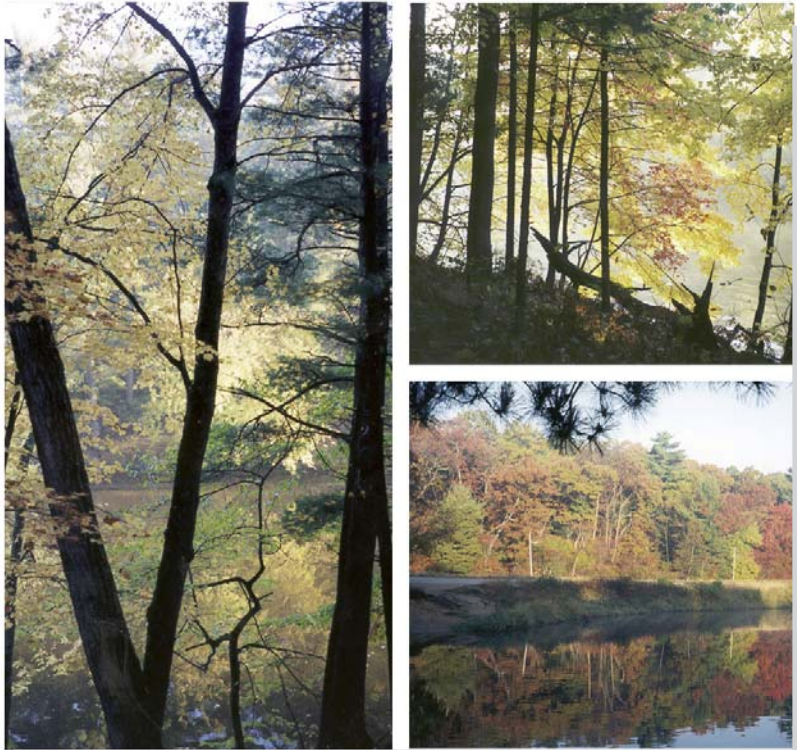


PALs



Biennial Report

2001-2003

What is PALs?

PALs is a group of parents and other caregivers who meet together five times during a year to:

- Learn about resources;
- Learn more about leadership and advocacy roles for parents of young children with special needs/disabilities ages birth to six;
- Explore topics of interest to group members, such as effective communication with professionals, inclusive education, futures planning, helping children make friends, financial resources, and family rights under the Americans with Disabilities Act;
- Meet some of the key people who make the policies and run the programs that affect children with special needs and their families in Wisconsin;
- Develop leadership skills;
- Work on projects that make their communities better places for children with disabilities and their families; and
- Become part of a network of parents who are knowledgeable about education, health, and social service issues; are active in their communities; support each other; and have fun together!

Community Projects

Brown County

- Presented at statewide Birth to 3 workshop on family routines in natural environments
- Testified at Joint Finance Committee hearing on funding for Family Support and other children's programs
- Are developing resources and strategies for managing stress when parenting children with special needs

Calumet County

- Joined local park committee to choose accessible playground equipment
- Provided tube feeding information to local schools
- Conducted training for families on tube feeding at large hospital in Milwaukee

- Provided local doctors with advice on how to communicate with families of children with disabilities

Calumet County

- Organized ongoing parent support group in school district

Dane County

- Participated in People Can't Wait and Family Support statewide funding campaigns
- Wrote to legislators about funding issues related to in-home autism and Family Support
- Started a church program integrating children with special needs and looking at ways to individualize the children's worship curriculum
- Joined a parent group

Community Projects

Dane County

- Working on software to improve team communication and information gathering for the IFSP process
- Coordinated Down syndrome Buddy Walk
- Leaders of local Down syndrome support group

Dane County

- Were featured in TV story on the importance of funding for in-home autism programs
- Talked to state legislators about in-home autism and Family Support funding
- Helped start a resource ministry at their church for people with disabilities

Eau Claire County

- Started a parent support group
- Located information on alternative therapies to share with other families
- Testified at Joint Finance Committee hearing on funding for programs supporting people with disabilities in their communities

Outagamie County

- Organized a regional workshop on oral motor therapy with a nationally-known therapist that attracted 140 participants
- Developed a scholarship program to allow families and providers to attend workshop and support private evaluation for families who attended the workshop

Marinette County

- Coordinates WI Cornelia DeLange Syndrome support group
- Serves as Children with Special Health Care Needs county parent liaison for her county
- Coordinates an adoptive parents support group to share strategies and resources

Outagamie County

- Working with local parks committees to install accessible playground equipment
- Researching ways to obtain extended school year services for preschool children in their school district

Outagamie County

- Organized written resources from PALS to share with Birth to 3 Program, providers and other parents

Washington County

- Joined county mothers support/information group
- Joined DAWN network and talked to gubernatorial candidates about her son
- Specializes within her office in special need/special education issues in her role as a juvenile public defender

2001-2003 PALs Report

PALs parents made changes in participation, ability, skills and knowledge to become better advocates for the needs of their children and communities.

The majority of participants reported active participation in:

- Their child's educational planning at school or with a community agency through IEP/IFSP meeting and contact with teachers,

- 53% commented on an influence on their participation in disability or advocacy related parent support groups.
- 62% experienced change in their communications with doctors and other health care professionals.

The majority of PALs parent activities were at the local level (68%), with some participation in state informational and advocacy activities.

"I feel like I am not alone any more with the problems we face. There is help out there."

"I am no longer afraid to ask or question a teacher or a doctor when I'm unclear on something about my child. I now have a better style that doesn't come across so confrontational."

therapists and school administrators. (83%)

- Regular conversations with health care professionals about the care of their child. (100%)
- Telling their family stories at legislative events, public hearings and parent groups, which was a new experience for many. (58%)

Parents credit PALs with influencing their participation in activities to advocate for their child and family:

- 69% reported a change in their participation as a member of their child's IFSP or IEP team.
- 84% reported an influence on their communications with teachers, therapists and school administrators.

For many families, this was their first experience with participation at the state level (i.e. testifying at public hearings and letter writing campaigns).

Additional changes in the parents' abilities were also reported:

80% reported major/extreme change in awareness of services available to address their child's needs.

80% reported major/extreme change in ability to assist others in obtaining the services and supports that they need for a member of their family with disabilities.

Specifically, families commented that they:

- Referred other families to PALs.
- Experienced major change in their ability to find services for their children.

2001-2003 PALs Report

- Told other parents about their experiences and information gathered.
- Planned to help other families in the future.

PALs training also was influential in supporting parents in developing their skills to become effective advocates.

- 82% considered PALs to have been a great or extreme influence on their advocacy skills.
- 82% also reported that their PALs experiences were of great or extreme value to them as a parent of a child with special needs.

PALs parents reported major and extreme changes in their **knowledge** as a result of their participation in the training activities and networking with other families.

"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."

"PALs has taught us that we need to be more involved both locally and at state and federal levels. It has also prepared us to be more effective in our advocating."

This increased knowledge supported families in:

- Changing their role in their child's educational planning. (81%)
- Understanding their legal rights. (88%)
- Considering ways to plan for their child's future. (94%)
- Helping family and friends understand their family. (75%)

- Locating and applying for services. (81%)
- Negotiating to get their family and child's needs met. (75%)
- Coordinating different services. (69%)

In addition to providing information on changes made as a result of participation in PALs, these families provided valuable information on the challenges they face in advocating for change in their communities.

Their challenges included:

- Finding information.
- Managing time.
- Finding energy for consuming tasks.
- Dealing with financial stressors.
- Organizing information.

- Responding to lack of understanding from family and friends of the stressors on their families.
- Educating family, friends and providers on their child's strengths, as well as challenges

2001-2003 PALs Report

Even in the face of these challenges, many PALs parents provided examples of specific changes they had made as a direct result of their PALs experiences:

Personal:

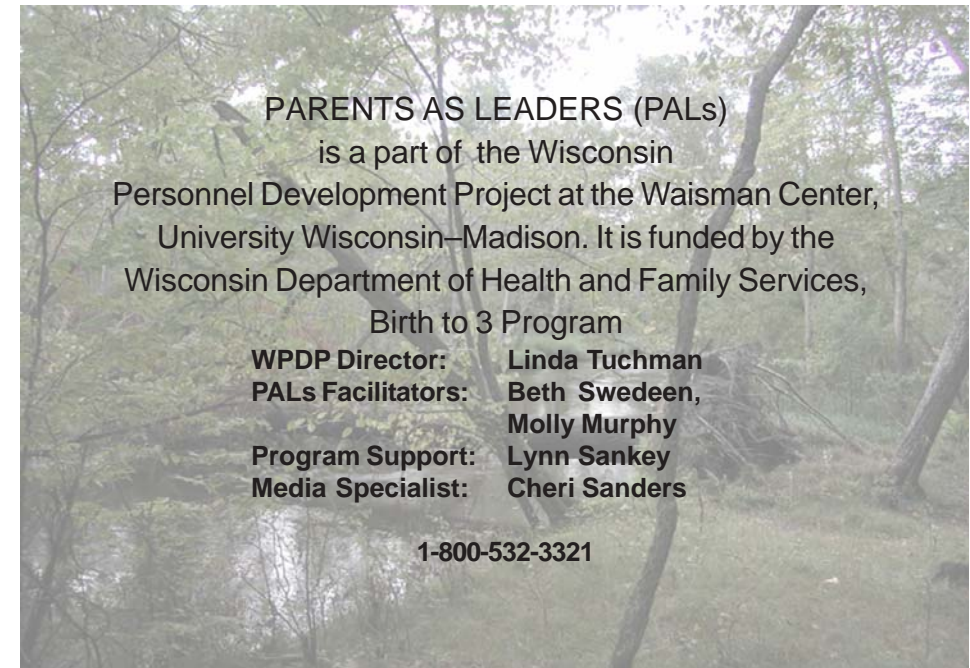
- Increased ability to ask questions, have confidence, be assertive, stay motivated
- Increased networking with other parents
- Improved parenting skills
- Decreased feelings of isolation

Family:

- Increased focus on inclusion, involving child in community activities
- Improved communication with extended family
- Shared vision as a couple for planning for the future

School/Community:

- Improved understanding of the system (e.g. IEP process)
- Increased access to services and resources
- Better relationships with providers
- Shared information about successful services and supports
- Increased participation in: volunteer work, public speaking, involvement with community groups
- Better communications with doctors and other health care professionals
- Increased access to services and resources



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