Assessment and Analysis of Self-Determination Efforts for People with Developmental Disabilities in New Jersey

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Executive Summary

This is the second report on the implementation of self-determination for people with developmental disabilities in New Jersey. The first report was a policy analysis, based primarily upon document review, key informant interviews, and focus groups. This second report is based on direct face to face visits with nearly all of the active participants in the New Jersey initiative. The primary intent of this part of the evaluation was to answer the fundamental question: **"Has this self-determination initiative made a difference in the lives of the participants? Are they 'better off' because of it?"**

In the previous report, we described some impediments and barriers to full and optimally successful implementation of self-determination in New Jersey. We provided a series of recommendations that would improve on the foundation already built. In the present report, we are judging the success of self-determination as it has been designed so far – and we are judging according to hard scientific measures of the well-being of the participants and their families.

What the data reveal is that, despite any and all implementation problems and impediments, the early phases of self-determination in New Jersey have been overwhelmingly successful. We come to this conclusion by testing the three elements of the "theory" of self-determination in the individual lives of the participants:

1. **If power shifts (carefully, gradually, responsibly, case-by-case) from paid professionals toward the people and their freely chosen allies,**
2. **Then lives will improve,**
3. **And costs will be the same or lower than they would be in the traditional professionally dominated approach.**

First, we find that power has in fact shifted from paid workers toward the participants and their families. On a 100 point scale of control over life decisions, we measured a power shift of 6 points during the early stages of self-determination. This is somewhat larger than the 4 point gain we observed in the original self-determination demonstration in New Hampshire, and compares favorably to results seen in other states. Hence we conclude that power has shifted for the participants, and in all probability, still is shifting.

Second, we find that the participants and their families report that their quality of life has improved in 14 out of 14 dimensions measured – and every change is highly statistically significant. The overall 100 point quality of life scale went up by 13 points, which was as much as seen in many states with 3 years of effort. Moreover, an objective measure of integration (the Integrative Activities Scale) increased from an average of 13 outings per month to 43 per month – an astounding increase, larger than the increases seen when people move from institutions to community homes. The people on New Jersey's waiting list appear to have been largely isolated in their families' homes, unable to go out and do things in their communities, but now, they are almost at the national average of integrative activities for non-disabled citizens (about 48 outings per month).

An unexpected finding in the quality dimension was in the amount of time spent in organized daily activities. Even though the New Jersey version of self-determination did not permit funds to be used for day programs, the average number of hours per week of involvement in some form of structured day activity shot up from 17 hours to 41 hours. This finding strongly suggests that families have "cost-shifted" in major ways – now that residential expenses are taken care of, they have found the resources needed for daily activities from other sources, and now the participants are far "better off" than they were before, in the sense that they are busier and more engaged.

Also within the quality dimension, the data from Personal Interviews with participants and with family members demonstrate very strongly that self-determination is welcomed. We have learned from family members that this is a lot of work for them – and not every person has relatives who are able and willing to do all that is necessary – but for those who do, the early results are phenomenally good.

With regard to the third part of the theory of self-determination, we find that expenditures are almost exactly what they would have been if these waiting list members had gone into traditional community based services. In fact, if the cost of real estate were factored in, the self-determination pilot would have to be seen as less costly than traditional models.

Moreover, the average $52,000 cost of supporting people in self-determination is far below the average cost of $120,000 for keeping a New Jersey citizen in one of the public institutional Developmental Centers. We recommend that DDD consider the possibility of bringing people out of Developmental Centers using the principles of self-determination, including power and control over an individual budget of similar but perhaps less magnitude.

Like most states, New Jersey has experienced a growing "waiting list" of people with developmental disabilities who need support, but for whom there just has not been room in the traditional service system. New Jersey's decision was to utilize self-determination principles in its attempts to address the waiting list. (Maryland made the same choice with its Robert Wood Johnson Foundation grant.) This was a good decision, in the opinion of this research team. It allowed for experimentation and creativity among people and families who had not yet become accustomed to traditional service practices and structures. It also ameliorated some of the tension in the ever-growing waiting list.

In New Jersey, the method for assigning an individual dollar amount to a person was to determine what kind of service the person would receive if he/she went into the traditional system, and then allow the person to control exactly that amount to purchase the supports they wanted and needed. Naturally, this approach meant that the New Jersey self-determination individual plans would come out costing the same as traditional services. Our data do in fact show just that. (Although if we include capital costs for real estate purchase and renovation of group homes, then the cost of a traditional group home is higher than the average amount spent in self-determination – and much lower than the cost of an institutional placement.)

We recommend that this notion of cost-equivalence be "opened up" for further thought and discussion. We have obtained compelling evidence in other states, including New Hampshire, Michigan, and California, that self-determination principles can achieve more than cost neutrality. By turning over control of resources to people and their allies, purchasing can become more precise. While "saving money" is emphatically not the driving force behind self-determination, serving more people with the same resources could become a welcome consequence of future efforts toward self-determination in New Jersey.

Self-Determination in New Jersey

History

The Self-Determination movement that began in New Hampshire through the efforts of local agency professionals has a different history in every state. We have seen efforts that were initiated by state officials (Wisconsin), Developmental Disabilities Councils (North Carolina), self-advocates (New York), a community of service providers (Arizona,) and a state legislature (California.)

Self-Determination in New Jersey began in 1995 when the Division of Developmental Disabilities' Director Robert Nicholas, the UAP, and the Council on Developmental Disabilities formed a Task Force to develop an application to the Robert Wood Johnson Foundation's Self-Determination initiative. The Task Force saw the request for proposals as an opportunity to implement an existing plan for the New Jersey waiting list that was based on choice and community values.

Although New Jersey was not an RWJF grant recipient, the Policy Action Committee (PAC) proposed in the application was convened in the spring of 1996. The PAC used the proposal as a blueprint to proceed with implementing the principles of self-determination in New Jersey. Courageous decisions were made, including statewide eligibility, a mandate for people to select their own support brokers, and an allocation of $4 million to test the process with 100 people from the waiting list.

The original project had no budget caps but did include a proviso that costs would not exceed the costs of traditional community residential services. Implementation began in the spring of 1997 with funds from the first Governor's Waiting List Initiative. Six years later there are more than 300 families who have chosen the self-determination option. Some are buying an array of services from traditional provider agencies, others are developing and purchasing innovative and generic community services. It is all about choice and freedom.

Process

The DDD Office of Statewide Planning Coordination and Research is responsible for the self-determination initiative and has made major commitments such as the designation of state employees as regional coordinators and long term funding for training, planning, and a statewide fiscal intermediary entity.

When an individual chooses the self-determination option, the next step is to hire a Support Broker. The Boggs Center (New Jersey's Center of Excellence) maintains and disseminates a list of trained support brokers. The person, the family, DDD Case Manager, and the Support Broker begin work on a person centered service plan. The Case Manager is responsible for establishing a Level of Need and identifying all available resources, including eligibility for Medicaid services. The question is then asked, "What traditional program would best meet the needs of this individual?" The choices (with average costs ranging from $15,000 to $60,000 per year) are:

- Unsupervised apartment
- Supported living
- Supervised apartment
- Group home
- Special needs group home

When the type of living arrangement is selected, the Case Manager identifies three programs in the appropriate county and calculates the average cost for that selection. A formula is applied to account for disposable personal income, wage contributions, and Medicaid reimbursable services to arrive at the DDD Individual

Rate. The Individual Rate does not include funds for day activities. A decision was made early on to keep day and residential funding separate.

While working on the individual plan and budget, all stakeholders are encouraged to participate in training courses provided by the Boggs Center. The curriculum includes a one day overview of self-determination for everyone, an additional day for families, and two additional days for Support Brokers. The training is required for Support Brokers.

When the individual plan and budget are approved, people and families can begin to hire staff and purchase services. At this point, there is another important choice to be made. The self-determination participant can pay an existing agency to provide service and to be responsible for hiring, training and supervising staff. Another choice is to use the services of a fiscal intermediary and hire staff directly. DDD has entered into a contract with Easter Seals to act as the fiscal intermediary for all self-determination participants, fulfilling the roles of bill payer and employer of record.

As happened nationally, interest and excitement appear to be spreading rapidly within New Jersey. Self-Advocates and younger parents are demanding more choice and input with regard to service delivery. Self-determination is a method that can meet the needs of service recipients and the need of state officials to be fiscally conservative stewards of public funds.

Methods

Our evaluation design called for the collection of both qualitative and quantitative data. Qualitative methodology has a long history of application in program evaluation (Patton, 1987, 1982). We convened one parent focus group and conducted (18) key informant interviews. These methods allowed us to reach a large number of persons with limited resources. We also reviewed relevant policy statements and circulars disseminated by the New Jersey Division of Developmental Disabilities and training materials produced by the Boggs Center.

The intent of our efforts in this project was to understand the perceptions of multiple stakeholders regarding how self-determination may impact the current developmental disabilities service system in New Jersey. The materials generated from the qualitative evaluation were then cross-referenced with the quantitative data to present a total picture.

Our quantitative evaluation was based on individual visits to each participant. One hundred and eighty six individual visits were conducted to gather data regarding various qualities of life. Those visits were scheduled between January and August 2002. In many evaluations, COA includes a mailed family survey. Because so many of the New Jersey participants lived with their families, we included a family survey in the individual site visit data collection package. Finally, with the assistance of the DDD Central office, we received authorizations to collect individual self-determination budgets for 60 participants.

All of our quantitative data, including the family survey, can be compared to data collected with similar instruments for the evaluation of the Robert Wood Johnson Self-Determination Initiative and for independent pilots in other states.

Instruments

COA adapted its general package of instruments utilized in the national evaluation of self-determination for use in New Jersey. The main tool for our quantitative approach is the Personal Life Quality Protocol (PLQ). This package and its component instruments have been described in the literature and have been submitted to multiple tests of reliability. [1] The complete instrument used for this evaluation is attached as Appendix A.

Many elements of the PLQ evolved from the Pennhurst Longitudinal Study (Conroy & Bradley, 1985). Pennhurst Class members have been visited annually since 1978. An extensive battery of quality-related data has been collected on each visit. Over the years, other groups have been added to the data base; 600 people living in Community Living Arrangements in Philadelphia who were not members of the Pennhurst Class; more than 3,000 people receiving supports in Oklahoma; 2,400 people who moved from institution to community in California; and 2,500 people involved in self-determination efforts nationwide.

Our battery of instruments is based on the notion that "quality of life" is inherently multidimensional (Conroy, 1986). It is essential to measure many kinds of individual outcomes to gain an understanding of what aspects of quality of life have changed over time (Conroy & Feinstein, 1990a). Modifications to the instruments over the years have been based on the concept of "valued outcomes" (Conroy & Feinstein, 1990b; Shea, 1992). Professionals may value some outcomes most highly, such as behavioral development; parents and other relatives may value permanence, safety, and comfort more highly; and people with mental

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[1] e.g., Conroy, J. (1995, January, Revised December). *Reliability of the Personal Life Quality Protocol. Report Number 7 of the 5 Year Coffelt Quality Tracking Project.* Submitted to the New Jersey Department of Developmental Services and New Jersey Protection & Advocacy, Inc. Ardmore, PA: The Center for Outcome Analysis. Also see: Fullerton, A. Douglass, M. & Dodder, R. (1999). A reliability study of measures assessing the impact of deinstitutionalization. *Research in Developmental Disabilities, Vol. 20, No. 6,* pp. 387-400.

retardation may value having freedom, money, and friends most highly. The goal in our research on deinstitutionalization, and later on self-determination, has been to learn how to measure aspects of all of these "valued outcomes" reliably.

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 surrogates provide approximately 85% of responses to this scale. 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 contained two open-ended questions. Answers to these are recorded verbatim for qualitative analysis. (Example: “Any comments about self-determination?” and “If you had one wish, what would you wish for?”)

Some of the data collection instruments, and their reliability, were described in the Pennhurst reports and subsequent documents (Conroy & Bradley, 1985; Devlin, 1989; Lemanowicz, Levine, Feinstein, & Conroy, 1990.) Since that time, more detailed and rigorous reliability studies have been published (Conroy, 1995; Dodder, Foster, & Bolin, 1999; Fullerton, Douglass, & Dodder, 1999.)

Family Survey

In most of the evaluations conducted by the Center for Outcome Analysis, we collect family names and addresses during the personal life quality visit and then mail a survey to family members. We knew that the majority of New Jersey self-determination participants were living with their families and that families were very involved in the process, even for those living outside the family home. We therefore decided to include the family survey, with some modifications, as part of the package to be collected during the home visit.

Self-Determination Participants

The Division of Developmental Disabilities supplied us with a list of 318 self-determination participants. We proceeded to check this list with the regional self-determination coordinators and identified 6 people who had decided not to participate in the program. Many of the people on the master list were new to self-determination and in fact did not yet have individual budgets or authorized service plans in place. Because we wanted to evaluate people with experience in the program, we removed those people from the list, even though we had already conducted interviews with some of them.

We were unable to complete visits with 89 people. The reasons ranged from refusals (14), missing more than two scheduled appointments (3), inability to schedule due to unlisted or no phone service (21) or other reasons (51.) We were able to complete personal life quality surveys for 138 people who have individual plans and budgets. Their responses are the basis for this report.

Procedures

Data Collectors

The project recruited and trained people with experience in working with people with disabilities to perform a data collection visit with each participant. They were trained by COA staff on the New Jersey instrument and in general areas such as sensitivity and confidentiality. These data collectors, called "Visitors," functioned as independent contractors and were paid a fixed rate for each completed interview. Below are the Visitor instructions from our Personal Life Quality Protocol.

> This package is composed of many measures, scales, instruments, and interview items. Practically all of the information collected in this package is related to quality of life. In order to complete the package, you must have access to:
>
> 1. The person (to attempt a direct interview of any length, usually 5 to 15 minutes)
> 2. Whoever knows the individual best on a day to day basis (about 30 to 60 minutes)
> 3. The person's records, including medical records (about 5 to 10 minutes)
> 4. Sometimes, a health care professional familiar with the person (about 5 to 10 minutes)
>
> With access to these four sources of information, and after some practice sessions, you will probably be able to complete this package within the range of 45 to 95 minutes.

Sign language interpreters were hired as necessary. Visitor progress was monitored on a weekly basis. Each visitor was responsible for scheduling appointments and completing assigned visits. Visitors were instructed to respect programmatic needs, and to work around them. No person's daily schedule was to be disrupted by these visits. The amount of information collected, in relation to the relatively short duration of the visits, is worthy of comment. We were able to collect reliable quantitative data on dozens of qualities of life in a very short time, with very little intrusion into peoples' lives.

Individual Budgets

Our original plan was to ask individuals and families for copies of their individual budgets at the time of the home visit. We soon realized that this was not effective because many people did not have a current copy or did not have the resources to make a copy. We therefore prepared an explanatory letter and a release form that was mailed by DDD to all the participants. As DDD received the signed authorizations for release of information, the individual budgets were forwarded to the COA office. The final number of budgets received was 60.

Key Informant Interviews

Tom Nerney, Jim Conroy, and Marge Brown conducted the key informant interviews. The first meetings were with staff from the Council on Developmental Disabilities, DDD Central Office and DDD Regional Offices to collect background information on the project and to identify unique aspects of the New Jersey implementation process. These interviews also allowed us to elicit opinions and attitudes regarding the principles of self-determination and their specific application in New Jersey.

Subsequent key informant interviews were held with fiscal intermediary staff at Easter Seals, Agency and Independent Support Brokers, and Training Personnel from the Boggs Center. Marge Brown collected additional qualitative data through attendance at self-determination meetings at the Boggs Center and in the Southern Region.

Finally, Tom Nerney met with staff at the New Jersey Bureau of Guardianship to discuss the guardianship process in New Jersey and how that process impacts on the self-determination initiative.

Family Focus Group

Families are an important factor in the success of self-determination and we knew that many of the self-determination participants in New Jersey were living at home. We convened an informal family focus group dinner that was held in Princeton and attended by 12 parents, Tom Nerney, Jim Conroy, and Marge Brown. The agenda for the group was to describe their varied experiences with self-determination, to identify barriers and areas of excellence.

The reasons for deciding to participate in the pilot are as varied as the participants themselves. Key informants speculate that some are natural pioneers or risk takers and eager to try something new. Others had just about given up on getting what they need from the traditional system and were willing to take one more chance. Many were attracted by the concept of personal control and authority. Several respondents explained that many people were hesitant to participate because of additional responsibilities, but that education about the process and information about how it could make their lives different convinced them to sign up.

Results 1: The Personal Life Quality Protocol

Participant Demographics

The purpose of the first few questions in the survey is to describe the participants in various ways so that the results can be discussed with an understanding of the population. Similar demographic information from self-determination projects in other states are included for the comparison purposes.

Who participated in the project?

Percent Male	50.7%
Percent Minority	8.7%
Average Age	36.8

More than half of the participants were male (50.7%) and the majority was Caucasian (91.3%). The average age of the people interviewed was just under 37 years old.

Demographic Information for Self-Determination Participants in Several States

Demographics	CA	HI	MD	MI	OH	WI	NH
Number	66	74	15	135	62	89	42
Average Age	25	35	39	45	37	30	34
Percent Male	77%	43%	53%	55%	60%	58%	48%
Percent Minority	47%	78%	13%	14%	3%	7%	1%

The only clear difference between the New Jersey self-determination participants and those described in the table above is that the New Jersey population is most evenly distributed according to gender.

The next characteristic of participants is their types of mental retardation labels. Many self-advocates and their friends and allies object to labels, especially if they are used to allocate resources or assign people to restrictive programs. This is not the case with the self-determination participants and we only include this characteristic to show that self-determination is valued and utilized by people with a wide range of levels of mental retardation.

Level of Mental Retardation Label

Label	**Number**	**Percent**
Not labeled MR	23	16.7%
Mild	52	37.7%
Moderate	34	24.6%
Severe	15	10.9%
Profound	7	5.1%
Unknown	7	5.1%
Total	**138**	**100%**

The majority of the participants (62.3%) reported having either a mild or moderate mental retardation label. The next largest group (16.7%) reported having no mental retardation label and only 22 people (16%) carried the label of severe or profound mental retardation.

Mental Retardation Labels of Self-Determination Participants in Several States

Label	CA	HI	MD	MI	OH	WI
Not labeled MR	35.6%	4.1%	0.0%	3.1%	14.8%	20.2%
Mild	30.5%	27.0%	20.0%	46.6%	42.6%	27.0%
Moderate	8.5%	32.4%	13.3%	23.7%	24.1%	12.4%
Severe	13.6%	23.0%	26.7%	9.9%	13.0%	18.0%
Profound	5.1%	9.5%	20.0%	16.8%	5.6%	4.5%
MR present: No label assigned	6.8%	0.0%	0.0%	0.0%	0.0%	18.0%
Unknown	0.0%	4.1%	20.0%	0.0%	0.0%	0.0%

There are no obvious differences between the mental retardation labels for participants in New Jersey and in the states described above.

The next characteristic to be discussed is major secondary disabilities. This is important data for planning purposes because secondary disabilities (secondary to mental retardation) can have a major impact on the types and of supports individuals require. The table below shows the percentages of people reported to have a “Major Secondary Disability” other than mental retardation.

Percentages of People Reported to Have Secondary "Major Disabilities"

Major Secondary Disabilities	**Percent**
Ambulation	11%
Autism	6%
Behavior-Aggressive	4%
Behavior-Self Abusive	3%
Brain Injury	9%
Cerebral Palsy	9%
Communication	**27%**
Dementia	1%
Hearing	9%
Major Health Problems	12%
Mental Illness	8%
Other	18%
Physical Disability	4%
Seizures	**22%**
Substance Abuse	0%
Vision	9%

The most widely reported secondary disability was communication (26.8%) and the second was seizures (21.7%.) "Other" and Major Health problems were reported as a major secondary disability for 18.1% and 12.3% of the participants respectively. The next largest problem was ambulation for 10.9% of the people. The remaining types of secondary disabilities were reported by less than 10% of the sample.

Major Secondary Disabilities of Self-Determination Participants in Several States

Major Secondary Disabilities	CA	HI	MD	MI	OH	WI
Ambulation	22%	16%	14%	**26%**	24%	**31%**
Autism	18%	3%	0%	5%	6%	5%
Behavior-Aggressive	8%	3%	14%	5%	5%	1%
Behavior-Self Abusive	2%	1%	8%	5%	4%	5%
Brain Injury	13%	9%	0%	3%	4%	13%
Cerebral Palsy	11%	13%	8%	18%	**25%**	24%
Communication	**32%**	**26%**	8%	**26%**	19%	**31%**
Dementia	0%	1%	0%	0%	0%	0%
Health Problems	23%	7%	14%	20%	12%	7%
Hearing	3%	1%	15%	6%	5%	7%
Mental Illness	3%	8%	**21%**	*	9%	2%
Physical Disability	11%	12%	0%	11%	5%	11%
Seizures	15%	4%	0%	6%	9%	15%
Substance Abuse	2%	0%	0%	1%	2%	0%
Inability to Swallow	3%	0%	0%	0%	0%	0%
Vision	13%	7%	8%	6%	5%	7%
Other	7%	12%	0%	5%	12%	14%

* Data not collected

New Jersey participants are similar to the participants in the states above with regard to the large percentage of people reporting communication as a major secondary disability. Seizures are listed in this category more frequently in New Jersey than in the other states and ambulation is noted less in New Jersey than in the other states.

Legal Status

The concept of self-determination for people with cognitive disabilities is the subject of great debate. In fact, some people hold the opinion that self-determination only "works" for people who are verbal and can express their wishes and desires. This opinion could not be further removed from the original concept of self-determination. One of the great success stories from the original project in

New Hampshire was a young man who was in a coma. The true description of self-determination includes decision making by families and friends who care about the person with a developmental disability. Please refer to Appendix C for a discussion of guardianship in New Jersey.

The percentages of participants in New Jersey who have a guardian are shown in the table below.

Legal Status

Response Category	**Number**	**Percent**
Parent/Relative Full Guardian	69	50.4%
Parent/Relative Limited Guardian	6	4.4%
Non-Relative Full Guardian	1	0.7%
No Guardian or Own Guardian	61	44.5%
Total	137	100%

More than half of those interviewed (55.5%) were not their own full guardians. Most listed parents or relatives as guardians and one person reported having a non-relative as a full guardian.

Guardianship Status of Self-Determination Participants in Several States

Legal Status	**CA**	**HI**	**MD**	**MI**	**OH**	**WI**
Parent/Relative is Full Guardian	40.9%	26.0%	0.0%	23.7%	16.1%	60.5%
Parent/Relative is Limited Guardian	0.0%	2.7%	0.0%	12.2%	4.8%	1.2%
Non-Relative is Full Guardian	1.5%	5.5%	0.0%	23.7%	9.7%	11.6%
Non-Relative is Limited Guardian	0.0%	1.4%	100%	2.3%	0.0%	1.2%
Relative is Conservator	6.1%	0.0%	0.0%	0.0%	0.0%	0.0%
Non-Relative is Conservator	1.5%	0.0%	0.0%	0.0%	0.0%	0.0%
No Guardian or is Own Guardian	36.4%	6.8%	0.0%	38.2%	69.4%	0.0%
Parent/Relative Guardian, not court-appointed	0.0%	42.5%	0.0%	0.0%	0.0%	0.0%
Guardian is O.P.G.	0.0%	15.1%	0.0%	0.0%	0.0%	0.0%
Unknown	13.6%	0.0%	0.0%	0.0%	0.0%	25.6%

A comparison of New Jersey guardianship status with the states listed above shows that New Jersey is only exceeded by Ohio in the number of participants who are their own guardians (44.5 % v 69.4%.)

Living Situation and History

The place where people live is often a major factor in their perceived quality of life. In many of our evaluations, we are working with people who have recently moved from large, congregate care settings. We were therefore very interested in the living arrangements of the New Jersey participants because all of them had been living in the community (on the residential waiting list) prior to choosing the self-determination option.

Current Type of Home

Type of Home	**Number**	**Percent**
Own Home	46	33.6%
Parent/Other Relative's Home	68	49.6%
Supported Living in Community (Not GH)	9	6.6%
Other	14	10.2%
Total	137	100%

Almost half of the participants (49.6%) reported living with their parents or a relative. More than one-third of the respondents (33.6%) were living in their own home; while the remaining 16.8% of the participants reported living in a supported living setting, or some other living arrangement. These results are encouraging because more than half of the participants have used their individual plans and budgets to secure a living arrangement outside the family home.

Individual Budget Information

The following matrix of questions was posed to determine who has control and responsibility for various fiscal and administrative duties.

In What Ways Does This Person (With Unpaid Supports If Needed) Control His/Her Individual Budget?

Tasks	Percent Yes	Percent No
Took Part in the Original Development of the Budget	98.4%	1.6%
Keeps Track of How Budget is Being Spent	90.2%	9.8%
Decides How Much Personal Assistance S/he Wants Each Week	91.6%	8.4%
Signs and/or Authorizes Payments to Providers of Supports	87.4%	12.6%
Decides How Their Individual Budget Will Be Modified, With or Without Assistance	86.7%	13.3%
Selects and/or Directs A Fiscal Intermediary To Distribute Pay or Other Resources	80.2%	19.8%

As the table shows, the self-determination participants are very actively involved in the control and management of fiscal resources. Nearly all (98.4%) of the respondents took part in developing their original budget. More than 90% keep track of how their budgets are spent and decide how much personal assistance they need per week. The percentages decrease, but only slightly, for more complex tasks such as signing and authorizing payments (87.4%), deciding how the budget will be modified (86.7%), and selecting and directing a fiscal intermediary (80.2%.)

It is important to note that “yes” answers include families who assist their relatives in the performance of these tasks.

Training

The day to day tasks involved with the implementation of self-determination can be complex. Individuals and their families need to understand the system and how to keep records, fill out forms, and request modifications to their budgets or plans as needed. We therefore asked if the participants felt they had received enough training to accomplish their assigned tasks.

Do You Feel That You've Been Given Adequate Training to Handle Self-Determination?

Response	**Number**	**Percent**
Definitely Not.	12	9.4%
Probably Not.	26	20.5%
Maybe (In Between, Not Sure.)	15	11.8%
Yes, Probably.	40	31.5%
Yes, Definitely.	34	26.8%
Total	127	100%

The majority of respondents (58.3%) reported feeling that "yes, probably or yes, definitely," that they had received adequate Self-Determination training. However, almost 30% of the respondents (29.9%) felt that they "probably did not or definitely did not" receive enough training. The answers are puzzling and definitely require further scrutiny, to determine if the people who felt they were not adequately trained are in a particular region or entered self-determination in the same time period.

Individual Planning And Supports

A person's plan is the best place to look for the numbers and kinds of people and resources they are using. For this evaluation, COA used the "Elements of the Planning Process" scale to quantify the information received from the participants. The average scores on the 16 items provide a quick and reasonably accurate look at how the planning process took place. This scale ranges from 0 to 100, with a higher score indicating a higher degree of "person-centered planning." The average scores are shown in the following table.

Elements of the Planning Process

Before S-D	Now	Difference	Significance
58.0	80.2	22.1	0.000

The scores shown in the table above increased more than twenty points, indicating significant change. This change is a tribute to the person-centered planning training offered to individuals, families, and support brokers in New Jersey. It is also important to note that many of the participants did not have a formal plan prior to self-determination.

Support Broker Status

There are two major models of the Support Broker function: agency and self-employed. The New Jersey self-determination system allowed individuals and families to select their own brokers. The table below shows what individuals and families chose.

Support Broker Status	Frequency	Percent
Works For An Agency	55	44%
Works For Self	70	56%

The broker model selected by individuals and families broke down almost equally between agency and self-employed.

Because this choice has rarely been offered in other states' self-determination initiatives, it was of interest to explore differences between the two models. We found that the two models did not differ in the level of functioning of the people in the support broker's caseload, which means that agency and self-employed support brokers were serving similar people. However, there was a large difference in the frequency of contact between the two types of support brokers and the self-determination participants: 3.0 contacts per month for agency brokers and 6.4 per month for self-employed brokers. This difference was highly statistically significant, but its explanation is not immediately apparent and warrants further investigation. It should be noted that there is currently no formal requirement for frequency of contact, because each individual negotiates a contract with the broker.

Day Activity Program, Work, and School

Although New Jersey's self-determination initiative specifically excluded day programs and day activities, it was of great interest to measure what happened to peoples' daily routines. The next table simply shows how the number of hours per week of structured day activities changed from "before" self-determination to "during" self-determination.

Day Activity Program Hours Per Week

Before S-D	Now	Difference	Significance
17.1	41.3	24.3	0.000

The number of hours spent in day activity programs more than doubled from before self-determination to "Now." This is somewhat surprising as several of our key informants indicated that many participants had a day program prior to their enrollment in the self-determination initiative. We can only surmise that more control over residential funds allowed people and families to purchase more daytime activities or supports.

Decision Control Inventory

Almost every person interviewed by COA commented on the enthusiasm of the participants and their joy in being responsible for life decisions. The Decision Control Inventory measures who has power over 35 life areas such as clothes to wear, food to eat, places to go, and type of work or day program. The scale requires ratings from 0 to 10 on each dimension, with 0 meaning that paid staff hold all power, and 10 meaning that the focus person (and his/her freely chosen unpaid allies) hold all the power. A score of 5 or 6 means that power is shared about equally.

The following table shows the detail in changes in the scores on the Decision Control Inventory from “Then”, before self-determination, to “Now” or after self-determination began.

Changes in Decision Control Inventory Score

Decision Control Inventory Items	Before S-D	Now	Difference
Amount of time at work/day program*	5.8	7.0	1.2
Type of work/day program*	6.7	7.8	1.1
Express affection*	8.0	8.9	1.0
What to have for breakfast*	7.1	8.0	0.9
Taking naps evenings/weekends*	7.7	8.6	0.9
When to get up on weekends*	7.8	8.7	0.9
Transportation to/from work/day program*	6.1	6.9	0.8
What food to buy at home	7.5	8.3	0.8
What to have for dinner	7.5	8.3	0.8
When to go to bed on weekdays*	7.9	8.7	0.8
When to go to bed on weekends*	7.9	8.7	0.8
Option to hire/fire support personnel	6.0	6.8	0.8
Minor vices	8.2	8.9	0.8
Choice of support personnel	6.3	7.0	0.8
What clothes to wear on weekdays	7.8	8.5	0.7
Visiting with friends outside residence	7.6	8.4	0.7
What clothes to wear on weekends	7.7	8.4	0.7
Choice of furnishings/decor*	7.4	8.1	0.7
Time/Frequency of bathing	7.8	8.5	0.6
What to do with relaxation time	7.6	8.2	0.6
Choosing to decline group activities	7.9	8.4	0.5
When, where, and how to worship	8.2	8.7	0.5
Choice of places to go for recreation	7.8	8.3	0.5
Choice of Case Manager	2.7	3.2	0.5
Who you hang out with	7.6	8.1	0.5
Choosing restaurants	7.6	8.1	0.5
What to do with personal funds	7.7	8.2	0.5
Whether to have pets in home	8.5	9.0	0.5
Choice of service agency	6.4	6.9	0.4
Choosing who goes on outings	7.8	8.2	0.4
What clothes to buy in store	8.0	8.4	0.4
How to spend day activity funds	7.5	7.8	0.4
Choice of house or apartment	7.8	8.0	0.2
Choice of people to live with	8.1	8.2	0.1
How to spend residential funds	7.9	7.9	0.0

* indicates statistical significance at the .05 level

In all but one area (how to spend residential funds) there was a positive gain, but they were consistently small gains. We suspect that this is because the many people were living with their parents both before and after their participation in self-determination.

Ten items showed a statistically significant gain from Then to Now: Amount Of Time Spent Working Or At Day Program, Type Of Work Or Day Program, Express Affection, Including Sexual, What To Have For Breakfast, Taking Naps In Evenings/Weekends, When To Get Up On Weekends, Transportation To/From Work/Day Program, When To Go To Bed On Weekdays, When To Go To Bed On Weekends, and Choice Of Furnishings/Décor.

In addition to examining each of the 35 areas of life control in the Decision Control Inventory, the 35 areas can be combined into a single overall scale of choice making opportunities, and this overall scale is computed so that it can range from 0 to 100 points. Higher scores mean more individual control over life choices and less professional domination.

Decision Control Inventory

Before S-D	**Now**	**Difference**	**Significance**
73.9	80.3	6.4	0.060

As the table shows, the participants and their allies perceive that their control over life choices has increased significantly – by about 6 points out of 100. The average participant in the New Jersey initiative began with a fairly high score, 73.9 out of 100. During participation in self-determination, that average score went up by more than 6 points, to 80.3 – and this increase <u>almost</u> met the usual criterion for statistical significance, which is .050 or lower – the New Jersey significance level was .060. We recommend that this be taken as good evidence that power did shift in a meaningful way. (A shift this large might have happened by chance alone – but would be expected fewer than 6 times out of 100 tries.)

In Texas, using virtually the same "post-only" data collection methodology, the gain on this scale was 5 points. Hence New Jersey and Texas participants gained control over their lives at about the same level, with New Jersey slightly in the lead. In other states, where we utilized true "pre and post" data collection methods, the increases varied from 3.7 points to 19.2 points.

Gains in Power and Control Over Life Choices from Self-Determination Efforts in Several States

State	Time 1	Time 2	Change	Significance
California	80.9	88.9	8.0	0.028
Hawaii	36.4	43.7	7.3	0.021
Maryland	50.2	69.4	19.2	0.000
Michigan	61.6	74.7	13.1	0.000
Ohio	70.8	78.0	7.2	0.005
Wisconsin	73.6	77.3	3.7	0.022

It is very important to point out that some of the large increases in the table were from projects that lasted a full 3 years. Because the table above is from "pre and post" data collection, and from several multi-year projects, comparisons to the New Jersey findings must be very cautious.

Nonetheless, the gains we have measured in New Jersey are encouraging and very positive. The 6 point gain is all the more impressive because it reflects a perception of enhanced empowerment, even while most of the participants were living within family homes – hence the perceived decrease in professional domination of life choices is even more compelling.

Integrative Activities

COA's Integrative Activities scale is intended to measure how many opportunities people have for contact with people without disabilities in a typical month. The scale is comprised of 16 items, and asks how often the focus person goes to restaurants, shopping malls, civic events, churches or synagogues, and other types of community activities. The results for the New Jersey self-determination participants are shown in the next table.

Number of Integrative Activities Per Month

Before S-D	Now	Difference
12.9	42.8	29.9

* indicates statistical significance at the .05 level

The introduction of Self-Determination in New Jersey seems to have improved integration levels for the participants to an amazing degree. The average score "Then" was 12.9 or one activity every 2 or 3 days. Now, people who were interviewed are averaging more than 1.4 activities per day. This is tremendously heartening and a very positive outcome for all self-determination stakeholders in New Jersey.

Changes in Integrative Activities Per Month for Self-Determination Participants in Several States

State	Time 1	Time 2	Change	Significance
California	43.2	47.6	4.4	0.168
Hawaii	31.8	46.0	14.2	0.003
Maryland	22.4	32.2	9.8	0.074
Michigan	30.5	35.9	5.4	0.012
Ohio	39.2	37.6	-1.6	0.000
Wisconsin	41.2	38.4	-2.8	0.139

As the table above shows, the New Jersey participants far surpassed people in other states in increasing their numbers of integrative activities. In New Jersey the "pre"-self-determination numbers were the lowest reported (compare to "Time 1" numbers above.) We can only surmise that the low numbers of integrative activities was because people and families just did not have the staff support needed to get out and about. This suggestion is further supported by some of the participant and family comments presented later in this report.

Access to Transportation

Freedom and flexibility are important values for people learning to live self-determined lives. We therefore wanted to know if people could go somewhere on the spur of the moment whenever he/she wanted. If they could make that choice, ten out of ten times, they would score a 10 on the following scale. If they could never go anywhere on the spur of the moment, they would score a 0.

How Many Times (out of ten) Can You Go Somewhere On The Spur of The Moment?

Before S-D	Now	Difference
6.5	7.2	0.7

* indicates statistical significance at the .05 level

Gains in this score indicate an increasing level of freedom for the person. The table shows a statistically significant gain noted with the introduction of self-determination.

Quality of Life Changes

The Quality of Life scale addresses fourteen dimensions of quality of life, including health, friendships, safety, and comfort. The person, or whoever knew the person best, gave numeric ratings of the person's qualities of life before becoming involved with self-determination and during involvement with self-determination efforts.

This scale is designed to see if the person felt that the quality of their life has changed. This is a purely subjective scale, and it is intended as such. If a person feels that their life has improved, chances are that it has. The table below shows the results of the analysis of peoples' perceptions of the quality of their lives from "Then" to "Now," presented in order of the magnitude of change.

Quality of Life Changes

Quality of Life (Items)	Before S-D	Now	Difference
Running own life, making choice*	2.5	3.4	0.9
Treatment by staff/attendants*	2.8	3.6	0.8
What I do all day*	2.6	3.3	0.7
Privacy*	3.0	3.6	0.6
Comfort*	3.1	3.7	0.6
Overall Quality of Life*	3.1	3.6	0.6
Getting out and getting around*	2.8	3.4	0.6
Happiness*	3.1	3.6	0.5
Seeing friends, socializing*	2.6	3.1	0.4
Safety*	3.3	3.6	0.3
Family relationships*	3.2	3.5	0.3
Food*	3.1	3.4	0.3
Health*	2.9	3.2	0.3
Health care*	3.3	3.5	0.2

* indicates statistical significance at the .05 level

In this table, you can see improvement across the board. Every item showed positive, statistically significant, change from "Then" to "Now." This means that, on average, the people participating in New Jersey Self-Determination felt that their lives had gotten significantly better since they began the program.

We also calculated an overall Quality of Life Change Score, displayed below.

Perception of Quality of Life From "Then" to "Now"

Before S-D	Now	Difference	Significance
74.1	86.7	12.6	0.000

The changes in the overall quality of life scores are highly significant. Participants and those who now them best are very, very pleased with the changes in their lives from the time they were on the waiting list, to now when they are implementing their own person-centered plans.

Changes in Perception of Quality of Life From Self-Determination Participants in Several States

State	Time 1	Time 2	Change	Significance
California	63.2	81.6	18.4	0.000
Hawaii	60.0	70.2	10.2	0.000
Maryland	78.7	85.3	6.6	0.038
Michigan	65.2	79.6	14.3	0.000
Ohio	64.4	75.6	11.2	0.000
Wisconsin	44.7	51.2	6.5	0.000

The overall scores for New Jersey participants are the highest we have encountered (86.7 compared to the scores in the column above labeled “Time 2.”)

Results 2: Personal Interview

The second section of the PLQ is a personal interview that is conducted directly with the person with a disability - if he or she agrees. Our data collectors make every effort to communicate. In this survey, only 67 of the participants could or would respond to the personal interview, and some of that number chose not to answer every question.

How Do You Feel About Your Life?

Answer	Number	Percent
Bad	3	4.5%
Fair	9	13.4%
Good	31	46.3%
Very Good	24	35.8%
Total	67	100%

More than 82% of the respondents felt that their lives were either Good or Very Good at the time of the interview. Only 3 people felt that their lives were bad.

The place where a person lives is a very important aspect of individual life quality and so we asked participants if they would rather live somewhere else.

Would You Rather Live Somewhere Else?

Answer	Number	Percent
Definitely not	28	47.5
Probably not	10	16.9
Maybe	4	6.8
Yes, probably	8	13.6
Yes, definitely	9	15.3
Total	59	100.0

Almost two-thirds of the respondents (64.4%) "Definitely" or "Probably" did not want to live somewhere else when interviewed. Four people answered "Maybe" and seventeen people answered that "Probably" or "Definitely" they would rather live somewhere else. We view these percentages as positive as many of the self-determination participants are in the process of transitioning from their family homes to their own homes in the community.

The next question was to measure the degree to which participants had control over choosing the staff that worked with them.

Did You Pick the People Who Work Here?

Answers	Number	Percent
Others made the choice	8	15.1%
Person had little input	2	3.8%
Person had some input	15	28.3%
Person had major say, decision was shared	19	35.8%
Person chose	9	17.0%
Total	53	100%

The respondents picked who worked with them just 17% of the time. An additional 64.2% of the people had some measure of choice about who works with them. One in five (18.9%) had little or no input into hiring decisions.

For most people, the way they spend their days is a major indicator of their life quality. We therefore asked people if they got to choose what they do during the day.

Did You Pick Your Job, School, Day Program, or Workshop?

Response	Number	Percent
Others made the choice	9	16.4%
Person had little input	8	14.5%
Person had some input	12	21.8%
Person had major say, decision was shared	12	21.8%
Person chose	14	25.5%
Total	55	100%

Others made the decision about a day activity program for nine of the people who responded to the personal interview. Another 36.3% of those interviewed reported having "Little" or "Some" input into choosing their day activities.

Finally, 47.3% of the people said they had a "Major Say" or that they actually "Chose" their day activity. These percentages are very interesting in light of the fact that the New Jersey self-determination budgets do not include day program funds. We would expect to see higher levels of choice if people did have control over those resources.

Relationships

Relationships are important to how people feel about their lives. We therefore asked a series of questions about friends to get an idea of what kinds of people the self-determination participants have in their lives.

Do You Have Friends?

Answers	Number	Percent
No friends	3	4.4%
Just one	4	5.9%
A few	14	20.6%
Yes, some	18	26.5%
Yes, a lot	29	42.6%
Total	68	100%

Nearly half of those interviewed (42.6%) reported having a lot of friends. 47.1 % reported having some or a few friends. Three people reported having no friends.

Who is Your Best Friend?

Answers	Number	Percent
Staff member	8	27.6%
Other Paid Professional	1	3.4%
Family member	20	69.0%
Total	29	100%

Everyone who answered this question reported either having a paid professional or a family member as best friend. Categories that were not selected by anyone included Advocate/Guardian, Foster Family Member, Peer With a Disability, Unpaid Person Without a Disability, Boyfriend or Girlfriend. This table must be considered with caution as only 29 people chose to answer this question.

Do You Get Lonely?

Answers	Number	Percent
Yes, often	5	8.5%
Yes, sometimes	21	35.6%
In between	4	6.8%
No or very rarely	16	27.1%
No never	13	22.0%
Total	59	100%

Nearly half (49.1%) of the people reported that they ”Never” or “Rarely” get lonely. A slightly smaller number (44.1%) said that they get lonely “often” or “sometimes.” We must be careful in analyzing a question like this that can appear to be a “bad” question. Many people tend to answer “bad” questions in a positive light, thereby possibly skewing the results. We mention this because the responses are not what we would expect. We think it is natural for everyone to get lonely from time to time, but almost a quarter of the respondents (22%) said they never got lonely.

Religion

Religion is another factor that is of great importance to many people. In the context of this survey we wanted to know if religion was a large part of people’s lives and how they felt about that.

Is Religion a Large Part of Your Life?

Response	Number	Percent
Not at all	19	29.2%
Small	8	12.3%
In between	8	12.3%
Large	12	18.5%
Very large	18	27.7%
Total	65	100%

Religion was a large or very large part of almost half of the respondents' lives. Almost thirty percent reported that religion plays no part in their life currently.

Because so many of the participants lived with their families, we wanted to know if their level of religious participation was because they wanted it or because it was or was not a family value.

How Do You Feel About That?

Response	Number	Percent
Very bad	6	10.5%
Bad	1	1.8%
In between	8	14.0%
Good	27	47.4%
Very good	15	26.3%
Total	57	100%

Almost three-quarters of the respondents felt "Good" or "Very Good" about their current involvement in religion. However, seven people felt "Bad" or "Very Bad" about their situation. It is interesting to note that ten people who answered the first religion question did not answer the second religion question.

Self-Determination

Next, we asked participants how they felt about self-determination.

How Do You Feel about Self-Determination?

Response	Number	Percent
Very bad	1	2.0%
Bad	1	2.0%
Fair	3	6.0%
Good	18	36.0%
Very Good	27	54.0%
Total	50	100%

An overwhelming number of respondents (90%) felt that self-determination was "Good" or "Very Good." Only two people felt that it was "Bad" or "Very Bad."

One of the goals of self-determination is for people to take responsibility for their own lives. We therefore asked if participants are involved with the formal self-advocacy movement.

Do You Go to Any Self-Advocate Meetings?

Response	Number	Percent
No, never	23	51.1%
Hardly ever	8	17.8%
Once in awhile	4	8.9%
Often	4	8.9%
Very often	6	13.3%
Total	45	100%

Almost 70% of the respondents “Never” or Hardly Ever” go to self-advocate meetings. Only six people reported going “Very Often” and four reported going “Often.” These responses may be interpreted in several ways. Because most of the participants have actively involved family members, who advocate on their behalf, they may not feel the need to join an advocacy group. It could also be an indication that self-advocacy groups in New Jersey need to do more outreach.

The next question was an opportunity for participants to make a general comment about self-determination and their experiences so far.

Comments on Self-Determination

This program can turn peoples’ lives around. To give them choices on who, what, when things are done to or for them.
Like having choices
Don’t like not being own support broker. Everything else wonderful.
Likes living alone
Check into the programs that people have w/ the agency.
Enjoy going out w/ the staff
I feel very good about self-determination
Very good
It’s fine. Glad I have my support broker.
Like it “ok”.
The counselors were there for me - during difficult times.
I am very happy with it.
Likes program, likes home and living independently.
You like being on your own - no problems.
Without this program I could not go on vacation
Would like that the support broker would be more involved and not changing decreasing the budget
I think it’s a nice program
I wish we could get along better in my home. I love the program.
Program well thought out
When I joined self-determination I thought it would be different. I thought there would be more people.
Wants to thank the Governor for the program and life.

Like my freedom
Having her own place
Likes having his own place.
Helps with financial
Her independence
Likes his own apartment
We should get more money

Finally, we asked each participant, "If you had one wish, what would you wish for?" The responses are often as intriguing as they are revealing and are shown in the table below. Our Visitors recorded these responses verbatim. Names and other identifying items have been removed where necessary to maintain confidentiality.

"If you had one wish, what would you wish for?"

Good health and people to have the right to choose what they need to run their lives.
Be happy.
Townhouse; driving; cat
Get married to a nice guy.
More independence
Travel to see the world.
Group home
Just happy with life as it is.
Girlfriend
Have my own business
To work
To tell as many people about God through her & be published as often as she could.
A million $dollars.
Everything
Handle the money & check book without help.; Travel
Not to be a burden to parents
Own his own home
Would like to go dancing every night and eat out.

Working in a hospital -- took a nursing assistant course.
I wish I could talk to my grandmother.
Fine -- no special wish
Wish he could go to Myrtle Beach.
Wished her thyroid would work. Love being at the library.
Very happy / wish I get the volunteer site.
Be in my own apartment.
Make the world come to real life - and live - no more violence - no more wars
I am very happy.
That he could have a girlfriend.
A girlfriend -- and to be loved ! Independent transportation. Loose weight -
To visit other places.
French Fries
Would like to have her mother (deceased) back.
A new house for himself & Mom
Likes to get awards -- summer camp -- visit her sister
Like to be able to get back in cars - so I could do lots of things.
I wish I didn't have a disability.
To be healthy & live in Florida
Get married and move to Florida; singer in a rock band - dancer.
To have my father (deceased) back.
Very own mall -- big mall and "pepsi" !
Have your own business - data / typing with an IBM computer.
Wish his brother would work out with him more.
Wish I could ride horses again
Wants his eye-sight back
Watch more TV.
Travel to California to visit sister.
Walking with a walker
Have a wife and family
Her parents could live forever (sister too)!
To walk again
Likes to do arts and crafts.
He likes surprises
Wants to go to Italy.
I wish I could live closer to my sister
Be with people that care about her in a friendly environment
That people would speak to me more.
To live in a house or a condo with a female

Wish you had a little more money to spend how you want to
He would have a girlfriend and she would love him back
Hit the lottery
Town houses a little bit bigger with a sun porch for the rabbit
Like to have a wife and kids.
Would like a female companion.
Go to South America to live.
Make yourself a professional
S-D would work well for all people; children can be in S-D when they are 21, too
That I could travel to visit a friend in Arizona and brother in California
Wish I could drive
Be able to go to the (Name) restaurant - friends are there.
Hope to keep his family together since he lost his parents. Gramma and sister too.
I want $250,000.
Meet a rich man
Go on a trip to a town for vacation

Results 3: The Family Survey

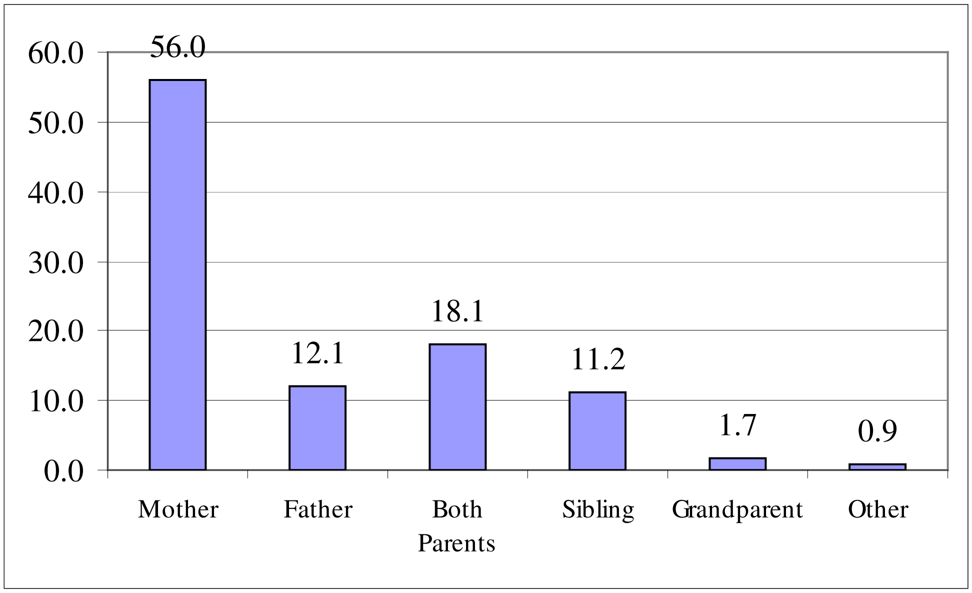
The New Jersey Self-Determination Family Survey was administered during the face-to-face visits as part of the Personal Life Quality protocol. The purpose of the family survey was to collect and measure family opinions about the self-determination initiative. In this way, COA obtained completed Family Surveys for 119 of the 138 people included in this report. This is a completion rate of 86%.

This Survey was essentially the same as the one we designed for the **National Self-Determination Family Survey** for the Robert Wood Johnson Foundation. The uniformity of the surveys permits national comparisons, so that we can obtain rough "benchmarks" about self-determination progress as perceived by families in New Jersey compared to projects in a dozen other states.

Relatives' Relationship to Participants

Family and other non-paid participation is an important element of self-determination. We therefore thought it would be valuable to find out what kinds of relatives responded to our survey. The results are shown in the Figure below.

Who Responded to the Family Survey?



The majority (87.8%) of the respondents were parents, 56% mothers, 12.1% fathers and 18.1% joint responses from mothers and fathers. The next highest percentage of respondents was 11.2% from sisters or brothers. The average age of the primary respondent to the Family Survey was 63.5 years.

Family Awareness

The original self-determination initiative emphasized the participation of families and friends in all aspects of service planning and implementation. We therefore thought it was important to measure family perceptions of their knowledge and involvement in the initiative. The 109 responses to this question broke down as shown in the table below.

Have You Heard of Self-Determination for People with Developmental Disabilities?

Response Category	Number	Percent
No, never heard of it	1	0.9%
Heard of it and know a little about it	6	5.5%
Yes, and I know a fair amount about it	33	30.3%
Yes, and I know a lot about it	69	63.3%
Total	109	100%

The majority (63.3%) of the family members who responded to this question reported they not only knew about self-determination but also knew a lot about it. Only .9% (or 1 family member) of the family members who responded to this question reported that they had never heard of self-determination. A little over 5% (5.5%) of the respondents said they had heard of self-determination and knew a little about it and 30.3% said they knew a fair amount about self-determination.

These percentages are significantly above the averages from our ***National Survey of Families of People Involved in Self-Determination***, shown below.

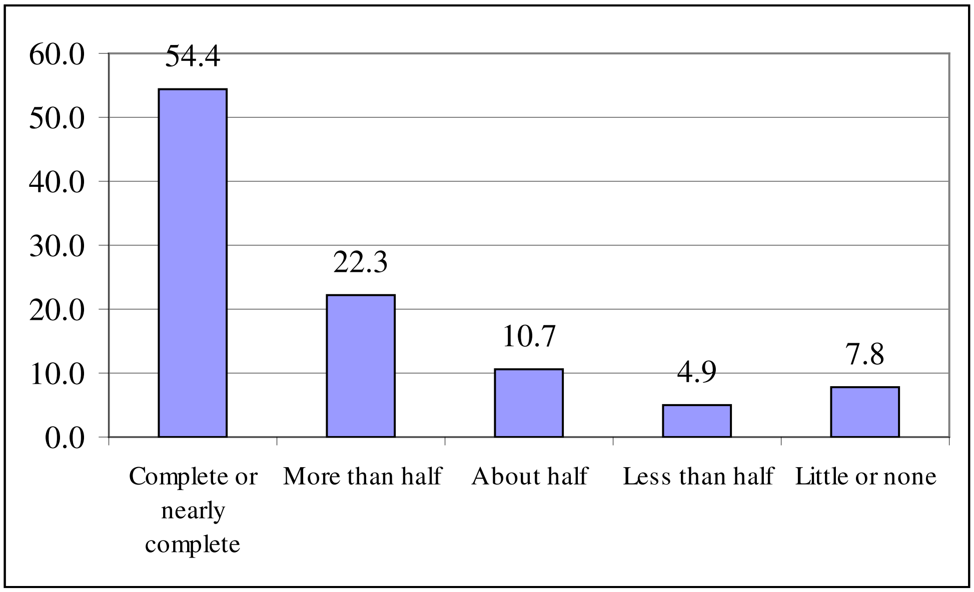
Response Category	Number	Percent
No, never heard of it	32	13.3%
Heard of it but don't know what it is	14	5.8%
Heard of it and know a little about it	45	18.7%
Yes, and I know a fair amount about it	83	34.4%
Yes, and I know a lot about it	67	27.8%
Total	241	100%

The majority of New Jersey families (63.3%) reported that they knew a lot about self-determination as compared to only 27.8% of the families who responded to our national survey. New Jersey's families were more likely to know about self-determination efforts than were families in projects in other states. This should be interpreted as indicative of relatively good outreach, training, and information sharing in the New Jersey project.

Power and Control

Because control of resources is a hallmark of self-determination, it was important to find out how families perceived their level of control over the public funds utilized to support the participants. The answers were given on 5-point scales in four categories as follows:

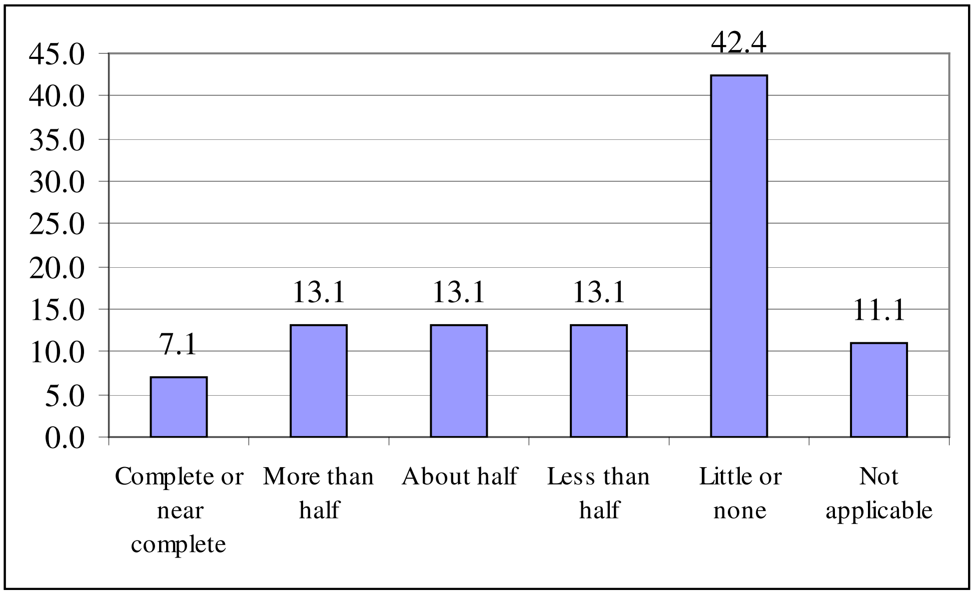
How Much Control Over Your Relative's Funds Do You Have?



Almost 54% of the respondents to the New Jersey Self-Determination Family Survey reported that they had “complete or nearly complete” control over the funds used to support their relative. Another 22.3% of the respondents reported having “more than half” of the control over the funds used to support their relative. Small percentages of the 103 family members who answered this question reported having “about half” (10.7%) or “less than half” (4.9%) of the control of the funds used to support their relative. Less than 8% of the family members who responded to this question on the Family Survey reported having “little or none” of the control over how funds are used to support their relative.

The responses from the 99 family members who answered the second question in the matrix are shown below.

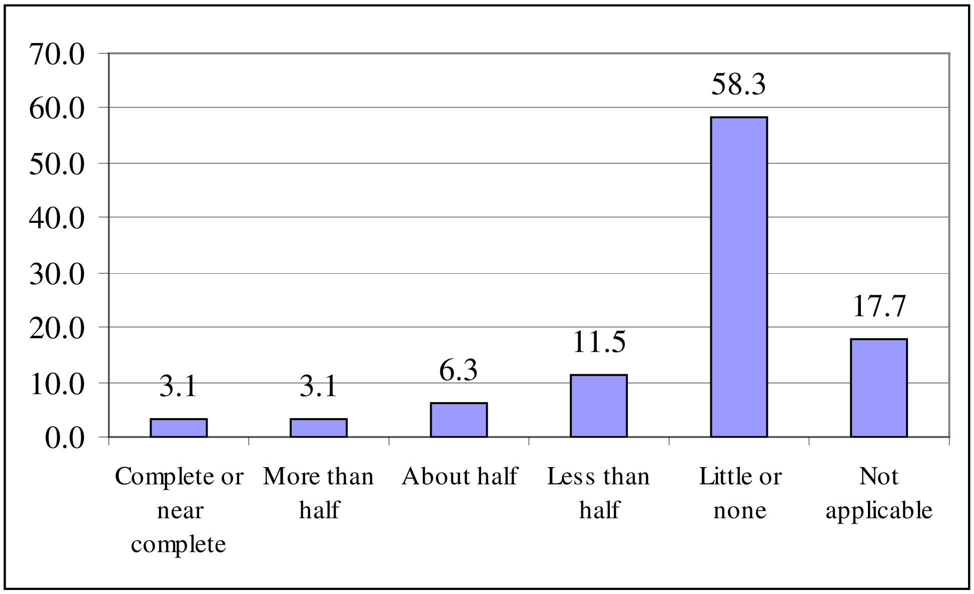
How Much Control Over Funds Does Your Relative Have?



More than 40% of the respondents reported that their relative had “little or no” control over the funds used to support him/her. About 7% reported their relative as having “complete or nearly complete” control, 13.1% reported their relative having "more than half" of the control, 13.1% reported their relative having "about half" and 13.1% reported their relative as having "less than half" of the control over the funds used to support him/her. A little over 11% of the family members who responded to this question felt that the question was "not applicable" to their relatives. The results of the previous two questions suggest that while family members feel they are gaining control over funds, the service recipients themselves have little control.

The next question related to perceptions about staff and agency control over funds. Results are shown below.

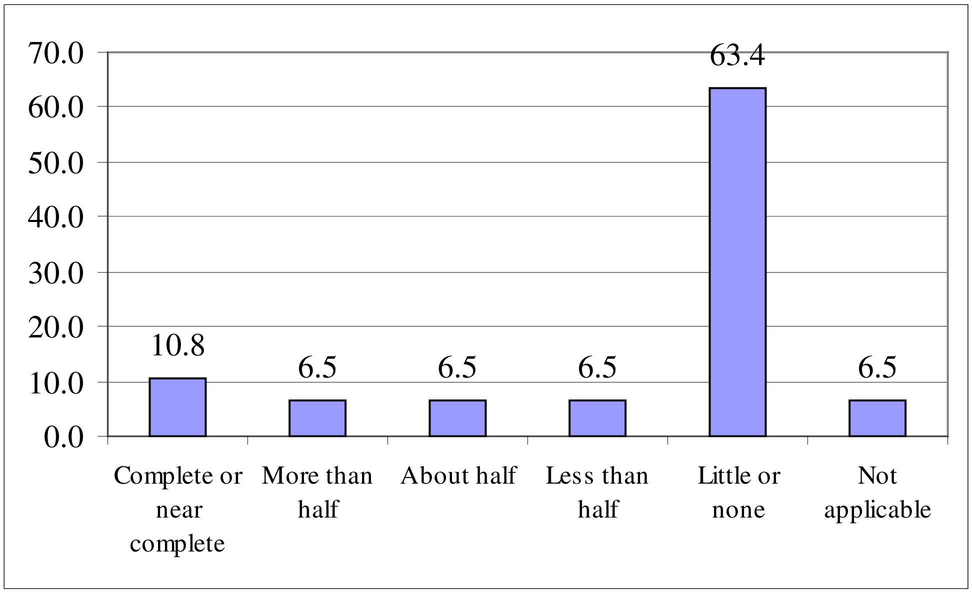
How Much Control Over Funds (If Any)
Do Staff Of The Service Agency Have?



The majority of family members felt that the staff of the service agency had "little or no" control over their relative's funds, with only 3.1% of the respondents reporting that they felt the staff of the service agency had "complete or nearly complete" control. Almost 18% of the respondents reported that the question was not applicable to their situation.

The final question about control of funds concerned the perceived authority of the fiscal intermediary.

How Much Control Over Funds (If Any) Does A Fiscal Intermediary Have?

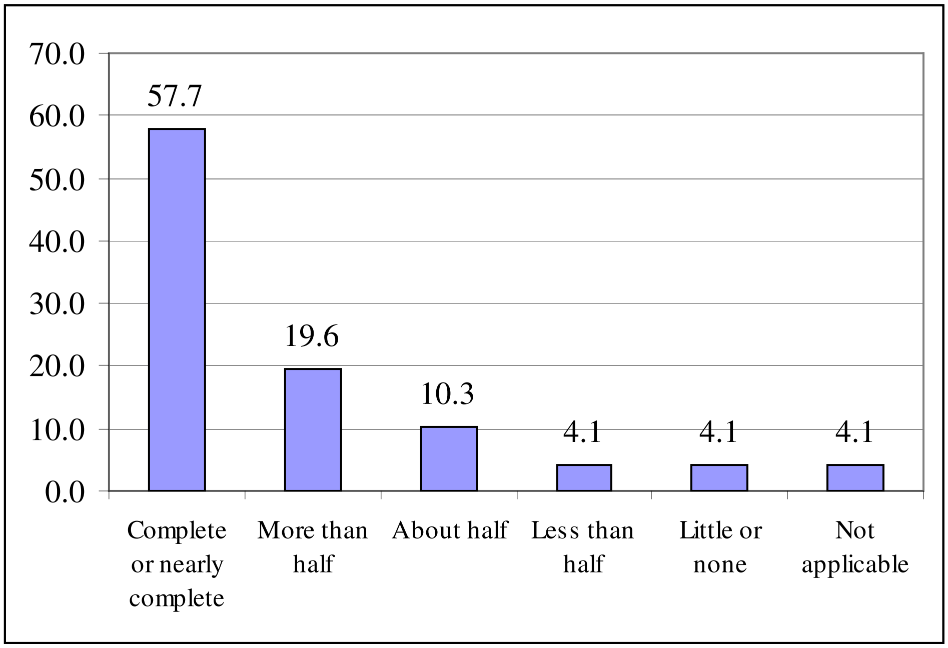


The majority (63.4%) of family members who responded to our Family Survey in New Jersey reported that the fiscal intermediary had "little or no" control over the funds used to support their relative. Less than 11% of the respondent said the fiscal intermediary had "complete or nearly complete" control over funds. Smaller percentages (6.5%) reported the fiscal intermediary as having "more than half" , "about half" or "less than half" of the control over the funds used to support their relative. Less than 7% of the family members reported that this question was "not applicable" to their situation.

The pattern that seems to be emerging from these data is that family members felt they have more control over their relative's funds than either their relatives, staff of service agencies, or the fiscal intermediary.

Next, we wanted to find out how families felt about another important control issue, hiring and firing staff. Had authority transferred partly or completely to the participants and their families? We asked another series of questions regarding control over staffing decisions. The results are shown below.

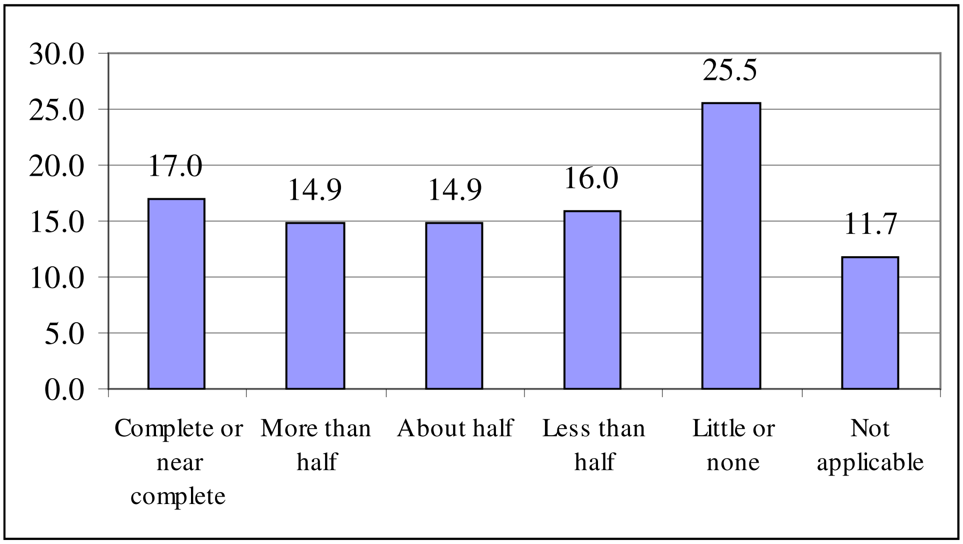
How Much Control Do You (Or You With Other Relatives And Friends) Have Over Hiring And Firing Support Staff For Your Relative?



Family members overwhelmingly reported that they have control over hiring and firing of staff, with close to 60% answering "complete or nearly complete." Only 4.1% of the family members surveyed reported that they had "less than half" or "little or no" control over the hiring and firing of staff.

The next question in this matrix was about participant control over staffing issues.

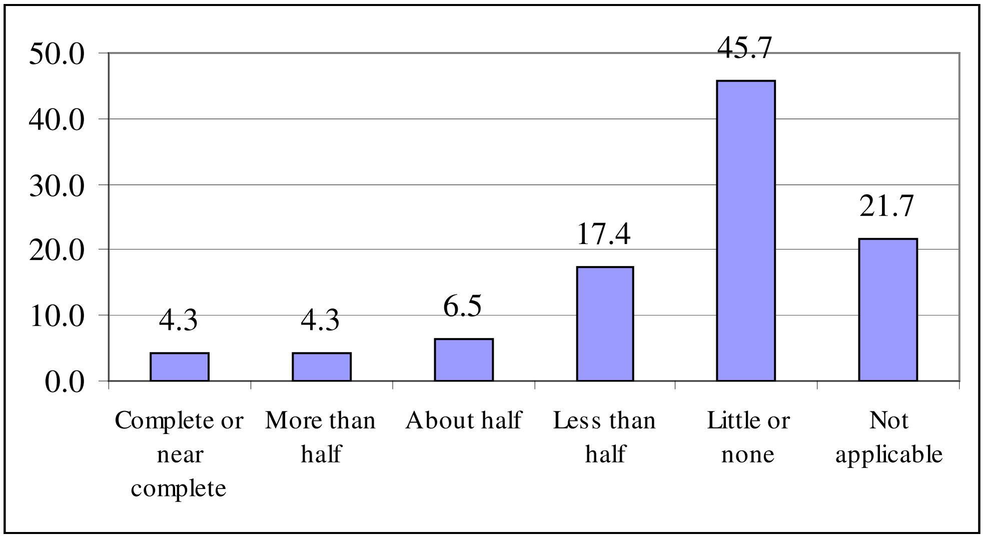
How Much Control Over Hiring And Firing Support Staff Does Your Relative Have?



About 25% of the family members reported that their relative had “little or no” control over hiring and/or firing support staff. Another 16% felt that their relative had “Less than Half” of the control over staffing decisions. Almost 30% of the respondents reported either that their relative had “About Half” or “More than Half” of the control over hiring and firing support staff.

The next question referred to the level of control over funds by provider agencies. The results are below.

How Much Control Over Hiring And Firing Support Staff Does A Provider Agency Have?



Almost 46% of the respondents reported that the provider agency had "Little or no" control over hiring and firing their relatives' support staff. Less than 5% of the respondents reported the provider agency having "Complete or near complete" control, and almost 22% reported that this question was "not applicable" to their situation.

Insofar as self-determination is supposed to move power over support provision toward people and their freely chosen allies, these tables demonstrate marked success within the New Jersey self-determination pilots. The results for all the questions about who controls hiring and firing staff seem to suggest that family members feel they have control over the funds and the hiring and firing of staff, with their relative having less power than the family, and the provider agency having even less power. In the long run, the participants themselves should become more able and enabled to express their preferences about the people who support them.

Family Ratings of “Most Important Things”

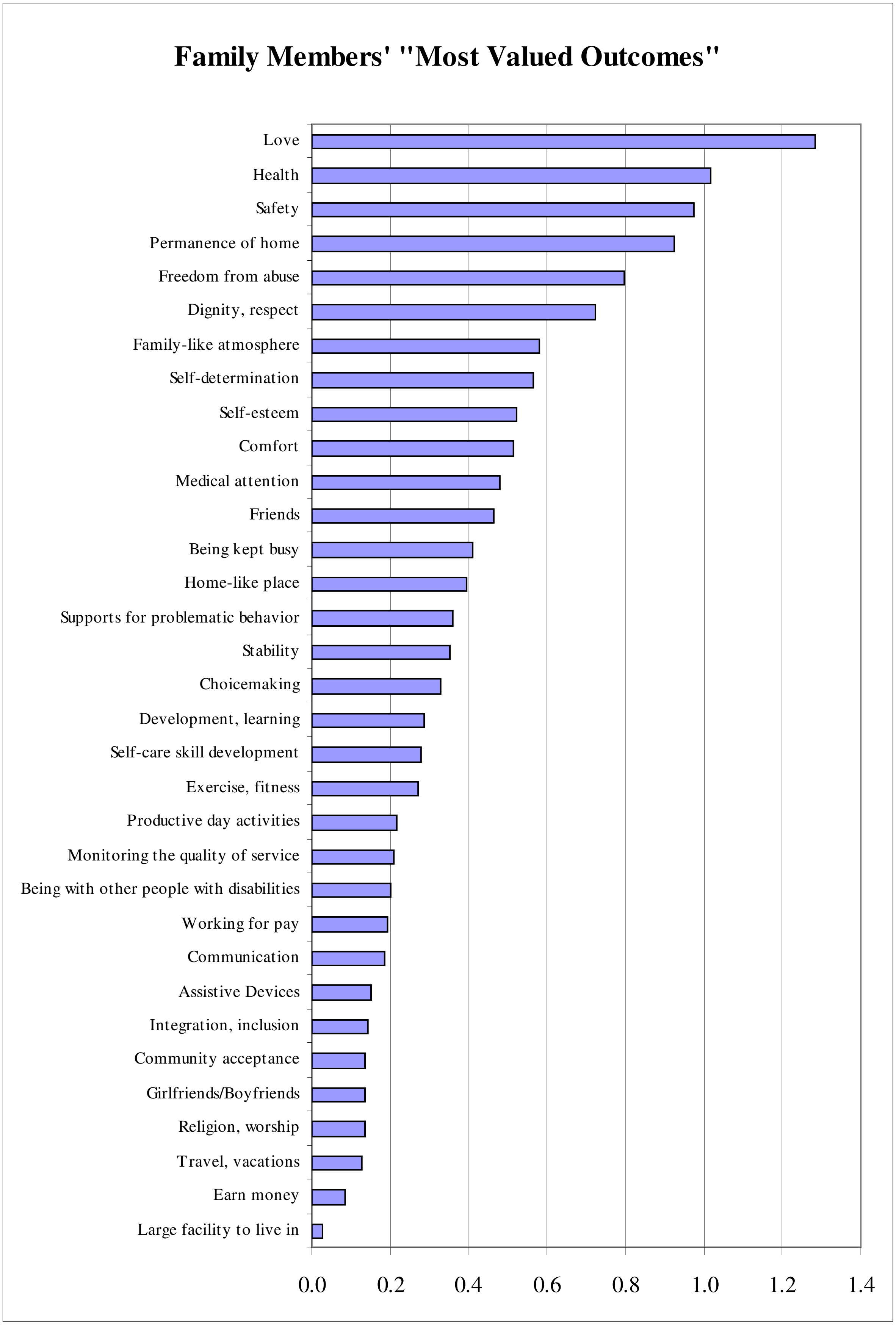
We asked family members to rate what they felt were the “five most important things” for their relatives’ well being. The main utility of this question is to help planners and policy makers understand the value systems within which the families of self-determination participants operate.

Because the value of families, participants, and professionals may be quite different, it was of great interest to find out what parents cared about the most.

(15) FIVE MOST IMPORTANT THINGS

- In the section below we would like to know what the **five** most important things are to you concerning your relative’s well being. **Please choose only five.**
- Please read through the list below and determine which of these is the #1 most important thing to you about your relative's well being. Please write a "1" next to that item. Then, please write a "2" next to the SECOND most important thing to you. Please continue writing numbers up to 5, for the fifth most important thing to you.

The results are shown in the graph below, presented according to the ranked importance selected by families. The numbers represent the <u>relative</u> importance of each area of life, as ranked by the families. The areas shown at the top of the graph were chosen by the most families.


Family Members' "Most Valued Outcomes"

We think these results are very revealing. The families expressed their highest values as Love, Health and Safety – not really different from the feelings of any parents. The next highest ranked values were "Permanence of home," "Freedom from Abuse" and "Dignity and Respect." The five items chosen least by respondents were "Girlfriend/Boyfriends," "Religion, Worship," "Travel/Vacations," and "Earning Money." None of the respondents chose a "Large Facility to Live In" as an important item for their relative's well being.

Some of the values that seem most related to self-determination, "Community Acceptance" and "Earning Money," were not ranked very highly by family members, while "Choicemaking" is found about mid-way in the hierarchy of values. What these findings might teach us is that while families value self-determination and tend to be very happy with it, they may see it as secondary to their highest values such as health and safety.

These expressions of family values are not the same as values often espoused by people with disabilities or professionals, and thus the unfolding of self-determination will have to include understanding and negotiation between and among families, participants, and professionals.

Family Comments About Self-Determination

To find out more about what family members think about self-determination in general and their relative's participation in it, we asked for comments. The following are verbatim responses from family members. Identifying information (names of individuals and/or service agencies) has been omitted.

Increase dignity & integration in community. Good because it provides for specific needs
Self-determination can be a very confusing experience when the client is not receptive to change; sometimes difficult to determine the right person to handle problems when they arise. The part-time relief by the support people so that she can go out without us.
Father wishes the support assistant would be more available.
1) Great opportunity to be 100% involved in managing loved one's well-being. 2) Need to understand it involves a lot of work. 3) "Budgeting process" should be addressed so plans are approved in a more timely manner.
A good program to help her have her own independent life.
An excellent program; one of the best things my son has ever experienced.
Best thing that ever happened for people w/ disabilities in New Jersey; need to build better system of communication & trust between all the principle players & agencies; support brokers should be paid more if they take on additional responsibilities; more recognition of family.
Brokers fees should be understood; what happens after our death?
Budget restrictions!
Can be instrument for independence; glad they have it.
Day program is going better now. Wanted to use our home as a permanent home for (name), self-determination says it is not possible.
Delighted with self-determination as it applies to our son. Found it very difficult to reach our goals as it pertains to the approval of the budget.
Excellent program for individuals. Challenge is obtaining consistent labor.
Excellent program for my daughter. Helpful people on staff. Wish that this program could transfer across state lines.
Good concept - fair plan, timeliness of reimbursement frustrating.
Good program -- staff issues -- hard to get staff.
Good program - allows daughter to be independent. Parents are getting older.
Good program - meets a big need for (name). Need more watchdogs for agencies to check on support staff.
Good program; needs improvement.
Grateful; made life considerably easier; 2 concerns: 1) bureaucracy in budget matters 2) keeping good staff.
Great praise for the program and hope it never ends.
Great program.
Great program - has given (name) an opportunity.

Great program. Broker is very helpful. Wonderful support.
Happy about making choices to do things, hard to find people to do it with.
Happy, allows (name) to be home and allows staff to come in and help.
Hardest thing ever had to do. With (name) it is very challenging because of special needs, finding staff has been extraordinarily tough.
Hasn't any longevity!
I'm very pleased with DDD services thus far.
I think it's an excellent idea for people with disabilities to get help in finding housing and getting out with people. And that Governors, starting with Whitman, were instrumental in starting this.
I think the initiative is working out well for him and for us. He seems happy & content.
I think this was a wonderful concept and it has been extremely successful for (name). However now the funding has become an issue so things have to change, which I am not happy with.
Re: selling home, they did not follow guidelines. Didn't give a fair appraisal - agreed to one then reneged.
Involved since mother's passing a year ago. Concerned about (name)'s future welfare.
It's about time. Wonderful idea. What we dreamed of years ago. Idea personified in self-determination - family is included.
It is a very good program. Think there should be classes for the people that work with (name.)
It has been a life-saver for him. He had nowhere to live. It has helped give him self-esteem.
It has helped and I love it. They give us the needed help for nursing.
It is a wonderful program for my sister. She can be independent. Without this program, she could never make it on her own.
It is an excellent program and we hope it will continue.
It is essential for our well being and the happiness and contentment of our daughter.
She has concerns about her aid- who does personal shopping and movies on work time. She likes fishing, buggy rides and track which she has done a few times. Doesn't follow any schedule. Takes her where she wants to go.
Like it - helped him to be independent
She's more independence than when she was home. Staff retention is a problem.
Lots of questions and people do not seem to have all the answers. Not clear on processing the program.

Made a difference in our lives; no appeal process for budget; God send for us. It's a lot of work - every day thing. Best option for us. Concern about over-regulation - red tape/ restrictions.
Material that is received in the mail does not pertain to this family and their disability. Getting support less than average and very hard to find.
Mom is now able to have some quality of life too. (Name) loves the provider. Provider &(Name) get along very well. Cost-effective.
More feedback should be obtained from family and participants.
New in the program, learning.
New to initiative. Hope to access all of the supports available.
Not pleased with changes in budget cuts: clothes, transportation, recreation, food / more flexible as children & parents get older.
Overall great idea; lower taxpayer expenses & deliver good service. Lack of staff or keep good staff.
Positive program. Sometimes communication breakdown with provider.
Program has merits. It does not meet all his needs though.
Program is great; need providers; agency problems.
Program keeps her here. They seem to be on top of things.
Questioning the longevity of her being on her own without complete family involvement. Needs to be someone to co-ordinate her life - other than family and broker.
Really like this program. Been able to express herself much more. DDD was to have provided occupational therapy-was not done-only now through self-determination does she receive it.
Really think it is good!
Self-determination initiative has allowed him to develop towards independence. It has also given him a life he would not have had living at home. In the future he has choices.
Self-determination is very important to my family because I have the right to choose. I have better supports than the traditional placement. However, the state needs to allow more flexibility with money increases to pay staff and high bills.
Self-determination should be transferable from state to state so family members can be close to him to monitor it.
Seems to be working well.
Self-determination has been an ideal program for our son; to be able to make the choice as to how we wish our son to live in the future and have support of self-determination has been very helpful.
Self-determination has helped him to accept new people to help him in his

life. I wish that self-determination had started sooner.
Self-determination has helped him to become more independent and self-assured and very happy.
Self-determination is a great program except communication with DDD, case managers, more money, more flexibility with funding. I think that once a budget is made funds should be carried over considering funds are approved for future years.
Simplify the administration of program. Make money easier. Do away with line item budgets. Approve budgets on time.
Since going self-determination, she has more staff and is happier.
Such a help and open up opportunities - she has blossomed.
Support it extremely -- but as it goes on it is limiting her choices - not always flexible - "caps" - limit choice.
She has really benefited by this program. It has given her a lot of new activities.
The best program to come out of the state/ an amount of money would not go through so many agencies
The initiative is wonderful. The problem lies in getting staff that is qualified.
The program has been excellent for (name)'s need.
The program is great - glad to be accepted in it. Opened up opportunities.
The program is the best thing that's happened to (name) and having a broker to help us has been an advantage.
The program is wonderful and has taken a load off sister's head.
The self-determination initiative has made a world of difference in the quality of (name)'s life. I cannot say enough good things about the initiative!
The survey takes too long.
They changed the one time money for bedroom furniture - to none/ Like support from Broker and Tutor Service.
Very active in the very beginning. Choices were limited wanted more consistency with her schizophrenia.
Very good program - like having her at home. Could not afford without the initiative.
Very good program.
Very great program. Not for group homes. Wants two brothers to stay in home together as long as possible.
Very helpful.
Very pleased with the program.
Very pleased with agency and broker.

Very poor training for support staff; brokers do not have services in place for a plan; dissatisfied with staff.
Very successful for brother and very good program for those who don't fit.
Very successful for people like my son but not good for people who need 24 hour services.
Very worthwhile program -- we are pleased! She is pleased - enjoys her freedom & home - has enhanced her self-esteem.
We'd like more flexibility in the budgeting process. Not necessary to have more money, just less restrictions on how it is used.
We are very pleased that we've been able to participate in self-determination. It has offered us the flexibility to support our family at home.
We do feel it has some limitations for someone who requires 24/7 to live independently.
Who would take over keeping the program going with (name) when parents are gone and what would happen?
Wish that parents had more movement of approved funds into areas where there is a need.
Wish we had more help to find housing and job hunting.
Wish there were other people in area to do activities & contact.
Wonderful program for people to live their own life.
Wonderful; very happy; staff is good.
Worked well & provide (name) the opportunity to be independent.
Working good; a help because daughter can be home.
Working well for (name).

The majority of these comments are positive. It appears that most families in New Jersey are happy with the self-determination initiative. The few negative comments include worries about their family member and the program in the future, concerns about the length of time it takes to get budget approval, and concerns about increased bureaucracy and regulation of the self-determination initiative.

We also asked family members to describe services or supports that they and/or their relative were able to purchase because of the self-determination initiative. Again, verbatim responses are shown below:

Staff support - needed staff support. She' a good person with a good personality, attitude & people skills. She's helped (name) to have a full life.
A place of her own with supports for success has given her a wonderful quality of life.
One-on-one job coach to allows her participation in the work program she attends.
Personal assistance & support.
40 hrs nurse - primary caregiver closed the gaps in the schedule. Keep him at home.
A van with a lift.
Additional hours for personal aid. Allows for freedom.
Afforded her to have her own place; watched her grow and make many decisions; good.
An apartment. It has given my son an independent lifestyle.
Being able to hire staff that we can choose personally is very helpful.
Better access to home care and activities because of the quality of life is improved and stress level is down.
Bought leather coach and chair ottoman.
Ceiling lift.
She was able to buy her own townhouse/condo. She bought it so she'd always have her own place to live.
Computer - has difficulty speaking and spelling. This is "write out loud."
Computer - taking computer courses.
Concerns: budget needed to be more flexible. More funding for "one-time" items. Very hard to get a tutor $30/hr is very low for a tutor. Networking for services is difficult.
Driver.
Enabled us to hire a support assistant.
Extra money.
Financial help very important - since mother died. Ability to go to camp.
Financial help, rent, clothing.
Financial help. Bed and chair, sofa-bed.
First year: funding for supports.
For him to have his own apartment with the rent paid by self-determination is the one cost factor that he/we never could have afforded. It has made all the difference.
Full-time in-home support staff; allows us to no longer try to fit a "square" into a "round" hole. Allows the program to flex to (name)'s needs rather than the other way around.

Getting support.
Handicap bathroom was desperately needed to give my sister a place to shower instead of sponge bath, and a proper toilet to make it easier to get up.
Having a personal assistant for (name) so that I can be less stressed.
Having her own place.
Helped fund the program that we could not do forever.
Her apartment!
Her staff.
His furniture for his new apartment. This has made him feel very complete as he has his very own furniture that he has chosen with the help of his Mom & Dad.
Home health staff.
Household furnishings.
Aides, - one especially has become a buddy, a friend, a role model very much needed.
Job coach & support.
Larger screen TV it is recreation for me. Socializing is very difficult on a day-to-day basis. Me & (name) sit together to watch TV.
Living independently & staff.
Nursing support has kept (name) healthy and active.
Obtain various services to permit interaction with the community.
Own apartment.
(Name)'s independent living & support.
Personal assistance.
Personal aid - 40 hrs/wk.
Personal assistant. Independent home.
Personal assistant/transportation for workshop/microwave.
Personal care assistance.
Personal care assistants. My son requires supervision around the clock.
Personal staff.
Personal support aides; her housing.
Private hire and give (name) a qualified personal assistant.
Pull out couches/vita mixer - helps with his food.
Rent, car insurance.
Same program living alone -- wouldn't have happened without "self-determination."
Secure a home for him and allow him to enjoy choices.
Service of support staff to get (name) out more.
Services were very important.

She is able to live on her own.
Staff – loving.
Staff.
Staff and having (name) live independently.
Staff and helping him own his own home.
Staff and his independence make him feel like an adult.
Staff, support and home.
Staffing, rent assistance, transportation.
Support aide.
Support aide -- while working, mom had surgery - and this was a miracle for (name).
Support aides.
Support broker and more support for staffing.
Support broker, more staffing hours, rent assistance, choice and responsibility.
Support service.
Support services and apartment allow (name) to live independently.
Support staff.
Support staff / moving my daughter out to her own apartment.
Support staff to allow for more care - quality of life.
The ability to go to camp - only 1 week if not in program. Financial help very important.
The individual assistance makes the family and life functional.
The part-time relief by the support people, so that she can go out without us for errands & recreation.
Therapies.
Therapies & staff.
Therapies / staff.
There are many things - for example - rent, lease car, cable TV, dental care.
Used for nursing care.
We got (name) a mattress.
We have (name) taking horseback lessons, swimming and volunteering at the hospital.
We were able to hire staff to work with (name).
We would not have been able to support him towards his independent lifestyle.
We, along with two similar families were able to purchase a home for our son. He is happy there because it is like the house he grew up in along with his brother & sisters.
Yes, a personal assistant. This allows my daughter to get out without relying

on family members. She is enjoying new experiences that she wouldn't have otherwise.
Yes. Person to take her to hospital procedures gave her advantage of being able to get to the hospital on her own.

Families of New Jersey Self-Determination participants overwhelmingly reported positive changes in their relative’s lives due to the self-determination initiative. Most of the comments expressed in response to this question described various services they had been able to purchase. Services mentioned most frequently were personal assistants, therapies, and the ability to get their relative into the living arrangements they desired.

Wishes

Finally, we asked families to share one wish for their relatives. The responses to this question, in the personal interviews with participants and in family surveys, are always poignant. Below are the verbatim responses of family members.

Good life after we are both dead.
A happy life.
A long, happy life.
Able to function on her own; she will need staff all her life.
After I am gone who will take care of him?
Also wishes (name) could have a girlfriend - phones one young lady - out of local area.
Be content in some well-managed place if she can't be at home. Agency is monitoring the situation.
Be happy.
Be happy & somebody to care for him.
Be happy and self-confident. Be able to live and be happy in what she is doing.
Be happy with his life.
Be happy, successful, and healthy.
Became responsible person for her daughter.

Believe in himself & be able to handle the house.
Continue budgeting.
Continue to be happy and healthy.
Feel good about herself & be happy.
Find a soul mate. One that could be trusted and someone who would love and help her through life.
Find some other friends so not as reliant on family.
For (name) to get out more.
For her to remain as she is but with more community outings.
For (name)'s happiness and security.
For (name) to enjoy a full happy life independent of Mom.
Future = parents getting older & worries about him; wants him to have the care he is currently getting after she passes.
Get longevity into the program.
Get over obsessive/compulsive behavior.
Good health & happiness in the future. Love of family.
Happiness and ability to enjoy life to the fullest.
Happiness and be able to continue living at home - in her own home.
Have a great friend.
He continues to be happy & healthy.
He could live independently forever with no help.
Health and weight - ok - long term.
Health improve.
His complete independence. We are seeing a wonderful miracle of him living on his own. We are so very grateful.
Hope she is happy with life.
Hope that the family can be there to allow her to stay at home. More assistance with her care.
I think this program is very good.
I wish she could find happiness.
I would wish for (name) to meet someone to love and have a lifetime companion.
(Name) should & must have physical therapy.
Know that she understands. Helps to have understanding.
That she has a permanent place to live and be safe of her choice.
Little more self-confident - talk more - develop job skills - his grave has already been purchased.
Living on her own/ love to see her living independently and happy.
Maintain life in a happy, secure environment.
More social interaction and hobbies.

Return to his outgoing self before his mother passed away.
(Name) continues to be happy.
Safe, happy and cared for without family.
See him happy.
Someone was always there to take of her.
Stay in his own family home for the rest of his life.
To be normal!
That he be self sufficient and that this program will continue for the lifetime of my son.
That he become independent enough so that after other family members have passed away, he be self-sufficient as best as is possible.
That he continues to be as happy as he is now.
That he didn't have those seizures.
That he is happy healthy and enjoys his life.
That he live a happy & productive life.
That he remain happy.
That he would have a home of his own and be healthy and happy.
That her health improves to the extent that she could be more self-reliant.
That (name) would become more independent & enjoy being alone in the condo occasionally.
That self-determination continue for his lifetime.
That she be safe from abuse, and continue to be appropriately supported by "self-determination" forever in the manner that she chooses to continue life's journey.
That she can stay with us and live a little longer. Whatever God allows.
That she could continue to live in the same family surrounding.
That she had a good friend.
That she had no problems.
That she has a happy and fulfilling life of her own choosing, with enough support to make it happen.
That she is happy.
That she would be happy.
That she would be willing to live independently from us.
That she would have inner happiness & a life with lots of love.
That we could find a satisfactory long-term residence solution that we could trust & feel comfortable with.
The assurance that she would always have access to the finances and personal assistance coverage that she has now and will need when we are no longer here to provide it.

This could continue beyond my ability to monitor it.
To always have somebody to be there for her.
To be able to live happily on her own with staff & friends.
To be able to live in this world with dignity & respect - respect her in the world - have choices.
To be able to live on her own without family support after we die.
To be able to maintain the same quality of life with this program.
To be able to survive happily on her own when she is not here.
To be able to talk.
To be alcohol free.
To be happy
To be happy in what he does.
To be normal and to be happy.
To be normal.
To be perfectly healthy
To be well taken care of for the rest of his life.
To experience her complete freedom.
To find good quality respite services within our home which could also provide for (name)'s diabetes needs at an acceptable cost to permit (name) to remain safely at home while Mom & Dad (main care-givers) have some well-deserved time away.
To get on with his life.
To have a full and happy life. To be content.
To have her health back.
To live as independently as he can in a safe environment.
To live in a home where he is loved.
To live in his community that he is familiar with and have the same freedom of choice as his siblings.
To live out her life in a loving safe environment surrounded by those of us who love her.
To make sure (name) will be taken care of in the future when I die with self-determination and support.
Want him to be healthy and happy.
When I am no longer here - that she is in a stable environment and self-sufficient.
When we are not here anymore - that he can be more independent in the proper direction and make good decisions.
Wish her to get all the good that she deserves.
Wish she be normal.

Wish she could stay with her sister.
Wish that the program will continue and allows for some respite from care.
Wish they were normal - able to manage themselves.
With them as long as absolutely possible.
Wonderful life.

Like most parents and family members, these respondents want their relatives to be healthy and happy, secure and loved.

Family Survey Summary

The results of the family survey lead to some defensible inferences. First, there is a suggestion that power has shifted toward families – and to a lesser degree toward individual participants. Second, the values of parents tend not to stress freedom, authority, support, responsibility, and self-advocacy nearly as much as their concern for health, safety, love, freedom from abuse, and permanence of home.

Family members report that self-determination has enabled them to purchase many of the services they need for their relative, and most comments about the self-determination initiative were overwhelmingly positive. All in all, the family survey leads to a cautious conclusion that the initiative has made some progress, and yet has a long way to go.

Results 4: Cost Analysis

The third hypothesis of self-determination is that "***costs will be the same or lower than they would be in the traditional professionally-dominated approach***."

An essential part of self-determination is having an individual budget. In most states and service systems (especially for residential and day services,) group budgets and provider contracts were in place prior to self-determination projects. Self-determination presumes that one cannot control resources for one's life needs unless one knows what resources are available. This means that "money must be attached to, and follow, the person." In most states and service systems, this has never been achieved, even up to the present.

In New Jersey, people with disabilities and their families were able to select self-determination as an alternative to traditional residential placement when their names rose to the top of the waiting list. This choice permitted them to negotiate an individual budget and to become active participants in the choice and management of their services. Each person was allocated an amount of money based on an assessed level of need and the costs for traditional services to meet the need.

The line item categories for expenses are the same ones used for traditional residential placements. An additional category for self-determination participants is a $4,000 allocation for a Support Broker. Another difference is a breakdown of personal assistance funds according to whether they are purchased through an existing provider agency or through the Easter Seals fiscal intermediary. DDD maintains an annual contract with Easter Seals, the cost of which is not reflected in individual budgets, however it is estimated that the cost per person is less than $2,000 per year.

The table below shows the average cost, by category, for the 60 people for whom we received official, approved budgets.

Budget Detail For 60 Participants

Budget Category	FY 2002
Primary Individual Assistant (ESSNJ)	$18,720.39
Primary Individual Assistant (Agency)	$7,992.16
Rent or Room & Board	$7,670.64
Support Broker	$4,050.00
Recreation	$2,188.97
Food/Household	$2,145.70
Travel & Reimbursement	$1,965.70
Medical	$1,370.37
Clothing	$1,072.76
Miscellaneous	$904.67
Utilities	$780.33
Education	$765.03
Insurance	$755.62
Communications	$426.39
Vacation	$381.50
Furniture	$373.77
Repairs & Maintenance	$365.45
Equipment	$293.93
Renovations	$226.78
Advertising	$111.18
Total Average Costs	$52,561.32

These 60 self-determination participants were allocated an average of $52,561 per year for residential supports. This is an acceptable figure when compared to the annual cost of traditional residential services in New Jersey: Developmental Centers at $120,000 in 2001; home or community based waiver placements at $52,024 annually. [2] According to DDD sources, annual costs for a Special Needs Group Home can be in excess of $60,000. It is important to note that the self-determination budgets do not include any public, capital acquisition

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[2] Lakin, Prouty and Smith (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2001.* Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

funds. Bond income is used in New Jersey to acquire the group homes owned and operated by provider agencies.

On the average, about half of the self-determination budgets were spent on individual assistants in the home ($26,713.) Room, board, and utilities cost an average of $8,451. Average ongoing costs may become even lower, because the costs for furniture, equipment, and renovations do not recur annually.

The consensus of opinion on cost is that it is always expensive to operate dual systems and that we probably need more time to fully understand the cost implications of self-determination. Some key informants suspect increased costs due to previously unidentified needs and the flexibility to spend funds in different ways. In contrast, one family member stated that actually providing people with what they need is less expensive in the long run.

Analysis of data from this relatively small sample does not assure us that the results would be the same if the entire developmental disabilities services system were converted to self-determination. Nevertheless, when placed side by side with our own rigorous findings in several other states, there is good reason to give credence to these findings. In New Hampshire, Michigan, Ohio, and Hawaii, we have obtained hard evidence that self-determination avoids cost increases, and in two of our studies (the ones that involved people in high cost congregate care settings), costs actually went down significantly.

The New Jersey fiscal data can best be interpreted as reasonably strong support for the notion that self-determination will slow the increase of costs in the future. At the same time, because quality of life and satisfaction measures have shown strong benefits associated with self-determination, it would seem that public policy should seriously consider self-determination as a major direction for the future in New Jersey.

Appendix A: Personal Life Quality Protocol and the Family Survey

Appendix B: Brief History of Self-Determination

Appendix C: Report 1 – Policy Analysis