



Parent-to-Parent Support

September, 2001

"I vaguely remember hospital staff's attempts to find us some support. I guess someone must have asked if we would like to be in contact with a parent who had a child with the same syndrome. I must have said yes. Within a few weeks I got a call from my parent match, although her child had been born several years earlier. I remember feeling a connection. We understood one another. She spent much of the time listening. I needed her to listen. I know this connection increased our quality of life."

— A parent

Parents whose children have special needs often feel helpless and alone. This can be true during times of stress, at the point of diagnosis, or when waiting, watching, and worrying that something is amiss with the child. Talking with another parent who has experienced a similar situation can help parents feel less alone and more hopeful. Findings from research and studies about the effectiveness of parent to parent support reveal the following outcomes:

- Parents' ability to cope is increased.
- Parent to parent support increases parents' acceptance of their situation.
- Over 80 percent of parents find parent to parent programs helpful.
- Parent-to-parent programs often begin spontaneously with grassroots effort, which validates the need and rationale that this initiative should be supported.
- This kind of support assists in the adjustment process and may avoid parents getting stuck in anger and denial.
- The kind of support parent-to-parent offers is unique and probably cannot come from any other source.
- Early connections with other parents leads to much lower utilization of advocacy later.
- Parents who are informed and supported learn to identify their own needs.
- Parents who are supported and informed are easier to work with from a system perspective.

The term parent-to-parent support refers to the various ways that one parent supports another parent in a one-to-one relationship. It refers to something different than a large group setting like a support group. There is a range of emotional and informational support provided to parents of children who have special needs in the various Parent-to-Parent Programs, with great variety in how formally the concept is designed or approached. It can include carefully made parent matches based on disability, child age, or family situation. Or, it can describe one veteran or mentor parent in a specific community

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or geographical area whose role is to connect with all parents in the area whose children have special needs, making informal matches or connections between parents locally as appropriate. The level of documentation each program requires can vary depending on the model designed by a community. Each model may be based on volunteerism, paid time, or a combination of both.

Indicators of Quality for Parent-to-Parent Programs

1. Mentor parents are trained and supported. Appropriate oversight is in place.
2. Provision is made for a range of contact (i.e. face-to-face, phone, in writing).
3. Connections between parents are based on: disability, issues or concerns, family type or situation.
4. Response time between request for activity and contact is timely and respectful.
5. Appropriate referrals, resources and information are provided.

Establishing a parent-to-parent program requires the interest and willingness of experienced parents to connect and support new parents. That interest is, for many, a naturally occurring byproduct of their own experience and emotional acceptance of their situation. Establishing a successful program also requires the partnership and assistance of service system providers. When parents and providers work in partnership to establish and maintain this effort, the resulting program can meet the needs of parents in a most meaningful way.

References:

Santelli, B., Turnbull, A., Marquis, J., and Lerner, E. ((1997). *Parent-to-Parent Programs: A Resource for Parents and Professionals*, Journal of Early Intervention, 1997. Vol. 21, No.1,73-83.

Santelli, B., Turnbull, A., Lerner, E., & Marquis, J. (1993). *Parent to Parent programs: A unique form of mutual support*, Infants and Young Children, October 1995, 48-57.

Parent to Parent of Vermont: A network of support and information for families, and a Resource for Professionals. Parent to Parent of Vermont, One Mail Street #69 Champlain Mill, Winooski, VT 05404. (802) 655-5290.

Pilot Parents of Northeast Minnesota, 201 Ordean Building, Duluth, MN 55802. (218) 726-4725.

Family Liaison Project, Arc Southeastern Minnesota , 903 West Center Street, Rochester, MN 55902. (507)287-2032.

