



WWW...The World Wide Web: For Families of Children with Disabilities

October, 2003

The World Wide Web can provide easy access to:

1. Information and data
2. Support and connections
3. Communication and distribution tools

For parents of children with disabilities the Web can offer access to:

- Specific information on a child's diagnosis
- Families with similar issues
- Service providers
- Interaction and communication with a variety of resources
- Research based treatment options
- School and other program regulations
- Financial information
- Web sites, chat rooms, on-line support groups and listservs

The Web can also be a source of information and support to siblings, grandparents and extended family who also require support and information. There are specific Web sites and on-line support groups for them along with the resources that parents might access.

The Web is ideal for:

- Parents who are isolated because of a medical condition, disability or geography
- Parents of a child with a rare syndrome or disability
- Keeping anonymity

Computer use in the home is growing dramatically. In light of this, some communities have established Web sites for parents of children with disabilities. While it is not appropriate to buy Internet accounts or buy computer equipment for individuals or single families there are ways to use the Web to support families.

Web Sites

A Web site consists of multiple Web pages and can include text, pictures, sound and video. Some potential uses for a Web site would be to inform families about resources and services such as; how to connect with other parents, where to receive emotional support, specific groups or organizations, special education, financial and health care services and supports, home health care, other contact and referral information. Many groups and organizations use their Web site to post: notices of upcoming meetings, support groups, trainings, newsletters, articles and other pertinent information. It also can provide an e-mail link to their local Family Support Contact.

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Listservs

A listserv lists the e-mail addresses of people who are interested in a particular subject. Most listservs are two-way exchanges with parents and professionals offering information and asking questions. Parents or individuals post a specific piece of information or question to the list. Replies are then received from others who are part of the listserv (locally or internationally).

Some examples of topics and questions posted on a listserv are; finding special equipment such as a new or better wheel chair, walkers, seating supports, explaining death to a sibling, negotiating with insurance or managed care provider to pay for specific services, finding needed emotional support or encouragement. For families of a child with a rare disorder this can be particularly helpful.

Chat Rooms

A chat room is a method of conversing with other Internet users in 'real time'. It is very much like a telephone conference call except that participants type instead of talk. Chat rooms can be targeted to a specific audience or topic and some even invite guest speakers to address a particular subject.

If you are considering a Web Site, Listserv or Chat Room some advance consideration and planning by your family support subcommittee is required.

Consider and answer the following questions for each of the approaches.

- Do we know how many families in our area either have computers or have access to computers to make use of the Web?
- How do we know this is what families want and will use?
- How do we know what information, resources or topics families want to see addressed?
- How will we track the usage of the approach we choose, i.e.; the number of 'hits' to the Web site, the amount of information and exchanges on the list serve and chat room?
- How will we keep a Web site and listserv updated and current?
- How will we use and monitor a listserv or chat room?
- How will we determine if it is useful to people? (Going beyond counting hits and usage and determining actual impact.)
- What kind of funds will be required and where will we get them?

Considerations and Cautions Regarding the Web

- ***The Web is not a replacement for relationships.*** It is another way to connect, not to be used 'instead of' making personal connections and relationships. Personal connections are significant to a child's and parent's well being.

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- ***There is no quality control on the Web.*** Presence on the Web does not guarantee truth or accuracy. This applies to Web sites, chat rooms, listservs, and publications. Be to check the validity of information from the Web with other sources.
Medical information found on the Web may not be accurate.
 1. Be skeptical of treatments that promote cures and always consider the source.
 2. Medical advice may be given out by non-medical personnel.
 3. Always consult with your doctor before acting on advice.
- ***Information from the Web may be coming from people with different standards.*** Each child and family has different expectations, abilities and resources that influence their choices about what is best for their child and family. Consider personal influences carefully before presuming another family's choices are right for everyone.
- ***Internet and computer use can be consuming.*** Over use of the Internet can almost be like an addiction. Pay attention to the amount of time spent on-line and the impact it is having on personal relationships with family and friends.
- ***The Web can provide a forum for people with a negative attitude or a personal agenda.*** Anyone with a computer and Internet access can share their views. The challenge is to sort out what is accurate information versus a person with a bias who has a negative attitude or a personal issue that is influencing what they are saying or posting on the Web.

It is not always easy to understand or decide what information on the Web is accurate and useful. If a person is willing to ask questions, check with other individuals and resources to validate and confirm the information, the Web can be a great resource for families.

Web Sites of Interest

- Family Village – www.familyvillage.wisc.edu/
- MUMS (Mothers United for Moral Support) – www.netnet.net/mums/
- NORD (National Organization for Rare Disorders) – www.rarediseases.org/
- Alliance of Genetic Support Groups – www.geneticalliance.org
- National Information Center for Children and Youth with Disabilities (NICHCY) – www.nichcy.org/
- This Web site has listings and links to many other resources pertinent to families of children with special needs - www.familyvillage.wisc.edu/websites.html
- The Beach Center at the University of Kansas- www.beachcenter.org/

These is not an exhaustive list, but may provide a starting point in your use of the Web

