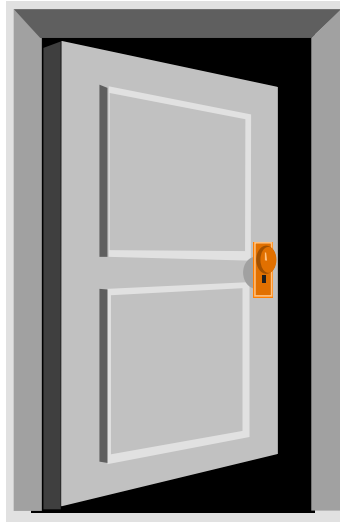


# **Delaware County Self-Determination**

## **How Are They Doing?**

Year 2002 Report of the Quality of Life Evaluation  
Of Self-determination Participants in Delaware County



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## **Introduction**

### **The History of Self-determination in Delaware County**

In the mid-1990s, the Delaware County Office of Mental Retardation began its preparation for a conversion to customer driven services with a series of infrastructure and systems changes. These changes included the gradual conversion of all provider contracts from program to fee-for-service funding. This change prepared the system for a Voucher initiative, and later, the self-determination effort. Today, the County has arguably the most experience and documentation regarding the operation of customer driven supports in the State of Pennsylvania. Given the fact that Delaware County was not one of the three Pennsylvania counties funded by the Robert Wood Johnson Foundation, these accomplishments speak to the commitment and dedication to self-determination by the County and its stakeholders.

The County Office of Mental Retardation created an Oversight Committee and an Evaluation Committee to oversee and advise on the implementation of the initiative. The Center for Outcome Analysis, the evaluator for the national Robert Wood Johnson Foundation Self-determination initiative, was hired to evaluate the Delaware County Project.

In September 1997, a group of individual service recipients was convened to provide feedback regarding their experiences to date and to identify their needs relative to full implementation of consumer directed services. A clearly identified need was further technical assistance. In February 1998, the County contracted with Ellen Cummings (the Supervisor for Case Managers in the original self-determination initiative at Monadnock Developmental Services in New Hampshire) to work with case managers. A significant recommendation was to reframe the Voucher program as a self-

determination initiative, thereby underscoring the principles of freedom, authority, support and responsibility. Additionally, Ms. Cummings recommended the development of a network of support brokers to assist case management with the additional tasks necessary for full implementation of a consumer driven approach.

In March 1998, the Delaware County Office of Mental Retardation formally re-named the Voucher program and incorporated the self-determination principles. Two months later, the Center for Outcome Analysis delivered both qualitative and quantitative reports detailing findings from the first year of the project. The quantitative baseline data on individual outcomes described the project's first 16 participants. They were all from the Delaware County waiting list for services. Twelve people lived with their families and four lived independently, with an average age of 32 years. While the quantitative results were baseline information only, the Center for Outcome Analysis was able to compare the Delaware County participants with persons engaged in self-determination in other states. The participants reported that their planning process was generally very person-centered, they exhibited a very high level of choice making, and in general felt that their quality of life was significantly better than it had been in the previous year.

The qualitative evaluation was based on focus groups and key informant interviews with the major stakeholder groups. This report indicated that people were beginning to have a broader understanding of the principles of self-determination. Specifically they reported feeling more empowered, having more choice, and that service quality had improved. They also felt that managing individual funds would allow scarce resources to be stretched further. Recommendations included the development of a

business plan to detail goals and outcomes of the initiative, the creation of support brokers, more involvement from self-advocates, and more emphasis on the systems change process with regard to the principles of self-determination.

In April 1998, more than 350 people attended the second annual Self-determination conference, sponsored by the Delaware County Office of Mental Retardation. Major stakeholder groups were queried at the conference about the movement toward self-determination. This exercise illuminated the differing perspectives among stakeholder groups regarding their roles and responsibilities relative to self-determination. It also underscored the need for a Business Plan, individual budgets, and the creation of Support Brokers.

In March 1999, the Center for Outcome Analysis facilitated a retreat for the self-determination Oversight Committee. Committee members expressed a commitment to learning more about self-determination efforts and to carry out various roles to implement the initiative. In June 1999 the Delaware County Office of Mental Retardation was awarded a County Commissioners Association of Pennsylvania grant to continue the implementation of self-determination. A sub-contract was awarded to the Center for Outcome Analysis to work with the Oversight Committee in developing a business plan and requests for proposals for support brokerage and business agent services.

The Self-Determination Oversight Committee and consultants from the Center for Outcome Analysis worked diligently throughout the 1999-2000 fiscal year:

The Education Subcommittee concentrated on collecting and developing resource materials, including videos, publications and FAQ sheets (frequently asked questions) geared to specific stakeholder groups and on planning the June 5, 2000, *Self-Determination, We're All In It Together*, conference. More than 200 people attended this conference.

The Policy and Procedures Subcommittee worked on the Business Plan, utilizing information provided by the Center for Outcome Analysis on strategies used in other states. The completed business plan became the blueprint for future activities.

The Oversight Committee was concerned with both of the previous tasks as well as the development of RFPs for the Support Broker and Business Agent entities. The result of this process was contract awards to Neighbours, Inc., to develop and train a Delaware County Association of support coordinators and to TeSak, Inc., to perform business agent services.

Delaware County was awarded additional grants in June 2000 and again in June 2001 from the County Commissioners Association of Pennsylvania to continue to implement the self-determination initiative as outlined in the business plan. Specific tasks included the development of a consolidated training calendar, hardware and software for county self-advocacy groups to access the Internet, and a self-determination newsletter. These were all issues identified by people in Delaware County as necessary elements for continued progress toward self-determination.

Delaware County has made incredible strides in the movement toward consumer directed services. The tasks and initiatives described above are

merely highlights of the intense work and energy devoted to this process. The Delaware County Association of Support Coordinators now represents more than 15 trained, independent brokers. Self-advocates, family members, provider and county staff have attended numerous self-determination conferences and workshops and been in contact with participants across Pennsylvania and the nation. The Office of Mental Retardation continues to provide opportunities for people with disabilities, their families, and paid staff to have a voice in the development and implementation of the initiative. This strategy has created a feeling of ownership and commitment on the part of all stakeholders. Self-determination is truly a way of doing business in Delaware County and will be for years to come.

### **The Spirit of Self-Determination**

Self-Determination and choice are rapidly becoming dominant themes in the lives of people with mental retardation and developmental disabilities (Nerney, Crowley, & Kappel, 1995; Stancliffe, 1995; Wehmeyer & Metzler, 1995). There is no single definition of the nature of a self-determination intervention, primarily because it is fundamentally and intrinsically different for every individual. Theoretical discussions on the nature of self-determination are available in the literature (Abery, 1993; Field & Hoffman, 1994; Wehmeyer, 1992a, 1992b; West, Rayfield, Wehman, & Kregel, 1993). Though some investigators have attempted to measure it (Abery, Rudrud, Arndt, Schauben, & Eggebeen, 1995; Field, Hoffman, St. Peter, & Sawilowsky, 1992; Jaskulski, Metzler, & Zierman, 1990; Jones & Crandall, 1986; Kishi, Teelucksingh, Zollers, Park-Lee, & Meyer, 1988; Stancliffe, 1995; Wehmeyer, 1993, 1994a&b; Wehmeyer & Kelchner, 1995;

Wehmeyer, Kelchner & Richards, 1995), self-determination remains difficult to define. A key component associated with all interpretations, however, concerns the notion of power.

According to Nerney & Shumway, Co-Directors of the National Self-Determination Initiative, people with disabilities have had no control over the nature of the services they purchase, nor the quality of those services. Further, their choices about services have been limited to a predetermined assemblage of professionals chosen by funding sources. Medicaid, which pays for more than half of America's residential services for people with developmental disabilities, is a system of payments to service providers, not to people themselves. Thus, "for this concept to work, nearly everything that had been put into place by organizations and regulations needed to be fundamentally altered or in some cases renegotiated" (Nerney, Crowley & Kappel et al. Al., 1995, p. 16).

The Self-Determination Project is based on four guiding principles: Freedom, Authority, Support, and Responsibility (Nerney & Shumway, 1996). According to the authors, these values serve as the philosophical foundation for the Self-Determination Project. The authors provided the following contextual definitions for the four overriding values of the project:

- Freedom: The ability for individuals with freely chosen family and/or friends to plan a life with necessary support rather than purchase a program.
- Authority: The ability for a person with a disability (with a social support network or circle if needed) to control a certain sum of dollars in order to purchase these supports.
- Support: The arranging of resources and personnel – both formal and informal – that will assist an individual with a disability to live a life in the community rich in community association and contribution.



- Responsibility: The acceptance of a valued role in a person's community through competitive employment, organizational affiliations, spiritual development and general caring for others in the community, as well as accountability for spending public dollars in ways that are life-enhancing for persons with disabilities (pp. 4,5).

Consistent with these values, the creators of Self-Determination believe true control and power are not possible unless people using services have authority to purchase support and decide their own futures. In order for that to happen, it is necessary for funding sources to provide support for individual choices as opposed to setting rates for segregated and congregate care options. In other words, people must be free to choose how to live their lives and be supported rather than having a government agency purchase a program. Such a shift in allocation of funds requires that dollars be allocated to individuals and not to programs. The concept of individual budgets "provides real freedom for individuals and families to both purchase what they truly need and pay only for what they get" (p.8).

## **Methods**

The Center for Outcome Analysis has tracked the development and implementation of self-determination in Delaware County through various methods, including focus groups, participation in committees, personal life quality interviews with participants, family and worker surveys.

Individual participants were interviewed in their homes, first in 1999 and then again in 2000 and in 2001. The Family and Worker surveys were conducted in 2002.

### **Instruments**

Over the past 20 years, Conroy (1995) has developed a package of instruments to measure dozens of qualities of life and outcomes, particularly among people with developmental disabilities. The package was adapted for use in the Delaware County Self-Determination Project. The entire package is referred to as the Personal Life Quality Protocol ©, and the personal control or choice-making section is called the Decision Control Inventory ©.

The Protocol's subsections have been found to display strong reliability (Conroy, 1995; Devlin, 1989; Fullerton, Douglass, & Dodder, 1999). The subsections are designed to be sensitive to issues identified as important by self-advocates over the years. The dimensions of quality also cover the general areas specified as central outcomes in the Developmental Disabilities Act Amendments of 1987: Independence, Productivity, Integration, and Satisfaction. The elements of the Protocol have been described in detail in the literature (Conroy, 1996).

The indicators of quality life and services measured for this evaluation include friendships, current capabilities and behavior, individual program plans, choice making, productive activities, integrative activities, health, and health care. Following are more detailed descriptions of the instruments.

### **Choice Making**

The scale we use to measure choice making is called the Decision Control Inventory. It is composed of 35 ratings of the extent to which minor and major life decisions are made by paid staff versus the focus person and/or unpaid friends and relatives. Each rating is given on a 10 point scale, where 0 means the choice is made entirely by paid staff/professionals, 10 means the choice is made entirely by the focus person (and/or unpaid trusted others), and 5 means the choice is shared equally. This is the same scale being used by the Robert Wood Johnson Foundation in its National Evaluation of Self-Determination in 29 states. The interrater reliability of the Inventory was reported as .86 (Conroy, 1995.)

### **Integration**

The scale used to assess integration was taken from the Harris poll of Americans with and without disabilities (Taylor, Kagay, & Leichenko, 1986). It measured how often people visit with friends, go shopping, go to a place of worship, engage in recreation, and so on, in the presence of non-disabled citizens. The scale tapped only half of the true meaning of integration; if integration is composed of both presence and participation, then the Harris scale reflects only the first part. Presence in the community is a necessary but not sufficient condition for participation in the community. The scale simply counts the number of “outings” to places where non-disabled citizens might be present. The scale is restricted to the

preceding month. The interrater reliability of this scale was reported to be very low when the two interviews were separated by 8 weeks, but when corrections were made for the time interval the reliability was high (.97.)

### **The Individual Planning Process**

The PLQ includes a scale to measure the “Elements of the Planning Process”, designed to reflect the degree to which planning is carried out in a “person-centered” manner. The Individual Planning section also captures aspects of how and how often planning events occur, and a snapshot of the plan’s content. This snapshot includes the nature of the top five goals in the plan, how much of the plan is addressed with informal supports, and the perceived amount of progress made toward each individual goal in the last year.

### **Connections with Family and Friends**

This section collects the frequency of several kinds of contact with family members. The number of friends is recorded, based on the person’s definition of friendship. The section concludes with the Close Friends Scale, which captures the characteristics and intensity of the person’s five closest friendships.

### **Perceived Quality of Life Changes**

The “Quality of Life Changes” Scale asks each person to rate his/her quality of life “A Year Ago” and “Now.” Ratings are given on 5 point, Likert scales, and cover 13 dimensions of quality. On this scale, we permit surrogates (whoever knows the participant best on a day to day basis) to respond. In our experience approximately 85% of responses to this scale are provided by surrogates. The interrater reliability of the Quality of Life Changes Scale was found to be .76.

## **Personal Interview**

One of the central problems in measuring quality of life for people with developmental disabilities is that many people cannot communicate with interviewers, whether by traditional verbal, or by any non-traditional, means. Hence many researchers have permitted surrogates to “speak for” the person. We reserve the Personal Interview section of the PLQ as the one section where surrogate responses are not permitted. This section is intended to capture the person’s thoughts, and none other.

The Personal Interview is left blank if we fail to find a way to communicate with the person. This is unfortunate, yet it is mitigated by the fact that we still have all the dozens of other quality of life measures that can be collected from third parties. In the final analysis, we must have one place that requires first party thoughts and feelings.

The Personal Interview uses five point scales, which can be asked as two “Either-Or” questions. For example, 1) “How is the food here? Good? 2) “OK, would you say Good, or Very Good?” We know from the work of Sigelman et al. (1981) that “Yes-No” questions should be avoided when interviewing people with cognitive disabilities, because of the threats of acquiescence and nay-saying. The Personal Interview also contains open-ended questions. Answers to these are recorded verbatim for qualitative analysis. (Example: “What things are most important for you to be happy?” and “If you had one wish, what would you wish for?”)

## Results

### Characteristics of the Participants

#### Demographic Characteristics of the Participants

Characteristic	Percent
Percent Male	63.0
Percent Minority	3.7
Average Age	33

The 27 participants in the Delaware County Self-Determination project were 63% male and overwhelmingly Caucasian, with only 3.7 percent of the participants being classified as belonging to a minority ethnic group. In the case of the Delaware County participants, the only minority category represented is African American.

#### Label of Mental Retardation of the Participants

Label of Mental Retardation	Number	Percent
No MR	0	0.0
Mild	13	48.1
Moderate	11	40.7
Severe	2	7.4
Profound	0	0.0
Unknown	1	3.7
Total	27	100.0

The majority of the participants were labeled as having either “mild” (48.1%) or “moderate” (40.7%) mental retardation. None of the participants were labeled as having “profound” mental retardation, and only 7.4% were labeled as having “severe” mental retardation. One person was categorized as having mental retardation, although the diagnosed level was “unknown”.

All participants in the Delaware County Self-Determination project were considered to have some level of mental retardation.

**People Reported to have “Major” Secondary Disabilities**

<b>Category of Secondary Disability</b>	<b>Number</b>	<b>Percent</b>
Ambulation	2	8.0
Autism	1	4.0
Behavior-Aggressive	1	4.0
Behavior-Self Abusive	0	0.0
Brain Injury	1	4.0
Cerebral Palsy	2	8.0
Communication	6	23.1
Dementia	0	0.0
Hearing	3	11.5
Major Health Problems	0	0.0
Mental Illness	3	12.0
Physical Disabilities	1	4.0
Seizures	0	0.0
Substance Abuse	0	0.0
Vision	2	7.7
Other	1	4.2

A large percentage (23.1%) of people in the Delaware County Self-Determination project were reported to have a major disability in terms of communication. Twelve percent were reported as having a major disability in terms of mental illness and eleven percent were reported as having a major hearing disability. Eight percent of the participants had major ambulation disabilities, and eight percent were also reported as having cerebral palsy. Only one person (4%) was reported as displaying major aggressive behavior, and no participants were reported as displaying self-abusive behavior. In addition, there were no participants who were reported as having a major seizure disability.

## Elements of the Planning Process

### Changes in Elements of the Planning Process from 2000 to 2001

<b>Characteristic of the Planning Process</b>	<b>1999</b>	<b>2000</b>	<b>Change</b>	<b>Significance</b>
Process defined or regulated?	3.4	4.7	1.3	0.015*
Process consider money?	2.9	3.6	0.7	0.233
Unpaid group members have real power?	3.2	3.9	0.6	0.297
Building a network of support?	2.6	3.1	0.6	0.368
Consider plan to be person-centered?	3.8	4.3	0.5	0.236
Process flexible?	4.0	4.5	0.5	0.261
Conflict resolution?	3.8	4.3	0.5	0.305
Process emphasizes person's relationships?	3.8	4.3	0.5	0.354
Process encourages creativity?	3.7	4.1	0.4	0.323
Does person have ultimate authority?	3.1	3.5	0.4	0.482
How involved in the planning process?	4.1	4.4	0.3	0.499
Process emphasizes cooperation?	4.2	4.5	0.3	0.510
Meetings comfortable and relaxed?	4.2	4.3	0.1	0.745
Planning sessions scheduled as needed?	4.2	4.3	0.1	0.897
Planning group has control over resources?	3.0	2.9	-0.1	0.932
Long term dreams?	3.9	3.8	-0.1	0.772

The table above shows the items of the Elements of the Planning Process scale arranged by the magnitude of change in each item from 2000 to 2001. The elements of the planning process which showed the most change were the degree to which the planning process was defined or regulated, the degree to which the planning process considered money, the perception of the amount of power held by the unpaid planning participants, and the degree to which the plan focused on building a network of supports for the focus person. The changes were very slight, the only change showing statistical significance being the degree to which the planning process was defined or regulated. However, these are areas where we would



expect to see the first shifts occurring as self-determination initiatives are being implemented.

### **Progress Toward Goals**

When examining the Delaware County participants on the progress made on their goals from the 2000 visit to the 2001 visit, we found that the scores decreased slightly, from 70.1 out of 100 on reported progress toward goals to 66.3. This slight decrease was not statistically significant and may be explained by the transition during this period from multiple, generic goals to fewer, more individualized goals.

### **Integration**

Our measure of Integrative Activities is simply a count of “how many times the person went out” and went to places where any citizen might go. This includes visits to grocery stores, banks, restaurants, malls, parks and recreational activities, as well as activities such as attending civic events. In 2000, the Delaware Self-Determination Participants had an average of 32.2 integrative activities per month. In 2001, this average rose to 33.9. Although this slight increase in integration scale scores was not statistically significant, it does reflect movement in a positive direction.

## **Transportation**

### **Type of Transportation Utilized by Participant in the Past Month**

<b>Type of Transportation</b>	<b>2000</b>	<b>2001</b>
Agency car/van	16.7	33.3
Car/van assigned to home	5.6	0
Family member's car/van	84.6	100.0
Staff member's car/van	28.6	43.8
Friend's car/van	30.4	60.0
Person's own car/van	0	0
Agency bus	0	8.3
Taxicab	5.3	0
Public transportation	27.8	46.2
Paratransit	54.5	75.0

We compared the types of transportation utilized by the 27 Delaware County Self-Determination participants in 2000 and in 2001. One hundred percent of the participants had utilized their families' mode of transportation in 2001 compared to 84.6% in 2000. Another 75% of the participants had utilized paratransit in 2001, an increase from 54.5% in 2000. Sixty percent had utilized a friend's car or van in 2001, compared to 30.4% in 2000. All types of transportation utilized increased in 2001, with the exception of using the car or van assigned to their home and utilizing the person's own car or van, which was reported as being zero in both 2000 and in 2001.

In addition, we asked the question, "If this person wanted to go somewhere on the spur of the moment (beyond walking distance), how many times out of 10 would he/she be able to? For the 27 Delaware County Self-Determination participants, the average was 5.8 times out of 10 in 2000 and 5.7 times out of 10 in 2001. These two averages were not significantly different, statistically speaking.

## **Friends**

The average number of friends reported by the Delaware County Self-Determination participants in 2000 was eleven; in 2001 the average number of friends for the participants was eight. This difference did not quite achieve statistical significance at the .05 level. However, we were concerned about a drop in the number of friends for participants and so we analyzed the types of friends they reported. The results of that analysis are below.

### Types of Friends in 2000

Category label	Count	Percent of Responses	Percent of Cases
Relative	10	10.5	40.0
Staff of Home	1	1.1	4.0
Staff of Day Program	3	3.2	12.0
Other Paid	1	1.1	4.0
Co-worker or Schoolmate	52	54.7	208.0
Neighbor	15	15.8	60.0
Other	13	13.7	52.0
Total responses	95	100.0	380.0

### Types of Friends in 2001

Category label	Count	Percent of Responses	Percent of Cases
Relative	16	15.5	59.3
Staff of Home	5	4.9	18.5
Staff of Day Program	2	1.9	7.4
Other Paid	1	1.0	3.7
Housemate	1	1.0	3.7
Co-worker or Schoolmate	53	51.5	196.3
Neighbor	9	8.7	33.3
Merchant	1	1.0	3.7
Other	15	14.6	55.6
Total responses	103	100.0	381.5

## **Behavioral Measures**

The Delaware County Self-Determination participants did not display much “challenging” behavior. On a scale of 1 to 100, where a higher score indicates less “challenging” behavior, the Delaware County Self-Determination participants scored 96 in 2000 and 97.3 in 2001. While this is a positive increase in the ability to control “challenging” types of behaviors, the difference in scores was not statistically significant.

## **Productive Activities**

Many versions of the PLQ contain the “Orientation Toward Productive Activities” scale, composed of 14 simple items such as being on time, showing enthusiasm about work, keeping a job, and getting promotions. This scale has not yet been subjected to reliability testing. It did, however, show significant increases during the first New Hampshire implementation of self-determination, so there is some reason to believe that it is sensitive to meaningful changes.

## **ADD Day program TABLE**

The Delaware County Self-Determination participants scored an average of 71.2 on this scale in 1999 and 73.3 in 2000. This slight difference was not statistically significant. In 2000, the participants were spending an average of 24 hours a week engaged in some type of day program or work activity, and in 2001, this average had increased to 25.9 hours per week. This difference was not statistically significant.

The Delaware County Self-Determination project participants earned an average of \$53.10 a week in 2000 and this average decreased to \$42.90 in 2001.

### **Health Information**

The indicators we used to measure health and health care are simple and straightforward. Problems involved with getting health care for the person were rated on a five point scale (Very Difficult, Difficult, About Average, Easy, Very Easy). Number of days of restricted activity because of health problems, number of medications received daily, and percent receiving psychotropic medications, were scored as raw frequencies. Frequency of seeing physicians, of seeing specialists, of seeing dentists, of going to emergency rooms, and so forth were also included. The name and type of every medication was also collected.

We also asked the respondents to rate the focus person's health care. Table 6 below shows the comparison from 2000 to 2001.

**Table 6.**  
**Overall, How good is Health Care?**

<b>Response Category</b>	<b>2000</b>	<b>2001</b>
Fair	23.5	11.1
Good	52.9	70.4
Excellent	23.5	18.5

In addition, we asked the respondents to rate the general health of the focus person. The results of these ratings of general health for the 27 Delaware County Self-Determination participants in 2000 was reported at an average of 4.2 on a 5-point scale. This average rating on the general health of the participants had decreased to 3.9 in 2001, and this difference was statistically significant. The Delaware County Self-Determination

participants were ill more on average in 2001 than in 2000 although this difference was not statistically significant, with a reported mean of 1.4 days ill in the past 28 days in 2000 and a mean of 2.5 days in 2001. There was no significant difference in the number of times that the Delaware County Self-Determination participants had seen a dentist, however, visits to the doctor rose significantly for these 27 people from 2000 to 2001, with an average of 3.7 visits in 2000 and an average of 7.5 visits in 2001. As the 27 participants were reported to be less healthy generally in 2001, this increase in the average number of doctor visits seems appropriate.

The Delaware County Self-Determination participants were on more medications on average in 2001 than in 2000, and this difference was statistically significant. The changes are shown in Table 7.

### **Changes in Number of Daily Medications**

Number of Daily Medications	Number of People 2000	Percentage of People	Number of People 2001	Percentage of People	Change
0	14	51.9	9	33.3	
1	5	18.5	4	14.8	
2	4	14.8	5	18.5	
3	3	11.1	5	18.5	
4					
5			2	7.4	
6	1	3.7			
7			1	3.7	
8			1	3.7	
Total	27	100.0	27	100.0	

There were 14 people in 2000 who took no medications, compared with 9 in 2001. In addition, while only one person was taking 6 medications

in 2000, in 2001 there were two people taking 5 medications, one person taking 7 medications, and one person taking 8 medications. This may be a reflection of the fact that the overall general health of the 27 people was reported to be poorer in 2001 than in 2000.

The majority of participants were not taking psychotropic medications, a finding that is in line with the low reported incidence of challenging behavior for this group.

**Injuries and Allegations of Abuse**

Concern for the health and safety of people with disabilities remains a priority for Delaware County as it moves towards increased independence and self-determination for the people receiving services. The COA personal life protocol includes questions about the number of injuries incurred in the past year and numbers of allegations of abuse.

**Number of Injuries 2000 and 2001**

<b>Number of Injuries</b>	<b>Number of People 2000</b>	<b>Percent of People</b>	<b>Number of People 2001</b>	<b>Percent of People</b>
Zero	8	47.1	23	85.2
One	3	17.6	2	7.4
Two			1	3.7
Three	1	5.9		
Four	5	29.4	1	3.7
Five or More				
Missing	10		0	
<b>Total</b>	<b>27</b>	<b>100.0</b>	<b>27</b>	<b>100.</b>

The number of people who reported injuries decreased dramatically from 9 people reporting up to 4 injuries in the past year in 2000, to only 4 people reporting up to 4 injuries in the past year in 2001.

### Allegations of Abuse 2000 and 2001

<b>Number of Allegations</b>	<b>Number of People 2000</b>	<b>Percent of People</b>	<b>Number of People 2001</b>	<b>Percent of People</b>
Zero	14	60.9	22	95.7
One	7	30.4	1	4.3
Two	1	4.3		
Three				
Four	1	4.3		
Five or More	0			
Missing	4		4	
<b>Total</b>	<b>27</b>	<b>100</b>	<b>27</b>	<b>100</b>

Reported allegations of abuse also declined. In 2000 there were 9 people for who up to 4 allegations of abuse were reported, in 2001 this number has decreased to one person reporting one incident of an abuse allegation being made.



## **Self-Determination Outcomes**

The scale of choice making in the PLQ is called the Decision Control Inventory. It is composed of 35 ratings of the extent to which minor and major life decisions are made by paid staff versus the focus person and/or unpaid friends and relatives. Each rating is given on a 10 point scale, where 0 means the choice is made entirely by paid staff/professionals, 10 means the choice is made entirely by the focus person (and/or unpaid trusted others), and 5 means the choice is shared equally.

This is the same scale used for the National Evaluation of Self-Determination for the Robert Wood Johnson Foundation in 29 states. The interrater reliability of the Inventory was reported as .86 (Conroy, 1995). A separate form was recently developed for people living with their families rather than being supported by paid staff. In that form, the power balance is measured between the person and the relatives. The results of the Decision Control Inventory are shown below.

### **Decision Control Inventory Item Means in 2000 and 2001**

	2000	2001	Change	Significance
Time spent working/at day program*	6.0	9.1	3.1	0.015
Type of work or day program*	6.6	9.1	2.5	0.038
Transportation to and from day program	7.7	9.1	1.4	0.196
Choice of house or apartment	8.9	9.5	0.7	0.151
What clothes to wear on weekdays	9.4	10.0	0.6	0.188
When to go to bed/weekdays	9.4	10.0	0.6	0.188
When to go to bed/weekends	9.4	10.0	0.6	0.212
When to get up/weekends	9.4	10.0	0.6	0.212
Taking naps	9.4	10.0	0.6	0.212
Who you hang out with	9.0	9.6	0.5	0.211
Choosing restaurants	9.3	9.8	0.5	0.126
Express affection, including sexual	9.6	10.0	0.4	0.131
Bathing	9.6	10.0	0.4	0.131
What to have for dinner	9.3	9.6	0.3	0.248
Minor vices	9.5	9.8	0.2	0.640
What clothes to buy	9.3	9.6	0.2	0.737
What clothes to wear on weekends	9.8	10.0	0.2	0.213
Choice of furnishings/décor	9.0	9.1	0.2	0.773
Visiting with friends	9.9	10.0	0.1	0.186
Choice of places to go	9.4	9.6	0.1	0.186
What to do with relaxation time	9.4	9.6	0.1	0.186
Choosing to decline activities	9.4	9.6	0.1	0.186
Who goes on outings	9.4	9.6	0.1	0.186
What to do with personal funds	8.9	8.9	0.1	0.938
Choice of people to live with	9.3	9.3	0.0	0.937
Whether to have pets in the home	9.5	9.5	0.0	1.000
What to have for breakfast	9.5	9.4	-0.2	0.656
What foods to buy	9.6	9.4	-0.2	0.736
Worship	10.0	9.5	-0.4	0.383
Choice of service agency	6.4	4.5	-1.9	0.152
Choice of Case Manager	4.0	1.4	-2.6	0.078
How to spend day activity funds*	6.8	2.5	-4.3	0.022
Option to hire and fire*	7.5	3.1	-4.4	0.003
Choice of agency support person*	8.0	2.7	-5.3	0.001
How to spend residential funds	6.7	0.0	-6.7	0.184

\* Indicates statistical significance at the .05 level.

The top five areas of change in decision-making were in choice of amount of time spent in work or day program, choice of type of work or day program (both of which differences were significant), choice of type of transportation to take to and from work or day program, choice of house or apartment, and choice of what clothes to wear on weekdays. Areas which showed the least change, or negative change, from 2000 to 2001 were how to spend residential funds (only 3 respondents which affected the t-test results, showing non-significant findings), choice of agency support person, the option to hire and fire support staff, choice of how to spend day activity funds, and choice of case manager.

The differences in the choice of agency support person, the option to hire and fire support staff, and the choice of how to spend day activity funds were all statistically significant decreases from 2000 to 2001. We can only speculate on the meaning of these significant decreases. One scenario is that participants have not yet implemented their individual plans and individual budgets, a second is that there are not enough alternate choices to make decision making viable.

### **If you had one wish...**

As part of the personal interview with the focus person, we ask the question, "If you had one wish, what would it be?" Below are listed the verbatim responses matched by each person who responded to this question in 2000 and 2001.

<b>One wish 2000</b>	<b>One wish 2001</b>
Help mom buy food	Stay here not move
Money	To go on vacation
To drive	To be rich
Computer	To have my own apt. I can cook some and clean
That she could talk	Doesn't speak
To live with my family	Full time job
Don't know	Nothing
My birthday	Back street boys tickets

### **Visitors' Subjective Impressions**

The following table shows the comparisons from 2000 to 2001 on the Visitor's Subjective Impressions. These impressions are ratings given on a scale of 1 to 10 by the COA visitors after visiting peoples' homes and observing their living environment.

#### **Comparison of Visitor's Subjective Impression in 2000 and 2001**

Visitors Subjective Impressions	2000	2001	Change	Significance
How happy is person*	2.9	5.4	2.5	0.048
Quality of interpersonal interactions	4.3	5.9	1.6	0.211
Attitudes connected to self-determination	2.4	4.8	2.4	0.134
Staff attitudes about growth*	3.4	7.9	4.4	0.004
Feel about relative w/disability living in home*	3.3	7.1	3.9	0.017

\* Indicates significance at the .05 level.

There was a significant increase in the visitors' ratings of how happy the focus person seems to be from 2000 to 2001. This rating went from 2.9 to 5.4. There were also significant increases in the visitors' ratings on the staffs' attitudes about growth for the people they support, and the visitors' ratings on how they would feel if their own relative was living in the homes visited, from 3.4 to 7.9 and from 3.3 to 7.1 respectively. All subjective

ratings given by the visitors increased from 2000 to 2001, although there were only three that showed statistical significance.

These findings are very positive and reflect well on the system wide commitment to promoting individual planning and service delivery.

## References

Abery, B. (1993). A conceptual framework for enhancing self-determination. In M. Hayden & B. Abery (Eds.), Challenges for a service system in transition: Ensuring quality community experiences for persons with developmental disabilities (pp. 345-380). Baltimore: Brookes Publishing Co.

Abery, B.; Rudrud, L.; Arndt, K.; Schauben, L.; Eggebeen, A. (1995). Evaluating a Multicomponent Program for Enhancing the Self-Determination of Youth with Disabilities. Intervention in School and Clinic, 30(3), Jan, 170-179.

Conroy, J. (1995). Reliability of the personal life quality protocol. Report Number 7 of the 5-year Coffelt Quality Tracking Project. Submitted to the California Department of Developmental Services and California Protection and Advocacy, Inc. Ardmore, PA: Center for Outcome Analysis.

Conroy, J. (1996). The Hissom Outcomes Study: A Report on 6 Years of Movement into Supported Living. The People Who Once Lived at Hissom Memorial Center: Are They Better Off? Brief Report Number 1 of a Series on the Well-Being of People with Developmental Disabilities in Oklahoma. Submitted jointly to Oklahoma Department of Human Services and United States District Court, Northern District of Oklahoma. Ardmore, PA: The Center for Outcome Analysis.

Devlin, S. (1989). Reliability assessment of the instruments used to monitor the Pennhurst class members. Philadelphia: Temple University Developmental Disabilities Center.

Field, S., & Hoffman, A. (1994). Development of a model for self-determination. Career Development for Exceptional Individuals, 159-169.

Field, S., Hoffman, A., St. Peter, S.; Sawilowsky, S. (1992). Effects of disability labels on teachers' perceptions of students' self-determination. Perceptual & Motor Skills, 75(3), 931-934.

Fullerton, A. Douglass, M. & Dodder, R. (1999). A reliability study of measures assessing the impact of deinstitutionalization. Research in Developmental Disabilities, 20(6), pp. 387-400.

Jaskulski, T., Metzler, C., & Zierman, S. A. (1990). Forging a new era: The 1990 reports on people with developmental disabilities. Washington, DC: National Association of Developmental Disabilities Councils.

Jones, A., & Crandall, R. (1986). Validation of a short index of self-actualization. Personality and Social Psychology Bulletin, 12, 63-73.

Kishi, G., Teelucksingh, B., Zollers, N., Park-Lee, S., & Meyer, L. (1988). Daily decision-making in community residences: A social comparison of adults with and without mental retardation. American Journal on Mental Retardation, 92, 430-435.

Nerney, T., Crowley, R., & Kappel, B. (1995). An Affirmation of Community: A Revolution of Vision and Goals. Creating a Community to Support All People Including Those With Disabilities. Durham, NH: University of New Hampshire Institute on Disability.

Nerney, T. & Shumway, D. (1996). Beyond managed care: Self-Determination for people with disabilities (first edition). (Available from the authors, University of New Hampshire, Institute on Disabilities, Durham, NH).

Stancliffe, R. (1995). Assessing opportunities for choice making: A comparison of self-report and staff reports. American Journal on Mental Retardation, *99*, 418-429.

Wehmeyer, M. L. (1992a). Self-determination and the education of students with mental retardation. Education and Training in Mental Retardation, *27*, 302-314.

Wehmeyer, M. L. (1992b). Self-determination: Critical skills for outcome-oriented transition services. The Journal for Vocational Special Needs Education, *39*, 153-163.

Wehmeyer, M. L. (1993). Reliability and acquiescence in the measurement of locus of control with adolescents and adults with mental retardation. Psychological Reports, *75*, 527-537.

Wehmeyer, M. L. (1994a). Perceptions of self-determination and psychological empowerment of adolescents with mental retardation. Education and Training in Mental Retardation and Developmental Disability, *29*, 9-21.

Wehmeyer, M. L. (1994b). Reliability and acquiescence in the measurement of locus of control with adolescents and adults with mental retardation. Psychological Reports, *75*, 527-537.

Wehmeyer, M. L., & Kelchner, K. (1995). Measuring the autonomy of adults with mental retardation: A self-report version of the Autonomous Functioning Checklist. Career Development of Exceptional Individuals, *18*, 3-20.

Wehmeyer, M. L., & Kelchner, K., & Richards, S. (1995). Individual and environmental factors related to the self-determination of adults with mental retardation. Journal of Vocational Rehabilitation, *5*, 291-305.



West, M. D., Rayfield, R. G., Wehman, P., & Kregel, J. (1993).  
Assessing self-determination of youth with disabilities: A conceptual  
framework and model. Unpublished manuscript.

p.12 Progress made on goals table, 3 of goals

discuss transportation pg 13..aren't these really big changes? Are they  
significant?

Pg 14 friends...what kinds? Table and discuss..because # went down  
from 11 to eight. (not sig)

Pg 14..think we should list the kinds of day programs

Pg 15 general health sig decrease..need table and discussion

Pg 16..also sig increase in meds. Add table

P16 tables for abuse alleg and injuries...good news