Self-Determination, Self-Direction, Individual Budgeting:

How Do We Know This Works?

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Part 1: The Evidence of Positive Outcome[1]

This summary is drawn from scientific evaluation and research studies conducted from 1994 to 2014, and it shows compelling evidence that the social supports model called "self-determination" actually works. The evidence is compelling that personal budgeting is related to enhancements in qualities of life, independence, productivity, integration, health, safety, service delivery, and satisfaction. Moreover, it works in a wide variety of differing service systems.

The summary begins with a brief history of the original New Hampshire demonstration project and its outcomes. The remainder summarizes the findings of the evaluation of the Robert Wood Johnson Foundation's (RWJF) National Initiative on Self-Determination for People with Developmental Disabilities in 19 states, and independent evaluation studies in several others.

The way the authors think about "what works" has consistently been to ask and answer one question:

"Are people better off?"

This simple question, the ultimate question of accountability for social programs, can be enriched by adding more detail:

"Better off in what way(s), how much, and at what cost?"

Using these questions as unifying concepts, social scientists have amassed compelling evidence that self-determination is an effective and fiscally conservative approach in the human services.

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[1] This material has been summarized by James W. Conroy, Ph.D., but reflects the efforts of more than a dozen colleagues cited in the References section.

Outcome Evaluation – What to Measure, How to Measure

The first test of the idea of self-determination was conducted at the Monadnock Developmental Services agency in Keene, New Hampshire from 1994 to 1996, with funding provided by the Robert Wood Johnson Foundation (RWJF). As Independent Evaluator, my job as part of the funded team was to track and measure the outcomes of the work, in other words, to find out if the new approach really helped people improve their lives. We also wanted to know how the situations of support workers changed, and how the system changed in terms of efficiency and cost.

At the very beginning of the first Keene demonstration project, I and my Outcomes Team interviewed the implementers to ask what outcomes they would expect to see if their self-determination project worked perfectly. The answers consistently concerned a shift in power.[2]

The central tenet of the original proposal had been that people in traditional service systems were treated as objects to be "helped," "fixed," "cured," or given services that would make their disabilities less of an impediment to a good life. Professionals dominated their lives, wrote their plans, and made all the major life decisions for them. This gross imbalance of power was the core problem that self-determination was designed to remedy.[3]

The new "theory" of self-determination arose in a proposal for funding written to the Robert Wood Johnson Foundation in 1994. In order to test a theory empirically, it is essential to state the theory in observable, or measurable, terms. Writing the theory in observable terms is

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[2] The first of the implementers to state this succinctly to the Evaluators was Ellen Cummings, then head of Case Management at Monadnock. This footnote is intended to honor her memory. Ellen passed away in 2010 after a long illness, during which she bore her own increasing disabilities with great strength, dignity, and preservation of control over her own life.

[3] This is illustrated also by the first sentence of Monadnock's original funding proposal to the Robert Wood Johnson Foundation: *"For people with severe long term and chronic conditions, specifically developmental disabilities, our service delivery practices are so outmoded, so disenfranchising, and so costly that radical departures must be demonstrated and evaluated immediately*."

called an operational definition. That is, one defines something in terms of the operations that count as measuring it (Shoemaker, 2004). With self-determination, this meant that we had to specify what observable things about people's lives would, if present, be evidence of self-determination.

The first and simplest operational definition developed by our group in 1994 was:

Operational Definition of Self-Determination Version 1, 1994

If people gain control,
Their lives will improve,
And costs will decrease.

Later refinements and details were all built from this simple framework. A later version with a bit more detail was:

Operational Definition of Self-Determination with Added Detail, 1997

If Power Shifts	If people (and their freely chosen unpaid allies) gain control over their supports and lives,
Life Improves	Then lives will get better – qualities of life will increase measurably
Costs Go Down	And total public and private costs will tend to be the same or less than traditional services.

An operational definition is only valuable, of course, if a series of operations (measurements) in empirical reality can be devised that will tell us whether each part of the definition is true or false. This definition was designed with that in mind.

By mid-1994, we had studied the research and psychometric measurement literature on power over one's own life, and produced a scale that we were able to test in a large deinstitutionalization study in another state (Conroy, 1995). That scale, the 29 item Decision Control Inventory©, was tested for the three forms of reliability: internal consistency, test-retest, and inter-rater. Using item-total correlations and factor analysis procedures, we reduced the scale to 26 items by eliminating the least reliable ones. The Decision Control Inventory was found to be acceptable on all three kinds of reliability.[4]

We were quickly advised by the Monadnock implementers that in order for power to shift, they would first have to significantly alter the process of individual planning. The planning process in traditional service systems was perceived to be dominated by professionals, and the people and their allies were cast largely into the role of passive participants. Changing this meant strengthening a new emphasis on "Person-Centered Planning," an approach developed over the preceding decade by many practitioners, particularly Beth Mount (1987, 1992) and Connie Lyle and John O'Brien (described historically in O'Brien & O'Brien, 2000), specifically to put the people who were "being planned about" at the very center of the process. Their dreams and aspirations were to begin to supplant professional demands.

The simple human desire for friendships and romance, for example, designed to bring joy and fulfillment, might begin to replace professional prescriptions for therapies and medications, designed to "fix" what was "wrong" with the person. As stated by Mount (1992) and quoted by O'Brien & O'Brien (2000), the essence of Person-Centered Planning approaches was in:

> *….seeing people first rather than relating to diagnostic labels; using ordinary language and images rather than professional jargon; actively searching for a person's gifts and capacities in the context of community life; and strengthening the voice of the person and those who know the person best in accounting for their history, evaluating their present conditions in terms of valued experiences, and defining desirable changes in their lives (Mount, 1992).*

A scale to measure this aspect of the process was developed and tested during the 1990s, originally called the Elements of the Planning Process©.

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[4] The internal consistency was 0.95, and test-retest reliability was .98 over a four week period. The inter-rater reliability was estimated from the same study to lie between .76 and .86..

For the second element of the operational definition, that “life would get better,” we relied on nearly two decades of prior research on deinstitutionalization. During the course of measuring whether people were “better off” after moving from institutional to small community-based homes, we had already developed strong quality of life scales. They too had been tested for reliability and found acceptable (Conroy, 1995; Fullerton, Douglass, & Dodder, 1999). The instruments were based on interviews of the people able to express opinions, and of those who knew them best, plus families, and also on records-based measures of independence, productivity, integration, health, quality of life, choicemaking, service amounts and types, and indices of relationships.

The third element of the operational definition was about costs, and there was no doubt that these could be empirically determined. It was known to be difficult because of multiple funding streams and mechanisms, but it had been done before (Jones, Conroy, Feinstein, & Lemanowicz, 1984).

Thus we began our work with a clear operational definition of self-determination, which included what the expected outcomes would be. Equally important, we devised valid and reliable ways to measure each step of the operational definition or “theory of self-determination.”

Brief History of the First Demonstration Project

Because the modern self-determination movement for adults with developmental and intellectual disabilities began at Monadnock Developmental Services of Keene, New Hampshire, the history begins there. Monadnock or MDS became the hub of services in “Region V” of New Hampshire’s community system of services and supports. As summarized at the Monadnock website in 2004:

- 1972 Monadnock Workshop opens, the first sheltered workshop in Southwestern New Hampshire.

- 1978 Class Action lawsuit: Garrity v. Gallen, seeks to improve the conditions at Laconia State School and Training Center.
- 1979 First “group home” in Region V (in Peterborough).
- 1979 NH Division of Mental Health and Developmental Services created.
- 1980 Region V now has four group homes housing 30 people.
- 1981 Action for Independence, the result of the Garrity v. Gallen lawsuit, was the court-ordered plan for improving Laconia State School which had 500 residents and 1000 staff at that time.
- 1982 Founding of Monadnock Developmental Services, which became the hub of Region V.
- 1991 Last residents leave Laconia State School, and New Hampshire becomes the first state in the U.S. to have no citizens in public institutions for people with developmental and intellectual disabilities.
- 1991 Sheltered workshops closed in Region V.
- 1991 First individualized service programs in Region V.
- 1992 Three people given authority over their budget and services.
- 1993 Beginning of the Monadnock Self-Determination Project through the Robert Wood Johnson Foundation, 15 people each year for three years. It was “a test of whether self-determination would increase quality of life and decrease per capita spending.”
- 1995 Opening up of the Monadnock Self-Determination Project to everyone in Region V. Data were still collected and analyzed for the original 45 project participants.
- 1996 The Center for Outcome Analysis determines that the Monadnock Self-Determination project is successful in improving quality of life and decreasing per capita costs by 12 - 15%.
- •1996 The Robert Wood Johnson Foundation offers the Self-Determination Project nationally (12 states initially funded).

From 1988 to 1993, some of the most advanced thinkers in the field of developmental disabilities were invited to come to the Monadnock agency to offer advice about improving the service system.

The insights offered over those years by the experts led to the understanding that MDS was at the state of the art as a “good service system,” and yet it still tended to treat people as objects and held them back from obtaining simple decent lives that they enjoyed. These insights were clearly documented for the first time in ***An Affirmation of Community: A Revolution of Vision and Goals*** (Nerney, Crowley, & Kappel,

By 1993, a handful of “radical experiments” in control of public dollars had been tried, and they had been written up as suggestions of the promise of the new approach. The original descriptions of these four “experiments” are reproduced below.

> **Jack** had lived a life of terror and abuse, over-medicated for what appeared to be schizophrenia and a paranoid disorder; unable to walk or speak up for himself due to cerebral palsy; was sent to psychiatric

hospitals for any action he took to try to free himself. For more than 30 years he lived in his room on his knees – the door locked from the inside to keep him safe. He was placed in a community home with Harold who

Now, neither was homeless – and neither was happy. Behavioral issues and psychotic breaks continue until they were each given the opportunity so many of us take for granted – the freedom to choose people they care about – to live with. In July 1992, using a "brokering" system financed with state and Medicaid funding, Jack invited a close friend and her son (similar age as Jack) to move in with him. Harold invited a close friend and her family to help him find a home that they could share. Wonderful things began to happen! No intensive outbursts, no psychotic occurrences, reductions in psychotropic medications and no need for weekly counseling sessions. Most clinical supports have been replaced by having a REAL life and no "program."

Jack has literally unlocked his door and is releasing the ghosts which have haunted his mind for so long. Harold has a family, a home – as much his as theirs, and a business partner to assist in his carpentry business! The net savings was $60,000 annually.

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Bev lived with her natural family until she was 12 years old – that was the year her father died. She was then sent to a public institution. Her father who kept her from the institution also abused her. She became known for her outrageous aggressive incidents; she wore scars and bruises from self-mutilation. She screamed with a high pitch, cursed with gusto, and was labeled schizophrenic and later bipolar. She remained in the institution for 40 years, then was moved into her home community, into program-after-program-after-program, going from behaviorist to psychiatrist to the mental health unit. In 1990 Bev had her most severe series of aggressions, mutilations, and psychiatrist hospitalizations.

At that time, she was taking more than a dozen medications, including Cogentin, Symmetrel, Haldol, and Ativan. She had been on Lithium, Navane, and Prozac. She was hospitalized in August of 1990 and was held "in constant restraint." Those who have known her and cared about her began to form a "circle of support." She was given something she had never known before – POWER, CONTROL, AND TRUST. She, with the help of her circle of friends, hired her support staff, and was informed that her life was truly her own – she would choose how her life would look – others were here to support her – not manage her.

Two years later, Bev is with her circle of friends, deciding all facets of her life, no longer hurting herself or others, no longer so medicated that walking and talking were almost impossible. And the ONLY medication she takes is Synthroid for her thyroid dysfunction. Food, clothing, and shelter make life survivable – but empowerment, respect, and loving, trusting relationships make it worth living. Bev is funded with Medicaid and her chronic mental illness and related health problems have diminished to the extent that she requires less paid support.

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Sean had a serious car accident in 1990, soon after his high school graduation. He suffered a head injury that left him comatose. At the hospital, his life signs stabilized, and hospital staff (doctors, nurses, social workers) planned for his discharge. These professionals determined that Sean "needed" to be put into a nursing home that specialized in treating people with traumatic brain injury. However, there was no such facility in New Hampshire – so the professional planning team, with no input from friends or family, arranged to ship Sean 100 miles away, to a specialized TBI nursing home in Massachusetts.

Sean lived in that nursing home for several years. According to his parents, who visited as often as they could, he didn't get much individual attention, and he didn't improve. His care was costing more than $120,000 per year in state and federal dollars via the Medicaid program. No one was happy with the situation.

Sean's parents finally asked Monadnock's case manager, "Isn't there another way? How much is all this costing government?" When they heard the figure $120,000, they were incredulous. One of their reactions was to say "If we had control of that money, we would do things very differently." Once again, a seed of the notion of self-determination had been planted.

Without being threatened, and out of respect for the feelings of the family, Monadnock staff decided to listen very carefully. They asked Sean's parents, "What exactly would you do differently?" They said, "We would adapt a house for him right here. We would hire his high school friends to work as his attendants. We would hire nurses part time to oversee his care. And we would have him close to us and to his other relatives and friends."

Courageous Monadnock leaders went to state and federal officials, explained the situation, and asked permission to experiment with putting family in charge of how the money was spent. State and federal officials agreed to "look the other way" while regulations were being "bent," so that the new idea could be explored. Ultimately, Medicaid dollars were used for the down payment to buy a house, to make it accessible, and to put in a special bathroom and a lift. Indeed, local friends of Sean were hired as attendants. They took Sean into town on outings, and friends and relatives visited frequently, reading to Sean, playing music and talking in his presence, and touching him. The total dollars spent, even with the down payment on the new home and the payments on the mortgage, went down below $100,000, even in the first year. In subsequent years, costs went even lower.

In 1996, Sean began to open his eyes and focus. In 1997, he began to communicate with vocalizations. In 2000, he and his father attended a national self-advocacy conference in Rhode Island. His friends, his family, and the professionals at Monadnock believe that none of this would EVER have happened if Sean had stayed in that nursing home.

The lesson learned was the core of self-determination: When non-paid allies get to decide how to spend the available public dollars, they may spend it more precisely, and perhaps more wisely, than paid professionals. The question remaining for public policy was: Would this be true for other families? How many – a few, some, most, or all?

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Joan had been sent to an institution in childhood, because the doctors told her parents that it was the best thing to do. Many years later, Joan moved to a large group home in a small New Hampshire community. But, after difficulties, and another move to a traditional Medicaid certified home, Joan, her case manager and "circle" wanted something different. Joan was finding ways to express her strong dislike of her group home situation, with women she did not choose, in a house she did not like, in a neighborhood that was close to nothing of interest to Joan.

An intensive process of the relatively new "person-centered planning" was begun with Joan. No one working with Joan even knew that she had a twin sister until this planning began, and agency advocates investigated her life history more deeply. When Joan felt safe enough to express her own dreams, she revealed that she really wanted to live with her twin sister, her husband and two children in a neighboring state. The circle contacted Joan's sister. It quickly became clear that Joan's sister would have loved to welcome Joan into her home forever – but had been told that a few barriers were insurmountable. First, the twin sister lived in a different state – not far away, but across a state line. Second, the sister would have to give up her job or hire someone to support Joan during times when Joan was home but the sister was at work. Third, Joan could not be permitted to live in a non-Medicaid-certified home and still access any state or federal funds. Fourth, Joan's departure from the group home would leave a vacancy, and the service provider agency would suffer a financial loss.

Joan, her sister, her case manager, and the service provider agency all believed they were powerless to make this dream come true. Joan and her new family-oriented circle of support needed control over the decision making and funds allocated to her.

It turned out that Joan's sister was working at a very low paying job, that she didn't like, simply so she could get health insurance benefits. She said to the planning team that she'd quit her job in a second if only she had health coverage – at a cost of about $4,000 a year. All that was needed was to cross a state line with Medicaid supports (which is done routinely for nursing homes – but most professionals somehow thought to be against the rules in community programs), and funding for Joan's sister's family's health insurance. There was in reality no Medicaid ruling against crossing state lines. Second, it was not expressly forbidden to use Joan's funding in a new way, i.e., to pay for health benefits for her new caregiving unit. Third, flexible Waivers do permit support for people living with their families, not just people in group homes. Fourth, the regional authority promised to work with the provider so that the vacancy left by Joan would either be filled by someone who wanted and needed a placement like that, or the funding would be reorganized so that the provider's financial situation suffer little or no damage.

With considerable courage, the regional funding agency administrators, with the support of a courageous state official, case manager and case manager supervisor, agreed to permit an "experimental" move, and figure out the details as the barriers emerged. There was a conscious effort to simply ignore harmful policies. In most instances the barrier turned out to be someone's narrow interpretation of a policy, or mythical policy, not the policy itself. Joan's quality of life continues to improve, her life is filled with

> family and friends, and the public cost of Joan's support was reduced by 25%. Both Joan and public agencies benefited.

The dramatic power of these stories led the agency's leadership to suspect that a real world demonstration and evaluation might be "fundable" by an external foundation with interests in this area. Although the Robert Wood Johnson Foundation had never funded any project in the developmental disabilities area, other than for infant and child health care, that Foundation was targeted because of a new funding initiative for innovative projects. The funding initiative invited ideas that might hold down costs while maintaining quality. The title of the proposal was:

> **Supporting Self-Determination: Study of An Innovative Approach To Reduce the Public Cost of Long Term Care, And Enhance Quality of Life, For People with Severe Chronic Disabilities**

The original proposal began with this sentence:

> In the next decade, we **may** see massive changes in the way health care is organized in America. However, for people with severe long term and chronic conditions, specifically developmental disabilities, our service delivery practices are **so** outmoded, **so** disenfranchising, and **so** costly that radical departures **must** be demonstrated and evaluated immediately.

The project was, to the great surprise of most stakeholders, approved for funding. In the first Project Plan, three problems were identified for innovative approaches:

> There are three aspects to the problem we wish to address:
>
> - ludicrously high costs of care,
> - simultaneously increasing waiting lists, and
> - consumer dissatisfaction with the ways in which care is provided.
>
> For many citizens with severe chronic disabilities, a possible approach to lower costs, serving more people, and serving them in ways they will prefer, may be available. Its central notion is a radical departure from the current paradigm that governs service delivery. The current paradigm involves congregate-care thinking and paternalistic overprotection, while the new approach would set self-determination as the underlying concept governing the organization of service delivery.

The First Outcome Evaluation in Keene, New Hampshire, 1994-1996[5]

The first work on self-determination among adults was a revolutionary concept. A revolutionary change in a generally accepted pattern of thinking has been called a “paradigm shift” by described by Kuhn (1962) in *The Structure of Scientific Revolutions*. Kuhn wrote about science, but the notion of shifting paradigms has also been applied to other fields. Paradigm shift language has been used within the context of the human services. In health care, for example, individual autonomy may be replacing professional beneficence as the primary organizing principle as suggested long ago by Beauchamp & Childress (1989). Guba (1985) discussed the importance of research on emerging paradigms early, when they were still in the stages of resisted by the forces of orthodox thinkers and theories.

In the latter years of the twentieth century, evidence of a nascent paradigm shift was present in the developmental disabilities scientific literature (Ashbaugh, 1994; Boggs, 1994; Bradley, 1994; Bradley & Knoll, 1992; Evans & Meyer, 1993; Guess, Turnbull & Helmstetter, 1990; Yuskauskas, 1992). Identifiable elements of the emerging paradigm included individual autonomy, empowerment, choice, and self-determination, and the correspondent social values of individualization, diversity, and heterogeneity. Self-advocates 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 trends in thinking reflected a social revolution in the way persons with disabilities were perceived and treated. But despite individual success stories, there was little documentation of actual outcomes of changes due to these concepts. Moreover, changes at the individual level

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[5] This was adapted from our original final report on the Monadnock demonstration grant outcomes, 1996.

were shown to be fragile unless the large bureaucratic systems supporting them underwent simultaneous change (Hagner, Helm & Butterworth, 1996). Some observers believed that current community service systems, which were built on institutional and facility based programs and fiscal patterns, required an entirely new way of supporting people and designing services (Smull, 1990). They argued that a social revolution supporting the exercise of self-determination by people with disabilities would require much more than a change in language.

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.

This project emphasized adults. Although a few children took part in the demonstration, the efforts were aimed at the system of supports associated provided or brokered by the Monadnock Developmental Services agency. The demonstration was not designed to change the nature of power within the special education system. This kind of self-determination effort, in the schools and with children & families, was already well under way via the work of Michael Wehmeyer and his colleagues at the University of Kansas (1992a, 2014). The RWJF strand of self-determination was quite distinguishable from the "educational" strand fostered and led by Wehmeyer:

- The RWJF strand emphasized a civil rights approach to self-determination, in that every American citizen should have the right to maximal control of his/her own destiny – not because they learn enough to earn that right, but simply because it is fundamental and no service structure should ever take it away;

- The educational strand emphasized teaching students skills for decision making, assertiveness, and self-advocacy in preparation for graduation and the transition into adult life.

The Monadnock Self-determination Project was designed to increase the power, authority, and resources of individuals to control their own destinies (Nerney, Crowley, & Kappel et al.,1995, p. 16). It was "*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, people with disabilities had little or no control over the nature of the services purchased in their names. Further, their choices about services were 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 was 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 authors contended that true control and power were not possible unless people using services had authority over purchasing of services and supports. Such a shift in control of funds required that dollars be allocated to individuals and not to service providers. The mechanism the project implementers chose was called "individual budgeting." 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 were 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 allowed people to hire and manage their own support staff while another organization or person handled the federal and state employment requirements, such as employment taxes, minimum wage, overtime, and liability issues (p.9).

Community development was 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 was seen as a necessary part of designing supports. Thus, efforts were made to enhance people's connections, relationships, and community membership as an integral part of "service planning."

Methods

At the beginning, the RWJF self-determination work was so new and radically different from traditional approaches that the implementers and the evaluators were not certain what individual qualities of life would be affected. A change in a quality of life was seen as the definition of an "outcome" (Conroy, 1990). The proper approach in such a situation seemed to be 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

Conroy (1993) designed a package of instruments to measure dozens of qualities of life and outcomes, particularly among people with developmental disabilities. A new section on choice-making and personal control was added. The entire package was referred to as the Personal Life Quality Protocol©, and the personal control or choice-making section was called the Decision Control Inventory©.

The Protocol's subsections have been found to display strong reliability (Conroy, 1995; Devlin, 1989; Dodder, Foster, & Bolin, 1999; Fullerton, Douglass, & Dodder, 1999). The subsections are designed to be sensitive to issues identified as important by self-advocates over the years. The dimensions of quality also cover the general areas specified as central outcomes in the Developmental Disabilities Act as amended: Independence, Productivity, Integration, and Satisfaction. The dimensions in the instrument package also tap the qualities noted in the recent Final Rule for Home and Community-Based Services (CMS, 2014).

Design

The evaluative data reported here originated 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 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 <u>both</u> 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

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

Only two of the group differences were statistically significant. The participants were <u>lower</u> in adaptive behavior (<u>t</u>=1.95, 125 <u>df</u>, <u>p</u>=..027), and <u>lower</u> in vocational behavior (<u>t</u>=2.31, 95.70 <u>df</u>, <u>p</u>=..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 squared = 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

Dimension	Time-1 Mean	Time-2 Mean	Change	t	p	
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	t	p
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. 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).

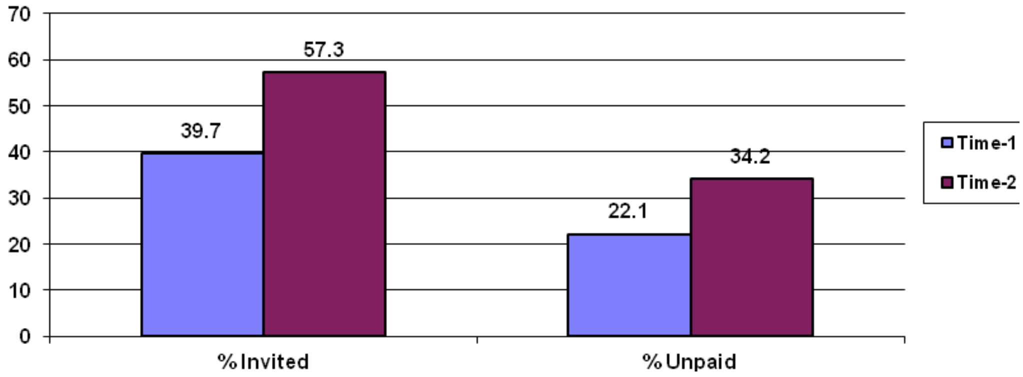
Results 5: Planning Team Composition

The self-determination approach stressed 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



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 inter-rater 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).

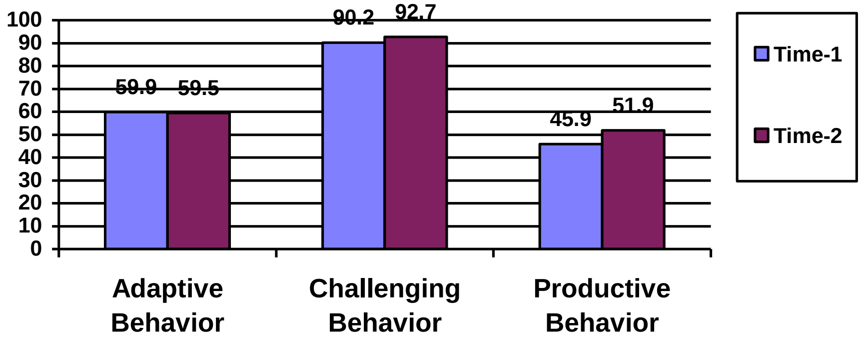
The productive behaviors scale was created by Conroy (1993). The scale included 10 items such as: Getting Up in the Morning, Working With Others, Following Safety Rules and Regulations, Quality of Work or Other Productive Activities, and Promptness and Attendance at Job or Day Program. The productive 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 *

Figure 4: Behavioral Changes from Time-1 to Time-2



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 5.0 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 deinstitutionalized people in California in 1994 was 64.3, and the MDS Self-determination participants began at 82.5.

The Physical Quality Index (PQI) was 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 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.

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 that a commitment to consumer choice and self-determination could lead to enhanced quality of life and satisfaction, while 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. Expenditures for individuals were not tracked. Even though one person in the home might be very independent, requiring little or no staff time, and therefore "cost less," the accounting systems did not reflect such variations. Budgets were written for each home, not each person. People did not have individual budgets.

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. 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. This "Method 1" included people who had just entered the system, and therefore had zero costs in the first year. The second analysis included fewer people but was a more fair estimation – it only included people who were receiving services at both times. The results are presented in Table 5.

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

	# People	1994-95	1996-97	Change	t	p
Method 1	40	$62,168	$54,470	- $,7698	4.02	.001
Method 2	22	$68,294	$57,699	- $10,594	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%. These figures lent strong support to the original claim of the self-determination project, that costs would decline as individual control and autonomy increased.

Discussion

The first evaluation of the Monadnock Self-Determination Project documented remarkably positive outcomes. Although this phase of the evaluation was rigorous and quantitative, its limitations must be understood. First, the design of this study was pre-post only ("before and after"), and did not include analysis of a comparison group. Hence we cannot rule out the possibility that non-participants experienced the same positive outcomes as the participants. Resources for the evaluation were insufficient to follow up and collect “post” data for the people in the comparison group. 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.

The second limitation of this evaluation concerns its generalizability. New Hampshire was an unusual state in many ways, and Monadnock Developmental Services was 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 existed may have deeply influenced 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 may have enabled the self-determination revolution to materialize at MDS.

Outcomes Summary

The outcomes resulting from the implementation of the self-determination principles at Monadnock Developmental Services from 1994 to 1995 are summarized in Table 6.

Table 6: Summary of Individual Outcomes

Quality Dimension	Outcome
Self-determination Scale	Large Improvement
Personal Satisfaction Scale from Interview	Large Improvement
Quality of Life Improvement in Past Year	Large Improvement
Circles of Friends, Number of Members	Large Improvement
Planning Team, Proportion Invited	Large Improvement
Planning Team, Proportion Unpaid	Large Improvement
Challenging Behavior	Large Improvement
Vocational Behavior	Large Improvement
Individualized Practices in the Home	Large Improvement
Physical Quality of the Home	Large Improvement
Hours of Day Program Activities Per Week	Large Improvement
Integration, Outings	Improvement
Minutes of Direct Service Per Day	Improvement
Earnings Per Week	Improvement
Relationships with Family	No Change
Relationships with Friends	No Change
Adaptive Behavior	No Change
Health and Health Care	No Change
Costs	12 - 15% Lower

The table shows a pattern of positive outcomes. Considering that the time period was just 18 months, the findings would seem to be compelling.

A few of the more remarkable features of the table deserve comment. 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 reductions in challenging behavior may be interpreted as a natural consequence of people having more responsibility for their own lives, and more freedom.

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 (Kim, Larson, & Lakin, 2001). 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 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 <u>without</u> 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 (Stancliffe & Lakin, 1998). 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 might 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. The fact that several major enhancements occurred in the lives of the participants at Monadnock suggests that Self-determination truly represented a fundamental improvement in the organization and delivery of services.

The National Evaluation, 1998 - 2002[6]

Just as the first outcome evaluation was being completed, the Robert Wood Johnson Foundation decided to fund a nationwide initiative so that many other states and agencies could "try out" the self-determination paradigm. The funding program was entitled *"National Initiative on Self-Determination for Persons with Developmental Disabilities*." The sequence of events was rapid:

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[6] This summary is taken from Conroy, J., Fullerton, A., Brown, M., & Garrow, J. (2002, December). ***Outcomes of the Robert Wood Johnson Foundation's National Initiative on Self-Determination for Persons with Developmental Disabilities: Final Report on 3 Years of Research and Analysis.*** Submitted to the Robert Wood Johnson Foundation as the Impact Assessment of the Foundation's National Initiative entitled Self-Determination for Persons with Developmental Disabilities. Narberth, PA: Center for Outcome Analysis.

Year	Milestone
1993	Original Proposal to RWJF
1995	Statewide in New Hampshire
1996	RWJF Decision to go National
1997	Grants to 19 States
1998	10 More Planning Grants
1998	National Evaluation Begins
1998	13 More States Join With State Funds
1999	Michigan shows positive results
2000	Ohio, Hawaii, Wisconsin, Maryland also show positive results
2002	Final summary report shows consistent positive results in all 10 states for which Pre and Post data could be collected

What Information Was Collected from People?

The Center had some accurate ways to measure important things like person-centered planning, power and control over one's own life, qualities of life, integration, friendships, health, satisfaction, service types and amounts, achievement of individual goals, independence, productivity, earnings, and so on. These measurement devices and scales were developed from those employed in more than a dozen large studies of deinstitutionalization. They were adapted and extended to track the specific issues of self-determination such as power, control, and the involvement of unpaid allies. The instruments were described in the previous section.

How Was the Study Done?

A few things about how the study was done are important. All the data were collected individually, through personal visits and interviews with the participants and whoever their closest allies were. The interviews used instruments that had been tested for accuracy (reliability and validity). The interviewers included people with disabilities, people without disabilities, family members, and all kinds of other people who had experience in the disability field and were sensitive to important issues of dignity and privacy. All the interviewers were trained by Center staff.

By the time the study got under way, several more states that had not gotten Robert Wood Johnson Foundation grants had joined the National Evaluation. In the end, the Center was able to complete "before and after" data collection with 827 participants in 10 states.

State	Number
CA	120
HI	74
MD	15
MI	135
NH	42
NJ	200
NC	40
OH	62
TX	50
WI	89
Total	827

What Did the Studies Find?

First, the interviews with people "before and after" showed that their individual planning had become much more "person-centered" than before. The Center used a scale from 0 to 100 to measure "how person-centered" each person's planning process was. The results from 8 of the 10 states are shown in this graph:[7]

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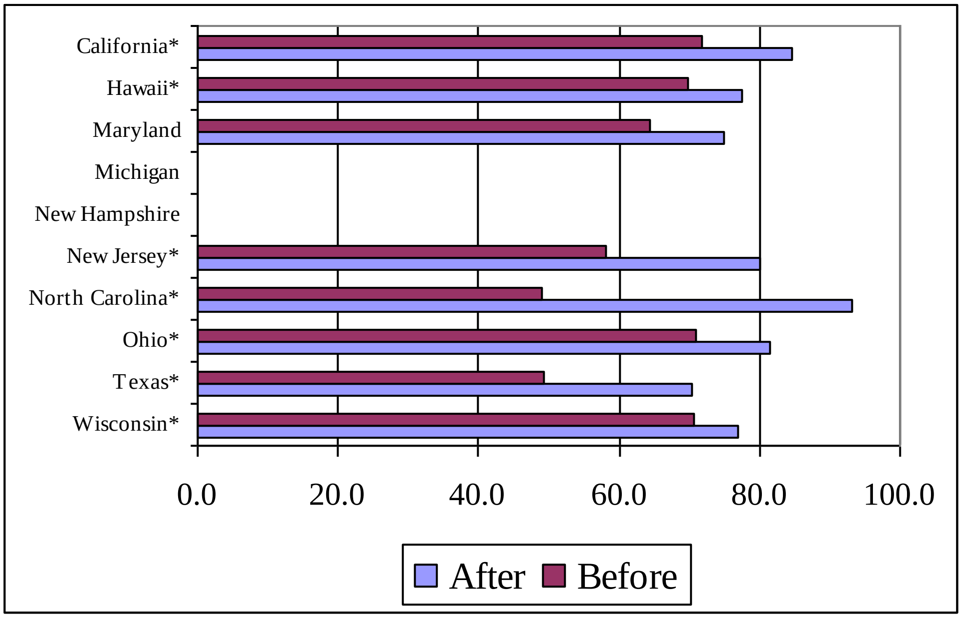
[7] Two of the states are missing because the person-centered planning scale was not used at the "before" visit.

Person-Centered Planning Before and After



The graph can be understood by looking at the colored bars. The red bars show the average person's "person-centered planning score" <u>before</u> getting involved in self-determination, and the blue bars show the average score <u>after</u> being involved. In every one of the eight states, the average person's planning experience became more person-centered.[8]

The early thinking about self-determination suggested that planning had to become more and more person-centered in order for real power to shift toward the people. This did, in fact, happen, in all 10 states.

Next, did power actually shift? The scale that measured power had been developed and tested over several years. It too was on a 0 to 100 point scale. Here is what was found from the participants in 10 states:

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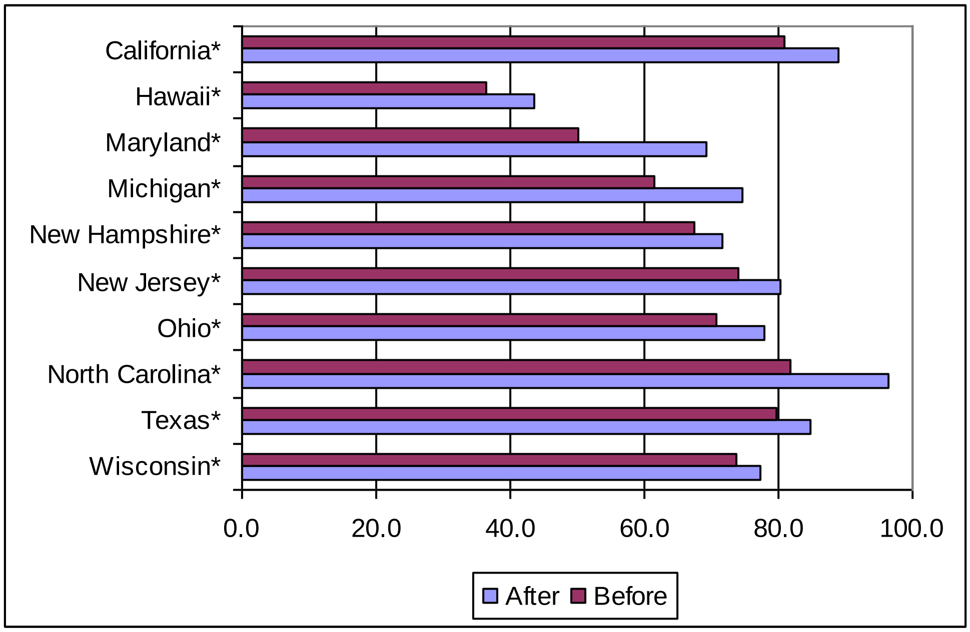
[8] And every one of the changes except Maryland's was statistically significant, meaning it didn't "just happen by chance," but rather, it was almost certainly a "real change." The test utilized was Student's t for paired observations, including the Bonferroni correction for multiple tests.

Power and Choicemaking Before and After



In every state, the blue bar was longer than the red bar.[9] This meant that, in every state, the average self-determination participant did gain power and control over his/her life choices. Thus the first part of the "theory" of self-determination was supported: Power did shift toward people and their freely chosen allies.

The next part of the "theory" of self-determination said that, once power shifted, that people's lives would get better – that quality of life would improve. The Center's scale of Qualities of Life asked people how good or bad their lives were in 14 areas – such as friendships, privacy, health, safety, freedom of movement, being included in the community, working, and so

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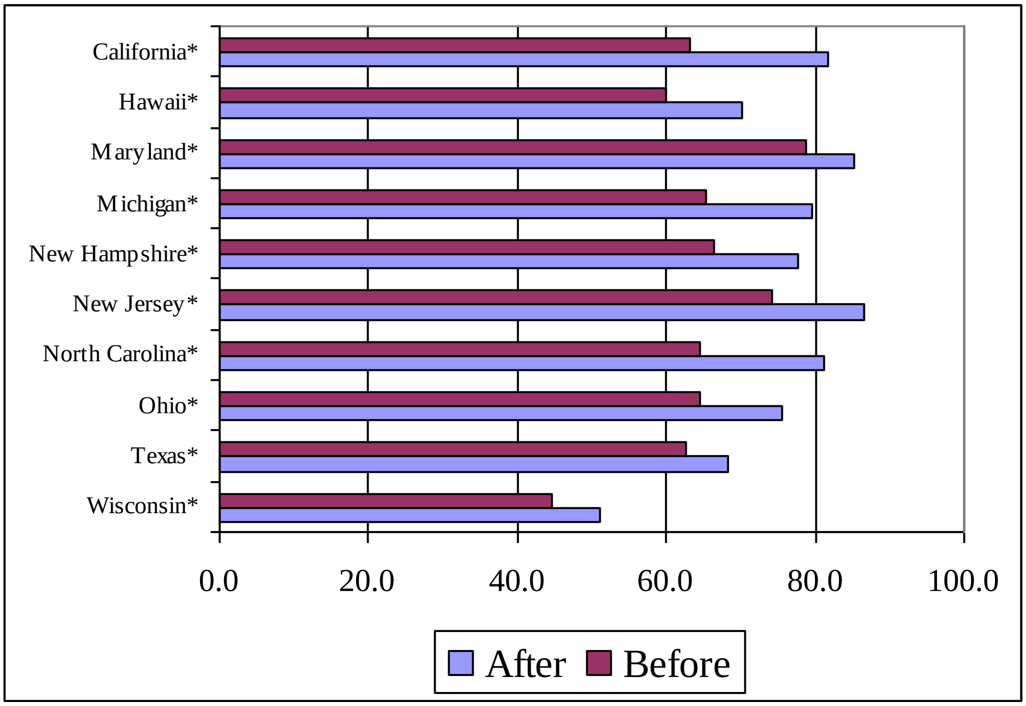
[9] And again, every change was statistically significant.

on. The 14 areas were combined, again, into a 100 point scale of overall quality of life. The results from the 10 states were as shown in the graph below.

Qualities of Life Before and After –Data from the Participants and Close Allies



As before, the blue bars were bigger than the red bars in all 10 states. So the participants and their allies believed their lives improved quite a bit since self-determination began.[10]

In another part of the study, the Center surveyed every family of every participant by mail, and found out that the families believed their relatives' lives had improved in quality in 14 out of 14 areas.[11] This further backed up the finding from the face to face interviews. Qualities of life were reported to have improved sharply.

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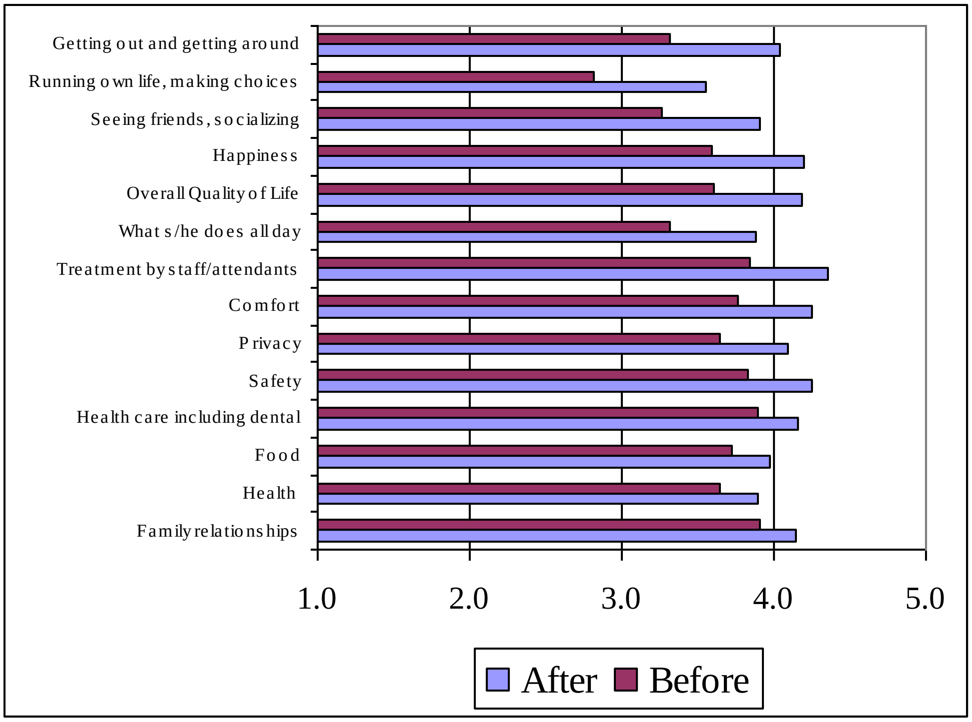
[10] And every change was statistically significant again.
[11] Every one statistically significant.

Family Perceptions of Qualities of Life Before and After



Thus far, two of the three central ideas of self-determination had been supported by the studies: person-centered planning improved leading to a measurable power shift, and life did “get better” according to the participants and their allies.

What about dollars and costs? In the first pilot study in New Hampshire, we found support for the theory that costs would decrease during self-determination. But New Hampshire was an unusual environment, so the problem of generalizing the findings remained. The National study gave us the chance to perform more studies in very different states and systems. The Center was able to complete four analyses of cost changes during the national outcome evaluation, and afterward, two more were completed in states that conducted their own demonstrations.[12]

In Michigan, costs decreased between 6% and 9%, again depending on how things were accounted for. We tabulated the actual expenditures as follows:

Conroy & Head's Michigan Study, 2005

	1998 Average Public Costs	2001 Average Public Costs	Change	significance, 1-tailed	% Change
Unadjusted	$61,788	$56,778	- $5,010	0.0047	-8%
Adjusted for Inflation, Using 2001 Dollars	$67,322	$56,778	- $10,545		-16%

The self-determination participants in Michigan decreased their reliance on public dollars, but the data from the same study showed that their satisfaction, service intensity, and quality of life outcomes improved (Conroy & Head, 2005).

In California, a "comparison group" was used – people who did <u>not</u> get involved in self-determination. There were 90 participants in 3 sites, plus a control group of 40 at one site. The study lasted 3 years. The study showed that costs increased both for the participants and the non-participating comparison group. But costs went up <u>twice as much</u> for the comparison group members. Thus the conclusion was that self-determination was fiscally conservative in California (Conroy, Brown, Fullerton, Beamer, Garrow, & Boisot, 2002).

In New Jersey, the average total cost of supports was the same for participants before and after getting involved (Conroy, Brown, Fullerton, & Garrow, 2002). There were 100 participants tracked and interviewed over a two year period. Cost analyses revealed the same average costs

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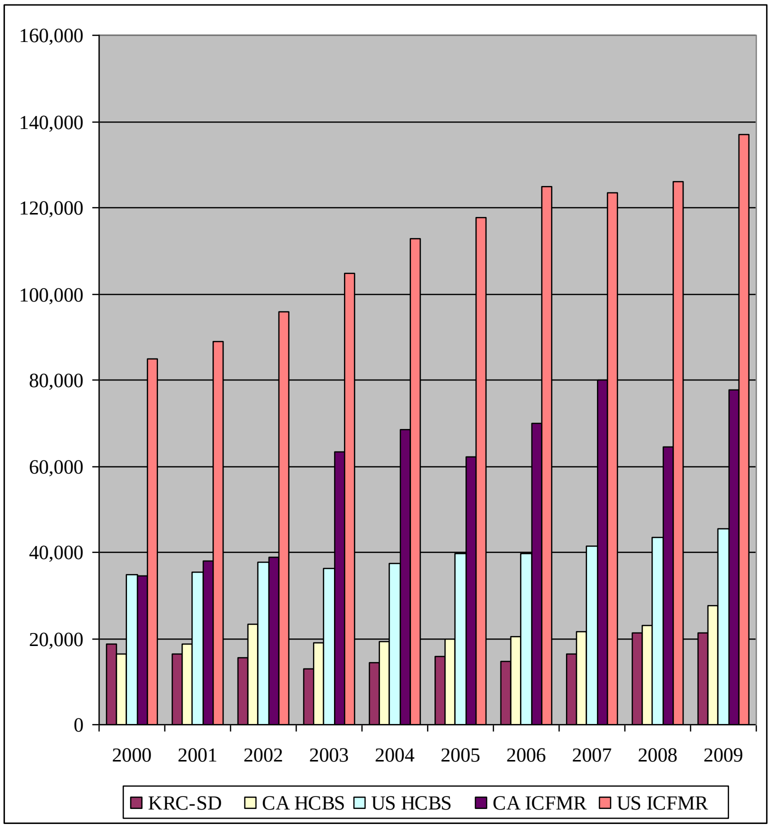
[12] Originally, the Robert Wood Johnson Foundation had given a contract to another organization to study the cost impacts of self-determination, but that study was never completed in that it did not answer the fundamental question about "before and after" cost reductions.

but significantly higher qualities of life and supports for the self-determination group. The authors suggested that the constant costs were probably caused by the simple fact that New Jersey's cost allocation system was to figure out what "traditional services" would have cost, and then to give exactly that amount to the person/family to spend as they saw fit. This made sure that the costs would come out the same, and that there could be no cost savings. Again, this study supported the idea that costs within self-determination would be "the same or lower."

In Allegan County Michigan, we found that costs were held down more than in any other county of Michigan while self-determination was being supported and implemented – and that this pattern persisted over more than a decade (Conroy & Devlin, 2008). We tracked 172 participants across 12 years; cost analyses demonstrated significant and increasing economies among self-determination participants, compared to people in traditional services, to other counties, and to state averages. Detailed corrections for changes in cost of living were included. In fact, costs for the people involved in self-determination in 2007 were slightly lower in constant dollars than they were back in 1996 (Conroy & Devlin, 2008). And both quality and satisfaction indicators increased during that time. This was dramatic support for the fiscal conservatism of self-determination.

In 2012, we completed a 10 year study of individual budgets and expenditures for a group of self-determination participants in rural California (Rankin, Conroy, & Clark, 2001). The graph below tells a striking story of the impact of individual budget control on system costs.

Average Annual Expenditures Per Person: Kern Self-Determination, California HCBS Waiver, U.S. HCBS Waiver, California ICF/MR, and U.S. ICF/MR



Abbreviation	Full Description of Analytical Group
KRC-SD	Kern Regional Center self-determination participants
CA HCBS	California's Home and Community Based Services (Medicaid Waiver) participants
US HCBS	Home and Community Based Services participants for the entire United States
CA ICFMR	California's Intermediate Care Facilities for the *[people who are]* Mentally Retarded
US ICFMY	Intermediate Care Facilities for the *[people who are]* Mentally Retarded for the entire United States

The smallest bars, and the lowest costs, are usually the dark red ones at the left for each year. They represent the Kern self-determination participant's expenditures over the years. They remained steady for many years, only increasing in the last two years when a new administration compromised the principles of self-determination and individual budgeting.

After the first year, the Kern self-determination participants always spent less than the runner up, the California HCBS or Medicaid Waiver participants. California, it should be noted, spent less per person in its Waiver than almost any other state during the period of this study. This is shown by the third light blue bars, which represent averages for the entire United States. Hence the Kern self-determination results compare very favorable against national Home and Community Based Services (HCBS or Medicaid Waiver) norms.

The most expensive funding models, even for well-matched similar people, are the so-called ICF/MR settings. The graph shows that they are the most costly of all the funding streams, and yet the evidence is very strong that they are associated with the least choice, integration, individual progress, and quality of life (Conroy, 1996).

The implication of the 10 year study in California is the same as that from Allegan County Michigan: self-determination and individual budgeting are extremely fiscally conservative and cost-effective ways to use public funds – even over the long term.

Part 1: Conclusions and Discussion

These strong and consistent findings across very different states suggest that the move toward self-determination, which is closely related to “consumer direction” and “cash & counseling,” is associated with strong positive outcomes. It also appears to be fiscally conservative.

Because similar findings are available in the research literature on physical disability and personal assistance services and home-care, the findings from self-determination for people with developmental disabilities should be joined with the physical disability findings. Moreover, the findings from the large scale Cash & Counseling projects in three states are now mostly available, and they too fit very well with the findings from the other two fields (RWJF, 2013).

One of the many facets of the increasing awareness of how money is handled in our human service systems is the realization that the so-called Medicaid "Waiver" program is completely backwards. The current system requires a person to "need" institutional care in order to be part of the government's permission to "waive" institutional care and use public money to live in community settings. This needs to be reversed. People should now be presumed to live in communities, and states and localities should be required to get special governmental permission, or "Waivers," to allow them to go to segregated congregate care settings. We have many decades of research now, which firmly support the practical, fiscal, and moral superiority of community versus institutional supports.

In a related vein, the Medicaid funding stream allows payment for "housing" when a person lives in an institutional setting such as a nursing home or a developmental center or an "ICF/MR." The housing costs are simply part of the rate. But the moment a person chooses to live in the community alongside the rest of "us," current rules forbid the Federal dollars to be used in any way to pay for housing. This makes zero sense, and must be changed. It is a massive fiscal disincentive for the necessary and beneficial and cost-effective reduction of reliance on congregate and segregated models of support. The Supreme Court's Olmstead decision of 1999 makes this process both recognizable and inevitable (Olmstead v L.C., 1999).

It may be time for all three groups, people with physical disabilities, developmental disabilities, and people of advanced years, to work together to support change. If these three powerful interest groups can convince the Congress and the public that public money can be spent more effectively and more wisely than at present, then the possibility of real change in funding programs like Medicaid arises.

The chapter closes with a personal observation from this author. I am a researcher, and may be naïve about politics. Yet, that said, it most certainly seems paradoxical to me, in the political atmosphere of 2014, with the so-called Tea Party still prominent – perhaps even ascendant – that a method shown to offer better value for the same social service dollar – is not yet embraced by all parties.

Part 2: The Paradox of Shared Power:[13]

A paradox about power within the service system became evident during the first pilot project in New Hampshire in the 1990s. The paradox emerged from our interviews, in which we asked about feelings of power, control, and authority. We found that both service provider workers (paid folks) and service recipient circles (focus folks and their unpaid allies) felt they had gained power and control over their life and work during the pilot. This chapter explores that paradox briefly, and suggests an explanation of its nature.

The self-determination movement is about <u>power</u> (Cummings, personal communication, 1993). The central question is: Who <u>has</u> control and power over the lives of people in the service system, and its corollary question is: Who <u>should</u> have it? Who controls the nature and direction of the life of a person who needs support to live a decent life? Will it be professionals and paid staff, or will it be the person, and the person's family and friends? This is a palpable and crucial question faced by people with disabilities, but not by the "rest of us." The fact that the question could even be asked was a source of deep concern to the founders and promoters of the Robert Wood Johnson Foundation's Self-Determination Initiative (Nerney & Shumway, 1996).

The human services system of the 1990s appeared to the New Hampshire self-determination creators to be in the midst of long term paradigm shift, and the fulcrum of the shift appeared to be individual autonomy in the sense of Beauchamp & Childress (1989) and McKnight (1989). The notion that power sharing might result in an enhance sense of control for

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[13] This material was written jointly by James W. Conroy, Richard F. Crowley, & Ellen Cummings.

both parties to the exchange (service providers and recipients) was sufficiently intriguing to justify further interviews and investigation.

Background of the New Hampshire Self-Determination Demonstration

The original RWJ self-determination project was conducted in southwestern New Hampshire, within a regional authority called Monadnock Developmental Services. The positive outcomes of the project were well documented:

1. Participants rapidly gained control over their own lives with the help of unpaid advisors, and "circles of support" which included family members and friends.
2. Their lives improved dramatically (according to reliable measures of quality such as individualized supports, physical quality of the home, decreased challenging behavior, increased time spent in productive activities).
3. Perceptions of life qualities changed sharply for the better (according to those who could communicate such feelings, and according to those who knew them best).
4. There was a dramatic increase in non paid people in their lives.
5. The total money spent to support them went <u>down</u>.

These outcomes were observed within a relatively short time, about 18 months. Both implementers and evaluators were surprised at the time, because they anticipated that years of effort would be required before any measurable changes appeared in the qualities of people's day to day lives.

Unexpected Findings Concerning Power Sharing

During our investigations and interviews in New Hampshire, we discovered that service recipients believed that they had gained power and control during the self-determination project. However, we also found that paid staff and "professionals" such as case managers and personal agents perceived that they too had gained in power and control. How could both groups gain power? If power is gained by service recipients, does it not have to be taken away from case managers and other professionals?

That is the definition of a “zero sum game” in decision theory and economic theory – any gain by one player means a loss for the other player(s). Power over life designs and choices is typically thought of as a zero sum game (Friedman, 2014).

What we observed in New Hampshire did not appear to fit the model of a zero sum game. Nor did it seem to be a simple case of “power sharing” in the sense of O’Brien & O’Brien (1996). One party did not cede some of its power to the other party. Both parties felt more empowered.

The first hint of a possible explanation emerged during an interview with Donald Shumway, New Hampshire’s state director of developmental disabilities services during the self-determination project. We asked about how power moved from agencies and professionals toward the people and their closest friends and relatives. Mr. Shumway suggested that power may not be a zero-sum game. In game theory (Shubik, 1964), a zero-sum game is any situation in which a gain by one player is always balanced by a loss from another player. If I gain one chip in a poker game with you, then you must have lost one chip. The sum of my winnings and your losses is always zero. If I am your case manager, and you gain power over your own life decisions, then that power must have been taken away from me.

The idea that power might not be a zero-sum game was an entirely new concept. How could a person receiving services begin to share control over those services, without the provider and the case manager losing power? We found it difficult to imagine this scenario, and yet we were repeatedly hearing it voiced in our interviews. Professionals were telling us that they felt no “loss” of power during self-determination, yet people and their families were reporting huge increases.

To begin to re-think the power situation in the human services, we began with the premise that there actually is a finite amount of power in any person's life. There are only so many decisions that can be made. These decisions are either made by the person and the person's unpaid circle of support (if any), or they are made by people who are paid to make them.

But after much thought and more interviews, we added a third repository of power: rules and regulations. Both professionals and service recipients told us that great power resided in the rules. The rules of Medicaid reimbursement, and state Policies and Procedures for developmental disability services, were voluminous, detailed, and generally thought of as inviolate. We found a strong perception that neither professional nor consumer could disobey that great power. And the power of rules was almost always exerted as a "No" – no, that's not allowed. The "rulebook" was perceived to be a set of restrictions and barriers, rather than a set of ideas for action.

This seemed to offer a way to resolve the apparent paradox. The new theory suggested that the bulk of the power over peoples' lives has been "hiding" in non-human hands. The new notion was that much of the power in the system was silently residing in rules, regulations, and fiscal policies. This power arose not only out of Federal Medicaid policies, but also equally from state and local bureaucratic processes.

One Illustrative Case Study

Rico[14] had been sent to a large public institution as a child. At the time, in the 1950s, it was the best and only option for young adults with developmental disabilities – primarily because they were not allowed to attend public school. At the institution, Rico experienced overcrowding and a bleak day to day life, as well as physical and sexual abuse. Rico left that

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[14] Identity and characteristics altered for privacy.

institution during the 1980s, when the institution was sued, and then phased down, and finally closed. He was placed into a large group home in a community setting. It was a great improvement over the institution.

After a few years, Rico began expressing frustration with the limits of his life in the group home. He did not choose the home, he was living with people he did not choose, and he went to a day program that he also did not choose and could not change.

During the rise of person-centered planning in the early 1990s, the community agency found that Rico really wanted to live with his twin brother and his wife and two children in a neighboring state. The brother wanted that too. The brother needed agency approval and modest, reasonable supports. But Rico, his brother, his case manager, and the service provider agency all believed they were powerless to make this dream come true. The primary reason was the universal belief that Medicaid and state funds could not be spent "across state lines." It would be "against the rules," everyone assumed, because, after all, there were New Hampshire tax dollars involved – and they could be expended only in New Hampshire – so they thought.

Rico and his brother were told that he could not go to live in another state and still receive support from the State Medicaid Waiver funding stream. That would be against state Medicaid policy. He could not go to live in a non-certified home; that would be against state and federal funding policies. Furthermore, he could not leave his current home, because that would leave a vacancy, and the service provider would suffer a financial loss. Rico, his brother, and the case manager felt powerless.

But while working on Rico's wishes, research into the rules and regulations began. The circle members found that there was no written rule against spending Medicaid or state dollars across state lines. The other barriers raised in meetings were similarly not found in actual written documents. In most instances the barrier was someone's narrow interpretation of a regulation, or mythical regulation, not the regulation itself. The power, as perceived in Rico's case, was in the rules and regulations, and in the interpretations of those regulations. Moreover, that rule-based manifestation of power was negative – it said "No."

Finally, though courage in abundance was required among all parties, Rico's wish was met. He moved in with his twin brother and his family just over the state line. The agencies continued to submit bills to the regional, state, and Federal authorities. The bills were paid without problems. Rico's quality of life soared, and his life became rich with family and friends. The total public costs dropped 25%.

Power and control were transferred from assumptions about rules & regulations to Rico, his intimate circle of family and friends, and selected support workers including the case manager.

The experience suggests that, too often, human service professionals fall victim to the feeling that "*I didn't make the rules – I just have to follow them.*" This attitude and world view may be a dominant mindset in traditional service systems.

The experience indicated that "rules and regulations and policies" can be misinterpreted or narrowly interpreted by the anointed overseers of public supports. Personnel engaged in this level of oversight are not trained or paid to make decisions based on the principles of life, liberty, and the pursuit of happiness. Rather, they are trained and paid to <u>control</u> the rate of expenditures and prevent any possibility of an audit exception or a finding of a deficiency in a licensing or accreditation review. This produces a strong negative and restrictive bias. Take no risk is the central organizing concept for fiscal officers.

One Theoretical Model for Interpretation

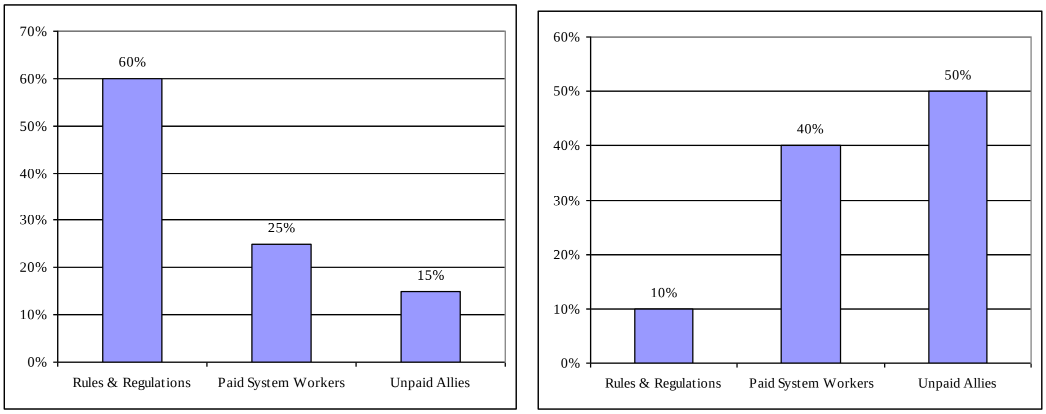
What may have happened in the initial Self-Determination Project, then, is that the Robert Wood Johnson Foundation grant moved, encouraged and supported administrators to become more flexible, to take some risks, to look beyond the faceless rules and regulations, and finally to truly make themselves accountable for giving people what they really wanted and needed. During the Self-Determination Project the Executive Director of the demonstration agency redefined his own job, with the encouragement of the case managers, and he called his new job “Barrier Remover.” His entire workday, along with other administrators and with the encouragement and support of case managers, became devoted to removing the reasons why people could not do the things they really wanted to do.

The stacks of Medicaid and state rules, regulations, and policies were de-emphasized under self-determination. They were not removed, just de-emphasized or re-interpreted in a more humane manner. Basic health and safety concerns did not vanish, but rather were put in their proper place. Concern over perceived legal and liability issues were made secondary to the effort to find out what each service recipient really wanted and trying to make that happen.

A visual representation of what we think took place in the Monadnock Self-Determination Project is presented in the following two figures.

Hypothetical Distribution of Power Among “Rules & Regulations,” Paid Workers in the Service System, and Unpaid Allies of the Person Receiving Supports

1. Traditional Service System 2. Self-Determination Support System



The graph on the left, representing the traditional service system, shows the bulk of the power over the lives and options of service recipients (60%) to be held within Rules & Regulations. And, as Rico’s experience illustrated, the interpretation of those Rules & Regulations is very likely to be overly cautious, overly restrictive, far beyond what they actually say. What may happen in the self-determination is a shift in courage. By this we mean that all parties gain the courage to ask “Where is that rule written? Let me see it!”

The graph on the right show a shift in power, away from assumptions and interpretations about the Rules & Regulations, toward the paid and unpaid folks who are actually designing a life around a recipient, a person like Rico. On the right, power over life choices is represented as 50% in the hands of the person and the person’s unpaid allies, 40% in the hands of providers and agency staff, and only 10% in the rules and regulations.

The percentages in the figures are not empirically derived, but rather are meant only to illustrate what the participants believed had happened in the way they experienced power.

This model of shifting power is a “thought experiment,” intended to explain why both paid folks and unpaid folks in the demonstration projects reported a sense of <u>increased</u> power.

Part 2: Conclusions & Discussion

If this theory is at all accurate, it follows that the entire self-determination paradigm shift may hinge on courage and leadership. The success of self-determination efforts may depend on the extent to which administrators and case managers and fiscal officers can summon the courage to investigate and sometimes re-interpret ignore rules and regulations that ignore common sense, civil rights, and personal freedom. The interviews indicated that thorough investigations of rules and regulations very often showed that what everyone thought was forbidden actually was not.

The original impetus for the self-determination efforts arose from the observation that people in traditional service systems are so dominated by professionals, and rules & regulations of the funding stream, that their lives are completely controlled with regard to where they will live, with whom, what they do during the day, where they may go when they go out to have fun, and with whom they may associate. This is an abridgement of individual freedom that is unimaginable to the "rest of us."

The sharing of power in the self-determination determination model may seem threatening to workers at all levels of the service system. Their misgivings may be described as "*my control of how services are delivered decreases, but my responsibility stays the same.*" However, we observed in our studies that the opposite actually happened. Workers at all levels reported a sense of <u>increased</u> power during the self-determination work.

The spirit of this insight was best expressed by a case manager during an interview in 1995. Asked about power, self-determination, and her job, she said:

> *I got into this work to help people. But for a long time, I felt like my job turned into mostly saying "No" to what people wanted. Now I feel like my job changed. Now I'm supposed to find ways to say "Yes" – safely and carefully, of course. But I feel much more powerful, more able to really help. I love it.*

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