Parent to Parent programs: A unique form of mutual support

Parents of young children with special needs are thrust into the world of disability—a life experience with unique coping, emotional and informational support to parents of children with special needs by matching a trained veteran parent in a one-to-one relationship with a parent newly referred to the program. This article reports the results of a national survey of veteran and referred parents participating in Parent to Parent programs and discusses how Parent to Parent support is an important part of comprehensive family-centered services for parents and providers. Key words: mentor parents, mutual support, parent support, Parent to Parent.

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With emerging emphasis on family-centered services, service providers are learning from families about the kinds of supports that are the most helpful to them.1 When parents of young children with special needs and early intervention practitioners were asked about their preferences for early intervention services, parents most frequently mentioned the importance of professional sensitivity to families. Emotional and informational support, informality, flexibility, responsiveness, and acceptance were all given as examples of this sensitivity, as well as simply allowing parents of infants and toddlers the time needed to learn about and live within their new world of disability. Families also mentioned how important it was to find and have support from other families with similar children.2 A unique model for personalizing family support services according to the needs and preferences of families exists in Parent to Parent programs.3 Parent to Parent programs provide factual information and emotional support to parents who have a child with special needs by establishing a one-to-one match between a trained veteran parent—someone who has had experience as a parent of a child with a disability—and a parent who is newly referred to the program. The referred parent generally has a child with a similar disability and has expressed an interest in receiving support from

another parent who has "been there." The opport
unity to share family experiences with others who
understand because they have had similar experi
ences is an important source of support, and it is
this opportunity that is the foundation of the Parent
to Parent match.
Often at the time of the match, the referred parent
has just been given the diagnosis or is just begin
ning a new era in the life of the child with a
disability, such as the transition from the neonatal
intensive care unit at the hospital to home or entry
into an early intervention program or public school.
The veteran parent provides emotional support to
and shares information with the referred parent in
a casual and flexible relationship. Many matches
evolve into life-long connections, with the veteran
parent becoming a reliable ally and friend. A
mother explains:
Our daughter has been in hospitals constantly. Our
support parents came down to see her in the hospital, call
us a lot, send letters. The dad...even gave blood for our
daughter's surgery. They took us out when our daughter
was in intensive care and we were far from home. ... They
came to our daughter's first birthday party and have
become some of our closest, closest friends.

In an effort to learn more about Parent to Parent
programs and the services they provide through the
one-to-one match, the Beach Center on Families
and Disability at The University of Kansas con
ducted a national survey of Parent to Parent pro
gram coordinators and the veteran and referred
parents who are participating in these programs.
The data from the programs participating in the
survey describe 267 Parent to Parent programs
serving approximately 20,000 families in 47 of the
50 states nationally. The vast majority of these
programs are cross-disability, matching parents
whose children have a wide range of physical,
mental, and/ or emotional disabilities, including
chronic illness and acquired disabilities.

A random sample of referred and veteran parents
participating in the Parent to Parent programs who
returned program surveys completed parent sur
veys and provided a wealth of information about
the nature of their participation and their prefer
ences for emotional and informational support.
This article presents and discusses the data from the
referred and veteran parents who participated in
the national survey to answer the following re
search questions:

- Who participates in Parent to Parent pro
grams, and what disabilities are represented?
- How are one-to-one matches made, and what
are the characteristics of the matched interac
tions?
- What types of emotional and informational
supports are provided to and preferred by
referred parents who participate in Parent to
Parent programs?
- What supports are veteran parents receiving
before and during their matches with referred
parents?

This article also discusses how Parent to Parent
programs can be a resource to both parents and
providers as an important piece of a comprehen
sive, family-centered service system.

METHOD

Two questionnaires were used in the current
study: one for parents who were participating in a
Parent to Parent program as referred parents and
one for parents who were serving as veteran
parents. The survey for referred parents consisted
of 46 questions, and the survey for veteran parents
included 75 questions. Both surveys had a combi
nation of closed and open-ended items as well as
opportunities for parents to rank the importance of
various items within some of the questions. Ques
tions on both surveys were divided into five major
categories: (1) participating family demographics,
(2) reasons for participation in the program, (3) the
nature of the match, (4) the type of emotional and
informational support received and preferred
through the one-to-one match, and (5) other pro
gram supports above and beyond the matched
experience. The survey for veteran parents con
tained additional questions related to the veteran
parent training. Both surveys were developed with
the assistance of seven national leaders in Parent to
Parents who served on the advisory committee for the project and in accordance with expected mail survey development guidelines. A total of 701 referred parent questionnaires and 620 veteran parent questionnaires were sent out to parents by Parents to Parent program coordinators. Program administrators received instructions for randomly selecting 30% of their referred and veteran parent to receive the questionnaire and needed only to provide the address labels for the envelopes and then forward the packets on to the parents. Over the course of 15 months and in response to 2 reminder postcards that were sent to parents who did not receive surveys, completed survey booklets were received from 240 referred and 330 veteran parents, representing 115 different Parent to Parent programs from 43 of the 50 states. Each of these parents received a free audiocassette from the 5th National Parent to Parent Conference, a certificate of recognition, and a summary of the survey findings for their important contributions to the project.

RESULTS

Family demographics

Of the referred parents and the veteran parents who were participating in Parents to Parent and who returned surveys, the greatest percentage (88%) of parents were Caucasian, with 12% representing minority group. Moreover, most of the parents were part of a two-parent household (90%); and 3% had an annual income of over $50,000. Data from the national census indicate that all families in the United States, 7% are Caucasian, 78% are two-parent households, and 24% have annual incomes of over $50,000.

Parent to Parent programs are providing emotional and informational support to parents whose sons and daughters have a wide range of disabilities, as depicted in Table 1. Nearly two thirds (63%) of the disabilities represented are moderate or severe.

Nature of the match

Referred parents found out about Parent to Parent programs from many different referral sources, and these connections are outlined in Fig 1. The vast majority of parents who marked other indicated on their surveys that they referred themselves after having seen a brochure, poster, or some other printed materials about the program. The greatest percentage (25%) of parents were referred to the program by another member of the medical profession (nurse and/or physician). Once a referred parent is connected to a Parent to Parent program, the program coordinator considers several different factors to ensure a successful match. Table 2 provides information about the factors that referred parents reported on the basis of their match, as well as the percentage of referred parents who ranked each factor as being important (one of the top three most important variables in their match). Similar disability and family issues are used most often and ranked as important by the greatest percentage of referred parents.

Once a referred parent and a veteran parent are matched, the match relationship evolves in an individualized manner based on the needs and preferences of the referred parents. The timing and frequency of contacts, as well as whether the contacts are in person or by telephone or mail, are different for each match. Some Parent to Parent matches are short term, lasting only a few days and having only a few contacts, while others last for much longer and have many contacts.

Table 1. Disability representation

<table>
<thead>
<tr>
<th>Type of disability</th>
<th>Parents reporting (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental delay</td>
<td>51</td>
</tr>
<tr>
<td>Down syndrome</td>
<td>21</td>
</tr>
<tr>
<td>Mental retardation</td>
<td>21</td>
</tr>
<tr>
<td>Learning disability</td>
<td>20</td>
</tr>
<tr>
<td>Visual impairment</td>
<td>16</td>
</tr>
<tr>
<td>Central palsy</td>
<td>15</td>
</tr>
<tr>
<td>Multiple disabilities</td>
<td>15</td>
</tr>
<tr>
<td>Chronic illness</td>
<td>15</td>
</tr>
<tr>
<td>Prematurity</td>
<td>10</td>
</tr>
<tr>
<td>Hearing impairment</td>
<td>10</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>8</td>
</tr>
<tr>
<td>Technology supported</td>
<td>8</td>
</tr>
<tr>
<td>Autism</td>
<td>3</td>
</tr>
</tbody>
</table>
reflected parents responding to the survey, 50% are in matches that have lasted more than 1 year, and 56% have had at least 7 contacts.

Supports for referred parents

Table 3 presents the emotional, informational, and other program supports that were provided to and preferred by referred parents. A preferred support is one that parents rated as one of the three most important to them.

Given that Parent to Parent programs have as their foundation the provision of support from someone with similar experiences who is available to listen, it is not surprising that this type of emotional support was listed most often as being provided in the match (72%) and ranked most often by referred parents as being preferred (66%).

Table 3 also describes the types of informational support that referred parents reported as being provided to them and how they ranked these supports in importance. Information about the disability and information about living with and caring for a family member with special needs were mentioned equally by referred parents (60%) as being provided to them, with 48% of the referred parents ranking disability information as preferred and 58% ranking information about living and caring for their son or daughter with a disability as a preferred support.

Many Parent to Parent programs provide a comprehensive array of support services in addition to the one-to-one match. Table 3 presents information on the supports above and beyond the one-to-one matched experience that were provided to and preferred by referred parents. Group meetings, both

Fig 1. Connections with Parent to Parent.
Table 2. Factors in peer matches

<table>
<thead>
<tr>
<th>Factors</th>
<th>Used for parents (%)</th>
<th>Preferred by parents (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family members have similar disabilities</td>
<td>96</td>
<td>96</td>
</tr>
<tr>
<td>Families faced similar problems</td>
<td>55</td>
<td>63</td>
</tr>
<tr>
<td>Family members with disability are same age</td>
<td>36</td>
<td>38</td>
</tr>
<tr>
<td>Family structure is similar</td>
<td>29</td>
<td>9</td>
</tr>
<tr>
<td>Parents are same age</td>
<td>28</td>
<td>15</td>
</tr>
<tr>
<td>Families live close by</td>
<td>27</td>
<td>18</td>
</tr>
<tr>
<td>Veteran parent could respond in 24 hours</td>
<td>25</td>
<td>24</td>
</tr>
<tr>
<td>Cultural-ethnic backgrounds are similar</td>
<td>23</td>
<td>9</td>
</tr>
<tr>
<td>Education and income level are similar</td>
<td>18</td>
<td>8</td>
</tr>
<tr>
<td>Families are similar size</td>
<td>17</td>
<td>4</td>
</tr>
<tr>
<td>Families both speak English as a second language</td>
<td>1</td>
<td>6</td>
</tr>
</tbody>
</table>

For educational and emotional support, were reported by the greatest percentage of parents (69% and 65%, respectively) as being offered by their program and were preferred by the largest percentages of referred parents (64% and 47%, respectively). While only 27% of the parents related that their program provided a 24-hour telephone “warm line,” this service was ranked as preferred by the third highest percentage (27%) of the referred parents.

Training for veteran parents

Veteran parents are the backbone of Parent to Parent programs, volunteering their time to provide emotional and informational support to parents.

Table 3. Supports provided by Parent to Parent programs

<table>
<thead>
<tr>
<th>Supports</th>
<th>Provided by program (%)</th>
<th>Preferred by parents (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional</td>
<td>72</td>
<td>66</td>
</tr>
<tr>
<td>Soften to listen and understand</td>
<td>65</td>
<td>55</td>
</tr>
<tr>
<td>Helping in times of stress</td>
<td>65</td>
<td>55</td>
</tr>
<tr>
<td>Knowledge of others who are doing OK</td>
<td>54</td>
<td>54</td>
</tr>
<tr>
<td>Hope for the future</td>
<td>59</td>
<td>58</td>
</tr>
<tr>
<td>Way to deal with stress</td>
<td>45</td>
<td>46</td>
</tr>
<tr>
<td>Problem-solving support</td>
<td>45</td>
<td>45</td>
</tr>
<tr>
<td>Informational</td>
<td>60</td>
<td>56</td>
</tr>
<tr>
<td>Disability information</td>
<td>56</td>
<td>56</td>
</tr>
<tr>
<td>Care for child</td>
<td>45</td>
<td>54</td>
</tr>
<tr>
<td>Ways to find and get services</td>
<td>50</td>
<td>47</td>
</tr>
<tr>
<td>Community resources</td>
<td>27</td>
<td>27</td>
</tr>
<tr>
<td>Financial information</td>
<td>27</td>
<td>27</td>
</tr>
<tr>
<td>Basic care information</td>
<td>28</td>
<td>17</td>
</tr>
<tr>
<td>Other program supports</td>
<td>65</td>
<td>48</td>
</tr>
<tr>
<td>Group meetings for emotional support</td>
<td>65</td>
<td>48</td>
</tr>
<tr>
<td>Group meetings for education</td>
<td>47</td>
<td>47</td>
</tr>
<tr>
<td>Group meetings for education</td>
<td>47</td>
<td>47</td>
</tr>
<tr>
<td>24-hour warm line</td>
<td>27</td>
<td>27</td>
</tr>
<tr>
<td>Social events</td>
<td>65</td>
<td>56</td>
</tr>
<tr>
<td>Activities for new family members</td>
<td>31</td>
<td>31</td>
</tr>
<tr>
<td>Chance to tell others about program</td>
<td>35</td>
<td>35</td>
</tr>
</tbody>
</table>
newly referred to the program, and most Parent to Parent programs (76%) train veteran parents in their important role. Fig. 2 presents information on the number of hours of initial training that veteran parents receive from their programs, with 64% of veteran parents indicating that they receive 10 or more hours of training.

Veteran parent training covers a wide range of topics as depicted in Table 4, with over 90% of the veteran parents reporting that they were provided with training in listening skills (94%), training in communication skills (93%), and an orientation to the Parent to Parent program goals, activities, and philosophy (92%). By far the greatest percentage of veteran parents (55%) ranked the training in listening skills as being (one of) the top three most important content areas.

Once matched and as their matches evolved, veteran parents indicated that they were provided with ongoing support and informal training from a variety of people connected to the program—the program coordinator (92%) and another veteran parent (57%) being mentioned most often.

**DISCUSSION**

**Participants in Parent to Parent programs**

Parents who are participating in a Parent to Parent program as either a referral or a veteran parent tend to be Caucasian mothers from two-parent families with an income above $55,000. That minority parents are not involved in Parent to Parent is a challenge not only for Parent to Parent but for other parent support efforts as well. Further
Table 6: Content of veteran parent training

<table>
<thead>
<tr>
<th>Content area</th>
<th>Provided by program (%)</th>
<th>Preferred by parents (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Listening skills</td>
<td>94</td>
<td>75</td>
</tr>
<tr>
<td>Communication skills</td>
<td>93</td>
<td>55</td>
</tr>
<tr>
<td>Orientation to program</td>
<td>92</td>
<td>11</td>
</tr>
<tr>
<td>Adjustment to the diagnosis</td>
<td>90</td>
<td>11</td>
</tr>
<tr>
<td>Community resources</td>
<td>69</td>
<td>57</td>
</tr>
<tr>
<td>Information about disabilities</td>
<td>81</td>
<td>65</td>
</tr>
<tr>
<td>Healthy lifestyle</td>
<td>80</td>
<td>27</td>
</tr>
<tr>
<td>Disability organizations</td>
<td>80</td>
<td>8</td>
</tr>
<tr>
<td>Referral process</td>
<td>74</td>
<td>13</td>
</tr>
<tr>
<td>Self-awareness</td>
<td>60</td>
<td>6</td>
</tr>
<tr>
<td>Financial information</td>
<td>58</td>
<td>5</td>
</tr>
<tr>
<td>Advocacy services</td>
<td>56</td>
<td>13</td>
</tr>
<tr>
<td>Sibling training</td>
<td>39</td>
<td>1</td>
</tr>
<tr>
<td>Cultural diversity training</td>
<td>37</td>
<td>2</td>
</tr>
</tbody>
</table>

Research is needed to understand why minority parents are underrepresented in Parent to Parent and other parent support programs. Perhaps because the first Parent to Parent programs were established in the early 1970s by middle-class Caucasian mothers, replication efforts were most easily undertaken by mothers with similar characteristics. Many Parent to Parent programs recognize the challenges of reaching families who are not fully represented in the service system, and several of these programs have developed some innovative outreach strategies for involving families of diverse racial, cultural, and ethnic backgrounds. Some successful strategies include involving a respected member of the community as the program coordinator, preparing printed materials in languages other than English, subsidizing long-distance telephone calls between women and referred parents, and adding the Parent to Parent component to an existing successful family resource center.

Nature of the match

Referrals to a Parent to Parent program are vital to the success of the program, and parents learn about the Parent to Parent opportunity through a wide variety of sources. Perhaps because physicians often deliver the diagnosis of a disability to the family, and social workers connected with many different service provider agencies often provide ongoing support to the family, these professionals are mentioned more often by parents as referral sources. While Parent to Parent programs consider their public relations efforts to be among their most important activities, because 55% of Parent to Parent programs have annual budgets of less than $5,000, it is often impossible to advertise their existence to potential parent participants. Parent to Parent programs are usually not well-known in their communities. The Parent to Parent program provides contact information for several hundred Parent to Parent programs nationwide.

Matches in Parent to Parent programs are made with careful consideration of many different commonalities that a referred parent and a veteran parent may have. Referred parents report being matched more often (and preferring matches)
They are similar disability and family issues, with age of the family member with special needs being listed as used and preferred the next most frequently. Since the capacity for Parent to Parent programs to match around similar disability and family issues is directly related to the number and diversity of trained veteran parents within the program, Parent to Parent programs actively recruit parents with diverse family and disability experiences to serve in the veteran parent role. Service providers are in a good position to discuss the veteran parent opportunity with parents whose children they treat, and with the permission of the parents, to refer any interested prospective veteran parents to a Parent to Parent program.

Referred parents also mentioned that they preferred having the veteran parent able to contact them within 24 hours of their match. Once the decision is made by a referred parent to participate in a match, it may be that there is some anxiety about what the matched relationship will bring. Parent to Parent programs respond by encouraging veteran parents to contact the newly referred parent just as soon as possible after the initial referral. Once the Parent to Parent match is made, support can be (and is) activated at any time and through any type of contact (e.g., in person, by telephone, by mail), thus providing an easily accessible and responsive support system for parents. A referred parent describes the nature of her match:

"I think Parent to Parent is an invaluable support system, especially for parents who have just found out that their child has or might have a disability. It is so important to not feel alone, and to have someone to turn to who can be seen and not judge. My veteran parent initiated our first phone calls just to say hello and ask how things were going until I got comfortable calling her. She and I, our husbands and our sons with disabilities are near good friends and always will be."

Supports for referred parents

Just as the nature and development of each one-to-one match is unique, so too do the supports that referred parents are provided and prefer are individualized as the parents themselves. While most parents mention the emotional support of having someone who shares their experiences to listen and understand, information about disability includes today's living issues, and group meetings for emotional and educational support as being important parts of their match, each such fulfills individualized needs. Parent to Parent programs provide a broad range of supports, because they recognize that even those supports that are ranked as preferred by only a small percentage of parents are very important to those individual parents. However, the parental preferences for the various supports and services that are reported to Table 3 for new Parent to Parent programs as they prioritize the development of new components.

Training for veteran parents

Veteran parent training is recognized by Parent to Parent programs as being important not only for ensuring the quality of support that is provided to referred parents, but also for increasing the credibility of the program with potential referral sources. With families in early intervention indicating their preferences for relationships that are informal, individualized, built on trust, and responsive to family needs, veteran parents who are trained specifically in communication and intervening skills and who have years of personal and practical experiences with disability issues can serve as important links with early intervention professionals and with parents whose young children are receiving services. Veteran parents have the skills, the wisdom that comes only with personal experiences, and the ongoing support from the Parent to Parent program to be important and credible resources to other parents as well as to providers in early intervention services across the country.

CURRENT AND FUTURE DIRECTIONS

The national survey provided important descriptive information about Parent to Parent programs—information about where programs are, the types of services they provide, and structural information
from participating parents about how the Parent to Parent experience has been helpful to them. This information was used to design a study to determine the efficacy of Parent to Parent support for referred parents—a study that is being carried out by a participatory action research team of parents and researchers in four different states.4,5,6

Additional Parent to Parent research that the Beach Center is conducting includes a 5-year study to determine the longitudinal efficacy of Parent to Parent support for referred parents, veteran parents, and the child with a disability, and a national survey of statewide Parent to Parent programs to learn more about how they have developed and how they provide technical assistance to local programs.

Health care and early intervention professionals are in a unique position to benefit from Parent to Parent support and to contribute to its increased availability to families. Service providers benefit from Parent to Parent programs because these programs offer important connections between and among parents, and through these connections, they provide emotional and informational support from one parent to another in ways that are preferred by families. With the rapid development of early intervention services and the increased emphasis on family-centered services, professionals may sometimes feel caught between believing in the importance of involving and responding to families and the realities of staff time and experiences. Parent to Parent programs provide experienced veteran parents who volunteer their time to assist with other parents in ways that only parents can. One professional who is working closely with a Parent to Parent program speaks about the benefit of Parent to Parent for his staff.

When the Parent to Parent program was established, we knew that the program would be of assistance to families, but we didn’t realize until later that it would also be of great assistance to the staff. As professionals, we often feel inadequate because we cannot truly understand what families are going through since we haven’t actually experienced what they have. Our staff became aware that this program could fulfill a need for families that they as professionals could not. In this way the program supports the role of the professional as well as supporting the family.

Providers can contribute to Parent to Parent by referring parents to a Parent to Parent program and sponsoring a Parent to Parent program. Parent to Parent programs rely on referrals from service providers. When medical and other early intervention personnel are aware of a Parent to Parent program and tell parents about the opportunity to be matched with another parent, referred parents can begin receiving this important support at the time of birth or early diagnosis of their child.

Approximately half of the Parent to Parent programs responding to the national survey are sponsored by a service provider agency, and these are many ways in which agencies can sponsor a Parent to Parent program at no additional cost to the agency.8 A sponsoring agency may contribute to a Parent to Parent program by:

- allowing the Parent to Parent program to use its not-for-profit status for fundraising and grantwriting purposes;
- providing meeting room space or a telephone line;
- assisting with training for veteran parents and
- promoting the program to other professionals and parents.

All of these may give the program more credibility with potential referral and funding sources.

As service providers and parents collaborate to provide a system of family-centered early intervention services in their communities, perhaps the one-to-one matched opportunity provided by Parent to Parent programs can become an established component of the service system. Parent to Parent programs and early intervention efforts in partnership can provide families with a comprehensive array of professional and parent supports and services broader than either parents or professionals can provide alone.
REFERENCES


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