

# **Independent Evaluation of the Monadnock Self Determination Project**

*Submitted by:*

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## **Introduction**

Self determination and choice are rapidly becoming dominant themes in the lives of people with mental retardation and developmental disabilities (Nerney, Crowley, & Kappel, 1995; Stancliffe, 1995; Wehmeyer & Metzler, 1995). This is a report of the first comprehensive empirical evaluation of a self determination project in the State of New Hampshire.

The Robert Wood Johnson Self Determination Project in southwestern New Hampshire is testing the theory that if people with major developmental disabilities and those who support them gain control of their lives and resources, their quality of life will improve and the amount of government expenditures sustaining them will decrease. The project was conceived on the premise that current thinking and practices for supporting people with disabilities often prevent people from achieving their potential, and are extremely costly. In other words, as stated in the original proposal to the Foundation:

For people with developmental disabilities, our service delivery practices are so outmoded, so disenfranchising, and so costly that radical departures must be demonstrated and evaluated immediately (Nerney, Crowley, & Conroy, 1993, page 1).

The project has attempted to implement a new service paradigm, linking the current system to managed care concepts such as individual choice and responsibility, capitation, and cost control.

### **Paradigm Shift**

A revolutionary change in our pattern of thinking or world-view, commonly referred to as a paradigm shift, was originally described by Kuhn (1970). It is only recently that paradigm changes have been addressed within the context of the human services. In health care, for example, individual autonomy is beginning to replace professional beneficence as the primary organizing principle (Beauchamp & Childress, 1989). Likewise, because hierarchical social structures are rapidly becoming decentralized, diverse, and complex (Guba, 1985; Guba & Lincoln, 1989; Lincoln, 1985; Lincoln & Guba, 1985; Schwartz & Ogilvy, 1979), the necessity for individual autonomy and self determination is growing.

In recent years, evidence of a nascent paradigm shift has been described in the developmental disabilities literature (Ashbaugh, 1994; Boggs, 1994; Bradley, 1994; Bradley & Knoll, 1992; Evans & Meyer, 1993; Guess, Turnbull & Helmstetter, 1990; Haring & White,

1990; Meyer & Evans, 1993; Racino, 1994; Yuskas, 1992; Zeph, 1989). Some identifiable elements of the emerging paradigm are individual autonomy, empowerment, choice, and self determination, and the correspondent social values of individualization, diversity, and heterogeneity.

Self-advocates have supported the goals of autonomy and self determination (Kennedy, 1993; Ward, 1988; Williams, 1989). Likewise, professional disability associations have identified the need for new policies that promote individual autonomy (AAMR, 1993). These forces appear to be propelling a social revolution in the way persons with disabilities are perceived and treated. But despite individual success stories, there has been little documentation of actual achievements in radical systems change incorporating these concepts. Moreover, changes at the individual level have proven fragile unless the large bureaucratic systems supporting them undergo simultaneous change (Hagner, Helm & Butterworth, 1996). Some advocates believe that current community service systems, which were built on institutional and facility based programs and fiscal patterns, require an entirely new way of supporting people and designing services (Racino, 1994; Smull, 1990). They argue that a social revolution supporting the exercise of self determination by people with disabilities requires much more than a change in language or conceptual recognition of a shifting paradigm.

### **Implementation of Self Determination**

In 1993, the Robert Wood Johnson Foundation awarded a three year grant to Monadnock Developmental Services of Keene, New Hampshire, to assist in answering this central question: “How would a system of supports look if people with disabilities and their circle of friends, or network, were truly in charge of their own services, if they achieved self determination?” (Nerney, Crowley, & Kappel, 1995, p.5). The New Hampshire Self Determination Project was intended to implement and test such an approach.

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

Stancliffe, 1995; Wehmeyer, 1993, 1994a&b; Wehmeyer & Kelchner, 1995; Wehmeyer, Kelchner & Richards, 1995), self determination remains difficult to define. A key component associated with all interpretations, however, concerns the notion of power.

The Monadnock Self Determination Project is a revolution in that it increases the power, authority, and resources of individuals to control their own destinies (Nerney, Crowley, & Kappel et al., 1995, p. 16). It is “an attempt to fundamentally reform both financing mechanisms and basic structural aspects of the current service delivery system” (Nerney & Shumway, 1996, p.7). The Monadnock service organization addressed three fundamental issues: (a) enabling individuals and their families to control dollars without dealing with cash; (b) changing the role of case management to personal agents chosen by the consumer and independent brokers of services; and (c) organizing a coherent response to a managed care culture (p.4).

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

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

Freedom: The ability for individuals with freely chosen family and/or friends to plan a life with necessary support rather than purchase a program;

Authority: The ability for a person with a disability (with a social support network or circle if needed) to control a certain sum of dollars in order to purchase these supports;

Support: The arranging of resources and personnel - both formal and informal - that will assist an individual with a disability to live a life in the community rich in community association and contribution; and

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

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

In addition to individualized budgets, the notion of "fiscal intermediaries" was created. These entities are intended to provide technical and fiscal supports without usurping the primacy of the individual with a disability, family and friends. The utilization of fiscal intermediaries allows people to hire and manage their own support staff while another organization or person handles the federal and state employment requirements, such as employment taxes, minimum wage, overtime, and liability issues (p.9).

Community development is also a key to the advancement of the Self Determination model. Assisting a person with a disability to nurture and create an informal support network is necessary part of relationship building. Thus, efforts are made to enhance people's associational life and advance the goal of inclusive communities in which everyone is welcome.

The four principles - Freedom, Authority, Support, and Responsibility, and other program implementation details are described further in Nerney & Shumway (1996). These components served as a foundation for the Self Determination Project at the Monadnock agency in New Hampshire, and will continue to serve as a basis for the national project.

## **Methods**

The Self Determination Project has unfolded in different ways for different participants. Part of the experimental nature of the Project has been to ask: “How far can these principles can be extended, to what kinds of people, with what outcomes?” At the outset, then, the expected outcomes of the Self Determination Project were not operationalized in detail. In other words, program implementers were not entirely sure how the Project would affect measurable qualities of life of the participants. The proper approach in such a situation is to measure as many outcome dimensions as possible. Quality of life is inherently multidimensional, and different people attach differing degrees of importance to each dimension (Conroy, 1990).

### **Instruments**

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

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

### **Design**

The evaluative data reported here originate from a simple prepost design. We visited and collected information on 42 Project participants at the beginning of the Project. Then, at 18 months, we visited and collected data for 43 participants. Because a few people left the Project and were replaced, there were 38 people for whom we had complete data from Time-1 (the beginning) and Time-2 (18 months). In this report, we explore what (if any) qualities of life had changed among the 38 people during 18 months of Self Determination Project implementation.

Data were also collected for 90 non-participants at Time-1, and will be collected again at Time-3 (late 1996) to provide a comparison group.

### **Procedures**

Data collectors initiated contact with participants and scheduled appointments. The collectors were instructed to be flexible, and to avoid interference with routines and schedules. Data collection required: (1) access to the person, (2) access to whoever knew the person best on a day-to-day basis, (3) access to the person's home, and (4) access to records concerning the person's services and supports. Data collection visits averaged approximately 70 minutes at the residence.

## Results

### **Results 1: Participants**

The analyses presented here concern 38 people who became involved in the Self Determination Project at varying times after November of 1993, and remained involved until February of 1996. Data collection was completed at both Time-1 and Time-2 for 38 participants. Because generalization is a critical issue, it is important to describe the 38 participants in comparison to the non-participants. If the participants were very different from the non-participants, then the outcomes for the participants might not be generalizable.

Table 1 shows the average age, the average number of years institutionalized, the percentage male, the percentage with other disabilities, the percentage with the severe or profound label, the average adaptive behavior score, the average vocational behavior score, and the average challenging behavior score.

**Table 1**  
**Characteristics of the Self Determination Participants and Non-Participants**

<b>CHARACTERISTICS</b>	<b>Participants</b>	<b>Non-Participants</b>	<b>p</b>
Average Age	39	42	NS
Average Years in Institutions	23	26	NS
Percent Male	46	54	NS
Percent with Other Disabilities	92	96	NS
Average Challenging Behavior Score	90	91	NS
Average Adaptive Behavior Score	61	69	.027
Average Productive Behavior Score	45	56	.012

Only two of the group differences were statistically significant. The participants were lower in adaptive behavior ( $t=1.95$ , 125 df,  $p=.027$ ), and lower in vocational behavior ( $t=2.31$ , 95.70 df,  $p=.012$ ), than the average MDS service recipient. In all other respects, the participants were quite similar to the non-participants. The similarities suggest the outcomes of Self Determination for the participants will be generalizable to non-participants should they join the Project at a later time.

## **Results 2: Self Determination Scale Changes**

The Decision Control Inventory© (DCI) was designed to tap the multiple dimensions of self determination. The DCI includes 26 dimensions of everyday life., such as use of personal money, choice of foods, choice of homes, choice of case managers, whether to have pets, and so on. In each dimension, respondents are asked to describe decision making on a 0 to 10 point scale, from 0 meaning decisions are made entirely by paid staff, to 10 meaning decisions are made entirely by the individuals and/or unpaid loved ones.

The overall scale is composed by combining the 26 dimensions. The DCI has been tested for reliability (Conroy, 1995). Internal consistency as measured by Cronbach's Alpha was .95. For test-retest reliability, the Pearson correlation between time 1 and time 2 was .98. The third test combined interrater reliability with test-retest, and the correlation was .86. The correlation of the DCI with overall adaptive behavior was 0.71, showing that about half of the variance in the Decision Control Inventory could be accounted for by adaptive behavior, and conversely, half could not ( $0.71^2 = 0.50$ , or 50%).

The prepost changes on the DCI are shown in Table 2 on the following page. Table 2 presents the mean scores from Time-1 (the baseline data from early 1994) and Time-2 (the most recent round of data collection in late 1995). The two rounds of data collection averaged 18 months apart. Table 2 also shows the change, the  $t$  test value, and the 1-tailed significance level for each dimension of the Decision Control Inventory.

There were 22 increases and 4 decreases among the 26 dimensions of the Decision Control Inventory. The paired t-test is the statistic of choice in the test-retest situation. In Table 2, the criterion was 0.10. By this criterion, there were significant increases in self determination scores on 11 of the 26 dimensions, and a decrease on 1 dimension. If we used 0.05 as the criterion, there would be 7 significant increases and no decreases. On the next following page is Figure 1, in which the bars represent the amount of change from Time-1 to Time-2 for each of the 26 dimensions, sorted by the magnitude of change.

**Table 2**  
**Decision Control Inventory Outcomes:**  
**Degree of Control Over 26 Dimensions of Life**  
**38 Participants in the RWJF Self Determination Project, Time-1 to Time-2**

	<b>Time-1</b>	<b>Time-2</b>	<b>Change</b>	<b>t</b>	<b>p</b>	
What to do with personal money	6.34	7.63	+1.29	-2.26	0.015	*
What to do with relaxation time	8.05	9.18	+1.13	-2.83	0.004	*
When to get up on weekends	8.00	9.08	+1.08	-1.98	0.028	*
Choice of house or apartment	4.53	5.53	+1.00	-1.18	0.124	
Taking naps evenings/weekends	8.74	9.71	+0.97	-2.40	0.011	*
Visiting w/ friends outside home	6.00	6.94	+0.94	-2.19	0.018	*
What foods to buy when shopping	5.43	6.35	+0.92	-1.75	0.044	*
Choice of furnishings, decoration	5.73	6.62	+0.89	-1.62	0.058	*
When to go to bed on weekends	8.08	8.95	+0.87	-1.53	0.067	*
Declining group activities	9.03	9.87	+0.84	-2.28	0.014	*
When to go to bed on weekdays	8.16	8.82	+0.66	-1.42	0.082	*
Express affection, including sexual	8.71	9.26	+0.55	-1.39	0.087	*
Having pet(s) in the home	7.61	8.06	+0.44	-0.59	0.278	
Choice of people to live with	4.55	4.97	+0.42	-0.50	0.311	
What to have for breakfast	7.68	7.97	+0.30	-0.65	0.260	
Type of work or day program	4.92	5.19	+0.27	-0.43	0.334	
"Minor vices"	7.60	7.86	+0.26	-0.32	0.377	
Choosing restaurants	6.68	6.92	+0.24	-0.47	0.320	
Choice of places to go	6.81	6.97	+0.16	-0.29	0.389	
What clothes to wear weekdays	7.47	7.63	+0.16	-0.29	0.386	
What clothes to wear weekends	7.55	7.71	+0.16	-0.31	0.379	
What clothes to buy in store	7.26	7.34	+0.08	-0.17	0.435	
What to have for dinner	6.73	6.41	-0.32	+0.59	0.279	
Choice of Case Manager	2.14	1.67	-0.47	+0.74	0.231	
Amount of time spent at work/DP	5.11	4.46	-0.65	+0.90	0.186	
Time & frequency of bathing	6.05	5.00	-1.05	+1.47	0.075	*

### **Results 3: Personal Interview and Satisfaction**

The interview included 24 questions, some with subsections and/or probes, and opportunities for open-ended comments. Also included was one scale of perceived changes in qualities of life during the past year. Examples of interview questions included:

- How do you feel about living here?
- Do you have enough privacy?
- How is the food here?
- How do you feel about the people you live with?
- How do you feel about the people who work with you at this home?
- How do you feel about your [job, day program, workshop, etc.]
- Do you feel that you are paid enough for the work you do?

At Time-1, 27 people, and at Time-2, 34 people were able to complete all or most of the interview. There were 27 people who were able to respond at both Time-1 and Time-2, and these were the people for whom we could analyze changes in satisfaction and perceived quality. Responses were placed onto 5 point scales, with higher values indicating higher satisfaction or quality. All of these items were then combined into a single overall scale of satisfaction. The overall scale was computed so that it could range from 0 to 100.

At Time-1, the average score among the 27 responding participants was 67.6. At Time-2, the average score among the same 27 people was 74.2. The average increase of 6.7 points out of 100 in an 18 month time period was significant ( $t=2.15$ , 26 df,  $p=.041$ ).

As part of the personal interview, we included an instrument called Quality of Life Changes. This scale asked the person to rate the quality of his/her life A YEAR AGO and then rate quality NOW. Ratings were presented on 1 to 5 point scales, with 1 being Very Bad and 5 being Very Good. This was the only part of the personal interview in which surrogates (usually residential staff) were allowed to give their opinions if the individual was unable or had difficulty. The ultimate answers were often the result of discussion. Ratings were collected for nine dimensions of quality, shown in Table 3.

**Table 3**  
**Perceived Changes in Quality of Life Over the Past Year**

	Time-1	Time-2	Change	<u>t</u>	<u>p</u>
Health	3.60	4.03	- .429	- 3.43	.001
Running my own life, making choices	3.46	4.20	- .743	- 5.38	.000
Family relationships	3.41	3.53	- .118	- 1.16	.254
Seeing Friends and socializing	3.46	3.97	- .514	- 5.41	.000
Getting out and getting around	3.54	4.03	- .486	- 4.09	.000
Day activities	3.46	4.14	- .686	- 4.51	.000
Food	3.62	4.23	- .618	- 3.66	.001
Happiness	3.63	4.46	- .829	- 6.24	.000
Comfort	3.63	4.37	- .743	- 6.27	.000

Comparing the average responses from A YEAR AGO to NOW revealed that every one of the nine dimensions was reported to be higher in quality NOW than A YEAR AGO. These outcomes are presented graphically in Figure 2 on the next page, sorted by the magnitude of the change.

The largest reported improvement among the nine quality of life dimensions was in Happiness, followed closely by Running My Own Life, and Making My Own Choices. Eight of the nine increases were statistically significant. The one change that was not statistically significant was Family Relationships.

Ratings from the 11 areas were also combined into overall ratings for A YEAR AGO and NOW. The average score for overall quality of life A YEAR AGO was 66.4. For NOW the average was 77.7. This difference was significant ( $t=2.96$ , 37 df,  $p=.003$ ). On the average, then, the participants reported (sometimes with assistance from others close to them) that their lives were considerably better NOW than A YEAR AGO.

#### **Results 4: Relationships and Integration**

During each data collection visit, we obtained estimates of the frequency of visits from relatives: “About how often do the [primary] relative/friend/guardian visit this person?” At Time-1, the median was 12 times per year, and at Time-2 the median was 8. The difference was not significant. There was no change in the frequency of visits from the participants’ primary relative, friend, or guardian. We also asked how many relatives “keep in contact with, visit, or help support this person.” The median was 2 at both times. Hence, the number of relatives engaged in the participants’ lives was unchanged. Responses to the question “About how many people in this person’s life would be described as “close friends?” increased from an average (mean) of 9.0 to 10.7, but the difference was not significant. In other words, the number of close friends was unchanged.

There was no change in the proportion of people reported to have a group that could be called a “circle of friends.” It was about 50% at both times. However, for those who had a circle of friends, the average number of members in the circle increased sharply from 4.7 to 10.5 (medians 4.0 and 10.0), and this increase was significant ( $t=2.32$ , 37 *df*,  $p=.020$ ). The sizes of circles of friends, for those that had them, more than doubled.

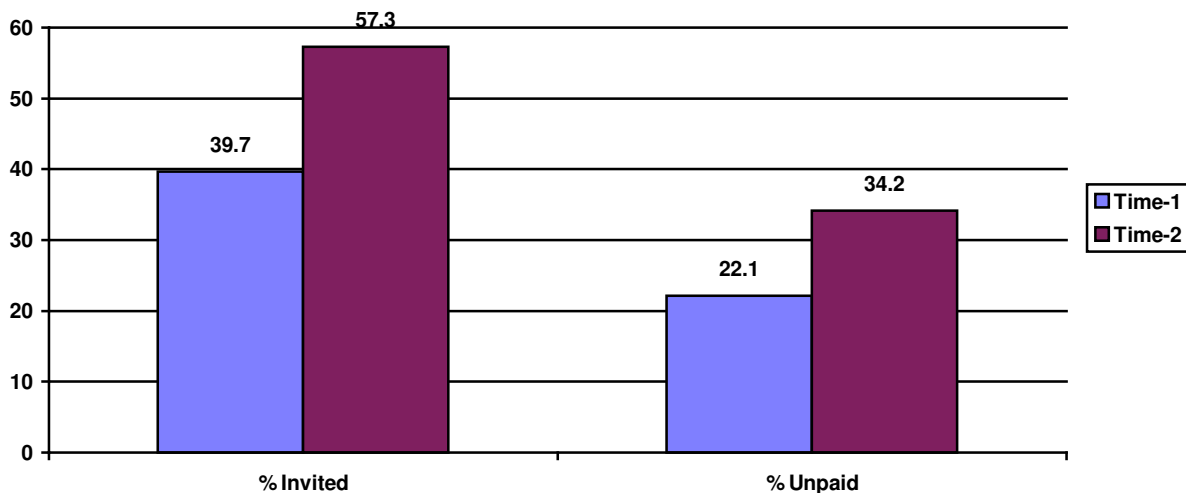
The Protocol contained a scale of Integrative Activities. It was originally adapted from a scale used by the Harris organization in its 1986 survey of Americans with disabilities (Taylor, Kagay, & Leichenko, 1986). It measured the frequency of outings to visit friends, go shopping, see a movie, go to a bank, church, club, arena, restaurant, park, and so on. The overall scale measured the total number of such events in the preceding month. The average increased from 47.4 events per month to 52.6, but the increase was not significant (although it approached significance, at  $p=.161$ ). The Self Determination process did not increase peoples’ frequency of outings. It is worth noting that the MDS Integrative Activities figures at Time-1 were already very high; they were about double the national average for people with developmental disabilities (Conroy, Feinstein, Lemanowicz, Devlin, & Metzler, 1990).

## **Results 5: Planning Team Composition**

The Self Determination approach stresses that decision making power should be moved away from paid staff, toward unpaid friends and loved ones. Moreover, decision making power should be in the hands of people chosen by the individual, to the extent possible. The evaluation included mapping the composition of each person's planning team. The individual plan at MDS was called the Individual Service Plan, or ISP. At Time-1, the average participant's team was composed of 22.1% unpaid people. At Time-2, the average team was 34.2% unpaid. The change was significant ( $t=3.95$ , 35  $df$ ,  $p<.001$ ). MDS planning teams for Self Determination participants sharply changed in the direction of increased membership of unpaid friends and loved ones.

Members of the planning team should be invited by the individual, according to the principles of Self Determination. At Time-1, 39.7% of the average team had been chosen by the individual (and/or the individual's closest contact). At Time-2, the average team was made up of 57.3% chosen members, and this was a significant increase ( $t=2.06$ , 29  $df$ ,  $p=.048$ ). Thus the Self Determination project substantially increased the role of consumer choice in the makeup of the planning teams. These two outcomes are presented visually in Figure 3. The graph supports the conclusion that, by the middle of the second year, major changes had already been made in the planning teams.

**Figure 3: Changes in the Composition of Planning Teams:  
Percent of Members Who Were Invited and Unpaid**



Source: The Center for Outcome Analysis, 1996  
Supported by the Robert Wood Johnson Foundation

## **Results 6: Behavioral Changes**

Despite the fact that Project implementers did not view behavior change as a priority goal of Self Determination, we included standardized instruments for adaptive, challenging, and productive behaviors. We believed it was possible that the Project might produce unexpected effects on some dimension(s) of behavior. Because such data are easy to collect and extremely reliable (Fullerton, Douglass, & Dodder, 1996), the three scales were included in the Personal Life Quality Protocol.

Each of the three scales was computed so that they could potentially range from 0 to 100 points, with higher scores being favorable on all three (including the challenging behavior scale). The adaptive behavior section contained 33 items covering a wide array of abilities. Some examples are: Food Preparation, Basic Medical Self-Help, Toileting, Community Money Handling, Ordering Food in Public, Participation in Social Activities, Attention Span, and Safety Awareness. In a conservative test of reliability that combined interrater with test-retest aspects, Conroy (1995) reported reliability of .97.

The challenging behavior section contained 16 items, such as: Self-Injury, Assaulting Others, Damaging Property, Social Withdrawal or Depressive Symptoms, Poor Grooming or Cleanliness, Inappropriate Sexuality, and Stealing. Its reliability, combining interrater with test-retest aspects, was .87 (Conroy, 1995).

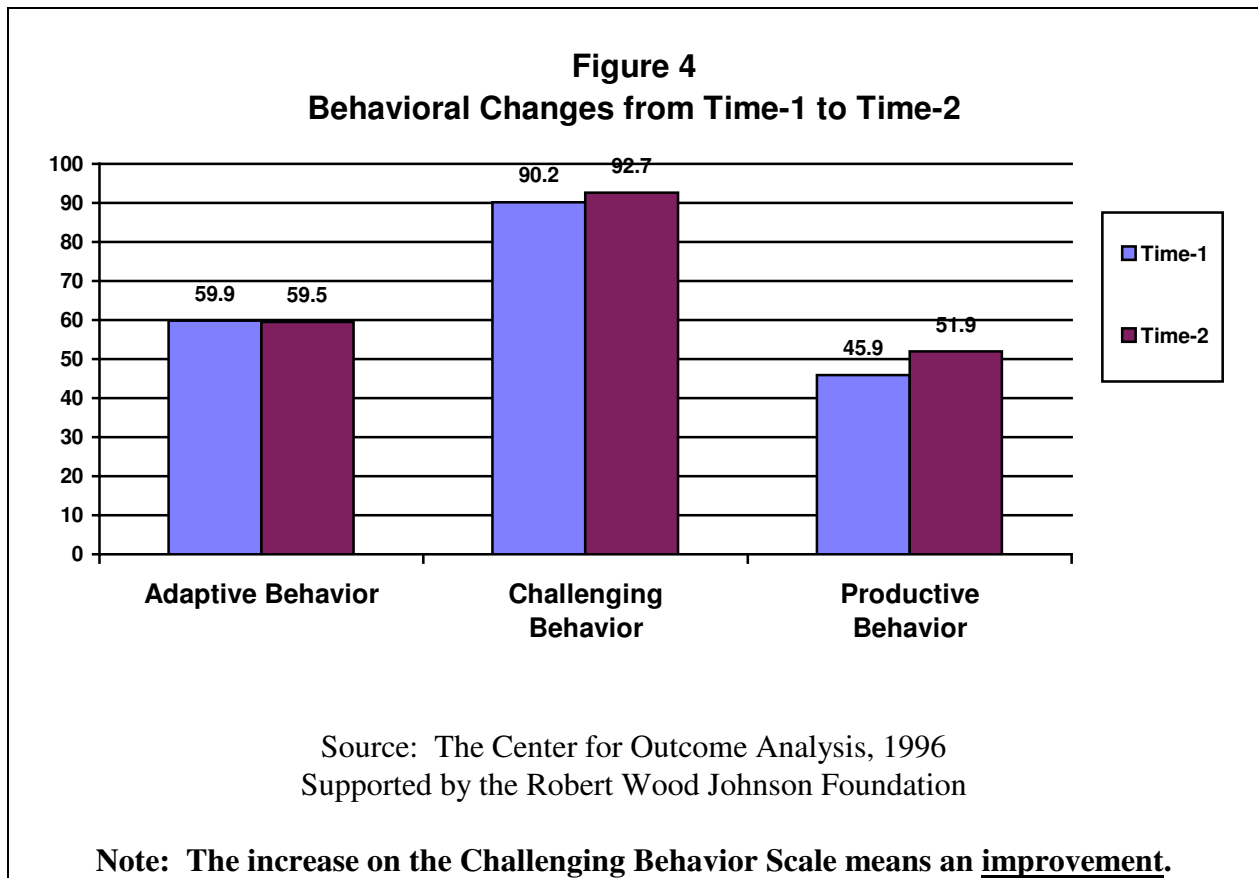
The productive behaviors scale was created by Conroy (1993). The scale included 10 items such as: Getting Up in the Morning, Working With Others, Following Safety Rules and Regulations, Quality of Work or Other Productive Activities, and Promptness and Attendance at Job or Day Program. The productive behaviors scale has not been formally tested for reliability, but the correlation between scores at Time 1 and the next round of data collection (almost a year apart) was .78. This suggested that the productive behaviors scale was very reliable.

Table 4 and Figure 4 summarize behavioral changes detected among the Self Determination Project participants after 18 months of program implementation. Adaptive behavior was unchanged. Significant improvements were detected in the areas of challenging behavior and productive behavior. The challenging behavior score increased by 2.5 points, meaning that at Time-2, the participants exhibited less challenging behavior than before. In other

words, participants became more able to control their own behavior. The productive behavior scale score increased by 6.0 points. But the skill level of participants did not change.

**Table 4**  
**Behavioral Changes**

	Time-1	Time-2	Change	t	Signif.
Adaptive Behavior	59.9	59.5	-0.4	0.27	.395 NS
Challenging Behavior	90.2	92.7	+2.5	1.69	.050 *
Productive Behavior	45.9	51.9	+6.0	1.90	.033 *



That these behavior changes were neither predicted nor sought after by the Project implementers made them all the more remarkable. These findings provided evidence that Self Determination helped people to control their own challenging behaviors, and to become more oriented toward productive activities, but it did not require them to learn new skills in order to gain control over their lives.

### **Results 7: Service and Support Indicators**

The instrument package contained a scale measuring individualization in day to day rules, routines, and practices: the Individualized Practices Scale (IPS). It assessed whether practices in the home were flexible, and could be tailored to individual needs and preferences, versus inflexibly applied to all people in the home. The IPS was based on an instrument developed by Pratt (unpublished, 1979) in New York, which was a revision of the Resident Management Practices Inventory developed by McLain, Silverstein, Hubbel, & Brownlee (1975). The latter was in turn an adaptation of the Child Management Scale produced by King, Raynes, & Tizard (1971) in England and subsequently used in several cross-cultural studies by Zigler and his colleagues at Yale (Balla, Butterfield, & Zigler, 1974).

For the Self Determination Project participants, the average score on the IPS before Self Determination began (Time-1) was 82.5. At Time-2, this had risen to 87.5, an increase of 5 points on a scale of 100. This increase was significant ( $t=2.31$ , 37 df,  $p=.015$ ). The participants' home environments had become more individualized during the Self Determination Project, according to the IPS measure. This was remarkable because the Time-1 scores were already high. The average score for recently deinstitutionalized people in California is 64.3, and the MDS Self Determination participants began at 82.5.

The Physical Quality Index (PQI) was originally modified from Seltzer's (1980) instrument, which was in turn derived from portions of the Multiphasic Environmental Rating Procedure (Moos, Lemke, & Mehren, 1979). It was a measure of how home-like, comfortable, attractive, orderly, and pleasant the setting was. The PQI has been used by The Center for Outcome Analysis in many prior projects, covering thousands of people.

The average PQI score for Project participants at baseline (Time-1) was 64.1. At Time-2 the average had increased to 71.0, and this was significant ( $t=3.61$ , 37 df,  $p=.001$ ). The participants were living in more home-like, pleasant settings after 18 months of Self Determination.

We counted the number of goals in each person's Individual Service Plan or ISP. At Time-1, the average was 3.9 goals; at Time-2, this had been reduced to 2.4, and the change was significant ( $t=3.46$ , 37 df,  $p=.001$ ). The plans had apparently become more focused on fewer goals. Further analysis of the details of these changes would be a useful pursuit in future work.

The number of minutes per day of formal service delivery was measured. Service amounts were measured in 11 areas, such as basic self-care skills training, appropriate social behavior training, physical therapy, vocational or other day programs, and community skills training. At the Time-1 baseline, the average person was receiving 250 minutes per day of such services. At Time-2, this had increased to 372 minutes, but the variations among people were so great that this average change was not statistically significant. Hence we concluded that there was no change in the overall intensity of service delivery. If there were changes in service delivery, they must have been in the way services were organized and how they were delivered, not the amount.

The amount of time spent in day activities was collected. At Time-1, the average was 26.5 hours per week. At Time-2, the average was 29.2 hours, for an increase of 2.7 hours per week. The increase was significant ( $t=1.93$ , 37 df,  $p=.031$ ). During Self Determination, the average participant increased the amount of time spent in productive educational or vocational daytime activities.

In addition, average weekly earnings increased from \$25.10 to \$32.69, but this was not a significant increase. We concluded that the outcome of productivity had increased in terms of time spent, but not in terms of income.

We collected dozens of indicators of health, health care utilization, and health care satisfaction. None of them changed significantly from Time-1 to Time-2. Overall patterns of medication administration were also unchanged. We concluded that the Self Determination intervention was not, at least thus far, related to acute care practices, quality, or satisfaction.

## **Results 8: Costs**

The Self Determination Project was designed to test the notion that movement of power and control toward service recipients would reduce expenditures. Originally, work in New Hampshire (prior to RWJF funding) strongly suggested a commitment to consumer choice and self determination could lead to enhanced quality of life and satisfaction, at the same time reducing costs. The results presented thus far have supported the first premise, showing increased quality of life outcomes. In order to examine the second premise of cost reductions, it was necessary to track expenditures for all of the Self Determination Participants over a 3 year period.

This was difficult because, like most extant human service systems, the MDS accounting systems had originally been set up by cost centers, not people. Categories of expenditure were easy to summarize: by vendor or home, for rent, food or staff salaries. Expenditures for individuals were harder to determine, and in most cases, had to be estimates. Even though one person in the home might be very independent, requiring little or no staff time, the accounting systems did not reflect this variation. People did not have individual budgets. The same was true for day programs.

A critical step in this Project, MDS began to change its entire accounting system to reflect individual budget tracking. Ascertaining the baseline costs by extricating individual costs from congregate costs required extensive work and estimation. The three primary kinds of expenditures were residential program costs, day program costs, and the costs of coordination (case management, administrative, etc.). In collaboration with the evaluator, the fiscal department at MDS began the process of identifying the most accurate cost estimates for each individual participant. This process began in early 1996, and was completed for the 43 participants who were still active in September 1996. The data were broken down by the three primary categories of cost, for 3 years (1994-95, 1995-96, and 1996-97). Considerable progress had been made by the end of the second year. It should be noted this cost analysis departed slightly from the analyses above. More than 38 people could be included because (a) of the availability of data, and (b) more recent data were available about costs.

Before running statistical tests, it was necessary to convert to constant dollars. Because of inflation, the value of a dollar was not the same in 1996-97 as it was in 1994-95. Department of Labor statistics showed that the Consumer Price Index for all items increased 2.9% from

1994-95 to 1995-96, and 3.0% the following year. We converted all cost data into 1994-95 constant dollars. This had the effect of leveling the cost comparisons into 1994-95 “buying power” units.

The first analysis was a conservative one with 40 people, including even those for whom uncontrolled life events had altered their costs markedly. The second analysis included fewer people but was a more fair estimation. The results are presented in Table 5.

**Table 5**  
**Annual Per Person Cost Changes, 1994-95 to 1996-97**  
**Two Methods**

	<b># People</b>	<b>1994-95</b>	<b>1996-97</b>	<b>Change</b>	<b>t</b>	<b>p</b>
<b>Method 1</b>	40	\$62168	\$54470	- \$7698	4.02	.001
<b>Method 2</b>	22	\$68294	\$57699	- \$10594	3.98	.001

By either method, the cost reductions were statistically significant. The Table shows the t-test value and the p significance value. Both p values were .001, meaning such large changes would occur by chance less than 1 time in 1,000 experiments. The more conservative method, with all 40 people, showed an average saving of \$7,698 per person. Calculating percentages, this meant that in 1996-97, costs were 87.6% of what they had been in 1994-95. The second method, with only 22 people, showed an average saving of \$10,594, meaning costs were reduced to 84.5% of the baseline costs. Taking the conservative method, the total projected savings across 40 people were \$307,920. The second method did not lend itself to extrapolation, but would have been even larger.

The best conclusion to draw from the two methods of analyses was that cost savings had been realized. Costs were reduced by between 12.4% and 15.5%. Further research should serve to tighten these estimates, with improved bookkeeping methods tied to the individual budgeting process. These figures lend very strong support to the original claim of the Self Determination Project, that costs would decline as individual control and autonomy increased.

## **Discussion**

This evaluation of the Monadnock Self Determination Project has documented remarkably positive outcomes. Here in the Discussion section, we will endeavor to place these outcomes into currently relevant contexts of managed care and a shifting paradigm so as to offer some explanations and interpretations of the information and its policy implications.

### **Limitations of the Study**

Although this phase of the evaluation was rigorous and quantitative, its limitations must be understood. First, the design of this study was prepost only (“before and after”), and did not include analysis of a comparison group. Hence we cannot yet rule out the possibility that non-participants experienced the same positive outcomes as the participants. Future analyses in this series will test this possibility. We do know the non-participants were not greatly different from the participants in their basic characteristics, and this strongly suggests the impacts of Self Determination would be similar for both groups. However, until those analyses are performed, we cannot assume their results.

The second limitation of this evaluation concerns its generalizability. New Hampshire is an unusual state in many ways, and Monadnock Developmental Services is an unusual agency. New Hampshire was the first state to completely end its utilization of public institutions for people with developmental disabilities (Covert, MacIntosh, & Shumway, 1994). The fact that no institutional options exist may deeply influence thought and action in New Hampshire. In addition, Monadnock was already involved in massive efforts to transform the patterns of daily activities for its service recipients. The move was away from large segregated workshops, toward supported and competitive employment. Moreover, the Monadnock area is small and somewhat rural. To the extent that these factors are unique, we cannot be confident that Self Determination would work the same way in other places.

Third, generalizability may be further limited by the unique qualities of leadership that were present in the Monadnock initiative. The Self Determination Project required cooperation at the state level, and received it from the State’s Director of the Division of Mental Health and Developmental Services, Donald Shumway. The Project also required what Campbell (1967) called an “enlightened administrator,” who shared the basic values of Self Determination. The

MDS administrator was Richard Crowley, and he was unusual in that he welcomed these innovations, and made it abundantly clear to all workers that Self Determination had his full support. Most important, the Project required a person with vision, experience, and sufficient leadership skills to elicit support from agency staff to work toward the necessary changes. Thomas Nerney provided that leadership.

The synergy of these talented leaders enabled the Self Determination revolution to materialize at MDS. Is such leadership an essential element of the revolution? If so, what are the specific leadership characteristics that led to the outcomes in New Hampshire? From a scientific perspective, these questions of generalizability are imminently about whether the same principles can be applied in different places, with similar outcomes, without these specific leaders. The answer to this very important query cannot be provided from the present evaluation project. It will, however, be possible to obtain clarification by rigorously evaluating outcomes of future RWJF Self Determination initiatives, both quantitatively and qualitatively.

### **Outcomes Summary**

Outcome data in managed care initiatives in the developmental disabilities field have been scarce (NASDDDS, 1995). The outcomes resulting from the implementation of the Self Determination principles at Monadnock Developmental Services from 1994 to 1995 are summarized in Table 6. They are positive, encouraging, and unprecedented. Contrary to commonly held assumptions that "outcomes are slow to occur, making it difficult to measure successes and failures in the short run" (NASDDDS, 1995, p.8), this evaluation of 18 months of effort supports the conclusion that outcomes can be seen and measured rather quickly when the fundamental nature of the service system is changed.

**Table 6**  
**Summary of Individual Outcomes**

<b>Quality Dimension</b>	<b>Outcome</b>
Self Determination Scale	++
Personal Satisfaction Scale from Interview	++
Quality of Life Improvement in Past Year	++
Relationships with Family	0
Relationships with Friends	0
Circles of Friends, Number of Members	++
Integration, Outings	+
Planning Team, Proportion Invited	++
Planning Team, Proportion Unpaid	++
Adaptive Behavior	0
Challenging Behavior	++
Vocational Behavior	++
Individualized Practices in the Home	++
Physical Quality of the Home	++
Minutes of Direct Service Per Day	+
Hours of Day Program Activities Per Week	++
Earnings Per Week	+
Health and Health Care	0
Costs	<b>12 - 15% Lower</b>

**Key:**

- means a large change for the worse
- means a change for the worse, not statistically significant
- 0 means no change
- + means a change for the better, not statistically significant
- ++ means a large change for the better

It is worth emphasizing some of the findings summarized in Table 6. For the individuals who had circles of community friends, the number of community supporters more than doubled by the Self Determination efforts. Further, the number of unpaid and invited participants in the formal IHP planning teams increased significantly. These changes indicate more of a reliance on unpaid and invited community supports instead of paid service providers.

Behavior changes were not expected in this project, but they were detected nonetheless. The decreases in challenging behavior, and the increases in productive behavior are noteworthy.

With more opportunities to make life choices, and more hours spent in productive daytime activities, the behavior changes may be interpreted as a natural consequence of people having more responsibility for their own lives.

Perhaps the most informative outcome of all is the lack of change in adaptive behavior. In prior research, great emphasis was placed on skill acquisition, developmental progress, and achievement of self-care potential, that is, increases in adaptive behavior (Conroy & Bradley, 1986; Larson & Lakin, 1989). Conversely, in the Self Determination Project, people gained sharply in a variety of qualities of life, but not because they “learned” new skills or “earned” new rights. The old way of thinking, the “readiness” model, would require people to “learn and earn” the right to make their own life choices. The emphasis in such a model is on changing the person, and this kind of thinking has been sharply criticized (Taylor, 1988). In contrast, the Monadnock Self Determination Project set self determination as an inherent right, and not something that had to be earned. The Monadnock emphasis was on changing the support system, not the person. The quality of life outcomes that accrued from this were impressive, and they occurred without changes in functional abilities.

Finally, Monadnock’s emphasis on individual budgets was a central implementation issue. In other service systems, costs have been shown to have little or no relationship to individual needs or characteristics (Conroy, 1985; Stancliffe & Lakin, 1996). In most systems, residential costs in particular are fundamentally congregate – they are computed as the total cost divided by the number of beds. In such a system, individual needs cannot be strongly related to costs. At Monadnock, the effort was made to design individual budgets entirely from individual needs, characteristics, and aspirations – and costs decreased. This implies that an important direction for future funding policies and mechanisms will be to learn how to allocate and flexibly administer funds for people, in contrast to the currently dominant model of funding programs.

We want to emphasize that these outcomes are far more positive than we anticipated. It is not easy to measurably improve an already excellent service system. We believed the Self Determination Project was attempting to improve on an already good service system, and therefore early outcomes would probably be small. The fact that several major enhancements have occurred in the lives of the participants at Monadnock suggests that Self Determination

truly represents a fundamental change and improvement in the organization and delivery of services.

### **The Managed Care Context**

Because the principles of the Self Determination Project overlap considerably with some essential elements of managed care, these findings are extremely important for systems considering managed care service models. Though not a comprehensive study on managed care, this research cautiously suggests that some managed care principles can be applied in ways that increase rather than diminish individual and family choices, and enhance qualities of life, even while fewer public dollars are spent.

There are many similarities between self determination and managed care, among them the emphasis on individual responsibility, capitation, and single stream funding. However, some differences are evident, hence caution is warranted in drawing parallels between the two concepts. Some managed care approaches tend to limit the choices of services and providers available to health care consumers. Decision making for volume and type of services are left to a middle management level, and provider options are restricted to those chosen by the managed care company in accordance with designated cost and utilization limits (Nerney & Shumway, 1996, p. 19).

Managed care in the developmental disabilities field is not about acute health care, nor long term care. Rather, it is about lifetime supports, and as such, it is distinct and unique from other models. In their authoritative book on managed care and people with developmental disabilities, Ashbaugh & Smith (1995) described managed care as both an opportunity and a new challenge for people with developmental disabilities. The NASDDDS (1995) likewise cautioned that “mental retardation and developmental disabilities agencies should use the introduction of managed care as a service system improvement opportunity, not just a cost savings strategy” (p.5). Other leaders in the field have warned that “it is imperative to define the principles and values that must underlie managed care in developmental disabilities” (Center on Human Policy, et al, 1996). In short, in order to realize the benefits of this new approach to service delivery, the message is clear - we must proceed cautiously, with care, and with a clear set of principles and values.

The MDS Self Determination Project was implemented in exactly that way, with values at the core and caution along the way. The Project showed that the application of cost

containment principles, when adopted jointly with the values of individual autonomy and self determination, can lead to enhanced control, satisfaction, and community involvement, as well as positive behavior changes, and lower resource utilization.

### **The New Paradigm**

The MDS Self Determination Project must be viewed as a revolutionary attempt to implement an entirely new and different paradigm. In this new paradigm, service recipients and their significant others are the primary decision makers. Budgets are designed for individuals, not for programs. Service provider invoices are paid only after the person is satisfied with and has approved payment for the services. Case managers are personal agents and community liaisons who work for the individual. These changes necessarily reduce professional dominance.

Racino (1994) asserted that reducing system and professional dominance would inevitably be associated with enhanced community membership, and hence with improved quality of life outcomes. A greater reliance on communities, neighbors, friends, worship groups, and informal networks appears to have enhanced the Self Determination participants' qualities of life and their community membership. The potential savings benefits extend to taxpayers and to those on waiting lists.

Some analysts note challenges to Self Determination. Involvement in supported living and work may be associated with problems such as loneliness and poverty (O'Brien, 1993). Still others say that "unchanneled deference to choice can be an excuse for neglect" by professionals (Ferleger, 1994). However, in view of the positive outcomes of the Monadnock Self Determination Project, we must revisit and question the value of our current model of professional paternalism. Does the fact that peoples' lives improved when professionals relinquished power mean that professionally dominated interventions actually harmed people by unnecessarily restricting their freedoms? We think the answer is probably "Yes," although replications of this research are clearly needed to test the generalizability of these findings.

Much of the Self Determination paradigm can be viewed and understood within the framework of power. In fact, the Project may introduce a new understanding of power, having to do with power sharing rather than the unilateral power found in traditional service systems (see O'Brien & O'Brien, 1996). Implementers of the Self Determination Project believed the power imbalance found in traditional systems caused harm to the development, achievement of

potential, and full citizenship of people with disabilities. They took active measures to change it. Indeed, this study of the Self Determination Project provides support for what community activists have been saying for two decades - that public service systems evolve in ways that tend to support professional organizations at the expense of individuals:

*As the power of profession and service system ascends, the legitimacy, authority, and capacity of citizens and community descend. The citizen retreats. The client advances. The power of community action weakens. The authority of the service system strengthens (p. 9)...It is necessary to recognize that the human service tool typically limits, weakens, or replaces community, associational, and citizen tools. This is in the nature of any approach built on the premise that vulnerable people will be better off because an expert knows better (McKnight, 1989, p. 10).*

We believe that as more evidence accumulates, the ideas of Self Determination – increases in control, qualities of life, and community supports for service recipients, and decreases in public costs -- will become irresistible to taxpayers, politicians, advocates, and primary and secondary consumers. We may expect the strongest resistance from workers, particularly professionals, because many view power as a zero-sum game. Most people believe that as consumers gain power (self determination), it can only occur at the expense of someone else's power (professional dominance). Viewing power as a zero-sum game, however, may be a fundamental error (Shumway, personal communication, 1997). Specifically, some authors contend that power sharing is a more accurate way to conceptualize the notion of power (O'Brien & O'Brien, 1996).

In any event, our independent evaluation has demonstrated the value of their new way of thinking about the organization of services and supports for people with developmental disabilities, and further analyses may reveal that we would do well to reconceptualize our understanding of power and how it is applied in the lives of service users and professionals alike.

The Robert Wood Johnson Foundation has already expanded the project to the national level. By providing the first major support for the emergence of a new empowerment paradigm, the Foundation is enabling people to think differently about the service system, and more importantly about the people supported by it. This move by the Foundation is consistent with our

findings and beliefs: that the Monadnock Self Determination Project was highly successful, and it needs to be replicated and evaluated in other states.

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