



# Complex Child E-Magazine

www.ComplexChild.com

## Finding Peer Support as a Parent

by Susan Agrawal

We all know the saying that it takes a village to raise a child. When the child has special needs, this saying is even truer. We need a village to help us with all aspects of raising our children with complex issues, including physical help, assistance with caregiving, medical assistance, practical guidance from others who have walked in our shoes, or emotional support.

Finding peer support as a parent is probably the most important part of this "village." Not only can peer support provide you with the emotional support you need, but peers have also typically gone through many of the same experiences as you have. They can guide you through the many medical, legal, and educational challenges you may face, as well as providing practical tips on everything from equipment and technology to therapy and services.

How do you find peer support? There are four overlapping types of groups that may be helpful to you. These are:

- National organizations (mostly disease or condition-oriented)
- Local support groups
- Online support groups
- Peer-matching or parent to parent services

### **National Organizations**

National and international organizations, most of which have a discrete focus on a specific disease or condition, can be wonderful in helping you connect with other families from all over the world who are sharing the same struggles. Many of these organizations are quite large and have both a national and local presence in the community. Some, like Easter Seals or UCP, have a broad focus on helping all children with disabilities, while others are established solely to connect individuals with the exact same disease.

The best way to find these sorts of national organizations is to search the internet for your child's condition. If the condition is very common, like cerebral palsy or autism, it may be helpful to search for both the name of the condition and the word "support."

Another excellent resource is Exceptional Parent Magazine's annual resource guide, which lists organizations by disease, condition, or focus.

In general, national organizations use techniques such as newsletters, websites, internet forums, online conferencing, and national meetings to support their members. Some may also have separate local branches that allow parents to find similar families in their communities and become more involved on a day-to-day basis.

### **Local Support Groups**

Local support groups differ from national organizations in that they attempt to provide support between families in a more direct, face-to-face manner. Many have weekly, monthly, or bi-monthly meetings to socialize, plan events, and provide support. Many allow the entire family to participate, while some are restricted to certain types of individuals, such as dads or siblings.

Local support groups can be invaluable because they are filled with individuals who have not only walked in your shoes, but have done it in your very own community. They tend to know the best doctors, therapists, and services available, and can give very specific advice and support based on availability in the community.

Local support groups can be more difficult to find, especially if your child has a rare condition. Many times, local support groups have a broader focus, such as all children with physical disabilities or all children in special education. Even in large cities there may not be a support group for your child's specific condition.

Good resources for finding local support groups include contacting national organizations to see if they have a local branch, asking at schools, hospitals, and therapy centers, and of course searching the internet.

### **Online Support Groups**

Online support groups have grown and flourished over the past decade and have become the backbone of support for many families. Online groups not only allow people from all over the world to connect on a daily basis, but they have also made it possible for families with very unusual or rare conditions to find each other and provide emotional or practical assistance.

One of the best things about online groups is that they provide you with a sense of anonymity. You don't need to use your real name or provide details about yourself or your child if you don't feel comfortable doing so. You can ask questions in written form that you may be too embarrassed or ashamed to ask a doctor or another parent face-to-face.

Another fantastic thing about online support groups is that they allow you to both provide and receive support on a day-to-day basis. Many parents feel empowered when they are able to share their knowledge and support others, and many have commented that providing support has ultimately been the key to their own happiness and acceptance.

Finding online support groups is usually easy. Some may be associated with national organizations or on organization resource pages. Others, specifically tightly-focused or disease-specific groups, are typically housed on the sites Yahoo Groups or Google Groups, both of which have their own search engines. Larger and more broader sites, such as parent to parent sites, can be found by searching using terms like "special needs support site."

The quality of online support groups varies widely, and one group may or may not be a good fit for you as an individual. If this is the case, look for another group. They are out there.

### **Peer-Matching Services**

There are a few organizations out there that engage in peer matching, literally matching one family with another based on the child's condition and other provided information. These groups are not that common, though some national organizations are more than happy to provide peer-matching as part of their services.

Most states have a parent to parent program that will match families. To see if your state has this type of service, visit the website alliance for these programs at <http://www.p2pusa.org/> This website also contains detailed information on parent matching services.

Another popular group is MUMS, at <http://www.netnet.net/mums/matchq.htm>, though this group has changed its focus somewhat in the past few years.

### **Reap the Benefits**

At first, it may be awkward and uncomfortable to reach out to others for emotional or practical support. Take it one day at a time and you will most likely begin to see the benefits, as parents with experience help you through some of the most difficult situations you may encounter. Even if you can't do it for yourself, do it for your child. Every child, and especially a child with special needs, needs a village.