



**PAL Quality of Life Initiative**  
**Quality of Life- The Definition Is As Diverse As We Are**  
**2005-2008**



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Funded by the Rhode Island Department of Mental Health, Retardation and Hospitals

Division of Developmental Disabilities

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### ***Opening Thoughts***

Much is changing for all US citizens including Rhode Islanders with disabilities and those they employ. The system of supports for people with disabilities is being scrutinized extensively because of the challenges of having balanced budgets nationally and statewide. As we go through these changes it is critical we assess where people require supports and where less support has a positive impact on a person. Change is happening. Listening to the dreams and needs of individuals & their families is the most accurate way we can define and support what quality of life means to each individual. We must ask, listen, and converse; it is the only way.

Tomorrow is the most important thing in life.  
Comes into us at midnight very clean.  
It is perfect when it arrives and puts itself into our hands.  
It hopes we've learned something from yesterday.  
~ John Wayne (1907-1979)

### ***Introduction of the Quality of Life Initiative***

Since 1991, PAL, a parent information and advocacy organization, has been contracted by the Rhode Island Division of Developmental Disabilities (DDD), within the Department of Mental Health, Retardation and Hospitals, to assess individual and statewide satisfaction with services offered to Rhode Islanders with developmental disabilities and their families. The PAL Quality of Life Initiative (QLI) is a face-to-face opportunity for people to voice their experiences about the supports they receive. The project is also part of a national effort for comparison with other states called the National Core Indicators (NCI) project, which is administered by the National Association of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI).<sup>1</sup>

### ***Process***

A QLI Visitor meets for about 1.5 - 2 hours with people, asking questions about their lives at home and at work, their social opportunities, safety, goals and dreams. The process offers point-in-time information about how the person reports their overall experience of the supports and services provided. Each participant answers a series of approximately 100 questions. Some questions are from the NCI project, available through HSRI for state-to-state comparison and some questions are used in RI only.

<sup>1</sup> A report of responses to NCI questions with state-to-state comparison is available at [www.hsri.org](http://www.hsri.org)

## ***RI/QLI Data Collection***

For your perusal, at the end of this report, we have included the past 4 years of our data. We can compare some questions over 9 years but due to changes QLI and HSRI have made in the questionnaire and background information form, others have been asked for various years and some for 1 year only. We continuously try to meet the ongoing challenge to get as close to a person's real feelings & as accurate a response as possible, however frequent changes impact the ability to compare outcomes year to year. It's a balance.

In August 2003, CMS (Centers for Medicare and Medicaid Services) created a Participant Experience Survey, which had some of the exact questions we had on our questionnaire and we added new questions directly from their tool. It is documented on our questionnaire<sup>1</sup>, which questions are also on the CMS Participant Experience Survey.<sup>2</sup>

Also, Rhode Island did not collect the data on who responded for each RI question and at times, a staff person, family member, advocate or other person assisted the participant in answering the questions. The ability of participants to respond to our questions varies widely, from independently answering all questions to participation through a helper/representative. Some NCI questions (Part 1) require that an answer be coded as "9- don't know, no response, unclear response" on the data sheet if someone other than the participant answers, however in RI, we have opted to include Part 1 answers from other respondents. Also, HSRI adjusts their data through analysis and excludes answers they determine unreliable.

We did not plan to include data from the 2007-08 project year, because we had made changes in our questionnaire and background information form. HSRI then made substantial changes in their 2008-09 questionnaire before the project year started, so we are including 2007-08 data but cannot compare some questions to previous years. For fiscal year 2008-2009 the D.D.D. has decided not to participate in this project, so there will be no NCI/QLI visits done this year.

## ***Project Scope***

For the last 2 years, we have asked each agency for an updated list or census of the people they support as their primary agency. Our focus is to visit people who have not been visited or were visited 5 years ago or more. From September of 1999 to June of 2008, approximately 5988 people were selected to be visited. In the past 4 project years, 2388 people have been asked to participate and of these approximately 1,513 people have been visited, 511 declined and the remaining 364 people, we either did not receive the requested background information form from the agency or the visit could not be schedule. To find this information broken down by agency, see the Background Information section of this report.

An effort has been made over the years of this project to proportionately distribute the participant interviews among the current licensed private providers, the state's public provider, people who administer their own plans through a fiscal intermediary and people who are not supported through an agency. Because of the length of the BIF, people who have agency support are our primary focus because we have found agencies are more responsive to our request for Background Information than people who manage their own plan or people who do not receive agency support. We can not always meet a proportionate distribution by agency due to these variables.

<sup>1</sup> A copy of the full questionnaire and background information form is available upon request.

<sup>2</sup> [http://www.cms.hhs.gov/HCBS/downloads/3\\_PES\\_ED.pdf](http://www.cms.hhs.gov/HCBS/downloads/3_PES_ED.pdf)

## ***Report Details***

Our *Quality of Life- The Definition is as Diverse as We Are: September 2004- June 2008* includes the data we have collected over the past 4 project years, plus at times, we compare similar questions back to 1999 and to other states. It consists of seven sections, with items representative of the full questionnaire: background information, employment/day support, home, health and safety, relationships, support, choice and human rights, and community access. The questions represent domains and sub-domains of the Core Indicators developed by NASDDDS and HSRI, and specific areas of interest identified by stakeholders in RI. This report is intended as a source of information for assessing our collective progress in the supports for adults Rhode Islanders with developmental disabilities and determining the areas that need increased focus.

PAL's staff and visitors would like to say there are some amazing people, families, direct support staff, agencies, and DD social workers in Rhode Island. We have been very honored to have met you and we are grateful you participated in the Quality of Life Project. Although we point out areas that need focus, we celebrate the many gains people have made through self determination, individualized supports and persistence to get what is needed for people.



Each section starts with "At a Glance" which is a quick look at data collected. It is followed by more detailed data and comments on the data outcomes.