



## Annual Summary

July 1, 2007 through June 30, 2008

PAL is a state- wide advocacy organization for individuals with developmental disabilities and their families. The mission of our organization is: “to support families, individuals with disabilities and their network of friends in their efforts to achieve their own personal dreams and to assume a social role of dignity as a valued member of their community”.



Over the last 23 years, we have worked with a network of more than 30 providers of services to individuals with developmental disabilities through the Department of Mental Health, Retardation and Hospitals, The Division of Developmental Disabilities in order to insure that individuals with disabilities have the tools they need to achieve meaningful lives as true members of their chosen community, with friends to spend time with, and an identified way for them to be contributing members of their community.

PAL has been involved with a national project developed by the NASDDDS for eight years, called the National Core Indicators (NCI) project. We interview 400 individuals a year with a questionnaire developed by NASDDDS with additional Rhode Island questions. To date, we have interviewed 3342 individuals. The information gathered reflects the quality of life for folks receiving services in the following areas:

- Access
- Health & Safety
- Human Rights
- Work/Day Activities
- Home
- Family and Friends
- Self Determination
- Community Integration

This information is shared with the providers of the services, the DD social workers and HSRI, who compiles information without names attached and does a comparison with the others 22 states that participate in the project. A Four Year Trends Report can be accessed on the PAL website: [www.pal-ri.org](http://www.pal-ri.org)

In addition to the national project, we engage in individual support to families and individuals by attending ISP's, IEP's; facilitating future's planning opportunities based on individual strengths, gifts and capacities; and assistance in navigating the sometimes complex systems of support.



PAL felt it was important to outreach to a group of individuals who haven't typically been part of the NCL survey. We wanted to interview individuals who choose to direct their services through the Options Program offered at Ocean State Community Resources, Inc. PAL created a modified version of the NCI Background Information form and questionnaire. We outreached to the 179 individuals using Options in an attempt to get feedback from them on the quality of their life through self directed supports.

30	Interviewed by phone or in their home
55	Did not have a phone or their phone was disconnected
39	Said they had just returned their questionnaire to OSCR by mail
48	Individuals who did not return phone calls or we were unable to reach
3	Declined to be interviewed
3	Requested the survey be mailed to them
1	People not receiving support
<b>179</b>	<b>Total</b>

Those individuals that were interviewed either by phone or in person expressed satisfaction with the services they were directing. Many of the family members stated that they would not be able to continue to have their son/daughter live at home without the supports. Many of them had high praise for support they got from the coordinator of the Options program. They described her as someone who was always willing to take their calls and respond quickly to their needs. As the DD system moves to more self directed supports, some issues to watch as the number of individuals choosing self directed supports grows are:

- While a plan writer is an optional feature, there is the potential for individuals who choose not to access a professional plan writer to end up with supports that might not necessarily meet their needs.
- While extended family members provide trusted care, there is a possibility that the only people in the lives of individuals with disabilities may be family and connections to their community of choice could be scarce at best.
- Families expressed concern that accessing home health aides and nurses is becoming more challenging.
- While a full description of the responsibilities of "being an employer" is given by Options administrators to people directing their own services there is still the reality of sometimes finding yourself in the position of being an employer without possessing all the necessary skills to manage employees.
- Many of the families we spoke with have elderly caregivers who express worry and concern over what will happen when they are not there.
- With new regulations about what Medicare will not pay for many people may be going without needed medical supplies.
- There is the potential for a perfect storm to be brewing with more families and individuals with disabilities who may have need for case management needs coinciding with fewer resources through DDD in the form of Social Workers to assist with that case management.



PAL has been supporting learning opportunities for individuals around Rhode Island since 1998 with the Facilitator's Forum. Between 25-30 individuals from across the state; individuals with disabilities, family members, staff from DD providers agencies and staff from DDD, come together to learn, practice and build capacity around:

- Establishing a framework for problem solving conversations
- Role Playing
- Graphic Recording
- Building Tool Kits with Resources

Several Facilitator Forum participants were recruited for the Summits and mini summits that the State held in November, 2007. PAL also hosted five (5) family conversations in order to give families and individuals with disabilities a voice into PAL and Advocates in Action's response to the state's RFI process.

Our second Annual Alliance for Full Participation Celebration (AFP) was held in November, 2007. Mr. Tom Kohler, Citizen Advocacy Coordinator from Savannah, Georgia was a keynote speaker. His most memorable comment of experiencing the evening was ***"I feel like I have stepped into a time machine and have arrived in the future and the future is now in Rhode Island. Witness this contribution that Rhode Islander's are making to our communities"***. The event was attended by over 250 people. Eighteen (18) individuals had tables with information, photos and/or audio equipment that helped them tell their stories of belonging and contributing to their community.

The following day was small group work comprised of stakeholders committed to deepening individual community connections for people they support.

As a follow up to previous work with Tom Kohler and five (5) community provider organizations, part two of "Lurking with Intent" happened in February, 2008. Working with five (5) previously identified individuals, we worked as teams to strengthen community roles of status for individuals who "yearned for community contribution".

On April 10, 2008, PAL hosted Mr. Jeff Strully, a parent of a daughter with disabilities and the Director of the Jay Nolan Community Services in Mission Hills, California. Ms. Jo Krippenstapel facilitated the day at Quidnessett Country Club. The topic of the day was "The Times They Are A Changin". Over 175 people participated in a conversation that reflected on:

- How do we build supportive communities
- How do we build our capacity to listen better and to believe in people's dreams
- How difficult is REAL change and where do we get the strength to make it happen

Participants who attended the event asked PAL to convene AFP stakeholders in order to engage in conversations as learning opportunities where people can safely talk about risk, lessons learned and best practices.

Over the course of FY 07-08, PAL staff outreached to over 185 families and worked with 110 of them on an individual basis on topics including but not limited to:

- Person Centered Planning
- Technical Assistance
- Safety Planning
- Human Rights and Responsibilities
- Supported Living Options
- Support Agreement Process
- Conflict Resolution
- Leadership Development

We attended four (4) Transition Fairs, sponsored by the Rhode Island Parent Information Network and local school districts. Over two hundred fifty (250) informational packets were disseminated. The content of the informational packets can be viewed on our web site: [www.pal-ri.org](http://www.pal-ri.org) on the Family Support page.

PAL has been working with several families in Little Compton on the Little Compton Housing Initiative (LCHI). Several residents and families of this community are looking for ways to provide holistic, affordable housing to life long residents of this community, some of whom have disabilities. This group of committed thoughtful, individuals have embarked on a journey to be inclusive, not exclusive; to develop a philosophy that will drive the process rather than have it driven by requirements of a bureaucratic mandate. Their hope is to create “**HERE COMES THE NEIGHBORHOOD**” a project they hope will be seen by other communities as a way to share collective wisdom; “work toward a common goal; and build a town that never forgets its roots or abandons those who have defined us for those who can afford us”.



Through our Employment Information Network (EIN) PAL supports 8 Mentors; individuals with disabilities who assist other individuals with disabilities in their quest to choose find and/or keep a job. Currently our Mentors are working with 29 Mentees.

We offer a W.O.R.K. Series:

- **W**hy Work
- **O**pportunities
- **R**esources
- **K**now your Social Security Work Incentives

The July, 2008 series was hosted at a local netWORKri office. Thirty Five (35) participants were given a tour of the offices, shown how to access the technology and what to do if they need assistance. That opportunity resulted in five Mentees (5) being identified and assigned to Mentors participating in the Peer Mentor Initiative.

There are monthly meetings of the Mentors. A variety of skills trainings is provided to the Mentors at these meetings in order to increase their capacity to support their Mentees.

Mentors are primarily responsible for insuring that Mentees follow a process by which the ultimate goal is meaningful employment. In order to insure Mentee satisfaction a survey has been created allowing Mentees to identify both areas of satisfaction and those that need improvement as it relates to Mentor service delivery. You are encouraged to view a copy of the survey and other tools created through EIN refer to: [www.pal-ri.org](http://www.pal-ri.org) on the EIN page.

We offer interested individuals the opportunity to use our YES program- a computer program that allows people to see, hear and learn about hundreds of different jobs. Individuals scroll through the program at their own pace, click on jobs or pieces of jobs that interest them and from that, a report is generated which identifies the skills needed for the areas of interest. This information is then used when these individuals and PAL staff meet with an ORS Counselor to assist with developing an individualized plan for employment.

## Yes - Your Employment Selections

The CD-Rom - is a *reading free* - job preference and career exploration tool for anyone who may have difficulty identifying meaningful work!

PAL co-facilitates an annual session on a Person Centered Employment Planning module as part of the Sherlock Center Supporting Meaningful Employment, a ACRE nationally certified program. PAL is member of the Supported Employment Council and the Rhodes to Independence Self Employment Committee.



In October of 2006, the ACT Initiative received three years of funding from the Office of Violence Against Women through its Education & Technical Assistance Grants to End Violence Against Women with Disabilities Program.

The ACT Collaborative, guiding this Initiative, is made up of three project partners – Day One, PAL and the RI Coalition Against Domestic Violence, and two affiliated member agencies – Advocates in Action and Blackstone Valley Advocacy Center – who have agreed to collaborate together in support of the mission and vision jointly created through this newly funded initiative.

The ACT Initiative was first created through previous OVW funding (2004), and the project partners are privileged to be strengthening both their collaborative and community work through this new grant. The vision of this initiative is to create an accessible system that is person-centered in its service delivery, provides a comprehensive spectrum of services, and is delivered by informed and accountable professionals to individuals with disabilities and Deaf individuals, who are survivors of domestic and sexual violence. This current grant will take the ACT Collaborative to the next step towards creating systems change, and allow us to provide intensive technical assistance and support to disability advocacy and violence response/prevention agencies in two RI Communities of Focus (COFs).

- Provide training, education and networking opportunities for professionals working in the fields of sexual assault, domestic violence and disability services to better detect, react to and reduce violence in the disability community;
- Develop a statewide network through open dialogue to improve the quality of supports, individuals with disabilities receive;
- Improve accessibility to advocacy and safety planning services for individuals with disabilities;
- Utilize a person-first approach for responding to violence against individuals with disabilities;
- Include Rhode Island's strong network of self-advocates in the planning and execution of all project goals.



# The Homestead Group

Supporting people with developmental disabilities for over 50 years.

Work concluded this year with a two year quality assurance project at The Homestead Group (THG). PAL provided human rights training for one hundred twelve (112) new employees with the assistance of individuals supported by the organization. The training centered on issues and barriers to promoting human rights as well as the responsibilities we all have when exercising our rights.

We provided support to the Homestead self advocacy office by initiating a Human Right of the Month project that was for all participants and staff. PAL assisted the self advocates in organizing a learning group that grew out of individual frustrations about perceived disrespect from peers and other individuals. Initially referred to as the “Don’t be Rude Conversations” it evolved into the “Good Will Hunting Project” when the group moved to solutions about how to build a culture of mutual respect, good will and leading by example.

In an effort to be proactive with students in transition who were contacting the agency about what the future could hold for them, quarterly meetings were set up in an effort to outreach to families and individual students and to have veteran families in the room to share their experiences with families just entering the adult world of support. Those meetings also acted as a way for the Agency to gather information on how well they were doing and what could be done differently to meet families needs.

Through work with incident management, PAL linked Incident Review meetings and information to the Human Rights Committee. We piloted an external investigation process for incidents that required an investigation per direction from DDD.

In order to expand on the Facilitator Forum work, PAL hosted an Open Space conversation for a management team at Homestead. Thirteen (13) individuals were introduced to the concept of “Open Space Technology”. They identified barriers to providing quality supports for individuals:

- People have small circles of support
- People have little or no choice of where they live
- People have limited skills
- People have to rely on supports.

The conversation helped the team recognize their ownership of some of the barriers; helped them identify some of the common threads of these barriers and then shifted the thinking into possibilities and opportunities to challenge those barriers.

There were several incidents in then past year where individuals with disabilities had been involved with the criminal justice system and the outcomes were less than favorable. PAL and Homestead offered a “train the trainer” session for several police departments and the State Police. Captain Christine Crocker from the Cumberland Police Department co-facilitated the session with Ken Renaud. The content of the training on how to be better prepared as a first responder when an individual with disabilities is involved contained:

- History of People with Disabilities
- Disability Etiquette
- Alternative methods of communication
- Examples of simple questions and statements
- Tone of voice and mental health perceptions
- Examples of how individuals with disabilities have different ways of processing information

Each participant was given a copy of “A Guide for Law Enforcement Personnel”, Individuals with Mental Retardation and the Criminal Justice System.

Laminated cards that are made to fit into a wallet with information on responding to disclosures were disseminated. After the training, another 400 “cop cards” were printed and disseminated.

In conclusion, it was an extremely busy year. It was not an easy year. Reports of dire fiscal conditions continued to unfold. Across our state, families mobilized around the proposed Global Waiver the potential changes for their family members. They offered testimony at the Legislature, organized informational meetings for families and a letter writing campaign. Working through uncertainty, frustration and anger they found courage to engage in conversation.

*“When a community of people discover that they share a concern, change begins. There is no power equal to a community discovering what it cares about”*

‘Meg Wheatley’  
Tuning to One Another