?
- Can you tell whether the information has been edited or checked by someone other than the author?
- If the information is historical or biographical, are the dates of events accurate?

Is the information current?

- Is there a date that the information was created, last updated or checked?
- Do the links to other sites work or have they have expired?

Whose point of view is being represented?

- Is the author promoting a therapy or product that they deliver or sell?
- Is there advertising on the page?
- Is the information composed mainly of testimonials or personal experiences?
- To what extent is the information trying to sway the opinion of the reader?

Are details of additional sources of support or information provided?

- Are there suggestions for further reading?
- Are there links to other sources of information or advice about conditions or treatment options?

How relevant is the information to you and your family?

- The same condition can affect individuals in very different ways; is this taken into account?
- If you are searching for information about a condition then you will probably find that the information given is about the whole spectrum of how someone might be affected, not all of which will necessarily be relevant to your child.
- Information about treatments may also be irrelevant to you, particularly if the source of the information is a website based on a personal story.

Cautionary note

Be cautiously sceptical when you come across websites with information about specific therapies. They will often have been written by the person who developed the treatment or therapy, and they may be selling the therapy. Therefore the website may not provide impartial or reliable information. Use a reliable website, such as the ones listed in this guide, to see whether the therapy in question has been subject to any high quality research.

Other guidance

There are other organisations which have produced guidance about appraising information that you find on the internet. Of particular note, Contact a Family produce a booklet entitled 'Finding Medical Information on the Internet'. They include a section on judging whether support group websites are genuine and a few cautions for looking at websites that include people's personal experiences. The booklet is available on their website, or by following this link:
<http://www.cafamily.org.uk/pdfs/paptInternetLeaflet.pdf>

Appraising research evidence

When you are looking for information on the Internet, particularly information on treatments, therapies and services, you will probably come across reports about research. It can be difficult to assess which research might be useful, and whether it is of a high quality.

Solutions for Public Health are a NHS organisation that has produced freely available checklists which you can use to appraise different types of research. This will help you to make decisions about whether it is a high-quality, reliable and useful piece of research. The checklists can be accessed at <http://tinyurl.com/2v8voy8>.

In addition, the Centre for Evidence Based Medicine provides Critical Appraisal Sheets for appraising Systematic Reviews and Randomised Controlled Trials (RCTs). These are types of research that you might come across. The Critical Appraisal Sheets can be accessed at <http://www.cebm.net/index.aspx?o=1157>.

You need to use slightly different guidance for research that uses different methods and designs, but in general it is useful to think about the research in terms of:

1. What are the results?
2. Are the results valid?
3. Are the results relevant to you?

The checklists recommended above will help you to answer these and other questions relating to the quality of the research that you are looking at.

When considering whether the research is relevant to you, you might want to think about:

- Did the children receiving the treatment, therapy, service, etc, being tested have a condition that you are interested in, i.e. if the children involved in the research had a diagnosis of Autistic Spectrum Disorder (ASD) and your child has a diagnosis of Global Developmental Delay then the results may not be relevant. There is no guarantee that children with different diagnoses will respond in the same way to a treatment, therapy or service.
- What outcomes does the research look at? For instance, if you are interested in the effect of a treatment or therapy on the time taken to get to sleep but the research you have found measures hours spent asleep then you will need to think carefully about whether this finding is relevant to you.

Other sources of information

We surveyed members of our PenCRU Family Faculty, asking where they searched for information. The Internet was the favoured option for all respondents. However health professionals and information leaflets were also commonly used. Support groups and Internet forums and chat rooms were quite popular, as were schools and relevant magazines. Few

people used their local library as a source of information. Some respondents suggested that books were useful; these were borrowed from schools or through Cerebra's lending library, or purchased if they had been recommended. Being on the local council's register of children with a disability was also suggested as a source of information.

The advice provided above applies when you are searching for information in all of these places, to ensure that what you find is reliable, trustworthy and relevant to you and your family.

Acknowledgement

We are grateful to several parents from the PenCRU Family Faculty who commented and made helpful suggestions on earlier versions of this briefing.

Who we are

The Peninsula Cerebra Research Unit (PenCRU) carries out a broad programme of applied research that aims to improve the health and wellbeing of disabled children and their families. We involve families affected by childhood disability in all aspects of our research and related activities through our Family Faculty.

PenCRU responds to questions from families about therapies and health services for children and young people affected by disability or who have special or additional health needs. We provide summaries of the evidence of the effectiveness of therapies to help families make decisions about treatments. Where the evidence is lacking we seek funding to conduct research to assess the effectiveness of interventions on outcomes that families tell us are important, such as functioning, social inclusion and participation, and quality of life. For more information see www.pencru.org.

Contact

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The Cerebra In-house Research Team carries out desk-based research into a number of areas, based upon parent and professional requests, new scientific evidence and issues raised by our staff. We aim to provide information that is relevant to parents and carers of children with disabilities as well as the professionals who come into contact with them. By empowering parents and professionals with knowledge, we can help them to improve the lives of the children they care for and support.

If you require further information or would like to suggest avenues for further research, please get in touch.

These reports are made possible only by the kindness and generosity of Cerebra's supporters. Cerebra is a charity that works for a future where children living with neurological conditions enjoy lives filled with learning, opportunities and joy. We fund vital research that aims to improve children's lives and those of their families. We directly support more than 10,000 affected children and families around the UK.

With your help we can reach out to so many more. To find out how, visit www.cerebra.org.uk/fundraising or call 01267 244 221 and ask for Sadie Clark.

Cerebra

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The views and recommendations expressed in this report are those of the author, not necessarily those of Cerebra.