Leadership Training for Parents of Children with Special Needs

2005-2007
“PALs has given me knowledge, and it also has given me an emotional life. Having the support of the PALs staff and PALs families is priceless.”

Families from 18 Wisconsin counties participated in the Parents as Leaders (PALs) leadership training during the 2005-2006 and 2006-2007 sessions, held in Green Lake, WI. These families committed to five sessions, Friday evening and all day Saturday. The PALs participants created changes in their own attitudes and knowledge, their families’ understanding, and have been agents of change in their schools, communities and throughout the state. In our initial conversations with parents they often shared their interests and what brought them to PALs. Many sought an experience that would connect them with other parents with similar life experiences. They needed information and practice in working with service systems. They wanted more practice in how to work effectively with providers and create collaborative goals, supports and strategies for their children. Many parents knew even before the first session that they wanted to see changes for their children, and that they had the resources to make a commitment to bringing community change for people with disabilities. Parents learned about PALs through friends, case managers, Birth to 3 program staff and school staff.

The families during these two years of training included:

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<thead>
<tr>
<th>Participants</th>
<th>2005-2006</th>
<th>2006-2007</th>
<th>2 year total</th>
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<tbody>
<tr>
<td>Dads</td>
<td>7</td>
<td>6</td>
<td>13</td>
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<tr>
<td>Moms</td>
<td>9</td>
<td>14</td>
<td>23</td>
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<tr>
<td>Other - Aunt</td>
<td>1</td>
<td>0</td>
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<tr>
<td>Total Number</td>
<td>17</td>
<td>20</td>
<td>37</td>
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Other Family Information

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<thead>
<tr>
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<th>2005-2006</th>
<th>2006-2007</th>
<th>2 year total</th>
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<tbody>
<tr>
<td>Dual Parent Family</td>
<td>9</td>
<td>13</td>
<td>22</td>
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<tr>
<td>Single Parent Family</td>
<td>0</td>
<td>1</td>
<td>1</td>
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<td>Children with Special Needs in Families</td>
<td>13</td>
<td>14</td>
<td>27</td>
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2005-2007 PALs families lived in these Wisconsin Counties:

Adams • Brown • Dane • Dodge • Green Lake • Jefferson • Marathon • Milwaukee • Oconto • Outagamie • Ozaukee • Portage • Racine • Rock • Sheboygan • Trempealeau • Vilas • Winnebago
This report summarizes findings in four areas:

1) Leadership skills and changes parents reported making that they attributed to their participation in PALs.

2) Leadership training topics identified by participants and covered in the sessions.

3) Community Action Projects that resulted from parents’ participation in PALs.

4) Participants’ self report of changes they have made in their efforts to advocate for their families and communities.
1) Leadership skills and changes parents reported making that they attributed to their participation in PALs

The majority of PALs families reported being very involved in planning for their child’s education by being a contributing member at IEP meetings (100%); meeting with teachers, therapists (100%) and health care providers (90%) regularly; participating in workshops and conferences and serving on committees (87%). All who participated in these areas attributed PALs as having had a positive influence on their participation in these activities.

Most of the activities that parents participated in were at the local level with some branching out to advocacy at the regional and state level. The use of new technology was evident in one family’s use of their internet blog to share disability issues with a wider audience. In addition to increasing parents’ activities in their communities, PALs also had a positive influence on their ability to access services and supports for their own families (75% reported major or extreme change) and a change in their ability to assist others in obtaining services (56%). Other families already had knowledge of supports, so PALs provided them with the opportunity to increase their own comfort with networking and connecting with others in their community with similar needs.

Participants commented that after their PALs experience they were more able to:

- find my personal vision/create a vision for my child;
- offer information to others more effectively;
- feel more empowered by the knowledge offered;
- interact more with people with different disabilities and their families;
- take an active role in my child’s educational and service planning;
- recruit others to get involved;
- have greater confidence; know where to go for information/resources;
- think outside the box;
- take on new activities (e.g. went to the Capitol to support legislation; communicated with legislators);
- have a stronger voice;
- increase knowledge, increase confidence, increase awareness;
- have better relationships with teachers; get therapists more involved; and
- have more awareness, confidence, knowledge, communication, resources and contacts.
Specific changes in parent’s knowledge

All of the participants in the 2006-07 group reported that “ways to plan for my child’s future” was the most significant change in their own knowledge. This contrasted with the response from the 2005-06 group: 50% of the participants reported this as a significant change in their knowledge. This difference points out how the PALs experience can be different for parents depending on their starting point. Our experience with the 2005-06 group was that the parents, many who had very young children, didn’t find it pertinent to imagine their child’s future at that time. In 2005-06, we had more success with the discussion when we focused on a parent’s vision for their child at any age, and less emphasis on what would or would not be available when their child was older.

Other areas of positive change noted by participants in both years were:
- How to negotiate to get what my child and family need (77%-88%)
- My role as a participant on my child’s IFSP/IEP team (60-75%)
- Our legal rights and how to use them (68%)
- Knowledge of legislation (88%)

Specific changes in parent’s skills

PALs leadership training has been most effective in helping parents to think differently about their knowledge of the system and their communities. We have seen less evidence from the participant’s perspective that they have made changes in the direct skills needed to be effective advocates and leaders in their communities. The five session training has not always provided parents with the real life practice, over time, that is needed for them to recognize a major change in their skills in these areas. While many parents reported only minor changes in many of their skills, there were responses that indicated change in skills in certain areas:
- Be an effective advocate (70-75%)
- Be an effective leader (50-63%)
- Express my ideas to a group (40-50%)
- Work in partnership with others (40%)

The majority of participants reported that they found the PALs program to be influential in supporting them to become advocates (80%). Participants also reported their experience to have been of great to very great value (100-93%) to them as a parent of a child with special needs.
Specific benefits

All participants reported a direct benefit for their child (100%), as a result of their own participation in PALS, as well as a benefit for themselves (70-100%) and for their immediate family. In the 2005-06 group, parents reported a significant benefit for their own spouses (80%) and a benefit for their communities (62%). Immediately after participating in the training parents were less able to see a wider benefit for other people with disabilities and the larger community. When asked about the benefit to society, one father commented, “As yet to be determined.”

2) Leadership training topics identified by participants

During the first weekend PALS parents engaged in a process of assessing their own needs for information, resources and skills to practice. The following topics were identified and addressed during the training sessions with an emphasis on leadership roles for families across topics. Teaching methods included: presentation by speakers; small group discussions facilitated by group members; large group discussions led by facilitators; reading material; videotape review and discussion; first person accounts by families and individuals with a disability; Community Action Projects.

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<tr>
<td>COMMUNITY RESOURCES</td>
<td>▪ ECO maps activity - Defining your community and personal resources</td>
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<td>▪ Pre and post training review of how parent’s communities/supports had changed</td>
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<td>▪ Written information and discussion of resources and systems in the state</td>
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<td><strong>COMMUNITY CHANGE</strong></td>
<td>▪ Grant writing and resource development</td>
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<td>▪ Focusing your advocacy message</td>
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<td>▪ The message triangle</td>
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<td>▪ Leadership and consensus building activities</td>
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<td>▪ Historical perspective on parent advocacy</td>
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<td>▪ PALs alumni share their leadership experiences</td>
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<td>▪ Time for family stories focused on steps toward change each session</td>
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<td></td>
<td>▪ Information on local and statewide advocacy opportunities</td>
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<td>▪ Community action projects</td>
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<td><strong>COLLABORATION WITH PROVIDERS</strong></td>
<td>▪ Rights and responsibilities in the schools</td>
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<td>▪ Models of inclusion – video and discussion</td>
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<td>▪ Working with conflict</td>
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<td><strong>FAMILY AND FUTURES PLANNING</strong></td>
<td>▪ Transition planning</td>
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<td>▪ Planning your vision for your child’s activities</td>
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<td>▪ Siblings as supports</td>
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3) Community Action Projects that resulted from parents’ participation in PALs

Each PALs family committed to a Community Action Project. Over the course of the training year participants received support in identifying needs in their communities, targeting a specific project/action for change, completing action steps and finding personal and community resources. Many of the projects during these two years of training were focused on individual efforts to expand parent’s participation in change at the personal and local levels.

Examples of Community Action Projects from 2005-2007;

• work on affordable housing options;
• revitalizing Down Syndrome Support Group;
• member of County Respite Board;
• member of Advisory Board of a new non-profit;
• member of Hands and Voices;
• member of Family Support Advisory;
• family Resource Council - ARC Committee for the early years;
• testified at Joint Finance Committee;
• participated in Capitol Steps for Autism;
• collaborative Parent Support group with school district; and
• group of women committed to a variety of community projects.
In addition to providing information on changes made as a result of participation in PALs, the families provided valuable information on the challenges they face in advocating for change in their communities.

Their challenges included:
- time to meet personal and family needs and then also work toward advocacy efforts;
- helping people in the community and even extended family understand that all children have similar needs and deserve the same opportunities;
- working with professionals who can really hear parents’ needs and desires;
- having services denied that parents knows could help their child;
- lack of personal confidence;
- not understanding how the IFSP/IEP process really works;
- figuring out how to convey the challenges of daily life; and
- finding a place in advocacy efforts for a child with significant needs.
Changes in action
Even though they were faced daily with these challenges, PALs parents provided examples of specific changes they had made as a direct result of their PALs experiences.

Changes for many families that happened first at the personal level:
- sharing their viewpoints for the first time and learning to work as a team;
- learning to notice their child’s strengths and to lessen their focus on the disability;
- having conversations with extended family members to help them understand their child better;
- recognizing their own stressors and joys and allowing those relationships to grow;
- communicating with more confidence and knowledge with teachers and service providers about what they want and what is important to their child;
- expanding relationships to be brave enough to talk to administrators and legislators, to be a voice on a county board, to forge connections with people who are in a position to support change;
- having increased compassion for and understanding of the experiences of people with disabilities and their families;
- experiencing the value and strength of compromise and perspective;
- learning about what is valuable to me, my child, and to the provider;
- developing a sense of responsibility for the outcomes of all children and families; and
- seeing beyond their own family needs.

Many families began by increasing their knowledge of resources, of their rights and responsibilities and of how the system works. This knowledge then helped many parents to have more confidence, which led them to try new activities that they would have not chosen to do before PALs. Specific skills such as how to frame their message and write a letter to a legislator have all been stepping stones for parents.

Three parents ended PALs considering a career change to working to support families with children with special needs.
Other parents commented on having:
- a more active role in their child’s IEP not relying on the “experts” opinion only;
- less fear about the future;
- become a more focused parent to both of her children;
- figured out a better balance -- what we need to do now for our child, and what can wait; and
- confirmation that her hunch about school not being a good fit for her child, and now knowing what to do about that.

Finally, parents acknowledged an increase in confidence to:
- seek an inclusive preschool instead of what the district has offered;
- take her child to church so he is a more visible part of their family’s faith community;
- seek discussion with his corporate employer about providing support to people with disabilities;
- lead and speak up at meetings instead of being a passive observer;
- weigh information and make their own decision whether it is popular or not; and
- stop assuming someone else will just step in and help.
Future PALs Recruitment

Parents/caregivers with children with special needs who are six years old or younger are encouraged to consider PALs. Feel free to download the PALs brochure available at www.waisman.wisc.edu/cedd/palsbrochure.pdf. The brochure details PALs dates, recruitment process and overview of the program.
PALs families engaged in activities
PARENTS AS LEADERS (PALS) is a part of the Wisconsin Personnel Development Project (WPDP) at the Waisman Center, University Wisconsin–Madison. PALs is funded by the Wisconsin Department of Health and Family Services, Birth to 3 Program

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Media Specialist: Cheri Sanders
WPDP Director: Linda Tuchman

http://www.waisman.wisc.edu/birthto3/
1-800-532-3321