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## An Evaluation of the Autism Pilot Program of the Division of Autism Services of the CT Department of Developmental Services

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## **Report Highlights**

### ***Program implementation***

- Eight key informants provide excellent insight into the accomplishments, difficulties, and problem-solving that the Autism Pilot Program (APP) has undergone since its inception.
- Not only are many participants and their families benefitting significantly from the services they receive, the costs overall are described as relatively low.
- Key informants are very happy with the way the APP functions and foresee an ongoing and increasing need to provide these services on a wider scale.

### ***APP participant outcomes***

- Improvement for participants included increased employment and improved attitudes about work.
- Participants increased their community involvement.
- Participants are receiving and utilizing more services, particularly in the areas of employment and recreation.
- Self-perceived emotional problems and related limitations diminished over the course of the year for the participants.
- Participants improved significantly in their social interaction, communication and living skills during their first year in the program.

### ***APP participant family member outcomes***

- Family members' feelings of burden diminished significantly over the year.
- Most family members indicated that they were less concerned about their relative than they had been a year ago.

### ***Goals met or partially met***

- 86 percent of the participants felt they had met or partially met their goal of improving life skills.
- 75 percent of the participants felt they had either met or partially met their goal for employment.
- 77 percent of the participants felt they had either met or partially met their goal to gain community experience.
- Families and the APP service coordinator gave similar ratings of goal achievement.

### ***Lessons learned***

- Almost all changes on the many outcomes examined were in a positive direction, showing improvement for these participants on multiple dimensions.
- Comments by participants and their family members about the APP indicate a great deal of optimism with regard to the program, a hope that it will continue, and that others will be able to take advantage of it.
- Some difficulties related to providers were noted including communication, appropriate training, turnover, and, from the providers' perspective, receiving inadequate background information on new participants.

- Many of the participants had additional disabling conditions, in particular mental health diagnoses. In retrospect, the program was not designed to provide adequate services for this population and they have made adjustments in eligibility and screening criteria.
- Both hours and wages from employment were low, and would not yield significant additional tax revenue for the government. However, employment, community involvement and increased independence may lead to a reduction or avoidance of the costs of other benefits, such as medical, mental health, housing, and other disability costs.
- Another benefit is the program's potential financial effect on family members/caregivers. As their caregiving time decreases, they are more available for employment and increased wages.

### ***Next steps***

- In the future, the APP should seek to identify any subgroup of participants who would benefit the most from the program, and vice versa, in order to target outreach and service package design to the greatest advantage for individuals on the Autism spectrum.
- The APP should continue to provide services in the two regions that they are currently serving.
- Respondents from key informant interviews uniformly asserted that the demand for these services is large and growing. The APP should expand services statewide.
- The program has developed some targeted training for the direct care staff that works well. APP should continue this training for providers who are involved with the program.

## **Executive Summary**

### ***Introduction***

The Autism Pilot Program (APP) is an endeavor of the Department of Developmental Services (DDS) to provide specific services to adults with Autism Spectrum Disorder (ASD) who do not have mental retardation. DDS engaged the University of Connecticut Health Center, Center on Aging (UCHC Center on Aging) to evaluate this program.

The provision of various support services can have a profound effect on participants' ability to live more independently. These services are tied to specific skills deficit areas and they include: case management services; life, social, educational and employment skills services; community mentor; job developer/career counselor; consultative services; and interpreter services.

As of December, 2008, there were a total of 52 participants enrolled in the APP in two regions of the state: 34 in New Haven County and 18 in Hartford County.

The primary goal of the UCHC Center on Aging evaluation is to document the APP implementation, short-term costs and benefits, and positive and negative effects of the program for participants and their families. Given the small number of initial participants, and the early developmental stage of the program itself, the information gathered is both preliminary and exploratory in nature. Nevertheless, the data will be of immediate use to policymakers in Connecticut and program providers as they determine future steps for this new and unique program.

Both key informant interviews with program staff, providers, and advisors, and interviews with participants and their family members were used to assess the success of the program. In addition, the Scales of Independent Behavior (Revised) (SIB-R) were assessed for all participants, before starting program services and after one year of receiving services, to determine if improvements in independent behavior were achieved.

The original intention was to enroll 25 individuals in the test group and an equal number in a comparison group. The test group was eligible to receive services at the inception of the program, and the comparison group would be eligible for the services after the completion of the study. Both groups would participate in surveys and interviews as part of the evaluative process. Only six participants ultimately enrolled in the comparison group before the enrollment period ended in June, 2008. As a result of the limited enrollment, findings are descriptive in nature and focus on changes over time for those who were enrolled as part of the program test group.

There were four components to the evaluation: 1) a description of the program implementation, 2) an analysis of program participants' early experiences, subjective outcomes, and objective outcomes, 3) an analysis of the program's costs and benefits, and 4) an overview of the DDS Level of Need (LON) tool, as it applies to the APP population.

Statistical computations were performed in analyzing the quantitative data. Qualitative data was analyzed separately based on a constructivist theoretical paradigm and grounded theory approach using the constant comparative method (Strauss & Corbin, 1998).

## **Results**

### Program Implementation

In-depth interviews were conducted with eight key informants representing the perspectives of advocates, clinical experts in ASD, program administrators and program providers. Respondents were drawn from the Autism Spectrum Disorders Advisory Council, two provider agencies affiliated with the APP, the two APP staff members from DDS, and the Connecticut Bureau of Rehabilitation Services. The interviews explored respondents' views on the successes and challenges of the program, potential demand for ASD services, program cost-effectiveness and potential impact on informal care presently provided. Each interview assessed respondents' experiences regarding five topics: 1.) What has gone well with the APP? 2) What has been difficult or not gone well with the APP? 3) What is the potential demand for the program going forward? 4) Do you think the program is cost effective? and 5) What is the program's impact on family members?

The eight key informants together provide excellent insight into the accomplishments, difficulties, and problem-solving that the Autism Pilot Program has undergone since its inception. Not only are many participants and their families benefitting significantly from the services they receive, the costs overall are perceived as relatively low. The program has evolved over time, refining eligibility criteria to identify people whose needs cannot be met by the program's services and implementing provider training specific to this population of people on the autism spectrum who do not have mental retardation. Overall, people are very happy with the way the APP functions and foresee an ongoing and increasing need to provide these services on a broader scale.

### Autism Pilot Program Participant Outcomes

There were notable changes from baseline to one year not only for APP participants but also for their family members in multiple areas. Areas of improvement for participants included employment and improved attitudes about work, increased participation in the community, and the fact that the participants were receiving and utilizing more services, particularly in the areas of employment and recreation. In addition, self-perceived emotional problems and limitations caused by any emotional problems diminished over the course of the year.

Improved scores on the Scales of Independent Behavior-Revised (SIB-R) from baseline to the one year follow up were significant with overall improvements in all independent living categories, in all but one maladaptive behavior indices, and in the overall support score. Specifically, participants' broad independence skills, motor skills, social interaction and communication skills, personal living skills, and community living skills all showed statistically significant improvements from baseline to follow up.

There were no notable changes in the participants' self-reported data in the areas of perceived health, communication with family or friends, or leisure activities such as watching TV or using the computer. Results from the Center for Epidemiologic Surveys-Depression scale (CES-D) scores also showed little change in symptoms of depression from baseline to follow up.

For the participants' family members, feelings of burden diminished significantly over the year and most family members indicated that they were now less concerned about their relative than they had been a year ago. Family members' symptoms of depression showed little change from baseline to follow up.

Successes were not only measured quantitatively by improvements in the above mentioned areas, but in terms of actual goals being met, both as evaluated by the APP service coordinator and as perceived by the participants and their families. Eighty-six percent of the participants felt that they had fully or at least partially met their life skills goals, 75 percent indicated that they had fully or partially met their employment goals, and 77 percent felt that they had fully or partially met their community involvement goals. From the perspective of the APP service coordinator, 87 percent of the participants met or partially met their goal of improving life skills, 65 percent of the participants either met or partially met their goals for employment, and 95 percent either met or partially met their goal to gain community experience. Participants also evaluated the services that they received in conjunction with each of their goals. For all employment, life skills, and community engagement services taken together, over 80 percent of the participants rated the services as very or somewhat helpful.

The goal of employment was particularly important for both participants and program staff. The APP partnered with the Bureau of Rehabilitation Services (BRS) to help participants gain employment. Over half of the participants worked with BRS to achieve this goal, with five participants finding jobs, three of them with help from BRS. Eight participants continued to work with BRS to seek employment as of December, 2008.

Comments by participants and their family members about the APP indicate a great deal of optimism with regard to the APP, a hope that the program will continue, and that others will be able to take advantage of it.

While too small to make statistical comparisons, there were no striking changes from baseline to one year later for the comparison group. By contrast, the changes seen in the test participants from baseline to one year after starting their services are very encouraging. Almost all changes on the many outcomes examined were in a positive direction, showing improvement for these participants on multiple dimensions. Given the small sample size of the participant group, seeing any significant changes is highly encouraging. It is even more notable when considering the fact that the program was new and therefore had to work out the difficulties associated with any new program during the evaluation period.

### Cost effectiveness

While a rigorous cost-benefit analysis cannot be completed from the pilot data, at the level of service provided, an increase in employment, quality of life, and level of functioning measures among pilot participants was noted. There is some indication that benefits may be higher among certain sub-groups of participants. Both hours and wages from employment were low, and would not yield significant additional tax revenue for the government. However, employment, community involvement and increased independence may lead to a reduction or avoidance of the costs of other benefits, such as medical, mental health, housing, and other disability costs. These elements were not included in this study. Another potential benefit that was not included in this study is the financial effect on family members/caregivers. As their caregiving time decreases, they are more available for employment and increased wages. This effect may be the subject of future study.

### Level of need assessment tool

The design of a Connecticut Level of Need Assessment and Screening Tool was an inclusive and comprehensive process undertaken by the Department of Developmental Services, with input from

diverse stakeholders and other sources sought and incorporated with each step. In collaboration with members of the Autism steering committee, the LON tool was adapted for utilization with the Autism Spectrum Disorders population.

As indicated by the close alignment with the SIB-R Support Score, the LON clearly works well to delineate the needs of people on the autism spectrum who do not have mental retardation. Analyses show that individuals in this group have significant needs in all of the LON summary domains.

## I. Introduction

The Autism Pilot Program (APP) is an endeavor of the Department of Developmental Services (DDS) to provide specific services to individuals with Autism Spectrum Disorder (ASD) who do not have mental retardation. DDS engaged the University of Connecticut Health Center, Center on Aging (UCHC Center on Aging) to do an evaluation of this program.

The APP was developed through the actions of the Connecticut Legislature and an appointed Steering Committee. The Steering Committee met every month and additionally, had a sub-committee focused solely on the evaluation of the pilot. The Steering Committee is comprised of state agency representatives, clinicians, researchers, advocates, families and consumers. The evaluation sub-committee and the Steering Committee, as well as the DDS and the University of Connecticut Health Center Institutional Review Boards, approved the APP methodology and measures.

Connecticut has developed this pilot project to serve individuals with ASD who do not have co-occurring mental retardation, and in the course of implementing the pilot, Connecticut has learned that the provision of various support services can have a profound effect on participants' ability to live more independently. These services are tied to specific skills deficit areas and they include:

- Case Management services to assist and enable an eligible person to gain access to services identified in each person's Individual Service Plan, including needed habilitative or developmental, medical, social, educational, or other services
- Life, Educational and Job Coaching Services, to assist with the development of appropriate social, communication, self care and maintenance, and employment skills
- Community Mentor, to assist in making strong and realistic connections of elements in each person's community
- Job Developer/Career Counselor, to assist in developing and finding employment opportunities
- Behavioral Services, to develop strategies to respond to individual needs that may arise, over both the long and short term
- Interpreter Services, to enable those whose primary language is not English to participate fully in the service
- Respite Services, Services provided to individuals unable to care for themselves; furnished on a short-term basis because of the absence or need for relief of those persons normally providing the care.
- Social Skills Groups, weekly group sessions of between 4-6 individuals to work on specific social skills.
- Specialized Driver Assessment, specialized assessment in order to evaluate individuals ability as a potential driver and ability to obtain a driver's license
- Personal Emergency Response Systems (PERS) PERS is an electronic device, which enables certain individuals at high risk of institutionalization to secure help in an emergency.

As of December, 2008, a total of 52 participants had enrolled in the APP in two regions of the state: 34 in New Haven County and 18 in Hartford County. Participants began enrolling in the program in September, 2006 and have received services for varied lengths of time, ranging from four months to 20 months.

The primary goal of the UCHC Center on Aging evaluation is to document the APP implementation, short-term costs and benefits and positive and negative effects of the program for participants and their families. Given the small number of initial participants, and the early developmental stage of the program itself, the information gathered is both preliminary and exploratory in nature. Nevertheless,

the data will be of immediate use to policymakers in Connecticut and program providers as they determine future steps for this new and unique program.

This project examines whether the APP improves the lives of adults with Autism Spectrum Disorder by providing services to these adults and their families. It is called a pilot study because it was offered to a limited number of people in only one part of the state. Results of this evaluation show how the program can be improved before it is offered to a larger number of people.

For the evaluation, the APP staff recruited program participants from New Haven County, determined eligibility, and enrolled people to participate in the program and the evaluation. They also tried to recruit a comparison group from a geographic area that was not initially eligible for the APP (Hartford County). APP staff also conducted a thorough assessment of the participants using two instruments: the DDS Level of Need Assessment and Screening Tool and the Scales of Independent Behavior.

The original intention was to enroll 25 individuals in the test group and an equal number in a comparison group. The test group was eligible to receive services at the inception of the program, and the comparison group would be eligible for the services after the completion of the study if there was an increase in funding. Both groups would participate in surveys and interviews as part of the evaluative process. For the individuals receiving services, these services were provided within available appropriations based on the needs of the individual and of the APP criteria. Because those in the comparison group were not guaranteed services, enrollment in the comparison group was very limited. Only six participants ultimately enrolled in the comparison group. As a result of the limited enrollment, findings are descriptive in nature and focus on changes over time for those who were enrolled as part of the program test group.

## **II. Evaluation Components**

There are four components to the evaluation: 1) a description of the program implementation, 2) an analysis of program participants' early experiences, subjective outcomes, and objective outcomes, 3) an analysis of the program's costs and benefits, and 4) an overview of the DDS Level of Need (LON) tool, as it applies to the APP population.

The first component of the evaluation is a description of the APP's implementation, including program successes and challenges, demand for program services, cost-effectiveness, and impact of the program on family members. Data for this component come from key informant interviews and should be used to advise project administrators and policymakers of potential program refinements that might encourage success of the project in Connecticut. These data may potentially be used in the future to inform the development and implementation of similar models in other states.

The second component comprises an analysis of both quantitative and qualitative data collected through interviews with program participants, their families, and the comparison group and their families. These data quantify participants' objective outcomes, including their positive and negative experiences with the pilot program and changes in their behaviors and attitudes from baseline to follow up. This component also presents an analysis of participants' level of success at achieving the outcomes specified in their Individual Service Plans (ISP). The ISP implemented for each of the test participants describes each individual's personal goals and a service plan or strategy for achieving those goals.

The third component of the evaluation is an analysis of the cost effectiveness of the APP. In seeking to determine whether and how to extend or expand the APP, it is important to understand its costs and benefits. This analysis may be used by program managers and policy makers to evaluate the extent to which the financial and quality goals of the program were met, and to chart a course for future funding and measurements of effectiveness.

The fourth and final evaluation component examines the applicability of the DDS Level of Need assessment tool for the ASD population and subsequent adaptations that were made to the LON tool.

### **III. Methodology and Analysis**

#### ***Key informant interviews***

To accomplish the first goal of describing program implementation, in-depth interviews were conducted with eight key informants representing the perspectives of advocates, professional experts in ASD, program administrators and program providers. Respondents were drawn from the Autism Spectrum Disorders Advisory Council, two provider agencies affiliated with the APP, the two APP staff members from DDS, and the Connecticut Bureau of Rehabilitation Services. The interviews explored respondents' views on the successes and challenges of the program, potential demand for ASD services, program cost-effectiveness and potential impact on informal care presently provided. All identified potential respondents completed interviews, which were all conducted by telephone by one senior member of the evaluation team.

#### ***Surveys and measures of participants and their family members***

The second component of the evaluation involved interviews with program participants, participant families, a comparison group, and comparison group families at baseline and after one year of receiving services. The comparison group did not receive any services during the one-year period between their interviews but were eligible to receive services after that time. All participants and comparison group volunteers were recruited, screened and enrolled by APP staff and signed a DDS-specific informed consent. All agreed to respond to the evaluation interviews as part of their APP participation. Each participant received a study information page and signed a HIPPA form, which were approved by the UCHC IRB.

All of the participants (n=34) responded to interviews at the time of enrollment: 28 in the test group; and 6 in the comparison group. The interviews were primarily conducted in person by a qualified UCHC research team member. A 36-item interview was developed to obtain information from the participant; and an additional 13-item interview was designed to obtain information from a family member of that participant (Appendix A). This initial interview was conducted in order to gain knowledge of the participants' previous experiences with services (if any), their reasons for joining the pilot, and their expectations for the program. Categories of interest included employment, social engagement, activities, services, physical and emotional health, and demographics. The family member section of the survey consisted of several scales to assess burden that the family member experienced, whether the responsibility of caring for their relative caused their activities to be limited, a depression scale, and demographics.

Data collected by the APP DDS program staff as part of their routine assessment and screening process were also made available. These data included the DDS Level of Need (LON) assessment, the Scales of Independent Behavior (revised) (SIB-R), and an Individual Service Plan (ISP). The LON assessment is routinely performed for individuals with mental retardation to determine service needs. A slightly adapted version was developed and tested for this study's population. The SIB-R assessment includes measurements of gross motor skills, fine motor skills, social interactions, language and comprehension, personal living skills, work skills and skills within the home and community. The ISP represents each individual's goals in terms of what outcomes he or she wanted to achieve by being enrolled in the APP, whether it be finding a job, becoming more involved with people or within the community, or improving their social skills. For each goal there was an accompanying service plan designed to help the participant reach each specific goal. The service plan was developed by the APP program staff, participants, and families, and included services such as job coaches, job developers, social skills coaches, or community mentors. The service schedule included the number of hours per week that the participant would take advantage of each service.

After 12 months of experience receiving services from the program, 33 of the original participants (27 test, 6 comparison) and 32 of their family members (26 test and 6 comparison) completed a follow up interview in order to assess changes over time in areas related to employment, social engagement, activities, services, and physical and emotional health. The follow up survey was virtually identical to the baseline survey. One additional question was included in the follow up survey both for the participant and the family member. For the participant, that question was, "Compared to last year, do you feel that your life is better, worse, or about the same?" For the family member, the new question was, "Compared to how you felt a year ago, are you more concerned, less concerned, or about the same with regard to your relative?" A second SIB-R was administered to those in both groups, and, for participants, a revisiting of their ISP. Participants and family members reviewed the individual goals and the service plans associated with the goals and evaluated how successful the participants were in reaching their goals, and how helpful the services were in providing assistance in reaching any particular goal.

### ***Cost effectiveness***

For the third component, cost effectiveness, potential costs and benefits of the APP were summarized from the perspective of participants, their families, and the government/taxpayers. Program budgets were determined by examining initial and revised budget documents for the 24 participants who received services through the APP throughout the pilot period (4 of the original 28 stopped their services at various points). Similarly, actual program costs were determined by examining records of actual expenditures for each participant, by month and by type of expense. Budgets and actual expenditures were summarized and compared. Average monthly and yearly budgets and expenditures, ranges, and standard deviations were calculated. Evidence of program benefits was gathered from participant and family responses to survey questions and from key informant interviews.

### ***Analysis***

All data were entered into Microsoft Access tables. This program is suitable to enter both quantitative and qualitative (open-ended responses) information. After data collection was complete, the data were converted to SPSS version 16.0, a statistical software package designed for both simple and complex analysis. Data were analyzed question by question and cross-tabulations were utilized to compare participants at baseline and at follow up.

Participants' responses at baseline were compared to their responses at the one year follow up. Variables that are dichotomous in nature were organized in a 2 x 2 format; a McNemar's change test was used to calculate the degree of association. The ordinal data was also tested using McNemar's change tests. For continuous variables, paired t-tests were computed to compare baseline and one-year scores. Statistical tests with a p-value of less than 0.05 are considered statistically significant.

The final stage of the statistical strategy was the analysis of the open-ended questions using qualitative methods. Responses to the open-ended questions were recorded by the interviewer and entered into the computer directly as written. The key informant interviews were recorded verbatim by the interviewer and entered simultaneously into a Microsoft Word interview transcript. Each of the major open-ended questions from the key informant and the participant interviews was analyzed separately using the constant comparative method (Strauss & Corbin, 1998). Recurrent themes were noted, and the text was clustered under these themes until no new themes emerged.

## **IV. Program Implementation**

### ***Key informant interviews***

In addition to interviewing APP participants, comparison group members, and their families, eight telephone interviews were conducted with program staff (n=2), advisory council and clinical consultation team members (n=3), and service providers (n=3). Each interview assessed respondents' experiences regarding five topics: 1.) What has gone well with the APP? 2) What has been difficult or not gone well with the APP? 3) What is the potential demand for the program going forward? 4) Do you think the program is cost effective? and 5) What is the program's impact on family members? Inset paragraphs in italics are direct quotes from the key informants.

### ***Program successes***

The APP's successes fall into two general categories: participant outcomes and program administration. Respondents described notable improvement in program participants' engagement in their communities through social groups and employment. The social skills group and the mentoring services have been particularly beneficial. A few people noted that the APP is most helpful for individuals who are motivated to take advantage of what the pilot provides.

*The individuals who have received the community based skills training services have really shown enrichment in their lives and increase in the social skills adults need to...function in the community and be workers.*

*APP is most successful at getting them out more and to try new things, into a social situation.*

In terms of program administration, several respondents praised the process of case reviews by the Clinical Consultation Team. These meetings include participants, family members, providers, program staff, and clinical consultants and are used to understand and address any issues the participant may experience.

Respondents are also pleased with the model used to run the program, which is based on the model used to administer the DDS Home and Community-Based Services (HCBS) Waiver. In particular, conducting the intake in the participants' homes "allows the staff person to really understand what the issues are by being in the individual's environment."

The program has developed some targeted training for the direct care staff that works well. Respondents described the staff as enthusiastic and excited. The providers and advisory council members uniformly praised the program staff's expertise, dedication, availability, communication skills, and collaborative approach.

### ***Program difficulties***

Respondents enumerated several difficulties with the program since its inception. Program staff and advisors have developed program improvements that have mitigated some of these difficulties at this point. While some program participants were highly motivated to take advantage of the services available, others appeared either ambivalent or reluctant to participate. Some were strongly encouraged to apply to the program by their families, but were not invested themselves. Respondents agreed that participants in the latter group did not benefit as much from the program. Further, a few people hypothesized that the program works better for younger participants who have been more recently involved in services through the school system.

*A lot of people are involved who had to be pushed to get into the program and who have no interest and no incentive to see their lives change. It is a combination of their own being stuck in what they're doing, they have things they enjoy – they spend time on video games, internet, chat rooms, that they find very rewarding and non-threatening... the individual is basically satisfied and not getting into trouble. It is hard to see that change when the change looks like it's going to be complicated. People try things and don't like it, then quit. I lay that in large part to their having lived this way after leaving school for many years. There wasn't much available when they got out of schools, so they found these lives. Those coming out of school are more amenable to taking advantage of opportunities, but we haven't seen a lot of them yet in the program.*

Respondents reported that they were surprised to find many participants with additional disabling conditions, in particular mental health diagnoses. In retrospect, the program was not designed to provide adequate services for this population and they have made adjustments in eligibility and screening criteria.

*When individuals have secondary mental health problems, providing services is more complicated. Autism issues get in the way of independence to start with; when you overlay that with mental health issues, it requires a different approach. We have adjusted the eligibility to exclude people with severe mental health issues and are working with [the Department of Mental Health and Addiction Services] (DMHAS). The pilot program is not equipped to serve this group, we refer them to DMHAS. It is a difficult issue because there is a strong correlation between having an autism spectrum disorder and mental health problems. It is something we need to figure out and it is getting attention on the national level too.*

Challenges working with families were also mentioned, both in terms of unrealistic expectations and in cases where family members did not support the program activities fully.

*The challenges are the expectations, not of the individuals, but more of the families especially with looking for jobs, and especially with the economy. People don't understand that it is hard, even for people who are not disabled, who are struggling to find jobs.*

*The APP needs to do a little more work with parents, getting the parents to let the staff do their jobs or back up what the staff are trying to do.*

Some difficulties related to providers were also noted including communication, appropriate training, turnover, and, from the providers' perspective, receiving inadequate background information on new participants.

*Staff from provider agencies had some difficulties with communication, for example they'd say they would call the individual on Friday morning. If they called Friday afternoon instead, the individual was thrown off kilter. There was a rough time, but the providers were great in working through it and having staff adjust the way they communicate with the individuals in the program. They now train staff that they have to do what they say and to be careful with slang/casual comments. The issue is now resolved.*

*A few staff left to pursue higher education; we've seen backsliding on some individuals they worked with. It has been a struggle to help them deal with that.*

*One of the things is not always getting enough information about a person. We don't get as much detailed information ahead of time as I'm used to getting with [Department of Developmental Services clients with mental retardation].*

### **Future demand for the APP services**

Respondents uniformly asserted that the demand for these services is large and growing. They foresee increased demands both within the two regions (New Haven and Hartford) where the pilot operates, as well as statewide. Program staff, advisory group members, and providers all reported receiving ongoing phone calls asking when the services will be available to additional people. Several respondents also noted that the incidence of autism spectrum diagnoses in school age children is growing. As these children leave school, they need services like those provided in the APP to transition into employment or higher education and to be integrated into their communities.

*People call me all the time to ask me about the pilot: when will it expand? When will it come to my area? When will there be a waiver? When will it be available for everyone?*

*The wave of people moving through the schools as the State Department of Education became aware of them in the early 90s is now hitting the streets. It is going to be substantial. Finding support sooner rather than way later is really advantageous for people. It's really important.*

*As I go to meetings at high schools, more people are plugging in, there is a wait list now, in New Haven definitely, and Hartford just filled. They are not anticipating openings. I still believe the need is there. It is more a matter of integrating the program with high schools for transition, so people know it is there and can plug in the services. They will need to raise the cap on the number of people they can serve. I certainly hope it will be expanded. The need is definitely there.*

### **Program cost effectiveness**

Overall, respondents believe that the program is cost effective. They feel that the costs are relatively low compared to the benefit derived by participants.

*We do this work with part time people; DDS uses Medicaid rates for services in general for this, which are relatively low. It is cost effective compared with most of DDS's clients.*

*The money spent is well worth it. Individuals are employed. Those working with [the Bureau of Rehabilitation Services] (BRS) benefit from the additional services of the Autism pilot program teaching them hygiene and social skills that help them keep a job. The program is overall a financial benefit to society and overall a health benefit to society. People are happier, have less secondary issues due to isolation and anxiety. For example, one... parent said the individual had not slept in sheets for eight years. The provider taught him to make his bed, wash his sheets, and sleep in the bed. One participant reported ... that before the program she had no reason to get up in the morning, now she does.*

*Medication can help with some symptoms but this is a population where counseling is not really effective (e.g., meeting once a month with a therapist). This population requires a community based approach combining teaching with opportunities for generalization in the community. The costs are necessary. A significant number of individuals [are] out there*

*without these supports who therefore require long term hospitalization or a lot more support to cope because they don't have the skills that this program teaches.*

A few respondents mentioned differences in cost effectiveness for certain subgroups of program participants.

*I think for the people who are really serious about getting everything they can get from the pilot they are using all of the money that has been budgeted. Others who are struggling with whether they actually want or need help, they have not used their budget.... A small handful are nowhere near using what they planned for. They have not and families have not fully bought into what we can offer them.*

*We found that there are folks who are more expensive...than we thought. We have found that the costs are less for folks that are younger. For folks who have not had much intervention earlier, the costs are much higher. For folks with mental health issues, the costs are much more.*

### **Program impact on family members**

Most respondents described highly positive effects of the program for participants' family members.

*Families that I've seen are hugely grateful for this program. They see it as a lifeline not only for their family member on the Autism spectrum but for themselves as well. They've given their lives to organize and plan for their adult family member. Now they have help.*

*The families are happy. The individuals are making meals, acting more a part of the family, taking some responsibility off of the parents. They are out in the community with someone from the program and so family members do not have to be 24/7 responsible.*

*Families are constantly saying it has made such a tremendous difference in their lives and in their children's lives.... I have not gotten any negative feedback, which is so unusual.*

However, a few people also noted some variation in family responses, particularly those with high expectations and those who feel more ambivalent about the program.

*There are two impacts. Many families have been very active in using the pilot and it has allowed them to facilitate the developmental process of creating more independent lives for their adult kids with autism spectrum disorders. For some families it has been hard for them to allow this independence. The idea of helping their child: yes, they want to do that. But the idea of the child moving out and being more independent is very difficult. The idea of facilitating independence was really hard for some families.*

*It's varied. Some have really liked what they've seen and are pleased. Other families are hoping for something more substantial to happen more quickly.... Some get mad at their sons or daughters; they wish they'd be willing to do more, take advantage of what the pilot has to offer, so there is frustration...because now that they are in the pilot, families feel that there is finally something for us. Then their son or daughter is rejecting it.*

## V. Autism Pilot Program Participant Outcomes

### Demographics

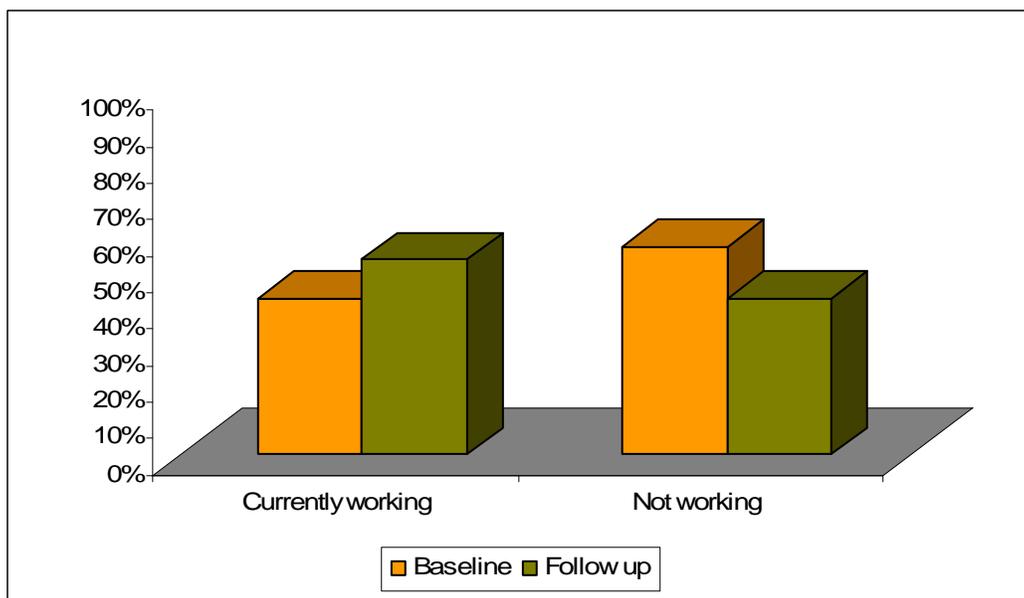
There were 28 participants in the baseline test group, 20 male and eight female. Twenty-three of those are white/Caucasian, two are Hispanic, two are African American and one is Asian. Half of the individuals have at least some college or a two-year associates degree; four have completed college; six have at least a high school diploma or GED; one of the participants has post high school training other than college; and only one participant has an eighth grade education or less.

At baseline, the majority of the participants lived with one or two parents (64%); eight lived by themselves; one lived with another relative; and one lived in a supervised living program apartment funded by the Department of Mental Health and Addiction Services (DMHAS). All of the participants were earning less than \$25,000 per year and 75 percent were earning under \$12,250 per year at baseline. Of those who reported family income (n=26), 35 percent of the families have incomes over \$100,000 per year; 27 percent have incomes from \$50,000 to just under \$100,000 per year, and 23 percent have incomes from \$25,000 to just under \$50,000 per year. Four of the family incomes are under \$25,000 per year.

### Work experience

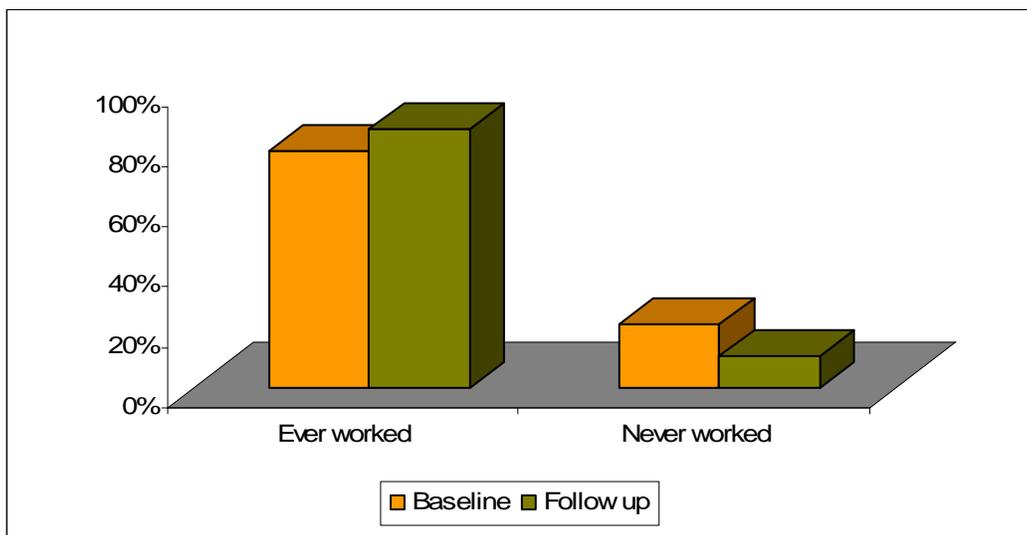
At baseline, 41 percent of the participants were working (n=11). Of those who were working at baseline, 55 percent continued to work after one year (n=6). Ten of the individuals indicated that they had worked in the past with nearly half (42%) indicating that they had last worked less than a year ago and an additional 42 percent saying that they had last worked one to five years ago. Six of the participants said that they had never worked for pay. After one year, seven of those who had worked in the past had jobs and two individuals who had never worked were working. But five participants who had been employed at baseline were no longer working one year later. While these changes in employment status are not statistically significant, there is a clear trend towards increased employment among participants, with a net increase of 4 more people employed after one year of program services.

Figure V-1. Participants who are working



Six individuals had never worked at baseline and at follow up three of these individuals had become employed. At baseline 79 percent of the participants had worked at some point in their lives and at follow up 86 percent of the group said that they were currently working or had worked at some point in their lives. Due to the very small numbers, these employment increases do not reach statistical significance, but finding employment for 50 percent of the group who had never had a job before joining the APP is a notable achievement.

Figure V-2. Participants who have ever worked or never worked



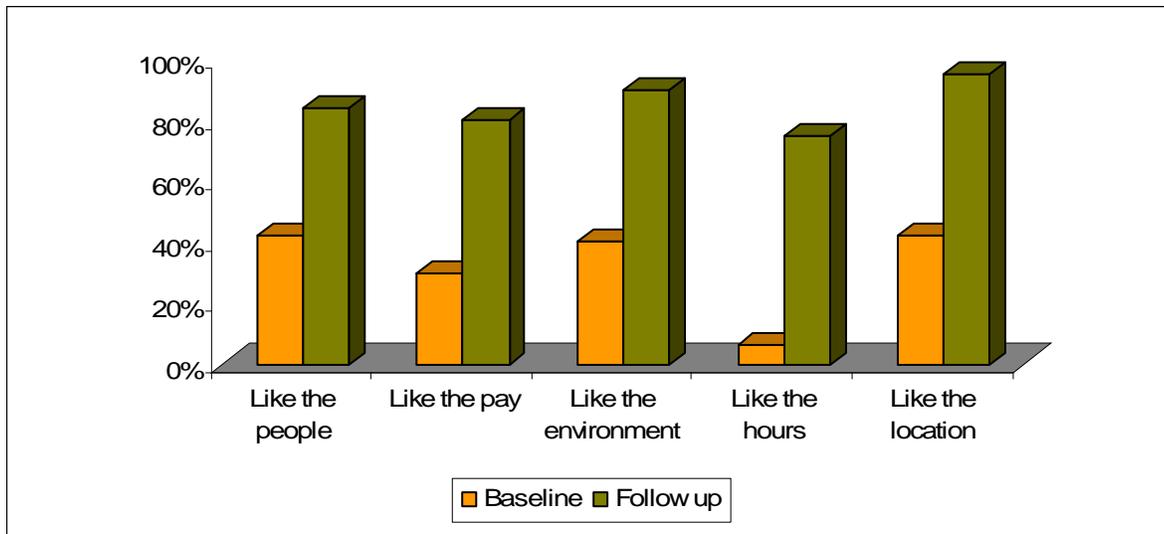
Only two of those who worked for pay received employment supports before enrolling in the APP, which was mainly in the form of a job coach, and at follow up three individuals were receiving employment supports.

Jobs were varied among the participants, including clerical positions (such as bookkeeper or proofreader), construction, service positions (such as grocery bagger or kitchen work) administrative assistants, and illustrators. The average number of hours for those who were working or who worked in the past was about 20 hours per week at both baseline and after one year in the APP. Average hourly wages varied. The majority of the participants who were working or had worked in the past (n=14) earned under \$10 an hour. Only six of the participants earned between \$10 and \$20 an hour at both baseline and one year later.

Participants were asked if they liked the people, the pay, the location, the hours, and the environment at their jobs. Fifty-eight percent of the participants at baseline said that they did not like the people at their job, however at the follow up interview, only 16 percent of those said that they did not like the people that they work with. Only 30 percent of the group was happy with the pay they received at their job at baseline, however at follow up, 80 percent of the people said that they were happy with their pay. Sixty percent of those who were working at baseline did not like the environment of their job, but the majority (90%) of those who were working at follow up said that they like their environment. Ninety-four percent of those who were working indicated that they were not happy with their hours, however by the second interview only 25 percent were not happy with their hours. Fifty-eight percent of the participants who work indicated initially that they were not happy with the location of their job, but after one year 95 percent of those working said that they were happy with the location

of their job. All of these changes from baseline to one year after starting services were statistically significant ( $p < 0.05$ ).

Figure V-3. What do you like about your job?



Some participants commented about why they were dissatisfied with certain aspects of their jobs:

*Stress, too fast-paced*

*Some of the managers were sarcastic*

*The work is monotonous and beneath me*

*No one is patient with me*

Five of the participants were involved in volunteer work for an organization, company or nonprofit agency at baseline. At the follow up interview, six participants were volunteering.

### **Family and friends**

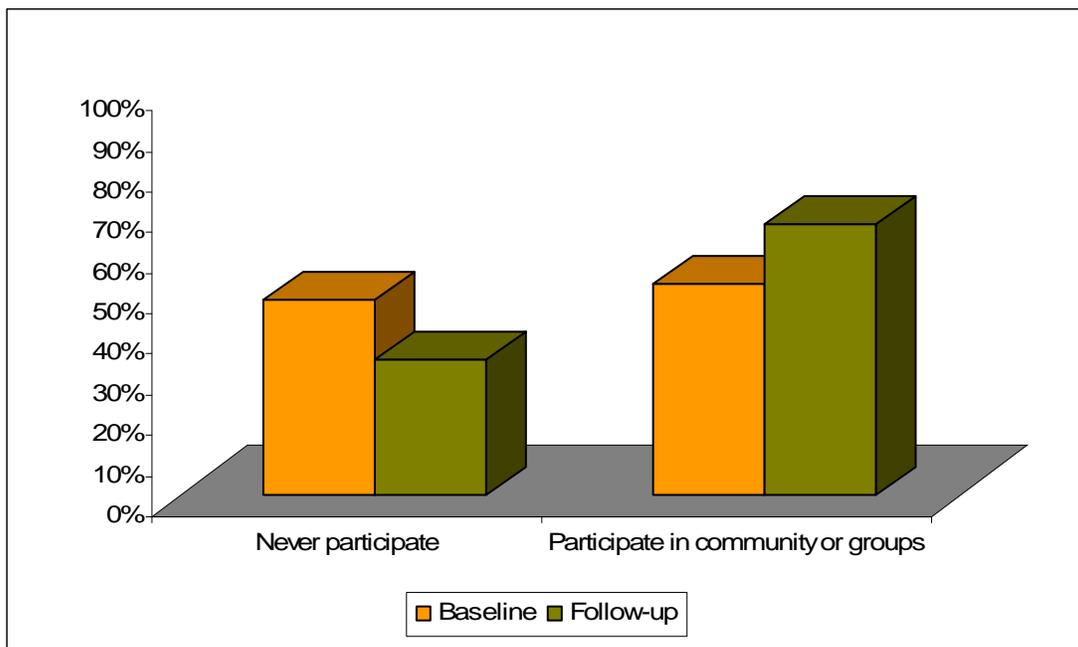
Involvement with family and friends was also an area of interest. Participants indicated how many close relatives and friends they have and how often they see these individuals on a regular basis. Overall, participants listed very few relatives or friends with whom they feel close, both at baseline and after one year. The average number of relatives is about two, with contact and communication only with one relative per month. The average number of friends is about one, with contact and communication with one friend per month. There were no significant differences between baseline and follow up involvement with family and friends. The mean results are given in the following table (Table V-1).

Table V-1. Family and friends

	Mean at baseline	Range at baseline	Mean at 1 year	Range at 1 year
How many relatives do you have that you feel close to?	2.64	0-10	1.44	0-7
How many of these relatives do you see at least once a month?	1.18	0-4	0.70	0-4
How many relatives do you talk on the phone with or exchange letters with or e-mails at least once a month?	1.64	0-6	0.78	0-3
How many close friends do you have?	1.68	0-5	1.59	0-10
How many close friends do you see at least once a month?	1.04	0-4	1.11	0-10
How many close friends do you talk on the phone with or exchange letters or e-mails?	1.50	0-5	0.96	0-4

At baseline, nearly half (48%) of the group said that they never participate in the community or groups. By the time of the follow up interview, 67 percent of the group said that they now participate in the community or in groups. This change does not quite reach statistical significance, but it is a notable difference given the small sample size.

Figure V-4. How often do you participate in the community or groups?



**Leisure activities**

Participants were also asked how many hours they watched TV, used the computer, or played video games per day. These total hours were added together for a measure of total “screen hours” per day. The average was about three hours for TV watching, three hours of computer use, and about an hour for video games. The number of hours for each of these activities ranged widely among the 27

participants who completed both interviews. While some people did not watch TV, use a computer, or play video games at all, others spent a huge amount of time: up to 12 hours per day watching television, 18 hours per day using a computer, or 8 hours per day playing video games. The average total screen hours was 7.81 at baseline and decreased modestly to 7.11 hours after one year. The total screen hours ranged from 0 to 38 at baseline and 0 to 35 at follow up. These numbers exceed 24 for one person who kept the television and computer on all the time. There was no significant difference between baseline and the follow up interview on any of these measures.

Table V-2. How many hours do you spend watching TV, using the computer, or playing video games?

	Mean at baseline	Range at baseline	Mean at 1 year	Range at 1 year
How many hours do you watch TV per day?	3.41	0-12	2.93	0-12
How many hours do you use the computer per day?	3.44	0-18	3.22	0-16
How many hours do you play video games, etc. per day?	.96	0-8	.96	0-7
Total screen hours per day.	7.81	0-38	7.11	0-35

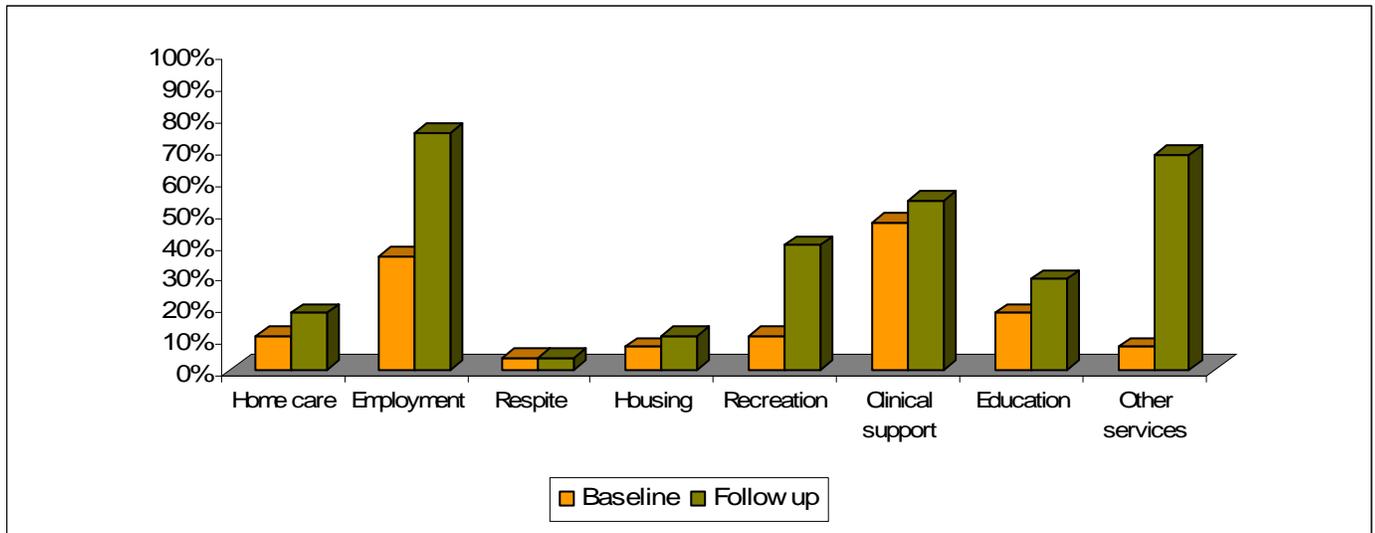
Leisure activities include active sports such as swimming, taking walks, doing physical exercises, working in the garden or yard, working at a hobby, going out to do some shopping, going out to a movie, restaurant or sporting event, reading books, magazines or newspapers, watching television, taking a day or overnight trip, doing unpaid community or volunteer work, doing paid community work, or playing cards, games or bingo with other people. Participants reported how frequently (often, sometimes, or never) they did each activity. A summary score on this measure could range from 0 to 28. On average, the leisure activities score was 12.37 at baseline and 12.22 after one year. Other activities mentioned by the participants included dancing, internet blogging, listening to music, riding a bike, taking college courses at a community college, drawing and writing.

### Services

Participants were asked if they were receiving any services, including but not limited to those that they received through the APP. At baseline, three of the participants were receiving home health care services and at 12 months, 4 were receiving home health care. The APP does not provide home health care services, but may facilitate the connection to home health care when needed. Some of the home health care involved help with medications, help with cooking and cleaning or checkbook balancing. Ten participants were receiving employment services at baseline and by the time of the follow up interview, 21 individuals were receiving employment services, a statistically significant increase ( $p = 0.001$ ). Many of the participants indicated that they were working with job coaches or getting support from the Bureau of Rehabilitation Services (BRS) to help them find jobs. Some were working with a job developer, employment specialist, or had a job assessment. Only one participant was receiving respite services which remained consistent from baseline to follow up. At baseline two individuals were receiving housing services and at follow up a total of three participants were receiving these services either to find an apartment or to find a supportive housing situation. Three of the participants indicated that they received recreation services at baseline and at the time of the follow up interview, 11 individuals were receiving these services, also a statistically significant increase ( $p = 0.021$ ). Many of these activities were funded through a modest annual activity fee provided by the APP. Activities included things like bowling, movies, and museums. Thirteen

participants were receiving clinical supports at baseline and 15 at follow up. These clinical supports included therapists, psychiatrists, social workers and counselors. Only five participants were receiving education services at baseline; however after one year, eight participants were receiving education services such as help in obtaining a GED, tutors, and note takers. Other services included many of the programs provided by the APP such as social skills group, community mentor program, social groups and support groups. At baseline, only two individuals had these services, however at follow up nearly 19 participants were receiving some sort of additional services which is statistically significant as well ( $p < 0.001$ ).

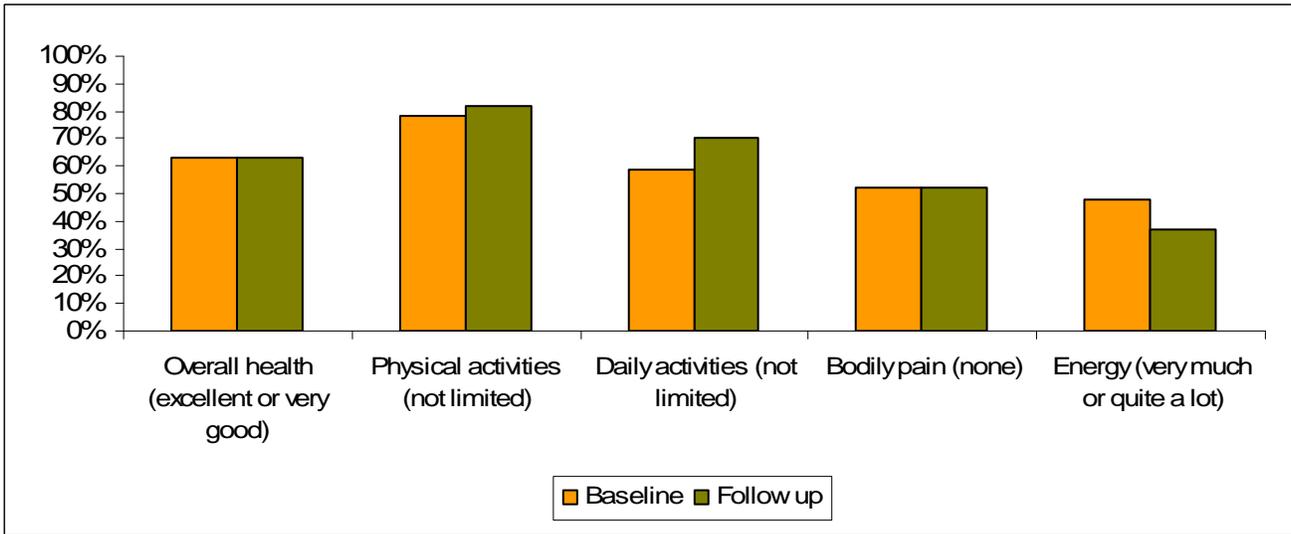
Figure V-5. Services received



### Health

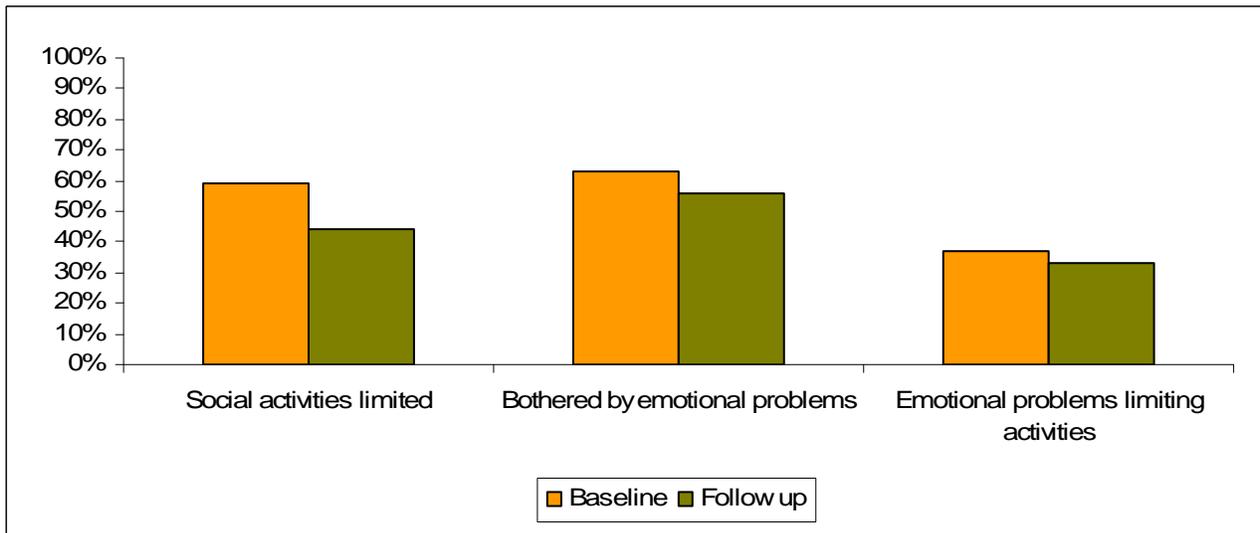
At baseline, 63 percent of the participants rated their health as either excellent or very good, while the remainder of the participants rated their health as only good, fair, or poor. The same percentage of participants rated their health as excellent or very good at the time of the follow up survey. Participants were then asked a series of health-related questions. In each instance the participant was reminded to think about the past four weeks when they answered the questions. At baseline, the majority of the respondents (78%) indicated that their physical activities, such as walking or climbing stairs, were not limited at all because of physical health problems. After one year the percentage of those who were not limited had risen to 82 percent. Participants were asked how much difficulty they had doing daily activities, both at home and away from home, because of their physical health. At baseline, a total of 59 percent of the participants indicated that they did not have any difficulties. After one year, the number of participants having no difficulty rose to 70 percent. Fifty-two percent of the participants reported that they had no bodily pain at all during the prior four weeks at baseline. The results after one year were consistent. Nearly half (48%) of the respondents indicated that they had either very much or quite a lot of energy, while the remaining respondents reported having either some or only a little energy. After one year, only 37 percent of the participants reported having very much or quite a lot of energy. None of these differences reached statistical significance.

Figure V-6. Rating of health



At baseline, 59 percent of the participants indicated that during the past four weeks their physical health or emotional problems limited their usual social activities with family or friends. After one year, only 44 percent of the participants indicated this, while the remaining participants said that this did not happen at all. Sixty-three percent of the participants at baseline indicated that they had been moderately or extremely bothered by emotional problems such as feeling anxious, depressed or irritable. After one year, 56 percent of the participants reported either moderate or extreme emotional problems. Only 37 percent of the participants at baseline indicated that personal or emotional problems kept them from doing their usual work, school, or other daily activities. After one year, 33 percent reported that emotional problems kept them from doing their usual activities. Overall, participants appear to rate their emotional health somewhat better after one year of services, although the changes were not statistically significant.

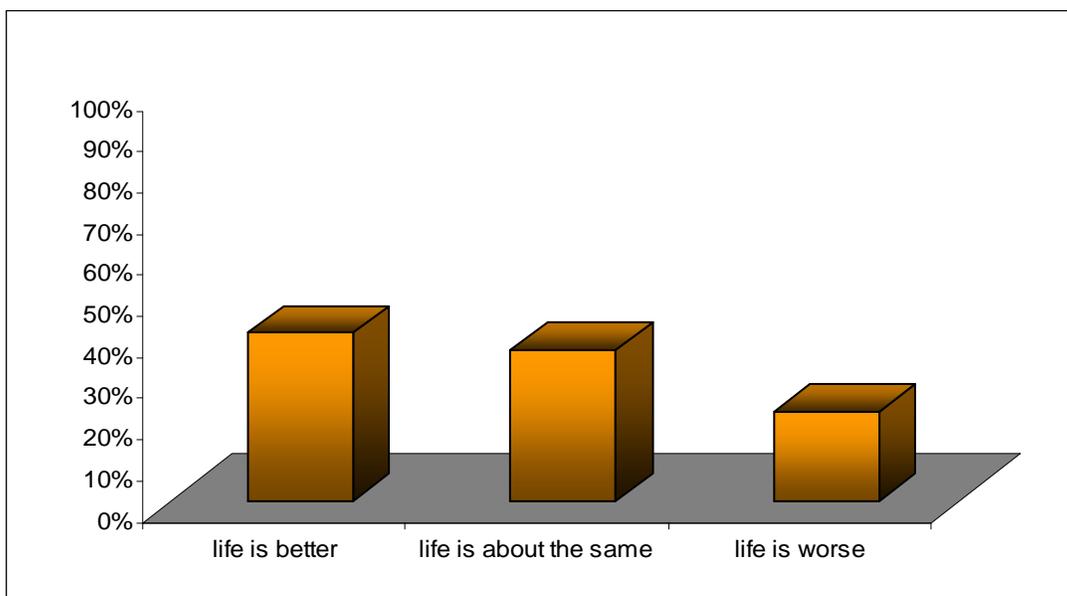
Figure V-7. Emotional problems affecting social activities or normal activities



Symptoms of depression were assessed using the 10-item Centers for Epidemiologic Studies – Depression scale (CES-D) (Irwin, Artin, & Oxman, 1999). Results from the CES-D scale yielded a mean summary score of 3.85 at baseline and a mean summary score of 3.81 after one year in the program.

At the one year follow up interview, participants were asked, “Compared to this time last year, do you feel that your life is better, worse or about the same?” Eleven people (41%) said their lives are better, ten people (37%) said about the same, and six answered worse (22%).

Figure V-8. Compared to this time last year, is your life better, worse, or about the same?

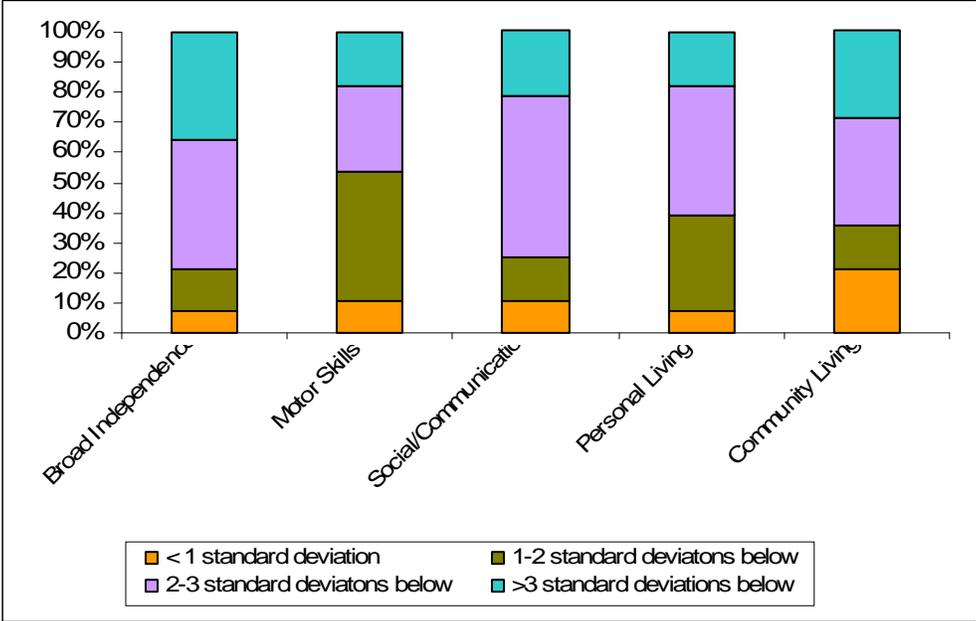


The Scales of Independent Behavior-Revised (SIB-R) (Bruininks, Woodcock, Weatherman & Hill, 1996) were administered to each participant at baseline and at follow up. This series of scales is used to measure motor skills, social interaction and communication skills, personal living skills, community living skills, and overall independence. Each of the sub-indices measures how well the individual is able to perform a number of tasks, and whether the individual can do it very well, fairly well, or not well at all. The scale also assesses that person’s need for help or supervision in performing any of the tasks.

In addition to a measure of broad independence skills, the major subscales of the SIB-R include: motor skills, such as gross motor skills and fine motor skills; social interaction and communication skills, which includes social interaction, language comprehension and language expression; personal living skills including eating and meal preparation, toileting, dressing, personal self-care, and domestic skills; and community living skills, including time and punctuality, money and value, work skills and home/community orientation. Each of these subscales is scored and then the scores are standardized so that a score of 100 on each subscale represents the norm for the general population, with a standard deviation of 15 points (Reynolds & Kamphaus, 2003).

Figure V-9 displays the distribution of scores on each subscale for the APP participants at baseline. This data indicates the relatively low level of functioning across all subscales for this population, relative to the normal population. For the broad independence subscale, standardized scores ranged from 33 to 108 with only seven percent of the participants falling within one standard deviation from the norm and 36 percent more than three standard deviations below the norm. Motor scores ranged from 36 to 115 with only three individuals less than one standard deviation below the norm and 18 percent more than three standard deviations below the norm. Social and communication scores ranged from 36 to 98 with three people within one standard deviation below the norm and 22 percent more than three standard deviations below the norm. Personal living scores ranged from 41 to 117 with only two individuals less than one standard deviation below the norm and 18 percent over 3 standard deviations below the norm.

Figure V-9. Baseline results of SIB-R subscales –  
 Percent of participants who fall below norm (in standard deviations of 15 points)



At follow up, the mean score for each of the subscales of the SIB-R had improved significantly. The results are represented in the following table (Table V-3).

Table V-3. SIB-R subscales at baseline and follow up

	N	Mean	Standard deviation	significance
Broad independence - baseline	25	60.12	14.65	
Broad independence – follow up	25	69.40	15.03	.000
Motor score - baseline	25	68.52	15.79	
Motor score – follow up	25	77.28	18.91	.007
Social/Communication - baseline	25	63.68	12.90	
Social/Communication – follow up	25	73.40	15.61	.001
Personal living - baseline	25	67.72	11.33	
Personal living – follow up	25	73.24	11.61	.011
Community living - baseline	25	65.60	20.89	
Community living – follow up	25	73.44	16.68	.004

In addition to the subscales described above, the SIB-R generates scores for four maladaptive indices and an overall support score. Results from the SIB-R evaluations from baseline compared to follow up also indicated statistically significant changes in the generalized maladaptive index (GMI), internalized maladaptive index (IMI), asocial maladaptive index (AMI), and in the overall support score (SS) which is a combination of the independent living and the maladaptive indexes. These changes were all improvements. Only the externalized maladaptive index (EMI) showed no change over time; the mean score on this index was already in the normal range at baseline. The index for GMI, IMI, AMI and the EMI are considered serious or very serious for outcomes below -31; moderately serious for scores of -30 to -25; marginally serious for scores in the range of -20 to -15; and normal for scores of -10 and above. Overall support scores also showed significant improvement although mean scores at both baseline (70) and follow up (84) fall within the intermittent support level. The results are shown in Table V-4.

Table V-4. SIB-R Maladaptive Indices and overall Support Score at baseline and follow up

	N	Mean	Standard deviation	significance
GMI at baseline	25	-19.64	23.34	
GMI at follow up	25	-10.68	10.26	.050
IMI at baseline	25	-23.88	13.45	
IMI at follow up	25	-16.52	12.57	.009
AMI at baseline	25	-13.68	11.74	
AMI at follow up	25	-6.64	9.73	.003
EMI at baseline	25	-3.32	7.24	
EMI at follow up	25	-2.20	8.84	.470
SS at baseline	24	74.62	10.94	
SS at follow up	24	81.83	10.43	.002

## ***Family members***

Family members of participants were also interviewed. At baseline, there were 28 family members who responded to the survey; 26 family members responded at one year. In one case, the participant had moved out of state, in the other case the participant completed the interview, but the family member was ill and not available. In most cases, the family member was a parent or grandparent (85%). Other family members included siblings or other relatives and in two cases, the person responding was a counselor and a conservator. The majority of family members were female (93%). Most family members were in the 45 to 64 age bracket (36% are 45 to 54; 21% are 55 to 64). Eighteen percent of the family members were 44 or younger and one-fourth (25%) of the family members were over the age of 65. The majority of family members were married (68%); one-fourth (25%) were either widowed or divorced/separated. The majority of family members (57%) had college degrees or post graduate degrees; one-fourth had at least some college or a two year degree; and five had at least a high school diploma or GED.

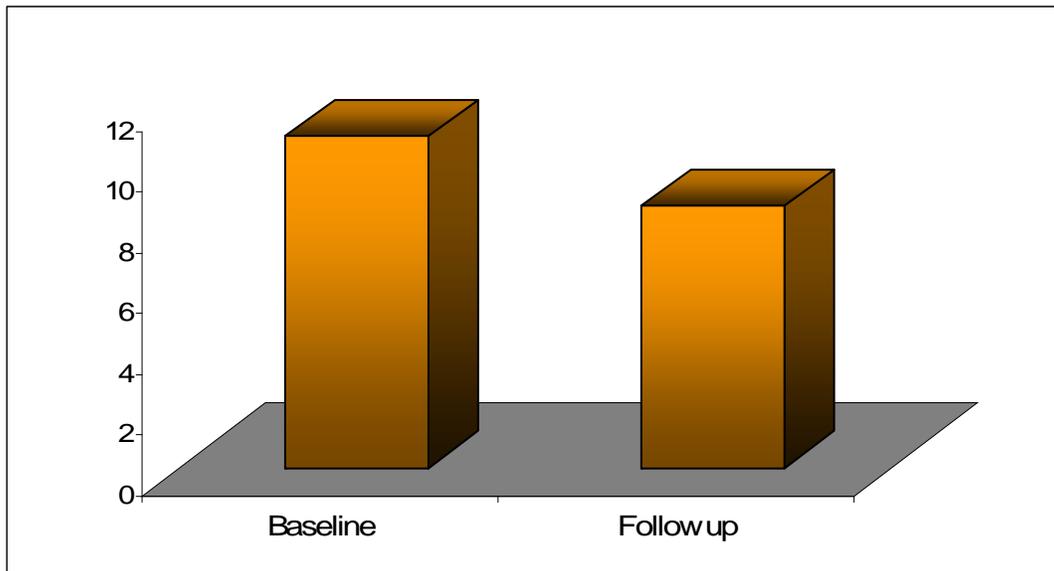
Sixty-eight percent of family members at baseline said that they had contact with the participant on a daily basis, however after one year, two of those family members indicated that they only had contact with their relative on a weekly basis or less. Of the eight family members who only had contact with the participant on a weekly basis or less at baseline, three of them now have contact on a daily basis at follow up.

## ***Burden***

A scale to measure burden to the family member included several items which would indicate the burden to that individual for having responsibility for their relative (Zarit Burden Scale) (Zarit, Reever, Bach-Peterson, 1980). The scale includes the following items: how often, because of the time you spend with your family member, do you feel you don't have enough time for yourself?; do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?; do you feel strained when you are around your relative?; are you afraid of what the future holds for him or her?; do you feel your health has suffered because of your involvement with your relative?

The mean summary score for the burden scale was 10.92 at baseline and 8.62 at the time of the follow up interview, which is a statistically significant improvement for families ( $p = 0.006$ ).

Figure V-10. Burden scale results (mean summary scores)



### Concerns

The family members were asked, both at baseline and follow up, to express their concerns regarding their relative in the APP. Most of the concerns expressed by families had to do with what would happen to their relative when they were no longer around. At the baseline interview, the following comments were made:

*I'm concerned about what will be after we are gone. We're both 77.*

*How she will get by when I am not around anymore. How she will get along on her own. How she will do at a job and make friends. Mostly, how she will be emotionally.*

*If I die what will happen to him? I have a trust in place, but my biggest concern is what will happen, who will take care of him?*

Finding a job and making friends and various other socialization issues was also a concern for most family members.

*Socialization. He has no contacts outside of the family, no relationships outside. If something happens to me, what would happen to him?*

*She has no job, doesn't drive, hard to get around ... hard to get things done. To make a phone call can be such an effort that she needs to rest for a day or more afterwards.*

*I am concerned about his social skills, his living skills and puberty. He has to be constantly redirected to complete tasks. He has no friends. I want him to have a full and active life.*

*He has no concept of money. Needs to save for the future. What will the future hold for him? What will happen to him when I'm gone?*

At one year after joining the APP, family members were still mainly concerned about the same issues.

*That he will be able to hold a job; that he'll have a life after we're gone; that he'll be protected and cared for. He's vulnerable – I worry. That his life in general will be okay, but especially once we're gone.*

*Hoping that he'll get a job and keep it. Future worry is that he'll be able to fit in.*

*His future. He has no concept of what it's like out there. He has a part time job. It doesn't even sustain his life, let alone contribute to the family. His social security was cut off because he's working. He lives at home. What will happen in the future?*

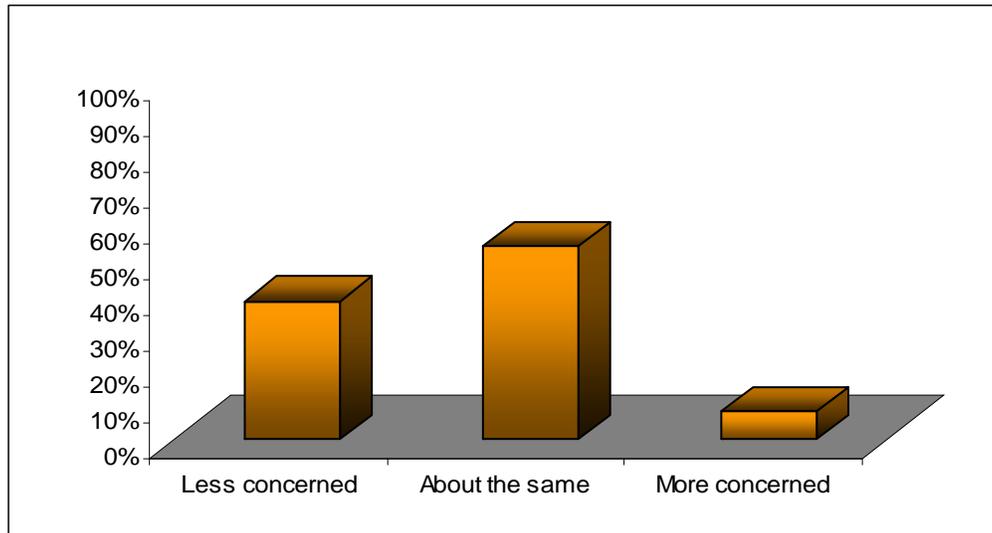
*What the future holds. What will happen when I'm no longer with him. Getting other people in the community to understand him; keeping him safe; getting him to grow up a little more and become more independent.*

*Where he'll be? Who will take care of him in the future? Don't want him in a home with people who are not functioning as well as he is. Want happiness in placement for him. He doesn't realize I won't be here forever to take care of him.*

*I worry if he's going to make friends, contacts. Will he get respect at his job and not be taken advantage of? Will he be able to get housing?*

Although the types of concerns did not notably change after joining the program, many family members felt less concerned overall than they had before the APP started. At the time of the follow up interview, family members of the participants were asked whether they were less concerned, more concerned or about the same as they were at baseline. Only 8 percent of the group said that they were more concerned. While about half (54%) said that their concern was about the same, over one-third of those who responded (39%) said that they were now less concerned.

Figure V-11. Compared to how you felt a year ago, do you feel more, same, or less concerned about your relative?



### ***Limited activity***

The Social/Role Activities Limitation Scale (Lorig, Stewart, Ritter, Gonzalez, Laurent & Lynch, 1996) assessed how much various activities of family members were affected by their involvement with their relative. Family members were asked to think about the prior four weeks, and assess how much their involvement with their relative had limited or interfered with any of these activities: normal social activities with family, friends, neighbors or groups; hobbies or recreational activities; household chores; and, errands and shopping. The mean summary score for this scale at baseline was 3.32 and, after one year, the mean summary score was 2.68 which is not a statistically significant decrease.

Only 28 percent of the family members indicated that taking care of their relative did not impose a financial strain at baseline. After one year, 36 percent of the family members said that taking care of their relative did not constrain their finances. This change was not statistically significant.

The symptoms of depression scale (CES-D) mean summary score for family members at baseline was 3.23 compared to the mean summary score of 3.31 at one year, which was not a statistically significant difference.

### ***Outcomes for participant goals***

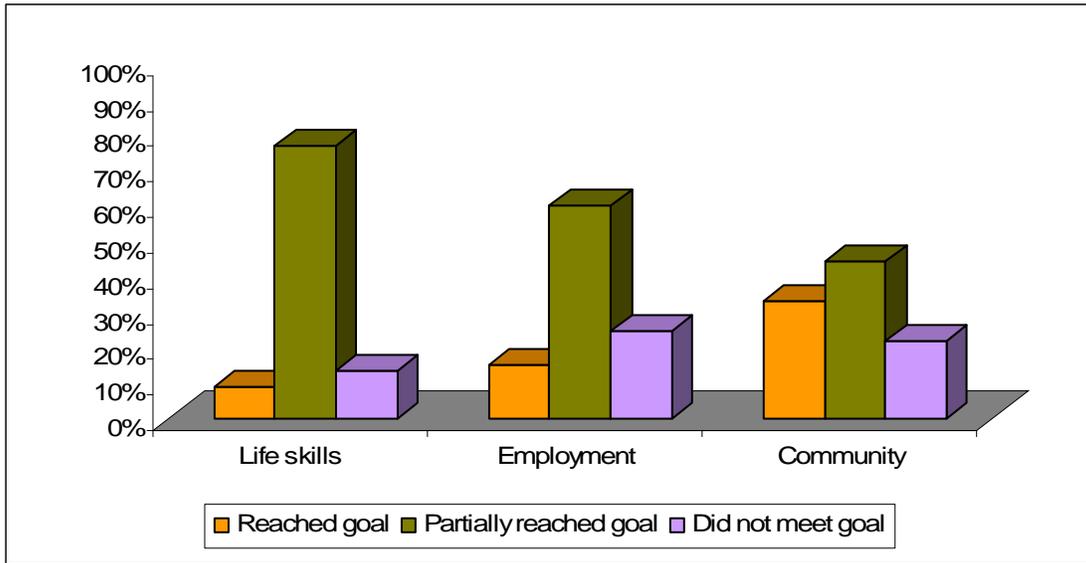
At baseline, each participant indicated the goals that they wanted to achieve as part of the APP. Based on these goals, an Individualized Service Plan (ISP) was developed. This plan not only indicated the goals of each participant, but also the services that would be needed for that individual in order to reach those goals whether it was a job coach, job developer, social skills training or community mentor.

Each of the participants made a list of various outcomes or goals that they wanted to achieve as part of their ISP. In addition, the APP service coordinator determined a plan of services that the participant would be receiving in order to achieve each goal. All of the participants listed at least one goal, 81 percent indicated two goals, 48 percent listed a third goal, 22 percent listed a fourth goal, and one participant listed five goals that they wanted to achieve.

After one year in the program, these goals were revisited by both the participant and their family member and, in reviewing them, the participant and the family member were asked how successful the participant was in achieving these goals - very, somewhat, a little or not at all successful. Goals were categorized under three broad areas: life skills, employment, and community involvement. Life skills goals included communication skills, getting more organized, performing the activities of daily living or instrumental activities of daily living, and social skills. Employment goals addressed finding a new job or improving job skills. Community involvement goals focused on getting out into the community more, engaging in specific activities, and building relationships. Twenty-two (81%) of the participants listed at least one life skills goal, 20 participants (74%) listed at least one employment related goal and 9 participants (33%) listed at least one community involvement goal. When a participant indicated more than one life skill goal, or more than one job related goal, etc., the goals were combined and the measure of success was determined by averaging the participant's or family member's appraisal of how successful the participant was in reaching each goal. Goals were considered to be "met" for those who indicated that the participant was very successful in meeting their goal, "partially met" for those who indicated the participant was either somewhat successful or a little successful, and "unmet" for those who indicated that the participant was not at all successful in reaching that goal.

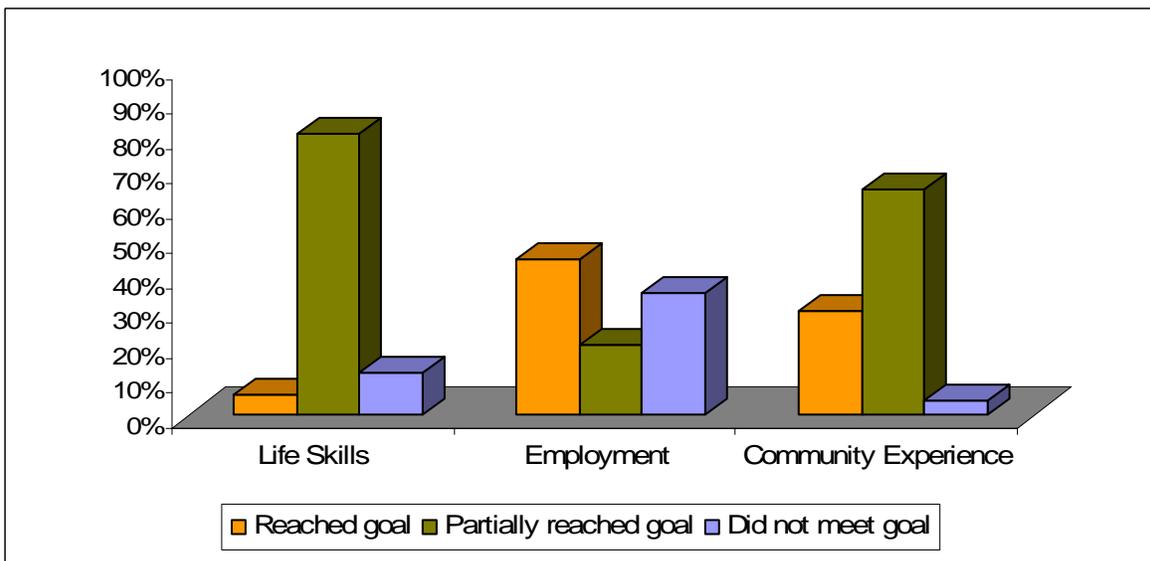
Twenty-two participants listed at least one life skill goal and of these, only two participants felt that they had totally met these goals. A majority of those who set life skills as a goal (77%) felt that they had at least partially met that goal, while three individuals indicated that they had not met this goal at all. Of the 20 participants who listed an employment goal, three participants felt that they had totally achieved this goal, while the majority (60%) felt that they had at least partially met their goal. Five participants indicated that they had not met this goal at all. Nine participants listed at least one goal of increasing their involvement in the community. Three of these indicated that they had achieved their goal, four individuals at least partially met this goal, and two participants said that they had not achieved this goal at all.

Figure V-12. Achieving outcomes – evaluation by participants



The APP service coordinator also rated participants' success at meeting their goals, organized into the same three categories: life skills, employment, and community experience. Each person with a goal in each category was rated as having met, partially met, or not met goals in each category. In terms of life skills, one person met, and 81 percent partially met, their goals. Only 12 percent (n=2) did not reach their goals with regard to life skills. All together, 45 percent of participants met and 20 percent partially met, their employment goals, while 35 percent did not meet their employment goals. Thirty percent of participants met, and 65 percent partially met, their expectations for community experience. Only one participant (4%) did not reach his/her goal for community experience.

Figure V-13. APP Service Coordinator's rating: Percent of individuals who met, partially met, or did not meet their goals

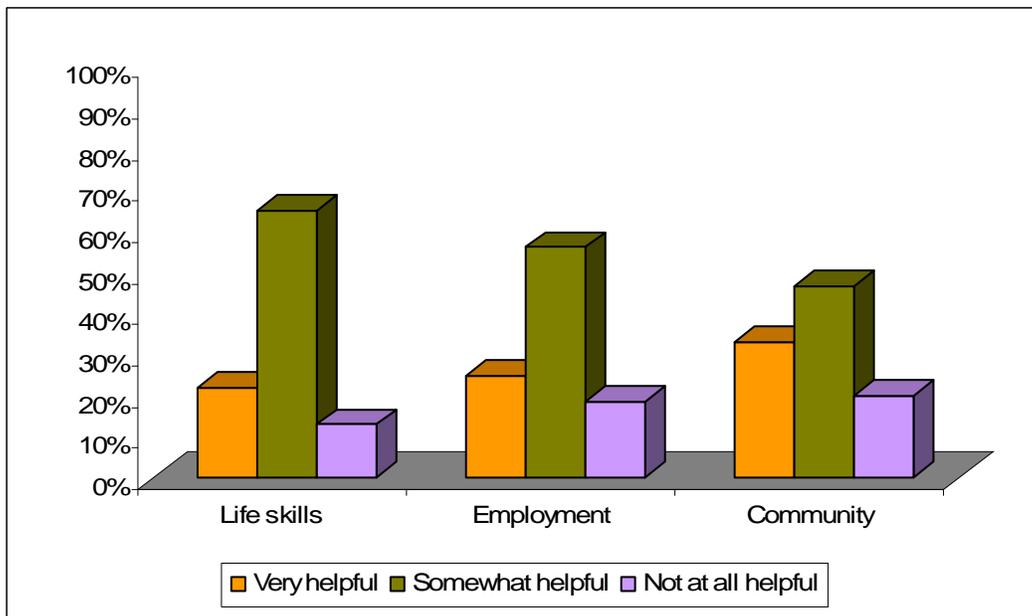


Another part of the ISP initiated at baseline was a list of possible services available to participants to help them achieve their goals. Each of the goals was matched to a service provided by the APP with an estimated number of hours per week that the particular service would be provided. In addition to services provided under the APP, the Connecticut Bureau of Rehabilitation Services (BRS) provided job coaches, vocational assessments, job development services and job skills.

Participants evaluated each of these services after one year in the program as being very, somewhat, a little, or not at all helpful. Services were also categorized into the same three broad areas. Life skills services included life skills coaches, social skills group, counseling, and speech therapy. Employment services included job coaches and job developers. Community involvement services included community mentor and activities participation.

Twenty-three of the participants received services associated with development of life skills, and, of these, five participants indicated that these services were very helpful; 65 percent said that the services were at least somewhat or a little helpful; and, only three individuals expressed dissatisfactions with the services. Sixteen of the participants received services associated with finding a job, and, of these, five individuals indicated that the services were very helpful; 47 percent said that the services were somewhat or a little helpful; and, only three individuals indicated that the services were not helpful at all. For community involvement, 15 participants received services related to this goal, and, of these, five said that the services they received were very helpful; seven individuals (47%) indicated that the services were at least somewhat or a little helpful; and, only three participants indicated that the services were not helpful at all.

Figure V-14. Evaluation by participants of the services associated with each of the goals



## **Comments by participants**

Most of the participants were happy to be part of the APP.

*Definitely glad to be in the program.*

*Project very helpful; helping me a lot; a real success.*

*I like it because the people are professional. There's camaraderie among the kids in the group. It's a tight group of people.*

*Glad to be in it. Helpful for me. I can learn to be independent in it. Feel like I will have the life of my dreams because of this program!*

*Job coach will do all he can, will bring newspaper, look at ads. He's really trying to help with job possibilities. I wish every state could have a similar program. Hope it continues. Without it we don't meet anyone like ourselves. This way we can meet someone and have a chance to make a connection.*

*Very successful so far. Made me accomplish a lot of things I wasn't getting before the program. Before I never had any hope and APP has done a lot for me. Now I have hope.*

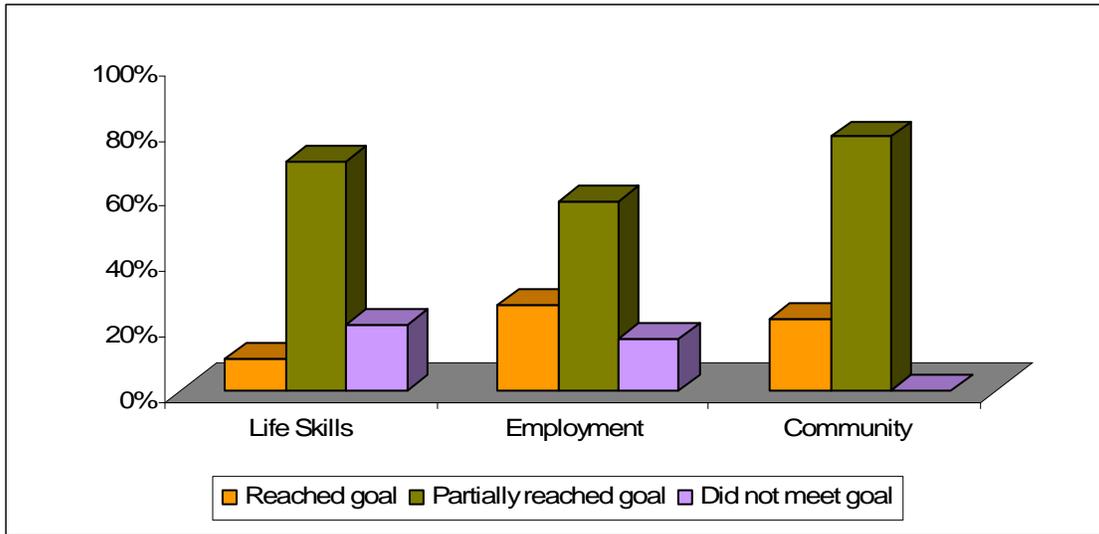
There were some, though, who expressed concerns about the program.

*I enjoy it. It helped me cook. But I wish the community mentor and life skills coach should be more responsive to our needs. APP is for us. We shouldn't have to jump through hoops to accommodate them. They should be doing it to help. The life skills coach is not being flexible.*

*Overall APP has been very helpful. The bureaucratic aspects can be irritating, paperwork and the slow pace of getting results.*

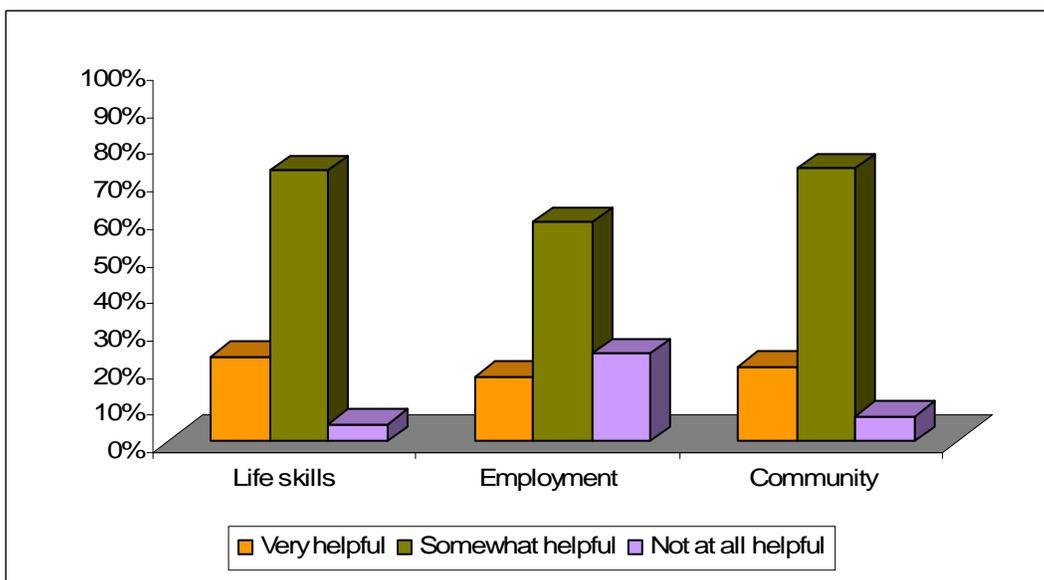
Based on the same participant outcomes, family members also indicated how successful their relative was in achieving their goals or outcomes. For life skills, two of the family members (9%) thought that the participant had successfully reached their goal in this area, while the majority (70%) indicated that the participant had at least partially met this goal. Four of the family members felt that their relative had not achieved this goal at all. For employment goals, five of the family members (25%) felt that their relative had successfully reached their goal; 58 percent of the family members felt that this goal was at least partially met; and, three family members said that this goal was not met at all. Two (12%) of the family members indicated that their relative had achieved their goal of community involvement, while 78 percent felt that this goal was at least partially achieved. None of the family members felt that their relative had not achieved this goal at all.

Figure V-15. Achieving outcomes – evaluation by family members



The family members also evaluated the services associated with each outcome. For those receiving life skills services (n=23), five family members thought that the services were very helpful; 73 percent thought that the services were at least somewhat or a little helpful; and, only one family member indicated that the services were not helpful at all. Regarding the services associated with finding a job (n=17), three family members thought that the services that their relative was receiving were very helpful; 59 percent thought that the services were at least somewhat or a little helpful; and, four individuals (24%) thought that the services were not helpful at all. For services associated with improving community involvement (n=15), three of the family members thought that the services were very helpful; 11 family members (73%) felt that the services were at least somewhat or a little helpful; and one family member indicated that the services were not helpful at all.

Figure V-16. Evaluation by family members of the services associated with each of the goals



The families of the participants were also very pleased with the program.

*He had been about to give up a couple of times in his life. We were losing him to his room. He was giving up just before the pilot program came along. It saved him (after a few false starts) with a fabulous job coach and getting a job with a great company with a future for him.*

*Very positive, very impressed. The level of funding has been terrific. Long term process ... We're very lucky that he is in the program. I still need to be involved and connect the dots, but now, over a year later, it really is going well ... Very exciting to see this happen especially for someone in his late 40s who went for so many years without help or any idea of what the problem was.*

*APP has helped a lot. She gets out of the house and opens up a little more. This was one of her goals.*

*It's great, but good that I didn't have huge expectations. It has provided an avenue for him to expand. Hoping for more in the future.*

*Finally now, she has gotten a job assessment. APP, very good. Don't see big improvement in my daughter but the program has been great. It sounds contradictory, I know, but I am very happy with the program and hoping to see good results in the future.*

*Fabulous. A number of positives, some subtle but very real. He has to make his own appointments, uses the phone. He never could have done that before, but now he's comfortable with it with any APP people ... But lots of important little subtle positive things have come out of it. Example: being on time. The experience of internships gave him a opportunity to find out he could do things he didn't know he could do, boosted his self-confidence, broadened his horizons.*

As with the participants, the family members also related some of the shortcomings of the program.

*The program is a great idea. I was so happy when he got accepted into it. But feel let down once again by professionals. Promises have not panned out. [The provider organization] is in Cheshire – too far away from Madison.*

*Some problems with the providers. The life skills coach has been wonderful, but the community mentor has been difficult – follow through not always good.*

Finding gainful employment was a goal for many of the participants. For the staff and program managers of the APP, it was also of particular interest. The APP partnered with the Bureau of Rehabilitation Services (BRS) to help participants find jobs. APP program records indicate that half of the participant group (n=14) worked with BRS staff during the pilot to help them achieve this goal. Three participants had already been working with BRS before entering the APP and had not yet found employment. Of the 11 others who began using BRS services after joining the pilot, three found jobs through BRS (only one was still employed in that job as of December, 2008), two found jobs on their own (not through BRS), one stopped working with BRS because the participant was not ready to go to

work, and five continue to work with BRS to find jobs. Although to date working with BRS has resulted in continued employment for few APP participants, APP program staff regard BRS as a strong and supportive partner and expect to see more successful employment outcomes achieved with BRS's assistance for APP participants in the future.

### **Comparison Group**

The comparison group consisted of only six individuals, all male, all white/Caucasian, all living with their parents, and all earning under \$12,250 per year. Due to the very small sample size, statistical comparisons between baseline and one year follow up were not possible. All results are therefore descriptive. At baseline four of them were working, although all of them were either currently working or had worked in the past, between one and five years ago. After one year, only two of the participants were still working. Of those who were working, only one participant was receiving employment supports. The mean for the number of hours typically worked each week was 26.67 at baseline and 26.17 after one year. Only one of the participants was earning over \$10 per hour, while the rest were receiving under \$10 per hour; this was consistent from baseline through follow up. Five out of six participants liked the people that they worked with in their current or former jobs, were happy with their pay, liked the environment at their job, and liked the location of their job both at baseline and at follow up. Only one person was dissatisfied with these things, both at baseline and after one year. One out of the six participants also was also involved in doing volunteer work both at baseline and at one year.

Involvement with family and friends was also an area of interest. Participants indicated how many close relatives and friends they have and how often they see these individuals on a regular basis. On average they had at least three family members with whom they had contact or communication at least once a month. They averaged only one friend with whom they had contact; phone communication was more limited. The mean results are shown in Table V-5.

Table V-5. Family and friends

	Mean at baseline	Range at baseline	Mean at 1 year	Range at 1 year
How many relatives do you have that you feel close to?	6.17	0-20	1.17	0-4
How many of these relatives do you see at least once a month?	3.50	0-12	1.17	0-4
How many relatives do you talk on the phone with or exchange letters with or e-mails at least once a month?	3.83	0-10	0.50	0-2
How many close friends do you have?	1.17	0-3	1.33	0-5
How many close friends do you see at least once a month?	1.00	0-3	0.50	0-1
How many close friends do you talk on the phone with or exchange letters or e-mails?	0.50	0-1	0.50	0-1

Fifty percent of the group was participating in the community and groups at baseline and the same people continued their participation after one year.

### **Leisure activities**

Comparison group members were also asked how many hours they watched TV, used the computer, or played video games per day. They averaged about three hours per day at baseline for TV watching, although this average dropped to two hours after one year; computer use was about two and a half hours per day both at baseline and follow up; playing video games went from one and a half hours at baseline to two and a half hours at follow up. Due to the very small sample size, small changes in one participant's response can lead to large changes in the group averages.

Table V-6. How many hours do you spend watching TV, using the computer, or playing video games?

	Mean at baseline	Mean at 1 year
How many hours do you watch TV per day?	3.17	2.00
How many hours do you use the computer per day?	2.50	2.67
How many hours do you play video games, etc. per day?	1.50	2.50

Leisure activities include active sports such as swimming, taking walks, doing physical exercises, working in the garden or yard, working at a hobby, going out to do some shopping, going out to a movie, restaurant or sporting event, reading books, magazines or newspapers, watching television, taking a day or overnight trip, doing unpaid community or volunteer work, doing paid community work, or playing cards, games or bingo with other people. The mean of the leisure activities summary score at baseline was 13.00 and after one year it was 13.33.

### **Services**

None of the comparison group participants were receiving home health care services, respite services, education services or housing services either at baseline or after one year. Two of the participants in this group were receiving employment services, both at baseline and follow up. This employment service was primarily through BRS. One of the participants was receiving recreation services at baseline and, after one year, two of the participants were receiving these services, including summer camp and recreation available through the town's Park and Recreation Department. At baseline, two of the participants were receiving clinical support services, and after one year, three of the participants were receiving these services, including services from social workers, psychiatrists or therapists.

### **Health**

At baseline, five out of the six participants rated their health as either excellent or very good. After one year only four of these continued to rate their health the same. Participants were then asked a series of health related questions. In each instance the participant was reminded to think about the past four weeks when they answered the questions. At baseline, four out of six indicated that their physical activities, such as walking or climbing stairs, were not limited at all because of physical health problems; however after a year, five of the six said that their physical activities were not limited. The same pattern occurred for their activities of daily living. Three of the participants had mild to severe bodily pain at baseline, however only two had pain at follow up. Two of the individuals indicated that they had very much or quite a lot of energy at baseline, and at follow up three of the individuals

indicated high energy levels. At baseline, four of the participants indicated that physical or emotional problems never limited their social activities, and after one year, five said that these problems did not limit social activities.

Emotional problems such as feeling anxious, depressed or irritable were never experienced by half of the group (n=3) at baseline, and after one year two of the participants who had said that they were bothered either moderately or extremely indicated that it was no longer a problem. At baseline, four of the participants indicated that emotional problems never kept them from doing their usual work, school, or other daily activities. After one year, five participants felt that emotional problems had not kept them from doing any activities.

The mean summary score for symptoms of depression (CES-D) for the comparison participants was 2.83 at baseline and 2.83 at follow up.

When asked in the second interview how their lives compared to one year earlier, four people said it was the same, one said it was better and one said it was worse.

Results of the SIB-R broad independence scale and the major subscales indicated that the six participants in the comparison group were quite impaired at baseline, similar to the pilot participant group (Table V-7). Broad independence scores ranged from 13 to 76 with all but one participant at least two standard deviations below the norm of 100. For motor skills, the scores ranged from 30 to 84 with four people at least two standard deviations below the norm. Social interaction and communications skills scores ranged from 32 to 104 with four people at least two standard deviations below the norm. Personal living scores ranged from 32 to 74 with four participants at least two standard deviations below the norm. Community living scores ranged from 7 to 84, also with four people more than two standard deviations below the norm.

Table V-7. Baseline results of comparison group SIB-R subscales –  
Number of participants who fall below norm (in standard deviations of 15 points)

	Broad Independence	Motor Score	Social/Communication	Personal Living	Community Living
< 1SD below norm	0	0	1	0	0
1-2 SD below norm	1	1	1	1	1
2-3 SD below norm	3	3	3	2	3
>3 SD below norm	2	2	1	3	2
Total	6	6	6	6	6

The mean scores for the SIB-R subscales (Table V-8) and the maladaptive indices and the overall support score (Table V-9) for the comparison group are presented below. With the exception of an improvement in the motor score between baseline and follow up, there are no notable differences from baseline to follow up for any of the summary measures for the comparison group. Again, it is too small a group to perform statistical testing on.

Table V-8. Comparison Group SIB-R subscales at baseline and follow up

	N	Mean	Standard deviation
Broad independence - baseline	6	52.33	21.30
Broad independence – follow up	6	56.17	27.64
Motor score - baseline	6	59.67	17.69
Motor score – follow up	6	73.67	23.60
Social/Communication - baseline	6	65.83	23.28
Social/Communication – follow up	6	63.50	22.31
Personal living - baseline	6	56.33	15.63
Personal living – follow up	6	58.50	21.74
Community living - baseline	6	56.33	26.34
Community living – follow up	6	59.00	32.45

Table V-9. Comparison group SIB-R Maladaptive Indices and overall Support Score at baseline and follow up

	N	Mean	Standard deviation
GMI at baseline	6	-21.83	17.08
GMI at follow up	6	-19.50	11.33
IMI at baseline	6	-23.88	13.45
IMI at follow up	6	-16.83	9.54
AMI at baseline	6	-16.17	12.02
AMI at follow up	6	-16.50	16.50
EMI at baseline	6	-15.17	17.68
EMI at follow up	6	-13.50	15.45
SS at baseline	6	67.00	19.45
SS at follow up	6	68.67	17.07

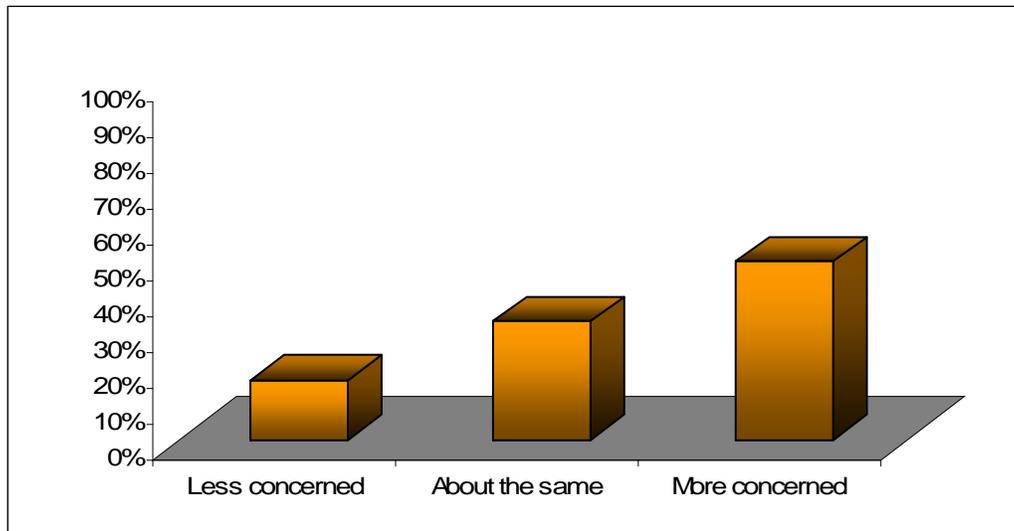
### ***Comparison group family members***

All six of the family members of the comparison group participants were parents who have daily contact with their child. The mean summary score for the burden scale was 14.17 at baseline and 12.83 at follow up.

Concerns expressed by the family members of the comparison group were similar to those of the test group, particularly the concern that if they should no longer be around or able to take care of that individual, who would care for their relative?

That concern was reflected in their response to the follow up question. After one year were they more concerned, less concerned, or about the same as they felt a year ago? Half of the family members (n=3) indicated that they were more concerned; 2 family members said that they felt about the same; and only one family member reported less concerned about their child than in the previous year.

Figure V-17. Comparison Group Family Members responses to: Compared to how you felt a year ago, do you feel more, the same, or less concerned about your relative?



### ***Limited Activity***

On the scale for family members' activity limitation due to their involvement with their relative, the mean score at baseline was 6.00 and at follow up the mean score was 5.50. Five out of the six family members indicated that taking care of their relative had created a financial strain, both at baseline and follow up.

The mean depressive symptom scale (CES-D) score for the family members was 6.00 at baseline and 5.00 after one year.

## **VI. Cost Effectiveness**

One important issue to consider with respect to any state-provided service is whether the program is cost effective. The purpose of a cost-benefit analysis is to answer the question of whether funding a program will increase the value of social resources, compared to using these funds for a different purpose. Typically, a cost-benefit analysis will identify all potential benefits and costs of a program, placing a dollar value on each where possible, and comparing the present value of benefits to society with the present value of program costs.

Cost-effectiveness may be viewed from two perspectives: either as a financial return on the investment of government dollars, or as the provision of a quality service in a cost-efficient manner. In the former view, an investment of state funds would be expected to produce a financial net benefit to the state and its taxpayers in the form of increased tax revenues from employment, and cost avoidance from reduced insurance or other benefit costs. In the latter view, state funds are cost-effective when quality services are provided at the lowest cost.

The APP may be analyzed as a hybrid of the two cost-effectiveness approaches. While there should be some measurable return to the state in the form of increased taxes from employment, the dollar value of that return would not be expected to exceed program costs. Cost avoidance (e.g. avoiding the future cost of placement in an ICF/MR or nursing facility when family members are no longer able to care for an individual) could easily exceed program costs, but can be difficult to predict. The program can, however, be expected to produce quality services at a reasonable cost to a population that has historically been disqualified from certain services. Return is measured not solely in terms of dollars but also in various quality of life and satisfaction measures.

The small number of participants and short duration of the pilot program preclude a rigorous and definitive cost-benefit analysis. However, the available budget and cost data, as well as directional information concerning program satisfaction, employment, engagement in the community and other measures relevant to the issue of cost-effectiveness can be analyzed.

### ***Potential costs and benefits***

Table VI-1 contains a list of potential costs and benefits of providing enhanced services to people with autism spectrum disorder who do not have mental retardation. From the individual and family perspective, benefits include the possibility of obtaining or increasing employment with related wages, benefits, and increased skills, as well as overall increases in quality of life measures, including self-esteem, independence, self-sufficiency, and community involvement. In addition, family members who serve as unpaid, informal caregivers may be relieved of certain duties, freeing up time for their own increased employment or other life activities. Potential costs to individuals and family members would include taxes on any increased earnings, work-related expenses, and reduced time for other endeavors. From the government/taxpayer perspective, potential benefits include increased tax revenue from employment and reduced or avoided costs of medical, mental health, housing and other supportive benefits. Costs include administrative and program service expenses.

Table VI-1. Potential costs and benefits of enhanced ASD services

<b>Potential Benefits</b>	<b>Potential Costs</b>
<b>For individuals &amp; families:</b>	<b>For individuals &amp; families:</b>
<p>If employment commenced or hours increased for individuals or caregiver/family members:</p> <ul style="list-style-type: none"> <li>• Higher earnings</li> <li>• Higher future Social Security benefits</li> <li>• Increased experience, skills, knowledge</li> </ul> <p>Other:</p> <ul style="list-style-type: none"> <li>• Increased quality of life, self-esteem, independence, self-sufficiency</li> <li>• Reduced caregiver burden</li> </ul>	<p>If employment commenced or hours increased for individuals or caregiver/family members:</p> <ul style="list-style-type: none"> <li>• Taxes on earnings</li> <li>• Work-related expenses (e.g. commuting, child care)</li> <li>• Reduced time for leisure, household maintenance, etc.</li> </ul>
<b>For government/taxpayers:</b>	<b>For government/taxpayers:</b>
<ul style="list-style-type: none"> <li>• Increased tax revenues</li> <li>• Reduced or avoided costs in medical, mental health, housing and disability systems</li> </ul>	<ul style="list-style-type: none"> <li>• Program service expenses</li> <li>• Program administrative expenses</li> </ul>

**Program costs**

The pilot program generated substantial data about the program’s budgets and direct service costs for the 24 participants who received services from the program throughout the pilot testing period. Each participant in the test group had an individual service plan and an individual annual service budget set up at commencement of services, based on level of functioning and indicated service need. Many individual budgets were later revised. Services contained in each budget varied, and included one or more of the following types of service, depending on each person’s needs and expressed goals:

- Job development
- Job coaching
- Community mentoring
- Community activity fees
- Speech assessment/speech therapy consultation
- Life/educational skills coaching
- Drivers’ assessment

The revised individual annual budgets for the 24 participants totaled \$644,066, for an average of \$26,836 per person (standard deviation = \$17,685). They ranged from a high of \$76,230 to a low of \$762.<sup>1</sup> Monthly budgets averaged \$2,236, with a range of \$6,353 to \$64 (standard deviation = \$1,474). Annual and monthly budget ranges are indicated in Table VI-2.

<sup>1</sup> These numbers differ slightly from those in O’Brien & Vorderer (2008), which used earlier budget figures for all 27 participants, including the three who did not receive services throughout the pilot period.

Table VI-2. Individual annual budget range per participant

<b>Annual budget range</b>	<b>Monthly budget range</b>	<b>Number of participants</b>
More than \$48,000	More than \$4,000	3
\$24,000 to \$48,000	\$2,000 to \$4,000	8
\$12,000 to \$24,000	\$1,000 to \$2,000	9
Less than \$12,000	Less than \$1,000	4

In addition to the services specified in their individual budgets, 17 of the 24 participants received social skills training at an additional cost of \$5,000 per person, or a total additional program cost of \$85,000. Adding this cost to the individual budgets would bring the total annual program budget to \$729,066 and the average per person annual budget to \$30,378.

In fact, actual program expenditures during the pilot were substantially lower than budgeted. The lower actual costs, however, should not in themselves be taken as evidence of cost-effectiveness. Reasons for the differences varied, but results of the key informant interviews indicate that in many cases it was the result of ambivalence or reluctance on the part of participants or their families to fully participate once the pilot was underway. People seriously committed to the program tended to use up all or most of their budget, while those struggling with the need for help or hesitant about its usefulness did not use all of their budgeted services.

Since not all participants received services for the same time period (ranging from four months to 20 months – see Table VI-3), the most useful comparison is actual vs. budgeted monthly expense. Whereas the average individual monthly budget was \$2,236, average monthly expenditures per person were \$1,206, or 54 percent of the budgeted amount<sup>2</sup>. On an annualized basis, average expenditures were \$14,472 compared to a budget of \$26,832. The range of actual vs. budgeted expenses is noted in Table VI-4.

Table VI-3. Number of months of program services

<b>Number of months</b>	<b>Number of participants</b>
18 to 20	7
13 to 17	6
10 to 12	7
Fewer than 10	4

Table VI-4. Range of individual budgeted vs. actual expenses

<b>Expense range</b>	<b>Number of monthly budgets in range</b>	<b>Number of monthly actual expenses in range</b>
More than \$4,000	3	0
\$2,000 to \$4,000	8	3
\$1,000 to \$2,000	9	11
Less than \$1,000	4	10

<sup>2</sup> If the \$5000 per person cost of social skills training is added to actual expenses for the 17 participants who received it, average expenditures were 67% of the budgeted amount

Direct service costs do not include the additional program and administrative costs of running and supervising the program. Case management, if provided under the DDS Targeted Case Management (TCM) program, would have a program staffing ratio of 1 case manager to 30 individuals, with an average annual cost per case manager of \$72,000 (O'Brien & Vorderer, 2008).

### ***Program benefits***

Some benefits can be measured for the 27 participants who completed both baseline and follow up interviews. These include the three participants who enrolled in the pilot but declined services and are not included in the cost data summarized in the previous section. There was a modest increase in the incidence of employment among the test group during the pilot period. At baseline, 10 participants (37% of the total) reported that they were currently working, for an average of 19 hours per week. Most reported wages of less than \$10 per hour. At follow up, 15 participants (56% of the total) reported that they were currently working, consisting of six of the individuals who were working at baseline plus nine additional individuals. Thus, while four people stopped working during the pilot, nine people began working – a net employment increase of five people. They reported an average work week of 18.1 hours and most had wages of less than \$10 per hour.

In addition to increases in employment among the test group, there are preliminary indications of benefits from increased quality of life indicators among program participants. These include satisfaction with jobs and co-workers (for those who were employed), participation in the community, lower burdens on family caregivers, and satisfaction with services provided, expressed by both participants and family members.

Additional though anecdotal evidence of cost-effectiveness comes from the key informant interviews. When asked their opinions on program cost-effectiveness, key informants in general believe that costs are low in comparison with benefits derived by participants and their families. They note, however, that the program appeared more effective for younger participants, and for those without any significant co-occurring mental health issues.

## **VII. Level of Need Assessment Tool**

### ***Background***

Connecticut's Department of Developmental Services (DDS) supports approximately 15,000 children, adults, and their families. However, while providing funding and supports for a significant number of people, DDS did not have one universal method to determine an individual's need for services and allocation of funding. Historically, Connecticut's allocation of resources was dependent upon variables such as when a program opened, the cost of a provider, and the amount of money available in the budget. Funding decisions often varied from year to year, and depended on the skill of the requester as well as influence from outside sources. As such, an individual's "need" was often dependent upon the presenter and the audience.

To address this issue, Connecticut, through the receipt of a federal grant<sup>3</sup>, set aside money to thoroughly understand the concept of "need" and develop a level of need assessment tool. The process ran from late 2004 to mid-2007. To assist in the tool development, Connecticut endorsed the study of multiple data collection instruments used by other states or agencies. In addition, DDS turned to an outside research team to lead the design and development of the end project (Gruman, Porter, Kellett, Robison & Reed, 2007). A Steering Committee was established which comprised members from all stakeholders, such as DDS, providers, advocates, family members, and consumers. This Steering Committee helped guide the design, research, and implementation of a new instrument to determine level of need for support for all DDS consumers.

The process used in Connecticut to develop a statewide level of need for funding tool differs from that used in most other states in several ways. Unlike most other states, Connecticut wanted the new assessment tool to be driven by those in the field, such as consumers, families, providers, case managers, and clinicians. Such a "bottoms up" strategy sought out the voice of the different stakeholders – family members, consumers, advocates, providers, policymakers, case managers, specialists, and representatives from DDS. This ensured that the tool was developed with adequate input from those most involved in the DDS system.

### ***Original LON methodology***

Created with input from the LON Steering Committee, the original plan in the development of a valid and reliable level of need instrument called for an examination of the methods used by other states as well as a review of relevant literature. This was combined with information from a number of interviews with various stakeholders to produce a draft level of need instrument to pilot.

The research team conducted 63 telephone interviews with family members, policymakers, providers, case managers, direct care staff, consumers, and specialists such as medical staff, psychiatrists, and behavioral specialists. These included ten pilot interviews, conducted with a diverse group of participants – three family members, three policymakers, two case managers, one provider, and one advocate – which were used to pilot the interview instrument and modify it using their feedback.

The key informant interviews were qualitative, in-depth interviews of people selected for their first-hand knowledge about DDS, the services DDS provides, consumers served by DDS, or family members supporting a person with intellectual challenges. The interviews followed a set of mostly

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<sup>3</sup> Independence Plus in Home and Community-Based Services Grant (#11-P-92079/1-01) funded by the Centers for Medicare and Medicaid Services

open-ended questions. Interviewers asked questions, probed for information, and took notes. With permission, interviews were audio-taped and later transcribed.

### ***Key issues for measurement of level of need***

A list of key issues important to cover when determining a person's level of need for funding was compiled from discussions with the Steering Committee, a review of the literature and existing level of need tools:

- Health care or medical issues
- Level of mental retardation or cognitive ability
- The family's ability to provide caregiving support
- Safety issues
- Challenging or difficult behaviors
- Ability to perform daily living skills, including basic self care
- The family's ability to provide financial support
- Level of physical disability
- Social skill level, including any social dysfunction
- Ability to use good judgment
- Any criminal issues

### ***LON assessment tool in the Autism Spectrum Disorders population***

The design of a Connecticut Level of Need Assessment and Screening Tool was an inclusive and comprehensive process, with input from diverse stakeholders and other sources sought and incorporated with each step. The initial project, though inclusive of people with ASD, also had a universal sample with intellectual disabilities. As a result, concern was raised that the level of need instrument lacked content specific to the population with ASD.

In collaboration with members of the Autism steering committee, 14 additional items were added to the LON instrument for further review. After additional data collection, analysis indicated that five of the items served to increase the sensitivity of the LON algorithm by collecting information unique to the population with autism spectrum disorders. These five items were refined and included in the LON tool (see Appendix B for details of the LON development process).

### ***LON assessment tool scoring***

The final LON tool results in a nine category level of need scale, based on the distribution of data collected for each individual assessed. A score of zero indicates that the individual has no need. Scores range from one, for individuals with a low level of need, to seven, for individuals with intense hands on, 24-hour care. Level eight is reserved for extremely complex individuals who require a highly specialized level of care that would likely be missed by the instrument.

### ***Relationship of the Scales of Independent Behavior (SIB-R) with LON score***

Using one-way ANOVA, the relationship between the SIB-R support score (SS) and the overall LON score was analyzed. Both the SS and LON composite scores predict the level of support a person would require based on the impact of a compendium of independent factors. The results demonstrated a strong positive correlation between the two variables that was significant at the  $p=.02$  level.

Table VII-1. Relationship of SIB-R and LON score

LON Composite Score	Mean Support Score
1	84
2	82
3	75
4	65
5	59
6	52
7	0
8	0
Between Groups	875.54
Within Groups	2177.84
Total	3053.39
F	4.623
Sig	.02

**LON scores for participants in the APP**

The figures below provide a graphical breakdown of each summary domain from the LON assessment instrument for the 28 participants enrolled in the APP evaluation. The data shows the percentage of respondents represented in each of the LON outcome categories.

Figure VII-1. Health and medical

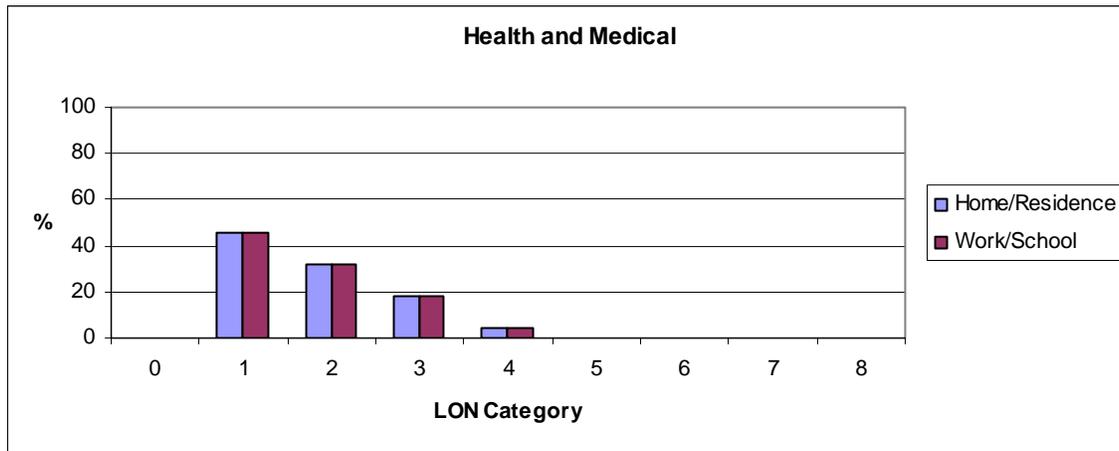


Figure VII-2. Behaviors

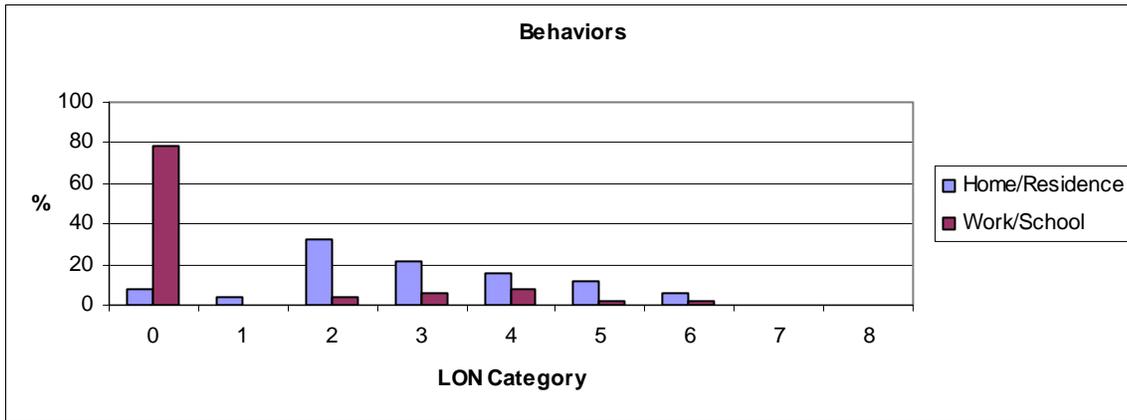


Figure VII-3. Psychiatric issues

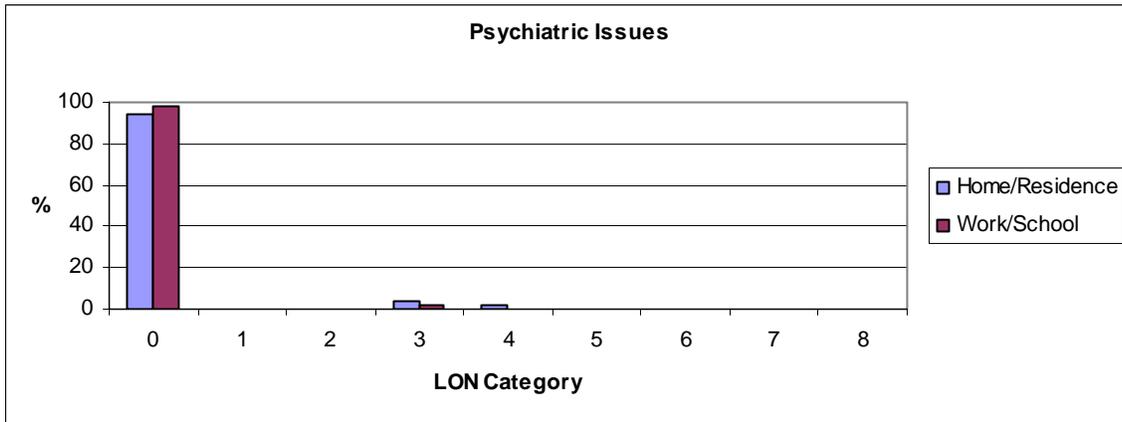


Figure VII-4. Criminal sexual issues

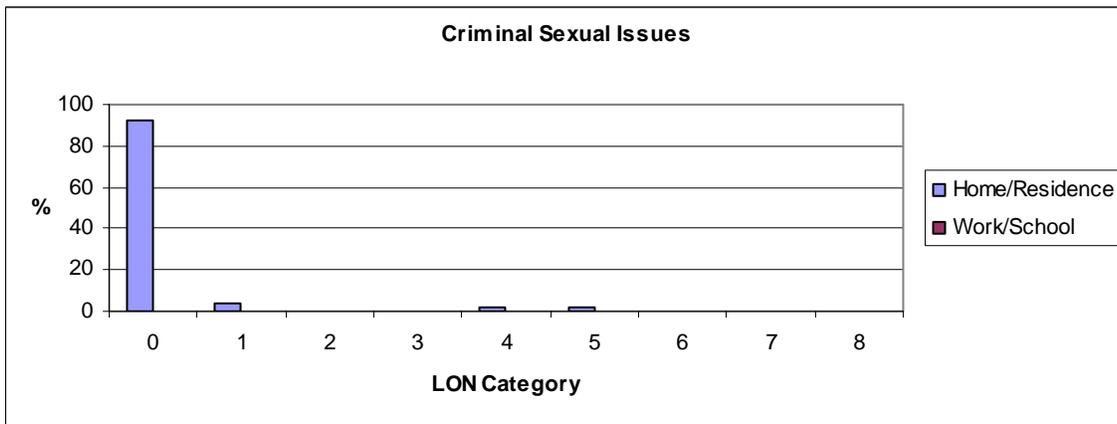


Figure VII-5. Mobility

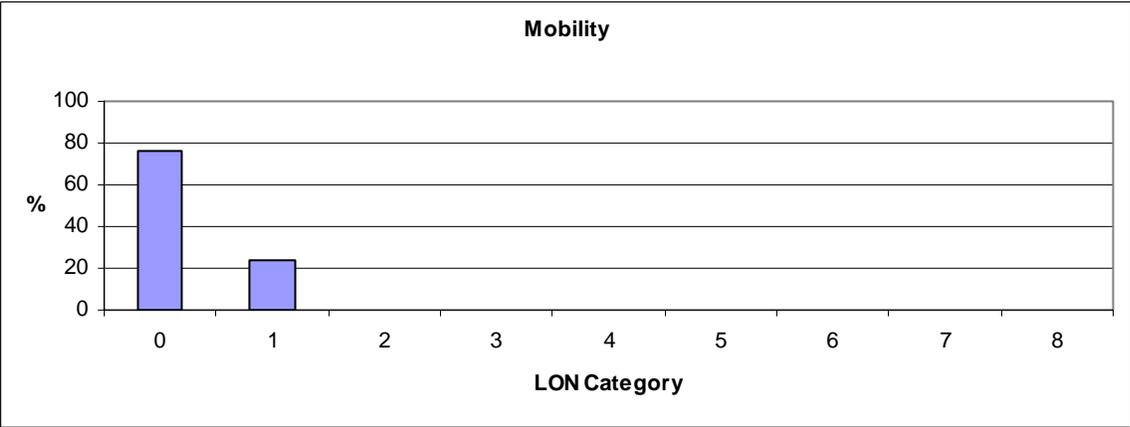


Figure VII-6. Safety

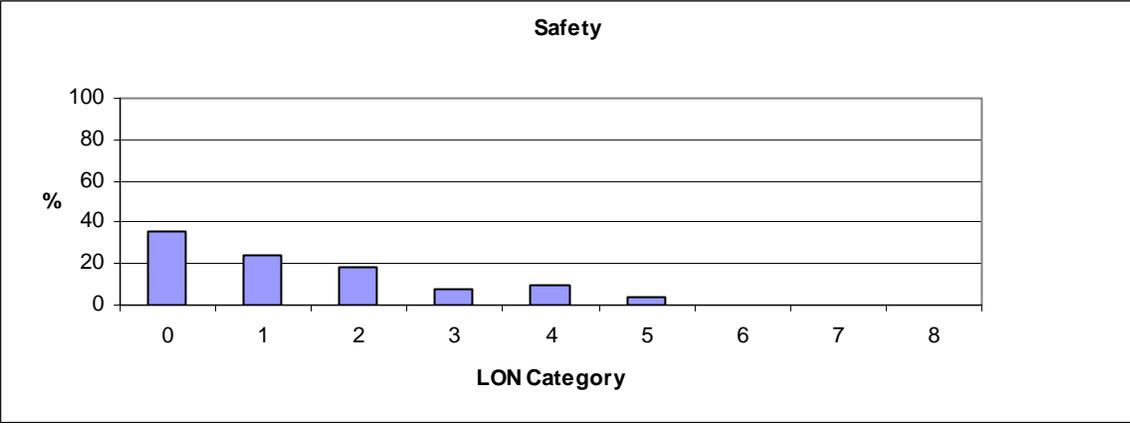


Figure VII-7. Comprehension and understanding

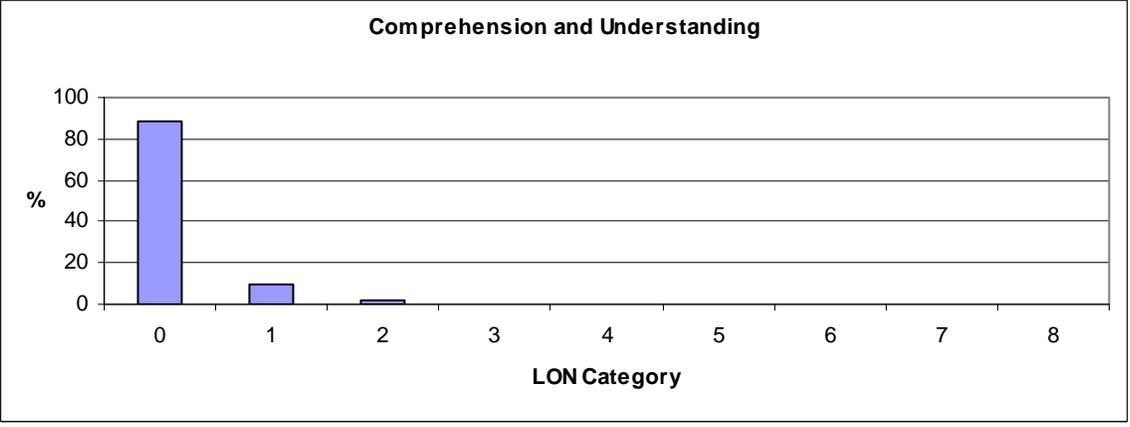


Figure VII-8. Social life

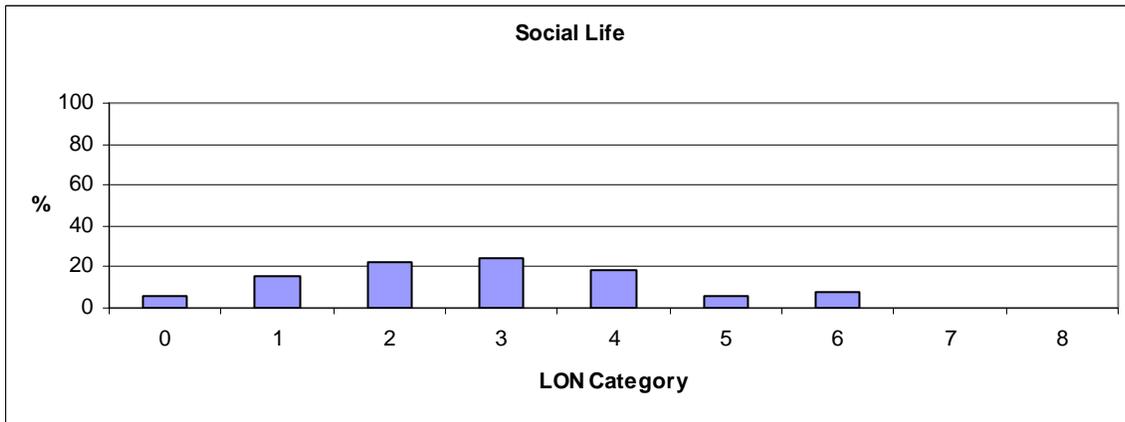


Figure VII-9. Communication

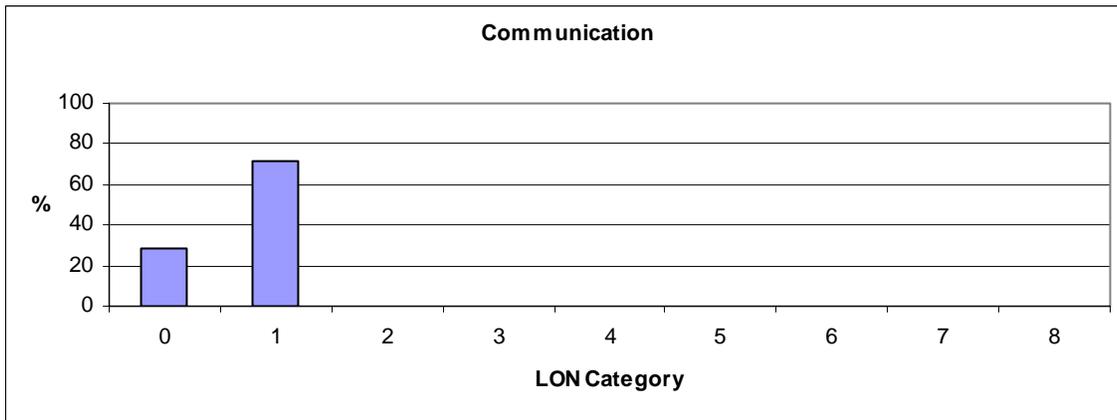


Figure VII-10. Personal care

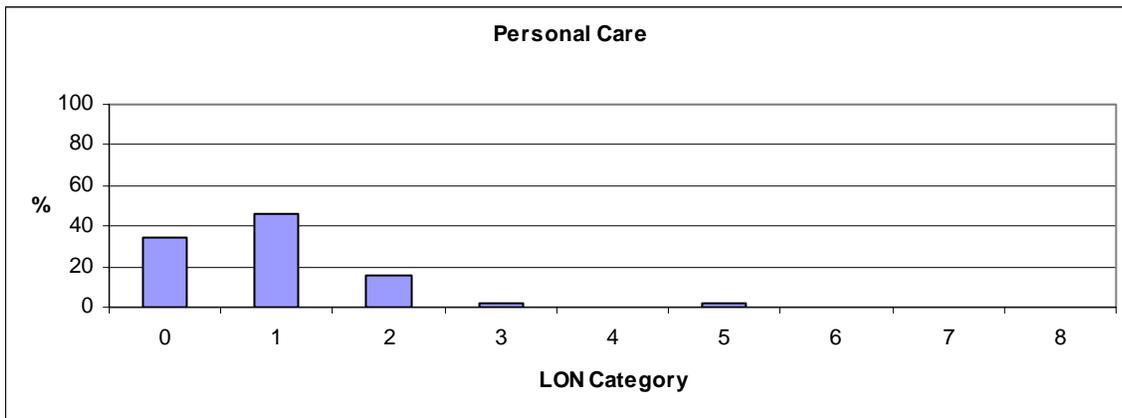


Figure VII-11. Daily living

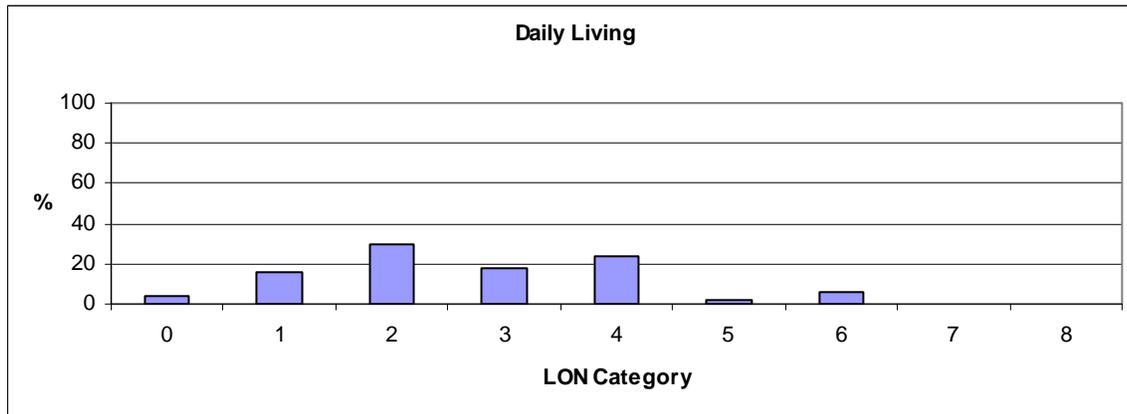
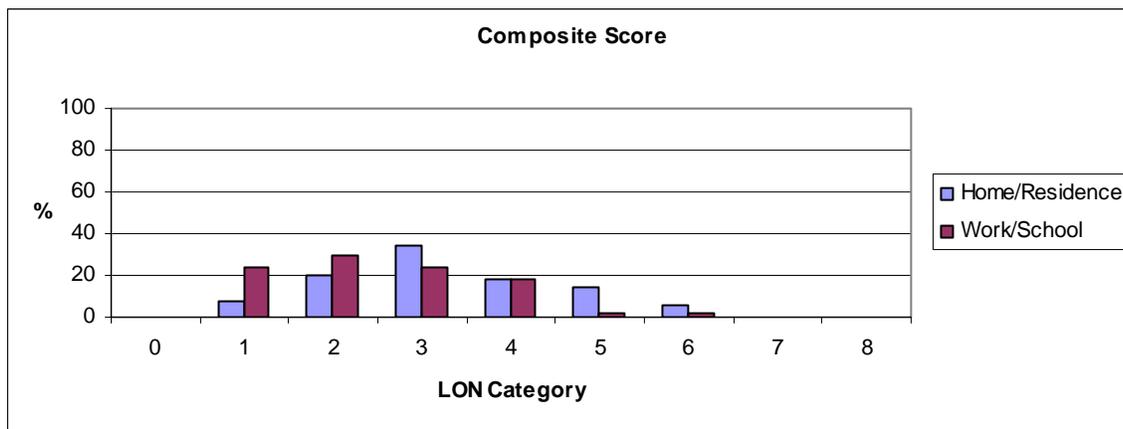


Figure VII-12. Composite score



## VIII. Conclusions

### *Program implementation*

The eight key informants together provide excellent insight into the accomplishments, difficulties, and problem-solving that the Autism Pilot Program has undergone since its inception. Not only are many participants and their families benefitting significantly from the services they receive, the costs overall are perceived as relatively low. The program has evolved over time, refining eligibility criteria to identify people whose needs cannot be met and implementing provider training specific to this population of people on the autism spectrum who do not have mental retardation. Overall, people are very happy with the way the APP functions and foresee an ongoing and increasing need to provide these services on a wider scale.

### *APP participant outcomes*

There were notable changes from baseline to one year not only for APP participants but also for their family members in multiple areas. Areas of improvement for participants included employment and improved attitudes about work, increased participation in the community, and the fact that the participants were receiving and utilizing more services, particularly in the areas of employment and recreation. In addition, self-perceived emotional problems and limitations caused by any emotional problems diminished over the course of the year. Table VIII-1 shows the areas of improvement for participants.

Table VIII-1. Notable areas of improvement for participants from baseline to one year

	<b>Baseline</b>	<b>Follow up</b>	<b>An increase of</b>
<b>Employment – those working</b>	37%	56%	19%
I like the people I work with	42%	84%	42%
I like the pay at my job	30%	80%	50%
I like the hours at my job	6%	75%	69%
I like the environment at my job	40%	90%	50%
I like the location of my job	42%	95%	53%
<b>Participation in the community</b>	52%	67%	15%
<b>Receiving services:</b>			
Employment services	36%	75%	39%
Recreation services	11%	39%	28%
Education services	17%	28%	11%
Other services	7%	68%	61%
<b>Emotional problems</b>			<b>A decrease of</b>
Physical or emotional problems interfering with social activities	59%	44%	15%
Being bothered by emotional problems, like feeling anxious, or depressed	63%	56%	7%
Having emotional problems keep you from doing normal activities	37%	33%	5%

Functional improvements as indicated by changes from baseline to follow up in the SIB-R subscales, maladaptive indices and overall support score were statistically significant with overall improvements in all but one category. Specifically, broad independent skills and each of the summary scales, including motor skills, social/communication skills, personal living skills, and community living skills all showed significant improvements after one year of receiving APP services.

There were no notable changes for the participants in the measures of perceived health, communication with family or friends, or leisure activities such as watching TV or using the computer. Participants also showed little change in symptoms of depression from baseline to follow up.

For the participants' family members, the feelings of burden diminished significantly over the year and most family members indicated that they were now less concerned about their relative than they had been a year ago. Symptoms of depression in family members showed little change from baseline to follow up.

Successes were not only measured quantitatively by improvements in the above mentioned areas, but in terms of actual goals being met, both as evaluated by the APP service coordinator and as perceived by the participants and their families. Eighty-six percent of the participants felt that they had at least partially met their life skills goals, 75 percent indicated that they had fully or partially met their employment goals, and 77 percent felt that they had fully or partially met their community involvement goals. From the perspective of the APP service coordinator, 87 percent of the participants met or partially met their goal of improving life skills, 65 percent of the participants either met or partially met their goals for employment, and 95 percent either met or partially met their goal to gain community experience. Participants also evaluated the services that they received in conjunction with each of their goals. For all employment, life skills, and community engagement services taken together, over 80 percent of the participants rated the services as very or somewhat helpful.

The goal of employment was particularly important for both participants and program staff. The APP partnered with the Bureau of Rehabilitation Services (BRS) to help participants gain employment. Over half of the participants worked with BRS to achieve this goal, with five participants finding jobs, three of them with help from BRS. Eight participants continued to work with BRS to seek employment as of December, 2008.

Comments by participants and their family members about the APP indicate a great deal of optimism with regard to the APP, a hope that the program will continue, and that others will be able to take advantage of it.

While too small to make statistical comparisons, there were no striking changes from baseline to one year later for the comparison group. Most differences were caused by one person moving up or down one category on a scale or question. By contrast, the changes seen in the test participants from baseline to one year after starting their services are very encouraging. Almost all changes on the many outcomes examined were in a positive direction, showing improvement for these participants on multiple dimensions. Given the small sample size of the participant group, seeing any significant changes is highly encouraging. It is even more notable when considering the fact that the program was new and therefore had to work out the difficulties associated with any new program during the evaluation period.

In the future, evaluation of the APP should seek to identify any subgroup of participants who benefit the most from the program, and vice versa, in order to target outreach and service package design to the greatest advantage for individuals on the Autism spectrum.

### ***Cost effectiveness***

While a rigorous cost-benefit analysis cannot be completed from the pilot data, at the level of service provided, an increase in employment, quality of life, and level of functioning indicators among pilot participants was noted. There is some indication that benefits may be higher among certain subgroups of participants. Both hours and wages from employment were low, and would not yield significant additional tax revenue for the government. However, employment, community involvement and increased independence may lead to a reduction or avoidance of the costs of other benefits, such as medical, mental health, housing, and other disability costs. These elements were not included in this study. Another potential benefit that was not included in this study is the financial effect on family members/caregivers. As their caregiving time decreases, they are more available for employment and increased wages. This effect may be the subject of future study.

### ***Level of Need assessment tool***

The design of a Connecticut Level of Need Assessment and Screening Tool was an inclusive and comprehensive process, with input from diverse stakeholders and other sources sought and incorporated with each step. In collaboration with members of the Autism steering committee, the LON tool was adapted for utilization with the Autism Spectrum Disorders population.

As indicated by the close alignment with the SIB-R Support Score, the LON clearly works well to delineate the needs of people on the Autism spectrum who do not have mental retardation. Analyses show that individuals in this group have significant needs in all of the LON summary domains.

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**Appendix A.**  
**Study Interviews**

**Participant and Family Member Interviews at Baseline**

**Additional Questions on the Follow up Interview**

**Participant Follow Up Outcomes and Services Checklist**

## Participant Interview

To be completed jointly by participant and a family member selected by the participant. Please check only box per question.

Date: \_\_\_\_\_

Participant Study ID: \_\_\_\_\_

Time start: \_\_\_\_\_

Interviewer: \_\_\_\_\_

### Employment

1. First we'd like to talk about your job or work. People are considered to be working if they are earning any amount of money for any amount of work performed. This includes working for an employer or being self-employed and working for yourself. Are you currently working according to this definition?
- Yes, I am currently working → **Go to Question 2**
- No, but I have worked for pay in the past → **Go to Question 3**
- No, I have never worked for pay → **Go to Question 9**

#### If currently working:

2. Are you receiving supported employment? That is, do you have a job coach or other individualized support staff who assists or assisted you to get, work at, or keep your job?
- Yes
- No
- Not sure (describe): \_\_\_\_\_

#### If worked in past but not currently:

3. When did you stop working?
- Less than 1 year ago
- 1 to 5 years ago
- More than 5 years ago

*For rest of employment questions, ask both currently working and worked in past:*

4. What is your current (most recent) job or position? If you work/ed at more than one job, think about the one where you earn/ed the most money.
- \_\_\_\_\_

5. How many hours do you typically work each week? \_\_\_\_\_ hours a week

6. What is/was your average hourly wage before taxes for your primary job?
- Less than \$7.00 an hour
  - \$7 – 7.99 an hour
  - \$8 – 9.99 an hour
  - \$10 – 14.99 an hour
  - \$15 – 19.99 an hour
  - \$20 or more an hour
  - Other: \$ \_\_\_\_\_ per \_\_\_\_\_
7. What do/did you like about your job?
- The people who work there
  - The pay
  - The environment
  - The hours
  - The location
  - Other: \_\_\_\_\_
8. What **don't/didn't** you like about your job?
- The people who work there
  - The pay
  - The environment
  - The hours
  - The location
  - Other: \_\_\_\_\_

**Social engagement/activities**

9. Do you currently volunteer outside the home, that is, do you work for an organization, company, or nonprofit agency without getting paid for your work?
- No
  - Yes → How many hours a month do you volunteer? \_\_\_\_\_ hours/month

**Close relatives**

10. In general, apart from any relatives you live with, how many other relatives do you have that you feel close to? That is, relatives you feel at ease with, can talk to about private matters, and can call on for help?)
- \_\_\_\_\_ (If no close relatives, go to Question 13)

11. How many of these close relatives do you see at least once a month?

\_\_\_\_\_

12. How many of these relatives do you talk on the phone with or exchange letters or e-mails with at least once a month?

\_\_\_\_\_

Close friends

13. In general, how many close friends do you have? Friends you feel at ease with, can talk to about private matters, and can call on for help?)

\_\_\_\_\_ (If no close friends, go to Question 16)

14. How many of these close friends do you see at least once a month?

\_\_\_\_\_

15. How many of these close friends do you talk on the phone with or exchange letters or e-mails with at least once a month?

\_\_\_\_\_

16. How often do you participate in any community activities or groups, such as a community center; social or work group; advocacy group; religious group; support group; sports group; or public service, arts, or any other community group?

- Never or almost never
- Once or twice a year
- Every few months
- Once or twice a month
- Once a week or more

17. How many hours a day do you:

- a. Watch TV/DVDs: \_\_\_\_\_ hours/day
- b. Use the computer or internet: \_\_\_\_\_ hours/day
- c. Play video games: \_\_\_\_\_ hours/day

18. Here is a list of things people do in their free time. In the past 4 weeks, how often have you done each of these things? Would you say Often, Sometimes, or Never?

Support	Often	Sometimes	Never
Active sports or swimming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Take walks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Work in the garden or yard	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do physical exercises	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Prepare your meals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Work at a hobby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Go out and do some shopping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Go out to a movie, restaurant, or sporting event	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Read books, magazines, newspapers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Watch television	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Take a day or overnight trip	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do unpaid community or volunteer work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do paid community work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Play cards, games, bingo with other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any other activities (write in)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Services**

19. Are you currently receiving any of the following formal or paid services, other than from the Autism Spectrum Disorders Pilot?

- a. Home Care  
 No  
 Yes → Please describe: \_\_\_\_\_
- b. Employment  
 No  
 Yes → Please describe: \_\_\_\_\_
- c. Respite  
 No  
 Yes → Please describe: \_\_\_\_\_
- d. Housing  
 No  
 Yes → Please describe: \_\_\_\_\_
- e. Recreation  
 No  
 Yes → Please describe: \_\_\_\_\_
- f. Clinical Supports  
 No  
 Yes → Please describe: \_\_\_\_\_
- g. Education  
 No  
 Yes → Please describe: \_\_\_\_\_
- h. Other services not listed  
 No  
 Yes → Please describe: \_\_\_\_\_

20. **If Yes to any of above services:** What, if anything, would you want to change about any of your services?

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### **Physical and emotional health**

21. Overall, how would you rate your health during the past 4 weeks?
- Excellent
  - Very good
  - Good
  - Fair
  - Poor
  - Very poor
22. During the past 4 weeks, how much did physical health problems limit your usual physical activities (such as walking or climbing stairs)?
- Not at all
  - Very Little
  - Somewhat
  - Quite a lot
  - Could not do physical activities
23. During the past 4 weeks, how much difficulty did you have doing your daily activities, both at home and away from home, because of your physical health?
- None at all
  - Very Little
  - Somewhat
  - Quite a lot
  - Could not do daily activities
24. How much bodily pain have you had during the past 4 weeks?
- None
  - Very mild
  - Mild
  - Moderate
  - Severe
  - Very severe
25. During the past 4 weeks, how much energy did you have?
- Very much
  - Quite a lot
  - Some
  - A little
  - None

26. During the past 4 weeks, how much did your physical health or emotional problems limit your usual social activities with family or friends?
- Not at all
  - Very Little
  - Somewhat
  - Quite a lot
  - Could not do social activities

27. During the past 4 weeks, how much have you been bothered by emotional problems (such as feeling anxious, depressed or irritable)?
- Not at all
  - Slightly
  - Moderately
  - Quite a lot
  - Extremely

28. During the past 4 weeks, how much did personal or emotional problems keep you from doing your usual work, school, or other daily activities?
- None at all
  - Very Little
  - Somewhat
  - Quite a lot
  - Could not do daily activities

29. Below is a list of ways you may have felt or behaved in the past week. Please tell me if you have felt this way during the past week:

	<u>Yes</u>	<u>No</u>
a. I felt depressed.	<input type="checkbox"/>	<input type="checkbox"/>
b. I felt that everything I did was an effort.	<input type="checkbox"/>	<input type="checkbox"/>
c. My sleep was restless.	<input type="checkbox"/>	<input type="checkbox"/>
d. I was happy.	<input type="checkbox"/>	<input type="checkbox"/>
e. I felt lonely.	<input type="checkbox"/>	<input type="checkbox"/>
f. People were unfriendly.	<input type="checkbox"/>	<input type="checkbox"/>
g. I enjoyed life.	<input type="checkbox"/>	<input type="checkbox"/>
h. I felt sad.	<input type="checkbox"/>	<input type="checkbox"/>
i. I felt that people disliked me.	<input type="checkbox"/>	<input type="checkbox"/>
j. I could not get "going."	<input type="checkbox"/>	<input type="checkbox"/>

**Demographics**

30. What is your age? \_\_\_\_\_
31. What is your gender?  
 Male  
 Female
32. What is your racial background? Please check one.  
 White or Caucasian  
 African American or Black  
 Latino or Hispanic  
 Asian or Pacific Islander  
 Native American  
 Other (specify) \_\_\_\_\_
33. What is the highest grade or year you finished in school? Please check only one.  
 8th grade or less  
 Some high school  
 Completed high school but did not receive diploma  
 High school diploma or GED  
 Post high school other than college (such as LPN or technical school)  
 Some college or 2 year degree  
 Completed 4 year college degree  
 Post-graduate
34. Which one best describes where you live?  
 By yourself  
 With your parents  
 With a spouse or partner  
 With another relative(s). Specify what relation: \_\_\_\_\_  
 With a friend or roommate  
 In a supervised living apartment or program (SLA/SLP or DMHAS funded apartment)  
 Some place else. Describe: \_\_\_\_\_

For statistical purposes, I need to ask you a question about your income. Let me remind you that all the information collected in this interview is completely confidential.

35. I'm going to read to you some income categories. Please stop me when I read the category into which your total family income from all sources fell last year before taxes.

- Under \$12250
- 12250 to under \$25,000
- \$25,000 to under \$50,000
- \$50,000 to under \$100,000
- \$100,000 or more

36. Next, please stop me when I read the category into which your total income from all sources fell last year before taxes. This would include only your total income from all sources.

- Under \$12250
- 12250 to under \$25,000
- \$25,000 to under \$50,000
- \$50,000 to under \$100,000
- \$100,000 or more

## Involved family member data

To be completed only by the family member selected by the participant.  
Please check only box per question.

37. First name: \_\_\_\_\_ Last name: \_\_\_\_\_

38. What is your relationship to the Pilot participant?

- Parent or grandparent
- Sibling
- Other relative
- Spouse, partner or boy/girl friend
- Friend
- Unrelated legal guardian or conservator
- Other (describe relationship): \_\_\_\_\_

39. How often do you have contact with the Pilot participant?

- Daily
- At least once a week
- At least once a month
- A few times a year or less

40. The following is a list of statements, which reflect how people sometimes feel when helping another person. Thinking about (name) \_\_\_\_\_, please tell me how often you feel this way: Never, rarely, sometimes, quite frequently, or nearly always.

	<u>Never</u>	<u>Rarely</u>	<u>Some- times</u>	<u>Quite frequently</u>	<u>Nearly always</u>
a. Do you feel that because of the time you spend with _____ that you don't have enough time for yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Do you feel stressed between caring for _____ and trying to meet other responsibilities for your family or work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Do you feel strained when you are around _____?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Are you afraid of what the future holds for _____?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Do you feel your health has suffered because of your involvement with _____?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

41. Please describe any concerns you have about (participant name):

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42. During the past 4 weeks, how much has your involvement with your relative limited or interfered with each of the following activities: Not at all, Slightly, Moderately, or Almost totally:

	<u>Not at all</u>	<u>Slightly</u>	<u>Moderately</u>	<u>Almost totally</u>
a. Normal social activities with family, friends, neighbors, or groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Hobbies or recreational activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Household chores	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Errands and shopping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

43. How much has taking care of \_\_\_\_\_ caused a financial strain?

- Not at all
- Sometimes
- Always

44. Below is a list of ways you may have felt or behaved in the past week. Please tell me if you have felt this way during the past week:

	<u>Yes</u>	<u>No</u>
a. I felt depressed.	<input type="checkbox"/>	<input type="checkbox"/>
b. I felt that everything I did was an effort.	<input type="checkbox"/>	<input type="checkbox"/>
c. My sleep was restless.	<input type="checkbox"/>	<input type="checkbox"/>
d. I was happy.	<input type="checkbox"/>	<input type="checkbox"/>
e. I felt lonely.	<input type="checkbox"/>	<input type="checkbox"/>
f. People were unfriendly.	<input type="checkbox"/>	<input type="checkbox"/>
g. I enjoyed life.	<input type="checkbox"/>	<input type="checkbox"/>
h. I felt sad.	<input type="checkbox"/>	<input type="checkbox"/>
i. I felt that people disliked me.	<input type="checkbox"/>	<input type="checkbox"/>
j. I could not get "going."	<input type="checkbox"/>	<input type="checkbox"/>

**Demographics**

45. What is your age?

- Less than 25
- 25 – 34
- 35 – 44
- 45 – 54
- 55 – 64
- 65 – 75
- 76 – 84
- 85 or more

46. What is your gender?

- Male
- Female

47. What is your racial background?

- White or Caucasian
- African American or Black
- Latino or Hispanic
- Asian or Pacific islander
- Native American
- Other (specify) \_\_\_\_\_

48. What is the highest grade or year you finished in school?
- 8th grade or less
  - Some high school
  - Completed high school but did not receive diploma
  - High school diploma or GED
  - Post high school other than college (such as LPN or technical school)
  - Some college or 2 year degree
  - Completed 4 year college degree
  - Post-graduate

49. What is your current marital status?
- Married
  - Widowed
  - Divorced or Separated
  - Single, never married
  - Living together as though married

Time end: \_\_\_\_\_

Total time: \_\_\_\_\_ minutes

### **Additional Questions on the Follow up Interview**

**The follow up interview included all of the questions from the Baseline interview plus one new question for participants and one new question for family members.**

#### **Participant**

- 29a. Compared to this time last year (give month + date), do you feel that your life is:
- Better
  - About the same
  - Worse

#### **Family Member**

- 36a. Compared to how you felt a year ago, do you feel more, same, or less concerned about (name) \_\_\_\_\_?
- Less Concerned
  - About the same
  - More concerned

## Participant Follow Up Outcomes and Services Checklist

**One form each to be completed separately by participant and a family member selected by the participant. Please check only box per question.**

Date: \_\_\_\_\_

Participant Study ID: \_\_\_\_\_

Interviewer: \_\_\_\_\_

Outcome	How successfully have you achieved each outcome?			
Interviewer: Write in each outcome from the ISP	Not at all	A little	Somewhat	Very
1.	1	2	3	4
2.	1	2	3	4
3.	1	2	3	4
4.	1	2	3	4

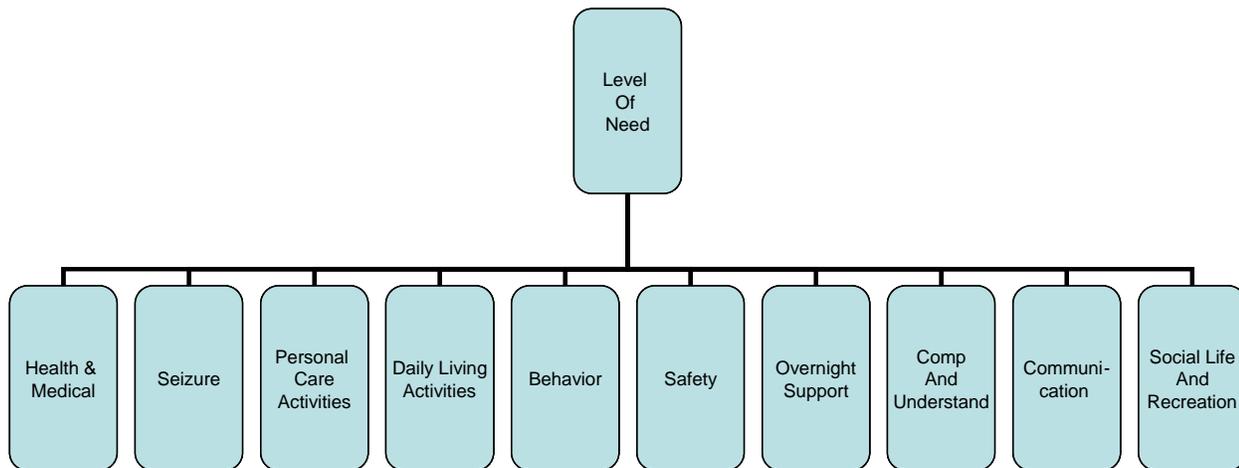
Service	How helpful has it been?			
Interviewer: Write in each service from the ISP	Not at all	A little	Somewhat	Very
1.	1	2	3	4
2.	1	2	3	4
3.	1	2	3	4
4.	1	2	3	4
5.	1	2	3	4
6.	1	2	3	4

## Appendix B.

### Development of the Connecticut level of need assessment and screening tool algorithm

Identifying the content areas to be included in the instrument was straight-forward. Transitioning to the next level posed a greater challenge. As it lacked a clear dependent variable and had over one hundred independent variables, it was clear that scale development would be the best means of working with the complex data. The first analysis included data on 585 individuals. Ten major content areas were identified, as shown in Figure B -1.

Figure B -1. Content areas for level of need



However, one problem with the newly designed instrument remained: the entire sample of individuals included in the research process had intellectual disabilities. While some individuals did have an ASD diagnosis, none were without cognitive limitations. As a result, concern was raised that the level of need instrument lacked content specific to the population with autism spectrum disorders.

In collaboration with members of the Autism steering committee, 14 additional items were added to the LON instrument for further review. It was hypothesized that these items would serve to increase the sensitivity of the LON algorithm by collecting information unique to the population with autism spectrum disorders. The intent was to add additional items that were not already captured, either directly or indirectly, in the instrument.

New items included the following (answer choices for questions 1 to 10 were “rarely,” “sometimes,” “usually,” and “always”):

- 1) Refuse to bathe or shower?
- 2) Refuse to groom him/herself or refuse to do other appropriate personal care?
- 3) Use appropriate toileting etiquette?
- 4) Eat food that is inappropriate or medically restricted for person?

- 5) Observe common table manners and etiquette?
- 6) Walk with unusual gait or mannerisms?
- 7) Refuse to take prescribed medications?
- \*8) Have difficulty transitioning from one activity to another, such as stopping one activity and beginning another one upon request either at home, school, work or other environments?
- \*9) Talks obsessively which interferes with social interaction?
- \*10) Makes inappropriate comments which are alarming, threatening or inappropriate?
- \*11) Shopping: includes shopping for groceries or other goods in neighborhood area.
- Shops for groceries, etc., in neighborhood stores independently. Excludes any transportation. May use assistive devices.
  - Shops in neighborhood stores with prompting, monitoring or instruction. Excludes any transportation.
  - Requires assistance for shopping, such as someone to make the grocery list or pay the cashier; or cannot do any part of shopping at all. Excludes any transportation.
- \*12) Meal planning: includes planning for meals.
- Plans appropriate meals independently. May use assistive devices.
  - Plans appropriate meals with prompting, monitoring, or instruction.
  - Requires assistance for appropriate meal planning, or cannot do any part of meal planning at all.
- 13) The person understands and uses or applies information they have read or hear (for example, can the person understand and apply information from the local newspapers).
- Yes
  - No
- 14) The person expresses needs and wants appropriately.
- Yes
  - No

Ultimately, analysis revealed that five items, denoted with a (\*) above, added additional information to the instrument that was not already captured either directly or indirectly by another variable. Four of the five items were paired together creating two new items and the wording for the transitioning variable was amended to match the flow of the remaining items in the tool. The new items included in the instrument are as follows:

- 1) Shopping and meal planning – includes planning for meals and shopping for groceries or other goods in neighborhood area. Does not include any transportation required.
- Plans for meals and shops for groceries, etc., in neighborhood stores independently. Excludes any transportation. May use assistive devices.
  - Plans for meals and shops in neighborhood stores with prompting, monitoring, or instructions. Excludes any transportation.
  - Requires assistance for meal planning and shopping, such as someone to make the grocery list or pay the cashier; or cannot do any part of shopping and meal planning at all. Excludes any transportation.

2) Transitioning – includes being able to discontinue one activity or task and begin another, including activities at home, school, work, vocational or day program, and leisure or recreational activities.

- Transitions from or to activities or tasks by self independently;
- Transitions to or from an activity with prompting, monitoring, instruction or encouragement;
- Requires assistance in order to transition from one activity to another.

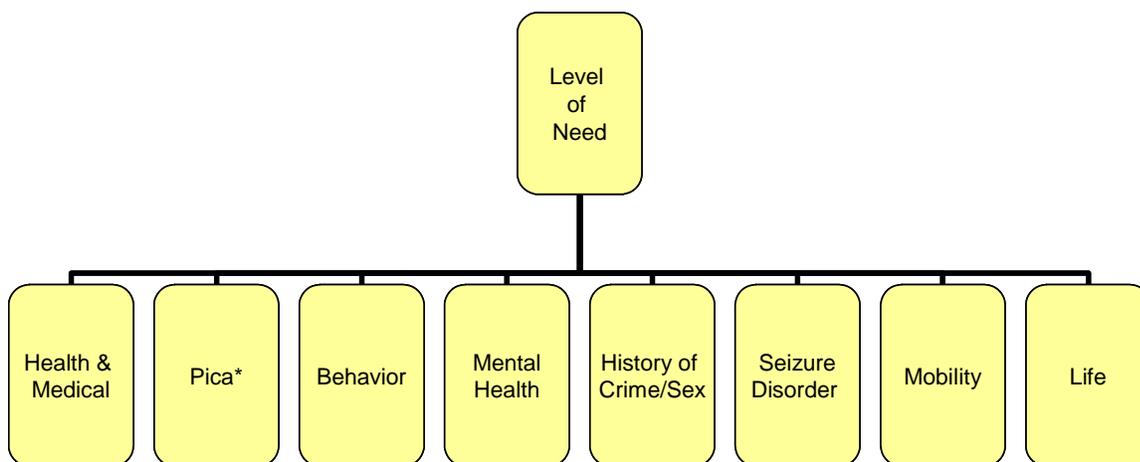
3) Does the person follow social rules of conversation appropriately, in different situations and with different listeners? This includes taking turns when speaking, using appropriate language, and using an appropriate tone of voice.

- Always or most of the time
- Some of the time
- Rarely
- Never

These newly formed items were included in the Master DDS Level of Need Instrument, the sample size was increased, and data was reanalyzed.

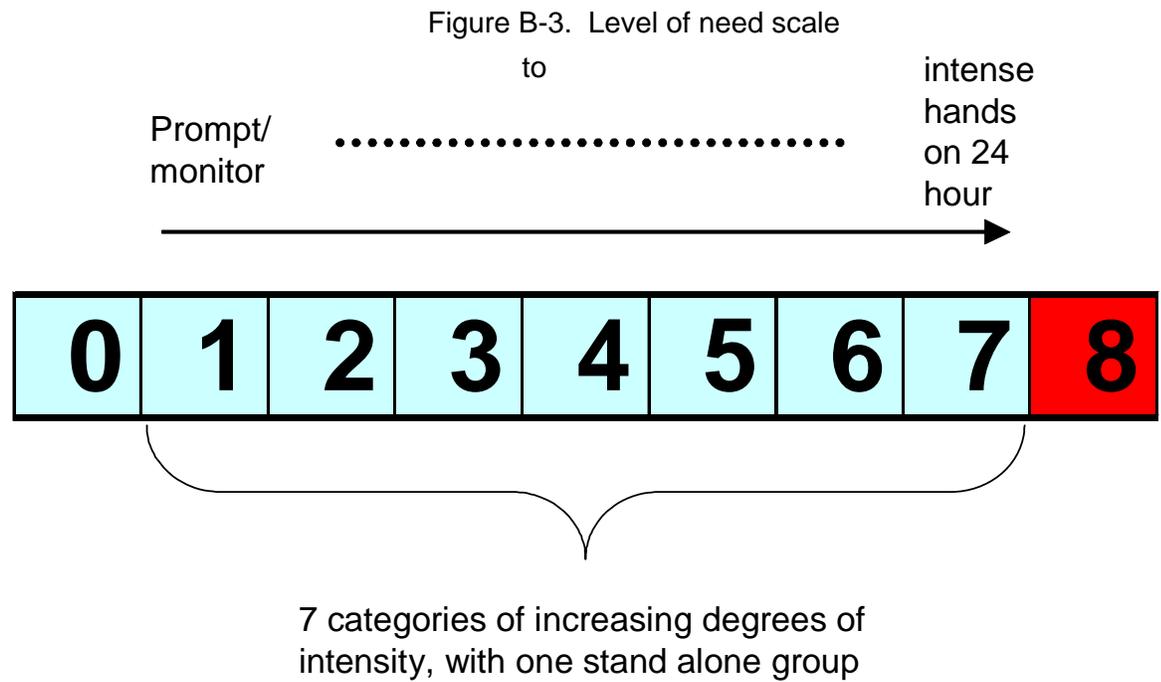
The most dramatic change occurred around the joining of multiple variables into one factor termed “life.” Individual item data demonstrated that this was a natural fit. Each of the individual categories, prior to merging, had extremely high alpha coefficients. Further, each set was highly correlated with the other. For example, an individual that needed a high level of support for personal care activities, almost always needed assistance with daily living and social activities. Advocates felt strongly that each item within the newly created life variable should be given equal weight, as an active social life is just as important as the ability to grocery shop. The research and development team agreed with this characterization.

Figure B-2. Revised content areas for level of need



\*Pica: Persistent eating of nonnutritive substances

This evolved into scale development for each of the variable groupings. The team adhered to the notion that all items are equal, except for behavior(s). Based on clinical guidance, behaviors fell into two areas of weighting: less and more. Content in the “less” category included: opposes support, disruptive behaviors, verbal aggression, mild physical assault, and wandering. All other variables were weighted equally in the “more” category. Since behaviors were viewed as the most critical component of the care plan, their distribution served as the origination of the nine category level of need scale, based on the distribution of the data. Zero was reserved for individuals with no need, which then ranged to seven for individuals with intense hands on, 24-hour care. Level eight was reserved for extremely complex individuals who require a highly specialized level of care that would likely be missed by the instrument. Figure B-3 presents a visual depiction.



The following itemization displays the level of need screening tool and variables that comprise the algorithm.

Health and medical

- Major prescribed treatments: catheter, needle injection, inhalation therapy, oxygen, respiratory suctioning, postural drainage, ostomy, tracheostomy, tube feeding, and artificial ventilation
- Support frequency for: catheter, needle injection, inhalation therapy, oxygen, respiratory suctioning, postural drainage, ostomy, tracheostomy, tube feeding, and artificial ventilation
- Specific diagnosis (e.g., asthma, autoimmune disorder, cancer, chronic constipation/diarrhea, dementia, dental disease, insulin dependent diabetes, dysphagia, eating disorder, foot/nail condition, hepatitis, pregnancy, pressure ulcer, pulmonary condition, stroke, current substance abuse, food consistency change in the last three months, history of dehydration, and two or more falls within past three months)
- Typical number of medical office visits, or off-site medical or mental health care

### Pica

- Diagnosis of Pica that requires support
- Diagnosis of Prader Willi that requires support

### Behavior

- Combination of behavior, support required AND support level
- Includes: opposes support, disruptive behaviors, verbal aggression, mild physical assault, severe physical assault, property destruction, bolting, self-injurious behavior, impulsive food ingestion, wandering, mood disorders
- Support required: no support, monitor only, verbal or gestural distraction, one person hands on, more than one person
- Support level: no support, less than monthly, 1-3 times a month, once a week, several times a week, once a day, continuous, line of sight, arms length.

### Mental health

- Specific to mental illness including, but not limited to: schizophrenia, psychosis, schizoaffective disorder, etc.\*  
\*Mood disorder falls into the behavior category

### Criminal/sexual

- Sexually inappropriate in the past year
- Criminal concerns in the past year
- History of sexual assault
- History of criminal concerns

### Seizure disorder

- None in past year
- Less than one a month
- Monthly
- Several times a month or weekly
- Several times a week or more

### Mobility

- Changing position in bed
- Transferring
- Mobility in the home
- Mobility outside the home

### Life

- Personal Care: dressing, bathing, grooming, toileting, eating, chewing, and taking medications
- Daily Living Tasks: telephone, chores, shopping, meal preparation, transitioning and transportation
- Safety: basic home safety, other home safety, obtaining emergency help, safe choices at home, safe choices not at home, and safety not at home
- Communication
- Social Life: friends, leisure, community
- Comprehension: simple, complex, reading

## ***Reliability and validity***

The two most important indicators of the precision of an instrument are reliability and validity. Validity and reliability testing was dynamic and on-going throughout this project. For example, on numerous occasions the research team had parents complete the LON separately on their child and then share with us their results and reactions. In other instances a case manager, a behaviorist, and a supportive living manager individually completed the LON on the same individual and results were compared. Though informal in nature, the process was critical for modifying questions that lead to highly accurate data collection. Virtually every question that was included in the various iterations of the instrument involved lengthy discussions about item meaning and intent. Validity testing was constantly present.

However, for purposes of credibility, the final stage of the project involved a more formalized process. This testing was conducted by a senior retired nurse from DDS along with several case managers. This individual was chosen based on extensive experience and knowledge of the system, a keen understanding of how individual client charts and files are organized, and experience with medical terminology.

### Reliability

The most common forms of reliability are test-retest reliability (more conservative), which refers to the reproducibility of values of a variable when you measure the same subjects twice or more, and interrater reliability, which includes separate individuals collecting information on the same person. The three main components to this method are as follows: 1) implement the measurement instrument at two separate times for each subject; 2) compute the correlation between the two separate measurements; and 3) assume there is no change in the underlying condition (or trait you are trying to measure) between test 1 and test 2. The following parameters were agreed upon prior to data collection for this final phase of the project:

- Include roughly an equal number of individuals from the three most common living arrangements: group homes, certified training homes, and supportive living;
- Select a group of individuals with mixed needs ranging from low to high (based on prior knowledge of the client or input from families and/or house staff);
- Collect as much information as possible falling short of requesting medical records not present in client files;
- Sample 20 individuals (22 individuals were included);
- As each baseline is collected, mail the form back to the research team (self-addressed envelopes were provided);
- Wait three weeks, but not more than four weeks to repeat the process for each individual;
- As each follow up is collected, mail the form back to the research team;
- Merge the two data collection time points for all individuals with data that had been independently collected by the case management team; and
- Analyze results

## Reliability Results

Typically data for this test is presented in the aggregate for each grouping under study (i.e., health, behavior, etc.) as noted in Table B-1.

Table B-1. Reliability test data

<u>LON Category</u>	<u>Test-Retest Pearson r</u>	<u>Interrater Reliability Pearson r</u>
Health and Medical	.976	.886
Pica	*	*
Behavior	.645	.598
Mental Health	.877	.820
Crime/Sex	.703	.728
Seizure	.998	.910
Mobility	.969	.967
Life	.954	.952
– Personal Care Activities	.926	.936
– Daily Living Activities	.921	.919
– Safety	.921	.897
– Comprehension and Understanding	.865	.866
– Communication	.964	.921
– Social Life	.905	.899

\*sample size too small to estimate

The following guidelines are often used for evaluating reliability coefficients:

- Less than .40 is poor
- .40 to .59 is fair
- .60 to .74 is good
- .75 or more excellent

Data from the table above provides strong support for the LON in all categories. The weakest test-retest domain was behavior, and individual item analysis revealed that the items with the lowest concordance were disruptive behaviors and verbal aggression. In part, these more minor behaviors on the continuum are more subjective in nature than, for example, self-injurious behavior.

## Validity

Validity refers to the strength of the conclusions, inferences, or propositions. A study is valid if its measures actually measure what they claim to, and if there are no logical errors in drawing conclusions from the data. There are many labels for different types of validity, but they all have to do with threats and biases that would undermine the meaningfulness of product. Four types of validity are described below:

- Face validity is the least statistical estimate. It is simply an assertion by the team claiming that they have reasonably measured what they intended to measure.
- Content validity goes back to the ideas of conceptualization and operationalization. If the team has focused in too closely on only one type of or a narrow dimension of a construct or concept, then it is conceivable that other indicators were overlooked. In such a case, the study lacks content validity. Content validity is making sure the team covered all the conceptual content.
- Criterion validity is using some standard or benchmark that is known to be a good indicator. There are different forms of criterion validity: concurrent validity (how well something estimates actual day-by-day behavior), and predictive validity (how well something estimates some future event or manifestation that has not happened yet).
- Construct validity is the extent to which the items are tapping into the underlying theory or model of behavior. It is how well the items hang together (convergent validity) or distinguish different people on certain traits or behaviors (discriminate validity).

This project began with a comprehensive review of the literature and many key informant interviews. It was further expanded through focus groups and individual interviews with families and other key providers of service. Draft surveys followed by field tests and statistical analysis lead to modifications and changes. This process was repeated multiple times over the course of two years. Throughout this project, experts in the field guided the content and specific questions. At times, questions that failed to meet statistical rigor were included because they made clinical sense, or they were part of the federal quality management system. Extremely high alpha coefficients (all greater than .853) and factor analysis assured the team and all steering committee members that the end product was meeting all conservative analytical estimates. Formal and informal tests further provided credence to the validity of the end product. For example, case managers would remark that the tool really does capture the needs of their clients. Parents would report that the instrument was accurate and thorough. From an analytic perspective, individuals with higher needs were receiving more care. Further, individuals with low needs globally, but unique needs specifically (e.g., Pica), were receiving more care and supervision.

## **Conclusion**

The project undertaken to develop the LON assessment tool was dynamic, collaborative, collegial, and open to close scrutiny. The end product is for people and about people, and the utmost care and respect went into the design of this instrument. Although not an intended result, the process of developing the LON tool made the current system of funding, and its challenges, more transparent to families, advocates, providers, and DDS representatives alike. Applying the LON tool to all DDS clients will help to remove barriers to equitable funding such as:

- Lack of choice in how an individual chooses to spend their funding,
- Lack of individual or family choice in programs or providers,

- Lack of choice in services to be provided,
- Service use based on individual family knowledge of available state programs,
- Inequities in allocation from family lobbying, and
- Allocation of funds influenced by overall amount of funds which are (or are not) left.

Following through on promises, such as the inclusion of multiple stakeholders and the utilization of an open decision making process, increased confidence in the process. This inclusive process and the responsiveness of the research team to stakeholders' concerns worked to increase everyone's faith and trust in implementing the LON tool as the new method to determine funding – families, consumers, advocates, and providers alike.