



parenting plus

With a Little Help from My Friends

The Value of Parent Connections

By Dana Yarbrough,

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As I prepared to write this article, I couldn't help but think back to the time my daughter, Brooke, was born. Being a first time mom was overwhelming in itself, but taking care of a baby that weighed only two pounds threw me into a tailspin of fear, exhaustion, and grief. I was simply surviving at that time — coping and getting by one problem at a time, reacting with no sense of direction. I heard about a support group that matched parents one-to-one for emotional and informational support. The support given to me then by another mother who had gone through a similar situation, helped me in my move to motherhood.

That support and my deep belief in the value of parent to parent support led me to a higher level of involvement with that first support group. Since 1997, I have directed Virginia's state Parent to Parent program, helping local parent groups and organizations start parent to parent support programs and promoting best practice in peer support.

The following paragraph, adapted from an article on Parent to Parent support written by Betsy Santelli with the Beach Center on Disability, gives a good description of what parents can expect from a Parent to Parent group.

Parent to Parent is a program that provides information and one-to-one emotional support to parents of children who have disabilities. The program operates very simply. Trained and experienced parents are carefully matched in one-to-one relationships with parents who are new to the program. The matches are based upon similarities in disability and family issues. Parent to Parent matches are usually made very quickly, often within 24 hours of the referral. At the time of the match, parents contacting the program may have just learned that their child has a disability. Or the parents may be dealing with a new stage in their child's life. Once parent matches are made, each relationship develops on its own. A lot depends on what the parents seeking support need and want. Some parents are just looking for information about resources in the community, for example, or more in-depth information about the disability. These matches are usually short term. The parents get the information they need and use it to improve their daily life or address whatever concerns they have. For other parents, the match lasts for years and develops into a life-long friendship. The experienced parents can share a lot of "tips" that make daily living easier. Other things get shared,

too, like laughter and worries, stories about the children and the rest of the family, resources that might be helpful, strategies for dealing with issues the families have in common, how to deal with school systems and doctors, and the incredible joy and stress of parenting. Since the parents share so many common experiences, the Parent to Parent match offers a unique form of support. This support is different from the support that professionals provide. And, because the relationship between the parents is one to one, the support is different from that found in larger parent groups.

Having worked over the past decade with parents who have children with disabilities, I have seen how families experience great emotional chaos. We survive, we search for answers, we settle in and begin choosing our battles, and finally we adapt to our lives. Everyone needs support and opportunities for socialization. This is especially true for parents of children with disabilities. One way to help meet this need is with parent support groups like the parent to parent model.

I wish there was a directory of all of the support groups in Virginia, but at this time, that doesn't exist. There is a statewide database of resources for families that includes many support groups (www.specialneedsresourcesva.org) and Parent to Parent of Virginia can assist you in finding a support group in your region. If you are unable to find a support group that meets your needs, you may want to have a group of parents in your area begin meeting to assess the need to start a new group. Parent to Parent of Virginia can assist if you are interested in starting a local parent to parent program. Begin with surveying parents in your area to find out what type of support they are looking for. Don't just assume that all parents want to come to monthly support group meetings. Many may be looking for a short-term match with another parent to get them through the initial phase of shock, denial and grief, or for advocacy support at an IEP meeting; others may be searching for information and answers only. While for others, having a place to come one a month to laugh, cry and share stories is their lifeline and breaks their isolation from their family, friends, and community.

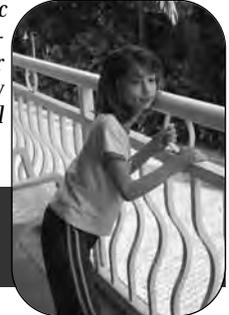
Once you know what type of support the parents in your area are looking for, it helps if some members of the group have the opportunity to sit in on other support

groups so discussion can take place on the structure and format of this new group. Preliminary decisions that need to be made include picking the "staff" (who will organize meetings or matches, who will facilitate meetings, etc.), choosing the format (time limited like one-to-one matching or ongoing monthly support groups), and securing funding (printing brochures, meeting costs, postage, etc.). There is information on the Internet about starting parent support groups and a lot of information is available on the best practice in starting and maintaining effective Parent to Parent programs through the national Parent to Parent network.

If you are interested in starting a local Parent to Parent program or learning more about the model, or are look-

ing for more information on how to start a parent support group in your area, please contact me at 804-795-1481 or PTPofVA@aol.com or visit www.ptpofva.com ■

Dana Yarbrough is the mother of Brooke, age 10 (shown in the photograph below), who has cerebral palsy, epilepsy and cortical visual impairment. Yarbrough is the executive director of Parent to Parent of Virginia, a statewide disability education and advocacy organization; works as an inclusion specialist in the Weinstein JCC preschool; volunteers as a Court-Appointed Special Advocate for Henrico's Juvenile & Domestic Relations Court; and coordinates several family support programs at the Partnership for People with Disabilities, Virginia's University Center for Excellence in Developmental Disabilities.



Frequently Asked Questions

1. What makes the Parent to Parent program so special?

Hearing from your child's pediatrician that your child has a developmental disability is like riding a roller coaster - you are at the top of the first hill and your stomach drops as you plunge down - you scream in fear, cry in disbelief, and maybe even rage in anger. When the person in the seat next to you suddenly grabs onto your hand and doesn't let go - you realize you are not alone and can open your eyes and see the beautiful view, and even laugh. A Parent to Parent "parent partner" may only be one person to the world, but to the parent they support, they may be the world.

2. How do you start a Parent to Parent program?

All it takes is one parent or service provider saying aloud that they want to support families in whatever way makes sense to those families. And then it is about making the commitment to more formally develop a local parent to parent program. This means surveying families in the area (or served by the agency) about how they want to be supported (matched 1:1; monthly support group meetings, etc.); seeking a sponsoring organization (or starting a not-for-profit); raising funds; advertising the program; recruiting and training families; and facilitating matches/support group meetings.

3. How much does it cost to run a community program and where should organizers look for financial resources and support?

We see programs that are run with volunteers only (\$0), to programs that support one part-time parent coordinator (\$10,000), all the way to programs that support two or more full-time paid staff (\$75,000 - \$120,000). For example, a budget for a part-time director, working from home, may include \$20,000 for salary; \$8,000 for printing public awareness and training materials; \$2,000 for phone and Internet charges; \$800 for rent; \$1,500 for equipment; \$2,500 for travel; and \$2,500 for supplies.

Good sources may be through local, state or national foundations; United Way agency; local or state early intervention programs; state education/health/Medicaid/rehab services/developmental disability agencies; and/or state university centers on excellence in developmental disabilities and developmental disabilities councils. Some programs conduct fundraising activities but find not always much return on activities that require a lot of energy. Whether grant writing or fundraising, sustainability is always the issue. It is best if the parent to parent program can be funded independently so they have autonomy, but for many, knowing that they have stable funding if they become a program under a hospital's or state agency's umbrella is more practical.

4. How can organizers evaluate their programs to see what kind of difference the program is making?

At every parent partner training event, evaluate the training to see what worked and what didn't; contact parents matched for support to see what worked and what didn't work well; if a parent partner attends a special education planning (IEP) meeting with a family, contact the family to see what impact that support had on them and/or the outcome of the meeting; if offering in-service workshops, conduct pre- and post-tests to see if the attendees' knowledge level was increased and follow-up with the attendees three and six months later to find out if and how they are using what they learned; and conduct a focus group made up of local school divisions, early intervention providers, pediatricians, etc. to see how they feel your program is doing - what is working well and what is not. Having funding in your budget to contract with an independent research/evaluation specialist, or contacting local university professors for a class project, ensures that your evaluation is cleaner.