



Information, Referral and Resources

September, 2001

"It is much easier to work with families who are well informed." This quote, from a professional, has been echoed numerous times around the state.

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Along with emotional support, the need for information is consistently one of the top supports preferred by parents of children of all ages, regardless of the severity of their child's disability. These findings are the result of a long-term study undertaken by the Beach Center on Families and Disabilities located at the University of Kansas. When the broad category of information was further analyzed, the following four informational areas have the highest expressed need;

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- **Information about the disability**

Regardless of the severity of the child's disability, information about the disability was the type of information most often preferred by parents. Parents want to be informed and understand their child's disability.

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- **Living with and caring for the child**

This type of information was most often requested by parents of children with mild, moderate and severe disabilities. Throughout their life span parents are looking for information from other parents and professionals on how best to live with and care for their child with disabilities.

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- **Ways to find and get the best possible help**

Families want and need access to current and accurate information that will support them in making the best choices for their child. They also desire information on where and how to access that help for their child.

- **Community resources and services**

The need for this type of information was universal and did not differ based on age or the severity of the disabilities. Parents want to know what type of resources a community has to offer their child with disabilities. (Is there appropriate and accessible housing, recreational activities, transportation and community organizations?) Getting the appropriate services is an ongoing process for families because of the multitude of services available, various ways to access them and differing eligibility criteria.

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Financial information and respite care information were also expressed needs, but ranked much lower. In Minnesota, local family support surveys support these findings from the Beach Center study.

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The information that families require is diverse and covers a broad spectrum of disabilities, issues and concerns. There are many ways and formats in which families or professionals who are supporting families can access information.

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Resources and Materials that families find useful come in a variety of formats: newsletters, flyers, brochures, books, libraries, organizers/notebooks, videos, and the Internet, etc.

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Technology, such as access to and the use of the Internet can play a major role in families' search for information. They can find specific disability information or look for local, state, national, and now worldwide resources. Parents can visit online websites and individual web pages created by parents of children with disabilities or enter chat rooms and talk to other parents.

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Referral to both formal and informal community supports can be crucial to whether the family of a child with a disability simply survives, or thrives. When the word "referral" is used, it is often seen as synonymous with the formal service system. Referrals may be made by professionals, friends and family members, or community members. The study from the Beach Center on Families and Disabilities confirms the value of using informal supports and connecting families to other parents of children with disabilities. Receiving emotional support from another parent is important to the families' well being and the childrens' long-term outcomes.

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A parent's need for information is paramount in their understanding and acceptance of their child's disability. By providing and helping families access current and accurate information they are able to make the best choices for their child, access the needed community resources and services, and find the emotional support they need to remain a healthy and thriving family.

Promising Practices:

- Share complete and unbiased information with parents.
- Support parents in their search for information through formal and informal connections, printed materials, web site addresses and organizational tools.
- Refer families to services, agencies and individuals who may be a resource.

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NOTE: *In the past, family support dollars (FSC J) have been dedicated to the development and expansion of family support libraries. Creating or adding to an unusual family resource library is not an effective use of family support funds.*

Consider these questions as you develop this element and these strategies:

If you are buying books and developing a library, how do you measure and track the usage of those books?

Who and how will people have access to the library?

Should you consider working with existing libraries that are in the business of loaning books?

Is your purchase of books a way of spending (dumping) unused money at the end of the year?

What is the purpose of your newsletter, directory of resources, parent directory or flyer?

Is there another existing newsletter you could consider joining and working with?

Will you need to develop a mailing list for newsletters, flyers, brochures, etc.?

If so, how will you do that?

Is there already an existing mailing list or database? Can you access it?

Reference:

Santelli, B., Turnbull, A., Sergeant, J., Learner, L.P., Marquis, J.G. (1996). Parent to Parent Programs, Parent to Parent Preferences for Support, *Infants and Young Children*, 9 (1) 53-62. Aspen Publishers, Inc.