



Sunset at Green Lake

Parents as Leaders (PALs) is a part of the Wisconsin Personnel Development Project (WPDP) at the Waisman Center, University of Wisconsin–Madison. PALs is funded by the Wisconsin Department of Health Services, Birth to 3 Program.

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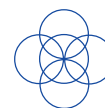
PALs

Biennial Report



Leadership Training for Parents of
Children with Special Needs

2007-2009



Waisman Center
University of Wisconsin–Madison
University Center for Excellence in Developmental Disabilities

"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."



Oak Mound Lodge, Pilgrim Center

aspect of my life". Other examples of how participants grew from the PALs program include:

- "I am now more aware of global disability issues."
- "I am vocalizing to my child's teachers and IEP participants my feelings about full inclusion."
- "I am more proactive with my child's doctors."
- "I now know how to talk to the school teachers better."
- "My confidence is much more secure."
- "I feel like I can have more control over the way my child receives services."
- "I feel ready now to attend conferences and trainings to continue to advance my knowledge."

Reflections of Co-Facilitators:

It is both humbling and empowering to act as program co-facilitators for PALs—to see participant's thirst for new resources, the growth in confidence around leadership skills and the comfort felt by participants being in each other's company. While each year is a new group of participants with different needs, strengths and personalities, it is evident that the gains and outcomes from the PALs program are fairly consistent and that participants are eager to get others to join the program.

As co-facilitators, we have appreciated the challenge of working with parents and arranging agendas based on their needs. We also have felt enriched by the informal interactions with PALs families—over meals, during breaks, in the evenings. These have afforded us a glimpse into their lives and the ability to call participants our friends.

Perhaps the biggest achievement of the PALs program for us as co-facilitators lies in a statement made by a family when asked "what did you enjoy most about the PALs program?" — "I enjoyed everything. I am recommending this program to every parent I meet with a kid with special needs"

Parents as Leaders Report 2007-2009



The PALs program is designed to bring together parents of children with special needs from around the state of Wisconsin for four to five weekends. This program is focused on those individuals who:

- 1) are ready to become leaders and advocates in their communities;
- 2) want to learn more about resources for children with special needs;
- 3) want to meet some of the key leaders who make the policies and run the programs that affect children with special needs and their families in Wisconsin; and
- 4) are interested in meeting other parents from around the state.

In this biennial report, we will provide an overview of the last two years of the program, specifically highlighting the following:

1. Leadership skills and knowledge that parents 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; and
4. Participants' self report of challenges they have faced and growth they have made in their efforts to advocate for their families and communities.

OVERVIEW OF THE PARENTS AS LEADERS PROGRAM

Demographics of PALs Participants:

In 2007-08, 14 individuals from six different counties participated in PALs. In 2008-09, 13 people from eight counties participated. Roughly half the participants in both years came together as partners and in one case a grandmother attended with her daughter-in-law, both of whom were caring for a family member. The remaining participants came without partners (all were mothers save for one father who attended alone in 2008-09).

Individual parents came alone for a variety of reasons including conflicting work schedules of their partner, lack of childcare, and in some cases the partner's lack of interest or hesitancy to get involved. Eighteen PALs participants were female and nine were male. The vast majority of participants for these two years were Euro-American, with two Hispanic participants.

The specific counties represented in both years were: Adams, Dane, Dodge, LaCrosse, Langlade, Marathon, Milwaukee, Outagamie, Ozaukee, Portage, St. Croix, Waukesha, showing geographic diversity across Wisconsin.



4. Participants' self report of challenges they have faced and growth they have made in their efforts to advocate for their families and communities:

As stated earlier in this report, families came to the PALs program because they wanted to help advocate for their children, gain new resources and to learn to overcome some of the "powerless" feelings they have had in their everyday lives. Participants listed the following as challenges they have faced:

- * Lack of knowledge of services
- * Overwhelming amount of paperwork
- * Financial challenges
- * Lack of options in a rural community
- * People not knowing about my child's disability
- * People looking at me like I am speaking another language
- * Lack of time

The impact of the PALs program on participants is perhaps best summed up through these statistics: 100% of participants who attended the program both years stated they experienced a good to a great benefit from the program (specifically, in both years all but one participant cited a great benefit). The benefits they received were not exclusive to just the actual participants. In both 2007-08 and 2008-09, 78% of participants said the PALs program benefited their family to a good or great level (100% noted at least a moderate benefit to their family).

The benefits continued to "trickle down" as evidenced by these numbers:

Benefit to your child who has a disability:
2007-08: 100% 2008-09: 88%

Benefit to your Birth-3 Program (if applicable):
2007-08: 100% 2008-09: 100%

Benefit to your Early Childhood Program (if applicable):
2007-08: 100% 2008-09: 75%

Benefit to your community (if applicable):
2007-08: 89% 2008-09: 88%

PALs participants seemed to feel newly empowered to work as leaders and advocates. One participant from 2008-09 summed this up by stating, "This program has changed the way I will deal with every

3. Community Action Projects that Resulted from Parents' Participation in PALS:

By participating in PALS, each family committed to pursuing a Community Action Project—a project wherein they chose one aspect of their community and acted as a change agent. The underlying goal of the Community Action Project was to encourage families to use the skills and knowledge acquired over the course of their PALS training on a focused project. Over the course of the training year, participants received support from PALS facilitators in identifying needs in their communities, targeting a specific project, and developing action steps towards completion.

Examples of Community Action Projects during the last two years included:

2007-08:

- Working with the County Division of Aging and the Sheriff's Department to implement Project LifeSaver in Adams County
- Forging stronger connections to the Wisconsin Seizure Network
- Attending Family Voices trainings, "Did You Know, Now You Know" and educated others in community about content
- Becoming a volunteer parent leader with WI FACETS
- Providing support to other parents through Parent-to-Parent of Wisconsin.
- Improving Spanish services and support in the Individual Education Plan (IEP) process

2008-09:

- Creating a brochure and resource binder for families with a child born with Spina Bifida, including the PALS mother as a parent resource
- Working with local emergency responders to develop a system to educate these agencies about children with special needs in the community
- Serving on the county Birth-3 advisory board
- Developing a Birth-3 transition to Early Childhood resource binder for a specific school district
- Develop a local family support group for parents/caregivers to gather and do social activities

How Participants Learned of the PALS Program:

Participants reported learning of the PALS program through a variety of resources including their Birth to 3 Program provider(s), Katie Beckett consultant, previous PALS participants, brochures, conference attendance, school staff—with a personal introduction to PALS being an important factor for most participants. In many instances this was having a Birth-3 service coordinator call a family and personally ask if they were interested in the program. This personal outreach to the family seemed to put the PALS program "front and center" and nudge the family towards participating.

Why Participants Joined PALS:

Individuals reported wanting to join PALS for several key reasons: connecting with other families; learning more local, regional and state-wide resources for children with special needs; gaining advocacy skills and wanting to have their children and families more involved in their community. Some participants were focused primarily on gaining this knowledge for their own family while others wanted to work for change in their communities.



1. Leadership skills and knowledge that parents attributed to their participation in PALs:

Advocacy Skills

Most PALs participants showed a tendency toward leadership and advocacy before getting involved in the program. Some had prior experience on advisory boards, working as parent liaisons with school districts, writing and editing family-centered literature on special needs and generally having a worldview beyond their own family's needs. This desire to "become an advocate" and "get involved" is the very characteristic that was most amplified over the course of each PALs year. In 2007-08, participants noted that the Parents as Leaders program had a major influence on their ability to become a more effective advocate (71% cited greatly influential or extremely influential on this item with the remaining 29% citing moderate influence). In 2008-09, participants provided even higher feedback on this item: 100% noted major or extreme change in knowledge of effective advocacy.

In both years, families made the following comments about their advocacy skills after PALs:

- "I am doing more advocating for myself and others."
- "I have found my voice when explaining [my daughter]."
- "I am working more with community officials."
- "I am ready to start doing whatever it takes to make life more successful for all children with special needs."
- "I feel I am better able to tell our story and communicate with others."

Resource Awareness

Another major area of leadership change came in the area of learning more about community, regional and state resources and how to access these. In 2007-08, most participants noted a major change in their awareness of services available and 86% of families cited a major or extreme change in their ability to access services and supports after their PALs participation. In the 2008-09 group, 89% of participants stated they had a major or extreme change in their knowledge of resources available to their child and family.

Families made the following comments about Resource Awareness:

- "I enjoyed finding out more about the resources that are available."
- "I appreciated learning information on how to help my kids, myself and my community."
- "I now know how to find out and access information."

Highlights of Training Topics for PALs 2008-09 included:

Becoming a Supportive PALs Community	Ground rules are established through group discussion.
The CORE of a Good Life	Mark Sweet, Disability Rights WI, facilitates a discussion on the power of language in building community connections for our children.
Portrait of a Learner	Participants are asked to think about the unique strengths of their children and to work towards a "wholistic" vision of who their children are in the community.
Internet Hunting	Resources of the world wide web are explored.
Taking Care of Ourselves in Order to Take Care of Our Children	Carol Eichinger, Birth-3 and psychotherapist, leads the group in a reflection activity around how we care for ourselves and our relationships.
Advocating for Our Children in Educational Settings	Jan Serak, from WI Special Education Mediation System, discusses a program designed to help parents advocate for their children in special education.
Eco-Mapping (see above)	
Community Action Projects (see above)	
Advocacy with Liz Hecht (see above)	

Highlights of training topics from PALs 2007-08 include:

TOPIC:	DETAILS:
Family ECO-mapping	A family's community and personal resources are defined through illustration and writing. During final PALs weekend, family determines if map changed after the PALs experience.
Parents as Leaders Program History and Opportunities in Birth to 3	Linda Tuchman, Waisman Center, shares PALs history and funding and invites participants to join in post-PALs benefits.
Community Action Project	Each family is asked to choose, refine and facilitate a community action project to "give back" to their communities.
Leadership Overview	An introduction to the many ways leadership can be defined in our world.
Wisconsin Resource Overview	Children and Youth with Special Health Care Needs (CYSHCN) professionals share state-wide resources.
Natural Supports	The philosophy behind including children with special needs in the community and keys to engaging community members in this process.
Play to Talk	Pam Stoika, both author and developmental psychologist, discusses communication skills with children with special needs.
Advocacy and the Importance of Family Stories	Liz Hecht, Family Voices, discusses opportunities across the state for family leadership and advocacy and using family stories to carry our message.
Sibling Relationships and Looking Towards the Future	Siblings of individuals with disabilities share their perspectives and youth with disabilities talk about schooling and life into adulthood.

Another important shift in the area of resource awareness was participant's willingness to become a resource for other families. In 2007-08, 75% of families said that they now assist others in obtaining services/resources and parents in both years made comments like:

- "I now am working towards bringing resources into my community."
- "I have passed on information to other families."
- "I have some additional skills and knowledge for helping other parents with children with special needs."

Building Natural Supports

Learning to communicate their child's strengths and challenges and helping others better understand and include children with special needs was an important topic during these two years. The co-facilitators introduced the topic of natural supports to participants in order to raise awareness of how to involve people/systems/resources already in place in communities—especially those with no outward connections to the disability community.

In 2007-08, 63% of participants noted a major or extreme change in their ability to help family and friends better understand their child's exceptional needs (in all, 88% cited at least a minor change in this area). In 2008-09, 89% of families stated a major or extreme change in this category with 100% citing a major or extreme change in knowledge of how to build natural supports for themselves, their child and their family.

PALs participants from both years made the following comments:

- "I am now thinking in a more community-focused way towards disabilities and access."
- "I feel I am better able to tell our story and communicate with others."
- "I now have my daughter in a play partnership with another child [who is typically developing]."

Dealing with Stress

Having a child with special needs can be a stressful component of family life so in both of these PALs years, participants wanted to explore how to deal with stress for themselves, in their relationships with their partners and overall stress in their families. In 2007-08, 78% of participants noted at least a minor change in their skill level around dealing with stress (with 50% noting a major or extreme change in this

area). In 2008-09, 100% of families cited a major or extreme change in their knowledge of “the importance of caring for myself, my relationships and my family” with 87% showing at least a minor change (67% noted a major or extreme change) in their level of skill in actually coping with stress more effectively after PALs:

Two of the most “telling” comments around this topic were:

- “I realized I needed to look at everything I was doing and cut anything that wasn’t necessary out so I could reduce my stress and take better care of myself and my family.”
- “Learning to cope with stress myself makes a huge difference for family functioning.”

Building Partnerships

Learning to assemble and nurture productive partnerships in their family’s lives—be it for medical, educational, social or other purposes—is an important step towards being an effective leader. In the 2007-08 PALs group, 88% of participants noted at least a minor change in their skill level around working in partnership with others. In the 2008-09 group, 78% stated they had a major or extreme change in their skills around partnership building.

Comments included the following:

- “I have learned that other people have valuable things to share and that sometimes listening can teach more than asking questions.”
- “I have learned how to network with other agencies/families.”
- “I am working more with my community officials.”

Effective Problem-Solving

Being able to confront problems, think critically, use available resources and work towards solving them is a skill that is especially important when advocating for a child’s needs. PALs families in the last two years have noted that at times they have felt “powerless” when confronted with problems and so wanted to discuss this and learn ways to feel more effective. In 2007-08, all participants noted at least a minor change in their ability to problem solve and in the 2008-09 group, 89% had at least a minor change in their skill level (with 63% of participants citing a major or extreme change in their problem-solving effectiveness).

Greatest Enjoyment from PALs

It seems evident from post-evaluations that PALs participants from both years learned a variety of skills and knowledge that they took back to their communities to use as effective leaders and advocates. But it was the environment in which this learning of skills and knowledge took place that seemed to have the biggest impact on participants. Leaving their families and communities and coming together in fellowship with other PALs participants for a 24 hour period enabled new relationships and a feeling of “not being alone”. Isolation and feeling misunderstood seemed a common theme for families in their daily lives so to be in a safe setting with other families with shared experiences proved to be a highlight of participant’s PALs experiences.

Comments provided to answer the question, “what did you most enjoy about the PALs program” included:

- “Meeting others and hearing their stories.”
- “The ability to bond with other parents with kids with special needs.”
- “Developing relationships with other families.”
- “Forming new friendships and support systems.”
- “Networking with other families.”

2. Leadership training topics identified by participants and covered in PALs sessions:

In order to ensure an agenda based on the needs of each PALs group, part of the first weekend session was spent assessing these needs and determining topics for future weekends. This was done through informal conversation with participants both prior to the start of PALs and during the actual weekends, a formal “open space” session wherein participants used post-it notes and wrote down potential topics, and as a part of each weekend’s evaluation (a question was always included that read “Questions I still have, or concerns I would like to talk more about are...”). Because of this, each year different topics were explored in different ways. There was, in both years, a common vein of leadership skills, advocacy and resource enrichment that prevailed.

The following is a list of topics that were identified and addressed during the training sessions with an emphasis on leadership roles for families across topics. Training methods included: presentation by guest speakers; large group discussions led by PALs facilitators; small group discussions facilitated by group members; reading material; DVD/ videotape/Internet resources review and discussion; first person accounts by families and individuals with a disability; and Community Action Projects. Some topics seem to be popular and well-received so are repeated each year.