SOCIAL INNOVATIONS Journal

Outcomes of Self-Determination in New Hampshire

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Abstract

Among change efforts in community services to increase the self determination of persons with developmental disabilities, few, if any, have empirically shown system wide benefits in the categories of improved quality of life, increased community membership, and cost reduction. We obtained outcome measures on 19 different dimensions of quality in the lives of persons who participated in a regional change effort at the Monadnock Development Services agency in southwestern New Hampshire. The project changed the package of services offered to people by furnishing them with portable, individualized budgets and choices related to service type and service vendors. Improvement was noted across most corollary indicators, and no negative outcomes were noted. The Project showed that autonomy and self determination could lead to enhanced satisfaction, community involvement, and resource savings.

Outcomes of Self-Determination in New Hampshire

The intellectual disability field has experienced a long term pattern of systematic underfunding (Spreat, in press). As a result, providers are unable to pay a living wage to Direct Support Professionals (Spreat, McHale, & Walker, 2017) and providers of intellectual disability services themselves are in serious financial jeopardy, with 1/3 of these providers losing money in each year of a five year study (Spreat, 2019).

It must be recognized that not only are the providers of intellectual disability services underfunded, most state directors of intellectual disability services are not being allocated sufficient funds to provide needed services. Hence, we have waiting lists and the Direct Support Professional Workforce crisis. Faced with this situation, many state intellectual disability directors have elected to impose some sort of price controls. These price controls have typically taken the form of either exceptionally complex fee for service models or some variant of managed care. Managed care, as practice in the intellectual disability field, might be more accurately called managed costs.

Economists tell us that price controls tend to have negative consequences (Pettinger, 2017). These negative consequences include 1) creation of shortages (think waiting lists, Direct Support Professional shortages), 2) development of black markets (rich families establishing their own programs), 3) cost diversion (divert funds from Direct Support Professionals to support program, divert funds from other programs), 4) reduced investment in the field, and 5) the manipulation of services to match funding contingencies rather than consumer need. Despite these warnings, our field has moved to adopt a variety of price control measures as a means with which to deal with chronic underfunding. It remains a curiosity that the addition of another layer of bureaucracy is expected to save any money.

The other alternative open to state intellectual disability directors is to support cheaper forms of service. To date, these efforts have largely been done via life sharing (adult foster care) or paying families to care for their family member who has a disability. While subjective impression of these efforts has largely been positive, neither model has been submitted to empirical validation as was the group home model (cf. Conroy & Bradley, 1985). Further, neither approach has been demonstrated to be viable for individual with significant medical and/or behavioral challenges.

There is an alternative to the top heavy managed care models and the untested reduced price models. 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 this premise by increasing the power, authority, and resources of individuals to control their own destinies (Nerney, Crowley, & Kappel, 1995). The Project was “an attempt to fundamentally reform both financing mechanisms and basic structural aspects of the current service delivery system” (Nerney & Shumway, 1996, p. 7). In so doing, the Monadnock service organization addressed three fundamental issues: (a) It enabled individuals and their families to control dollars without dealing with cash; (b) It changed the role of case management to that of personal agents and independent brokers of services chosen by the focus person; and (c) it organized a coherent response to a managed care culture.

In order to bring what appeared to be a complex intervention into the realm of scientific verifiability, it was necessary to distill the self-determination concept into a testable hypothetical form. This hypothesis had three propositions:

1. If people gain control,
2. Their lives will improve, and
3. Costs will decrease.

In this hypothesis, gaining control included control of resources. It also implied transfer of control from professionals toward the focus people and their freely chosen allies, usually unpaid, in other words, toward “circles of friends.” Improvement of lives meant measurable enhancements in one or more qualities of life. Decrease in costs referred to changes in the sum total of public dollars expended to support the person.

Each of these three propositions will be discussed.

If People Gain Control

The focus of this intervention was to provide a means with which consumers of service were enabled to gain a greater degree of control over their lives. The above referenced phrase, “if people gain control,” means several things. It means that service consumers and their freely chosen allies gain power over life choices. The creators of the self-determination principles and practices believed that American service systems had moved much too far in the direction of professional domination of people’s lives (Nemey, Crowley, & Kappel, 1995). Paid people were making all decisions, small and large, about every detail of the way people lived, worked, learned, and took part in leisure. The pendulum had swung too far.

Hence “people gaining control” means that professional domination of all life choices diminishes. Self-determination is fundamentally about power, and who wields it. It also means that the power held by professionals will transfer toward the person and the person’s freely chosen (usually unpaid) allies. This implies increased participation by unpaid people in the individual planning process.

“Gaining control” must be seen above all to mean control over resources. In the most radical statement of the importance of this facet, one of the founders of the movement has stated that “Person-centered planning without control of resources is cruel and unusual punishment.” The claim is that encouraging people to dream, and to design a life that would be enriching and fulfilling, without the power to allocate existing funds as needed to approach that dream, is not a kindness. Hence a central and irreplaceable component of self-determination is the development of individual budgets.

In order to gain control over resources, one must find out what public dollars are currently being spent from what coffers. This is not been an easy task in most states and localities. Once such a figure is determined for a person, it then becomes possible to work on an individual budget. By setting a "target" at the beginning, the planning group (variously called the team, the interdisciplinary team, the circle of friends, the circle, the support network, or a host of other terms) can aim to create the most engaging and fulfilling opportunities possible within the predetermined amount of money available.

Individual budgeting has proven to be among of the most difficult, and yet the most fundamental, of the preconditions for self-determination. Perhaps the thorniest problem is how to set a budget amount for people who are just entering the service and support system. What is "fair?" How can that be quantified? How much does one person and circle "deserve," and why is that different from some other person and circle? Some states have adopted the AAIDD Supports Intensity Scale as a means with which to ascertain the amount of financial support that is needed.

It is also important that "gaining control" was not interpreted to mean that the focus person had to be able to express all preferences and control all supports and budgets. With the essential adjunct of person-centered planning and its variants, the ultimate authority could be placed in the hands of the "team" when the team members were unable to understand or clearly interpret the person's desires

Improvement of Lives

The second part of the theory says that when power shifts away from professional domination, and toward people and their trusted allies (often unpaid), their lives will improve. But in what way? At the outset of this research on self-determination, no one really knew which of a person's dozens of qualities of life might be affected. Certainly, it was a given that power would shift, and if control over one's own life and making choices can be considered a "quality of life," then this had to be the first item on the agenda for measurement.

In the situation of uncertainty about how the intervention will affect people's lives, the only proper scientific approach is to measure a broad range of qualities of life. For this reason, the Personal Life Quality protocol was administered for each participant. The protocol is described in the Methods section below. The basic idea is that, if self-determination has impacts, they might be felt in one or more of dozens of dimensions.

Costs will Decrease

The third part of the self-determination "theory" is that "costs will decrease." This hypothesis was originally based on the observation of three "case study participants" in the original work at Monadnock Developmental Services, Inc., in New Hampshire (Nerney, Crowley, & Conroy, 1993). Project implementers noticed that reduction of professional domination in the planning process seemed to be associated with a new tendency for teams to purchase precisely what was needed and wanted, and no more. This was believed to be in contrast with the traditional service system, in which all the built-in incentives forced service providers to make sure every dollar was spent at the end of the fiscal year, and that more was requested in each subsequent year.

The original Monadnock demonstration concentrated on people who were living and working in "traditional" situations, meaning in small group homes and supported living arrangements. The grantee agency in New Hampshire did not have any ICFs/MR or large group homes (more than four people), nor was anyone in any public institution. Workshops had decreased sharply as well.

The purpose of this study is to describe the outcomes experienced by the 38 participants in the self determination project in the Monadnock Region of New Hampshire over an 18 month period. A variety of aspects of their qualities of life were obtained and compared. The results of that comparison constitute the body of this study.

Methods

Design

The evaluative data reported herein originated from a simple pre-post design. Information was collected from 42 of the 45 project participants at the beginning of the Project (three declined the entire research portion of the demonstration project at the beginning). Then, after 18 months, information was again collected from 38 of the 42 individuals from Time 1 (Four participants had either left the region or had ceased participation in the initiative, one by "graduating" entirely from the human service system).

Participants

The analyses presented herein concern 38 persons with developmental disabilities who received services through Monadnock Developmental Services, Inc., the local agency that administers services to persons with developmental disabilities in Region V of New Hampshire. The participants became involved in the Self Determination project at varying times after November 1993, and they were still involved in February 1996. Data collection was completed at both Time 1 and Time 2, spanning an 18 month period between each data collection.

At the beginning of the Project, there were approximately 175 persons with developmental disabilities who received major forms of support from Monadnock Developmental Services. These people formed the pool of individuals from which the project selected participants. The project proposed to include 45 people over a three year period. The agency requested "nominations" of people who were believed to be in difficult situations, or in situations in which their opportunities to make choices about their lives were overly restricted. Nominations were solicited from people receiving services, case managers, families, and providers. The first 45 nominations were accepted

Although labels for level of intellectual disability were not widely used in New Hampshire, about 32% of the participants were considered to have "severe or profound" intellectual disability; 26% were reported to have "moderate" intellectual disability; 18% were classified as having "mild" intellectual disability, and 24% were not labeled or the classification was unknown. Comparatively, a national sample from the late 1980s revealed that about 37% of people in small community living arrangements were classified as having severe or profound intellectual disability (Amado, Lakin, & Menke, 1990). There were 18 males and 20 females in the project. Mean age was 39 years. Other than intellectual disability, the most common disabilities were vision (27%), seizures (14%), mental illness (11%), major health problems (11%), and communication (8%).

At the beginning of the project, 25 of the participants (66%) lived in homes that were described as group homes or apartments with 24 hour supervision. Seven participants (18%) lived in family living or substitute family situations. One person lived in a relative's home, and three persons lived in independent homes. The living arrangements of the remaining two individuals were classified as "other."

Peoples' primary day activities at the beginning of the project were generally described as "non-vocational" in nature (26 persons, or 68%). Very few (7 or 18%) participated in any kind of employment situation, including supported, competitive, or self employed.

The average participant had contact with three relatives and received a median of 12 visits per year. The average participant was reported to have a mean of nine "close friends," of whom a mean of five were paid personnel.

Because generalization is a critical issue, it is important to compare the 38 participants to those individuals who did not participate in this Project. The latter group was composed of persons who also received supports from New Hampshire Region V, but who did not participate in the Self-Determination Project. No differences were detected between the groups with respect to age, number of years institutionalized, gender, additional disabilities, and challenging behavior. The participants were lower in adaptive behavior (t=1.95, df=125, p=.027) and lower in vocational behavior (t=2.31, df=95.70, p=.012) than the individuals who did not participate in the Project. Although the differences were small in magnitude, they did show that the participants were <u>lower</u> on these functional scales than the non-participants. These findings suggested strong support for the generalizability of findings from the participants to the rest of the agency population.

Instrumentation:

This evaluation was designed in an attempt to determine whether project participants increased in personal control, derived greater life satisfaction, and spent less money. Different instruments and procedures were employed to address each of these three basic premises of the Self-Determination movement. It should be noted that these instruments were part of a larger program evaluation package, the Personal Life Quality Protocol (Conroy, 1993), that was employed in the Monadnock project.

<u>Personal Control</u> – Personal control was assessed via the Decision Control Inventory (Conroy, 1995). The Decision Control Inventory was designed to tap the multiple dimensions of self determination. The scale is based on past efforts to measure the opportunity of individuals to make choices. The Decision Control Inventory includes 26 dimensions of everyday life, such as the use of personal money, choice of foods, choice of homes, choice of case managers, whether to have pets, and so on. For each of the 26 dimensions, respondents were asked to describe decision making on an 11 point scale, with the value of 0 meaning that decisions are made entirely by paid staff and the value of 10 meaning that decisions are made entirely by the individual and/or unpaid loved ones. The 26 items were summed and converted to a 100 point

metric. A score of 0 indicates that all control is vested in the hands of paid personnel, while a score of 100 indicates that all control is vested in the individual or his/her allies.

The Decision Control Inventory has been tested for reliability (Conroy, 1995). Internal consistency, as measured by Cronbach's alpha, was estimated to be .95. Test-retest reliability was estimated to be .98, based on a Pearson correlation between two temporally noncontiguous administrations of the instrument. The third test of the Decision Control Inventory combined test-retest with inter-rater reliability, and the correlation was .86. It should be noted that the Decision Control Inventory is linked with adaptive (and probably cognitive) abilities. The correlation between scores on the Decision Control Inventory and overall adaptive behavior was .71.

In addition to the Decision Control Inventory, we studied the composition of the teams supporting the service recipients. Specifically, we determined the percentage of persons on the teams who were paid by the service provider or a related agency. We also determined the percentage of persons who were invited by the service recipient (or his/her ally) to serve as team members.

Quality of Life – We identified six measures that addressed the issue of life quality. These measures were collected via a life satisfaction interview of the service recipients, the Individualized Practices Scale, the Physical Quality Inventory, identifying each individual's circle of friends, determining the extent to which each individual participated in community activities, and assessing the productivity of each individual. Each measure is discussed below.

Life Satisfaction Interview - Each visitor attempted to ask the person's own opinion about his/her life. This was done using an instrument called the Quality of Life Changes scale (Conroy, 2002). 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. Ten specific ratings were collected (Health, Making own decisions, Choices, Family Relationships, Seeing Friends and Socializing, Getting out and around, Day Activities, Food, Happiness, and Comfort). 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.

Individualized Practices Scale - The Personal Life Quality Protocol contained a scale measuring individualization in day to day rules, regulations, and practices. It was called the Individualized Practices Scale, and it assessed whether practices in the home were individualized versus group oriented, flexibly versus inflexibly applied, and whether practices could be tailored to individual needs and practices. It was derived from the work of Pratt, Luszcz, & Brown (1981), which was based on the Resident Management Practices Inventory developed by McLain, Silverstein, Hubbel, and Brownlee (1975), which in turn, was an adaptation of the Child Management Scale from the pioneering work of King, Raynes, and Tizard (1971). The latter was a measurement of resident- oriented versus staff-oriented practices, and was subsequently used in several cross cultural studies by Zigler and his colleagues at Yale (Balla, Butterfield, and Zigler, 1974).

The Individualized Practices Scale is simply a series of 15 scaled questions about how day to day matters were managed in the home. How bedtime was handled would be an example: Does everyone have to go to bed at the same time? Answers were given on a four point scale. Scores on the scale could thus range from 15 to 60, with higher scores indicating higher levels of individualization. The scale was collected by interview with someone familiar with the residential practices in the home, and took about 5 minutes to complete. Devlin (1989) reported inter-rater reliability of .78 and test-retest reliability of .86, both values satisfactory for group research (Anastasi, 1988).

<u>Physical Quality Inventory</u> - The Physical Quality Index was modified from Seltzer's (1980) instrument, which was in turn a derivative of portions of the Multiphasic Environmental Rating Procedure (Moos, Lemke, & Mehren, 1979). It is a measure of how home-like, comfortable, attractive, orderly, and pleasant the setting was. The Physical Quality Index is completed after the visiting data collector walks through the residence, rating each room on dimensions such as cleanliness, odors, condition of the furniture, individualized room decorations, and overall pleasantness. High scores on the Physical Quality Index, which yields scores that range from 0 to 100, suggest a more home-like environment. Interrater reliability on this instrument has been reported as .81, with test-retest reliability at .70 (Devlin, 1989). Again, both values were satisfactory for group research.

<u>Circle of Friends</u> – Circle of friends was quantified in terms of the number of team participants and whether team participants were paid or unpaid. For example, family and friends were likely to be unpaid, whereas any agency staff were paid.

<u>Community Integration</u> - The scale used to assess integration was taken from the Harris poll of disabled and non-disabled Americans of 1986 (Taylor, Kagay, & Leichenko, 1986). It simply measured how often people visit with friends, go shopping, go to a place of worship, go out for recreation, and so on, in the presence of persons without disabilities. The scale admittedly taps 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.

<u>Productivity</u> - The productivity 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, Promptness, and Attendance at Job or Day Program. Higher scores are indicative of greater degrees of productivity. Productivity was reflected by earnings and by the amount of time engaged in daytime activities that were designed to be productive (adult day activities, vocational training, workshops, supported, and competitive employment. The productivity scale has not been formally tested for reliability, but the correlation between the scores at Time 1 and Time 2 was .78, suggesting a satisfactory degree of reliability. It should be noted that reliability limits the extent to which two variables can correlated (see Cronbach, 1971 for discussion), such that unreliable measures would be unable to yield large correlations.

<u>Cost Analysis</u> – Expenditures for individuals were hard to determine, and in most cases, had to be estimates. In a critical step in this Project, Monadnock Developmental Services began ascertaining the baseline costs by extricating individual costs from congregate costs. This required extensive work and estimation, particularly on the part of the case managers and service providers. The three primary kinds of expenditures were residential program costs, day program costs, and the costs of coordination (case management, administration, etc.). Coordination costs

were separated from actual service costs so as to differentiate the portable from the non-portable costs. This process began in early 1996 and was completed for the 43 participants who were still active in September 1996.

Considerable progress had been made by the end of the second year. It should be noted that this cost analysis departed slightly from the analyses described above. More than 38 persons were included because (a) of the availability of data, and (b) more recent data were available about costs.

Before running statistical tests on cost changes between Time 1 and Time 2, it was necessary to convert to constant dollars. 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. All cost data were converted into 1994-95 constant dollars. This had the effect of leveling the cost comparisons into 1994-95 buying power units.

Data Collection Procedures

Each data collection visit required approximately 45 to 120 minutes per person. The data collectors, or visitors, were independent contractors who were familiar with the field of disabilities, but who were not currently receiving a paycheck from any of the agencies involved in the region. They received training on the data collection instruments from the principal investigator.

Results

The basic premise of the Monadnock Self-Determination Project was that if people gain control over their lives, their lives will improve and service costs will decline. We will address each of these three areas.

<u>Did people gain control?</u> – The Decision Control Inventory was administered twice for each project participant. This instrument indicates the extent to which an individual controls aspects of his/her life. A score of zero indicates that all aspects of that individual's life are controlled by paid personnel. A score of 100 (the maximum score) indicates that all aspects of that individual's life are controlled by the individual and/or his/her freely chosen unpaid allies. At Time 1, the mean scores for the 38 participants was 67.42 (sd = 20.37). At Time 2, the average score among these same 38 people was 71.53 (sd = 17.07). This increase of 4.1 points out of 100 over an 18 month period of time achieved statistical significance via correlated t-test (t = 1.73, df = 37, p = .046, one tailed).

In addition to the Decision Control Inventory, the composition of planning teams was evaluated. We reasoned that an increase in the number of unpaid members of the planning team would reflect a shift in power from the service provider to the service recipient. At Time 1, the mean percentage of unpaid team members was 22.1%. At Time 2, this mean percentage increased to 34.2%. The increase was statistically significant (t = 3.95, df = 35, p < .001, eta squared = .294). Participants in the Monadnock Self-Determination Project experienced increased team membership of unpaid friends and loved ones. It was also noted that at Time 1, 39.7% of the average team had been chose by the individual (and/ or the individual's closest contact). At

Time 2, the average team was made up of 57.3% chosen members. This increase was also statistically significant (t=2.06, df = 29, p = .048).

Did Their Lives Improve? – Life quality was assessed via direct interview of service recipients, ratings on the Individualized Practices Scale, and an assessment of the quality of the physical environment in which the service recipients lived. In addition, we considered the circle of friends for each individual, the frequency with which the individual participated in community outings, and productivity.

Ratings from the Personal Interview were collected for ten specific dimensions of quality, shown in Table 2. Ratings from the ten dimensions were combined into an overall rating for A YEAR AGO and for NOW. The average score for overall quality of life A YEAR AGO was 66.4 (sd = 24.5). For NOW the average was 77.7 (sd = 10.0). This difference was significant (t=2.96, 37 df, p=.003, eta squared = .205). 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.

For the Self Determination Project participants, the average score on the Individualized Practices Scale (IPS) before Self Determination began (Time-1) was 82.5 (sd = 10.2). At Time-2, this had risen to 87.5 (sd = 11.5), an increase of 5 points on a scale of 100. This increase was significant (t=2.31, 37 df, p=.015, eta squared = .175). This is consistent with the finding that 34% of the participants moved from group homes to supervised or supported living situations, where more personalization is possible. The participants' home environments had become more individualized during the Self Determination Project, according to the IPS measure. It should be noted that the Time-1 scores were already relatively high. The average score for recently deinstitutionalized people in California is 64.3, and the MDS Self Determination participants began at 82.5.

The average Physical Quality Index (PQI) score for Project participants at baseline (Time-1) was 64.1 (sd = 8.4) . At Time-2 the average had increased to 71.0 (sd = 9.0), and this was significant (t=3.61, 37 df, p=.001, eta squared = .277). The participants were living in more home-like, pleasant settings after 18 months of Self Determination.

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 (sd = 2.6) to 10.5 (sd = 10.5)(medians 4.0 and 10.0), and this increase was significant (t=2.32, 37 df, p=.020, eta squared = .329). The size of "circles of friends", for those that had them, more than doubled.

The Self Determination process was unrelated to any increase in peoples' frequency of outings. The average number of outings increased from 47.4 events per month (sd = 27.0) to 52.6 (sd = 25.2), but the increase was not significant . It is worth noting that the 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).

The average amount of time spent in day activities at Time-1 was 26.5 hours per week (sd = 8.7). At Time-2, the average was 29.2 hours (sd = 9.7) , for an increase of 2.7 hours per week. The increase was significant (t=1.93, 37 df, p=.031, eta squared = .096). During Self Determination, the average participant increased the amount of time spent in productive educational or vocational daytime activities. This again is consistent with the finding that participants involved in non-vocational day activities decreased from 68% to 34%, meaning that more people were involved in productive vocational activities after 18 months of the self determination project. 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.

Did costs decrease? - Two cost analyses were conducted. 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 excluded persons who experienced those uncontrollable life events; hence, the sample size is smaller. The results are presented in Table 4. 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 this analysis.

Discussion

The core principle underlying self-determination is choice. People must be afforded the opportunity to exercise choice to the greatest extent possible, rather than complying with the presumably better judgments of professionals (see Valdez, in press for discussion). It is curious that if one has an IQ of 75 and receives governmental supports, one typically receives a check or some sort of food stamp card. The recipient of these benefits is then, within broad limits, able to determine how the money should be spent. If, however, one’s IQ is 65 and one has the label of intellectual disability, it is most likely that someone else will make these decisions for the individual. In a sense, the label creates a dichotomy – able vs. not able, and ultimately, the most pervasive form of handicappism.

The self-determination model attempts to recognize the invalidity of a dichotomous model, stressing instead that the person receiving supports should, with the assistance of friends and family, be able to make decisions about needed supports and services. Rather than a decision making dichotomy, the self-determination model recognizes a continuum in which an individual, with necessary assistance, exercises a maximal degree of choice. As noted above, the model suggests that the person is not broken, but rather in need of some help.

The data presented within this report are dated; the most recent data collection was in 1996. Yet they remain timely in the midst of societal discussions of how to support people with intellectual disability for less money. The study suggests that satisfactory outcomes can be achieved at reduced costs by allowing individuals and their “circle of friends” to determine what supports are needed. Unlike most funding models currently under discussion, the self determination model stands alone in the ability to offer at least some sort of empirical evidence of its ability to save money. Rather than trying to somehow tighten spending by adding yet another layer of bureaucracy, perhaps it is time to seriously evaluate alternative models such as self-determination. This pilot study suggests that at least modest savings might be attained through the adoption of self determination methodology. While the evidence supporting the self-determination approach is not overwhelming, but it stands far above any evidence supporting the use of managed care approaches. A speaker at a recent planning event responded to a question about evidence supporting managed care by stating, “yes, that is the question, and we don’t have an answer” (Spreat, personal communication). Absent any empirical support for alternative approaches, it seems curious that the self-determination model seems to have fallen from the ranks of considered alternative. Our data suggest the model should at least be considered a potential alternative..

Part of the experimental nature of the Self Determination 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 impact <u>measurable</u> qualities of life of the participants. Thus, in this situation we measured as many outcome dimensions as possible. It should be recognized, however, that increased freedom, unless this increased freedom results in disastrous outcomes, is generally viewed as a positive outcome in and of itself. If people have more freedom and demonstrate that with appropriate support, they can exercise this increased freedom, the project must be considered successful. This must be the conclusion with respect to the Monadnock Self Determination Project. The primary outcome of the Monadnock Self Determination Project was quite simply, increased self-determination.

Although increased self-determination is the ultimate outcome of this project, corollary positive outcomes were evident. They are summarized in Table 5. Contrary to commonly held assumptions that "outcomes are slow to occur, making it difficult to measure successes and failures in the short run” (Gettings, 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.

It is worth emphasizing some of the findings summarized in Table 5. Participants significantly increased in their exercise of decision making about their lives. Personal satisfaction with their lives improved. For those who had circles of support, the average number of members increased by more than 50%. The number of unpaid members of participants’ planning teams increased significantly, as did the number of members chosen by the person. Finally, participants’ living environments became significantly more individualized and home-like, and many moved from group homes to supported or supervised living situations.

Perhaps the most informative outcome of all is the <u>lack</u> 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, 1985; Larson & Lakin, 1989). Conversely, in the Self Determination Project, people gained sharply in a variety of qualities of life, but <u>not</u> 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 quality of life outcomes that accrued from this Project were impressive. Yet 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. As such, 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.

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.

Limitations of the Study

Although this phase of the evaluation was rigorous and empirical, its limitations must be understood. First, the design of the study was pre-post only (“before and after”), and did not include an analysis of a comparison group, although we do know that the non-participants were very similar to the participants. Hence we cannot yet rule out the possibility that non-participants experienced the same positive outcomes as the participants. Some concern must be expressed that the selection process interacted with the nature of the Project itself to produce the outcomes.

The second limitation of this evaluation concerns its generalizability. Replication is a hallmark of the scientific process, and it certainly seems reasonable to question whether the results of the Monadnock Self-Determination Project could be replicated elsewhere. In asking this question, however, one must take care to identify replicable outcomes. Certainly, budgetary control can be shifted in other agencies, but there is no guarantee that this structural change will lead to the same corollary outcomes noted in the Monadnock Self Determination Project. Perhaps such similarity of corollary outcomes should not be expected. The purpose of self determination is to support and permit individuals to make decisions about their lives. This freedom to choose does not guarantee a positive outcome – merely freedom and perhaps dignity. To the extent that the exercise of choice is an outcome, replicability seems likely. Whether this exercise of choice invariably leads to the positive outcomes noted in the Monadnock Self Determination project remains open to empirical validation. We must note that 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 use of public institutions for people with developmental disabilities (Covert, MacIntosh, & Shumway, 1994), and many perceive New Hampshire as a leader in integrative service approaches. 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 yield similar corollary outcomes.

Instrumentation is a third area of concern. The Personal Life Quality Protocol is a collection of instruments whose psychometric properties are not fully understood. As noted above, most reliability estimates are well within acceptable ranges for use in this type of research (Spreat, 1999). Validation, on the other hand, remains open to question. There is a certain face validity to the notion that a scale that how much an individual works is an index of productivity. We must also note, on the other hand, that this package of instruments has been repeatedly tested for reliability over the years, as noted above. Moreover, the package has been applied thus far more than 100,000 times in face to face visits with people, and is subjected to revision whenever necessary. The scales have been found to be very useful in studies of deinstitutionalization, and by now conform very closely to what people and their families have told us is important to them.

Eleven statistical tests were run as part of this study, and nine of those tests yielded statistically significant results suggesting that people were “better off.” We resisted the inclination to correct our alpha level via Bonferroni correction because of the exploratory nature of this study. This study raises questions, rather than provides summative answers, and it is arguably preferable to cast a wider net to help set directions for future research. One also notes that the binomial probability of getting nine significant findings out of eleven tests would be approximately .000001.

Finally, some analysts note challenges to Self Determination. Involvement in more integrated services such as 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). Many believe that as people with disabilities gain control and power (self determination), it can only be realized at the expense of someone else’s power (professional dominance). Perhaps there is validity to some of these arguments, but there was an important distinction with respect to the Monadnock Self Determination Project. Rather than “unchanneled deference to choice,” the Monadnock Self Determination Project linked responsibilities to the choices. The budgets were finite, and within the limits imposed by the finiteness, needs still had to be met. In addition, one must question the concern regarding increased choice absent negative outcomes.

This independent evaluation has supported the viability of a new way of thinking about the organization of services and supports for people with developmental disabilities. 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. We suggest that in order to analyze current policies and practices, as well as new initiatives such as the self determination project, we must learn to understand power and how it is applied in the current system of services. Perhaps viewing power as a zero-sum game (as so often is the case) may be a fundamental error (Shumway, personal communication, 1997). Power sharing may be a more accurate way to conceptualize the notion of power (O’Brien & O’Brien, 1996). Ultimately, the challenge for us all is in operationalizing our understanding of power in order to move beyond the rhetoric of self determination, as was attempted in the Monadnock Region of New Hampshire.

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Table 1

Characteristics of the Self Determination Participants and Non-Participants

CHARACTERISTICS	Participants	Non-Participants	p
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

* $p \leq .05/26$

Table 2

Perceived Changes in Quality of Life Over the Past Year

Qualities of Life	Time-1	SD	Time-2	SD	Eta Sqrd
Health	3.60	.77	4.03	.66	.257
Running own life, making choices	3.46	.66	4.20	.68	.460
Family relationships	3.41	.92	3.53	1.05	.039
Seeing Friends and socializing	3.46	.61	3.97	.66	.463
Getting out and getting around	3.54	.66	4.03	.79	.330
Day activities	3.46	.70	4.14	.81	.374
Food	3.62	.65	4.23	.65	.288
Happiness	3.63	.60	4.46	.61	.534
Comfort	3.63	.60	4.37	.60	.537

Table 3

Behavioral Changes

Behavioral Scales	Time-1	SD	Time-2	SD	Signif.
Adaptive Behavior	59.9	18.52	59.5	18.87	.395 NS
Challenging Behavior	90.2	9.86	92.7	6.36	.050
Productive Behavior	45.9		51.9		.033

Table 4

Annual Per Person Cost Changes, 1994-95 to 1996-97

Two Methods

	# People	1994-95	1996-97	Change	T	p
Method 1	40	$62168	$54470	- $7698	4.02	.001
Method 2	22	$68294	$57699	- $10594	3.98	.001

Table 5

Summary of Individual Outcomes

Quality Dimension	Outcome
Power (Decision Control Inventory)	+
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	12 - 15% Lower

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