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
Route One and College Road East
PO Box 2316
Princeton, NJ 08543-2316
609-243-5869
Contract Number 31891

Submitted by:
James W. Conroy, Ph.D
Amanda Y. Fullerton, M.S.
Marguerite Brown, M.S.
James Garrow
Center for Outcome Analysis
201 Sabine Avenue, Suite 100
Narberth, PA 19072
610-668-9001, FAX 9002, e-mail jconroycoa@aol.com

December 31, 2002

Table of Contents

Acknowledgements

Thousands of people contributed to this effort. We are grateful to all – self-advocates, national leaders, state and local officials, advocates, provider agency staff, researchers, journalists, Robert Wood Johnson Foundation staff, and many others. But the greatest debt of gratitude is owed to the pioneers themselves – the participants and their allies – who had the astonishing courage to try to take their own lives back into their own hands, within human service systems that were not designed to make it easy to do so.

Executive Summary

Self-determination has become the single most influential concept in the field of developmental disabilities in just one decade. From its beginnings in southwestern New Hampshire in 1993, as an experiment with four people and their families, we have now seen 19 states receive large grants, 10 more received small grants, 13 more initiated projects with their own funds, and most recently the Centers for Medicare and Medicaid Service has issued "templates" for states to follow in applying self-determination within their Home and Community Based Waiver programs. National organizations and centers have sprung up. Professional conferences are dominated by presentations on the topic. An extraordinarily rapid shift in thinking about supporting people with disabilities has occurred.

With the continual support of the Robert Wood Johnson foundation, the Center for Outcome Analysis has been studying this phenomenon since its inception. We studied the outcomes of the original demonstration in New Hampshire from 1993 to 1996, and then the initiatives in more than 18 states that received grants from 1997 to 2001, and we continue to study self-determination efforts to the present day.

In this document, we present the usual introduction, background, history, hypotheses, methods, and results. But we are most pleased to share the results, because these are the hard scientific data which were collected to test the notion of self-determination: Does it work? Does it help people move toward better lives? Is it really fiscally conservative? The data are surprisingly consistent across very different states and service systems, and we therefore believe there is justification for a strong inference that the self-determination "hypothesis" is thus far supported.

We at the Center for Outcome Analysis (COA) have played the role of "evaluators." When the Robert Wood Johnson Foundation (RWJF) awarded the original 1994 grant to Monadnock Developmental Services to "try out" the self-determination concept, the Foundation requested that we maintain an arm's length relationship with the project. In that way, we could remain objective and independent of the day to day implementation of the demonstration project. This is important for quantitative scientific work. The Foundation therefore gave COA an entirely separate grant to conduct the Independent Evaluation of the Monadnock demonstration.

The final reports of the 3 years of study at Monadnock were completed in 1996. One contained the quantitative findings[1] and the other contained the qualitative findings[2]. Both reports suggested that the self-determination approach did "make a difference," that the theory was borne out in this first small demonstration.

The theory of self-determination, cast into operational terms, was this:

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

We detected a significant power shift away from paid professionals and toward the people and their freely chosen allies, mostly unpaid. We found evidence of enhanced quality of life in more than a dozen dimensions. And finally, we found a significant decrease in the average public dollars spent to support the participants. All three parts of the self-determination hypothesis were supported.

Given that the effort had been successful in one small part of New Hampshire, the most important and interesting question now became: Can this work in other places, with different service systems – or was Monadnock in New Hampshire unique? In scientific jargon, this is the question of "generalizability."

The opportunity to seek answers to the question of generalizability was offered by the Foundation's 1997 decision to fund a national initiative. We have been able to collect reliable scientific data on qualities of life and services for more than 1,000 people who participated in projects in 11 states. From them, we have succeeded in collecting "before and after" data for 441 people in 6 states – and it is from them that we have learned about the impacts of the self-determination approach.

---

[1] Conroy, J., & Yuskauskas, A. (1996, December). **Independent Evaluation of the Monadnock Self-Determination Project**. Submitted to the Robert Wood Johnson Foundation. Narberth, PA: The Center for Outcome Analysis.

[2] Yuskauskas, A., Conroy, J.W., & Elks, M. (1997, May). **Live Free or Die: A Qualitative Analysis of Systems Change in the Monadnock Self-Determination Project**. Submitted to the Robert Wood Johnson Foundation, Self-Determination Initiative National Program Office. Narberth, PA: The Center for Outcome Analysis.

In each of the states, we found evidence that power really did shift – significantly – just as it had in the original demonstration in New Hampshire. The gains ranged from 4 points to 19 points on our 100 point scale. The change in New Hampshire had been 4 points. Each of the changes was statistically significant.

Thus, the first part of the self-determination theory was consistently supported in our state studies. Power did shift measurably, away from paid workers[3] and toward individuals with disabilities and their allies.

The second part of the theory states that if power does shift, and people gain more control over their lives, that their lives will get "better." Because quality of life means many things, we measured many aspects of quality. On our Quality of Life Changes scales, there were large and significant perceived improvements in 14 out of 14 areas – and this too was consistent across states.

The same result was obtained from the Family Survey. The closest relatives of the participants believed that the participants' live had improved significantly in 14 out of 14 areas.

There were many other indicators of quality that were utilized across the states, including attainment of individual goals, friendships, person-centered planning, health, and integration. Although the findings on these dimensions varied somewhat across the states, the preponderance of significant changes were in positive directions.

These findings concerning life quality lend support to the second tenet of self-determination. We infer that, on the average, across many states, counties, and systems, people's lives did improve during self-determination – and by far the strongest indicators were self-perception and family perception.

Finally, the question of costs is essential to the third tenet of self-determination. We found it extremely difficult to measure <u>changes</u> in individual costs, mainly because in many systems cost were not individualized prior to self-determination. Moreover, many of the implementations in the RWJF initiative worked with people and families who had been on waiting lists. There was no way to measure changes in cost for them.

---

[3] In the future, the distinction between "paid and unpaid" allies will blur more and more – because when people obtain control of resources, they can choose to pay friends, neighbors, or relatives to provide the support and assistance that they need. In these early pilot projects, however, the distinction was still useful.

Nonetheless, the evidence we do have, from New Hampshire, Michigan, and California, is consistent. In New Hampshire, average public expenditures dropped between 12% and 15%. In Michigan, the average dropped about 7%. In California, where we had a comparison group, and where the participants were from an underserved group, the self-determination participants went up in costs – but not nearly as much as the comparison group.

We believe the evidence at this stage supports a very strong inference that the central tenets of self-determination are valid. When professional power is shifted, gradually and carefully, to people and their freely chosen allies, lives do generally improve, and costs do not increase. Self-determination is overwhelmingly supported by participants and families – and it appears to be quite fiscally conservative. This would lead to the conclusion that the Robert Wood Johnson Foundation's Self-Determination Initiative for People with Developmental Disabilities was a highly successful grant program – and it had the added advantage of revealing a new area for excellence in public policy.

Introduction

> *For people with … developmental disabilities, our service delivery practices are **so** outmoded, **so** disenfranchising, and **so** costly that radical departures **must** be demonstrated and evaluated immediately.*[4]

This was the second sentence of the original proposal from Monadnock Developmental Services in New Hampshire, written to the Robert Wood Johnson Foundation in 1993. The proposal was entitled "Self-Determination for Persons with Developmental Disabilities."

That sentence is an apt beginning for this Final Report of the National Impact Assessment. It reflected the intense dissatisfaction with the status quo that arose in the developmental disabilities field in the late 20th century.

To recapture what began this decade-long journey of demonstration and research, we return to that original proposal's second paragraph:

> *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 … 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.*

As evaluators, we had to cast this statement of policy into what is called a "hypothetical form," or an "operational definition." That is, the thoughts above had to be translated into something we could test and measure, to find out if the self-determination concept really worked. Accordingly, in 1994, COA posed the operational definition of self-determination in this way:

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

[4] From the proposal entitled "**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**" by Tom Nerney, Ric Crowley, Ellen Cummings, and Jim Conroy, 1993.

Each of these three elements of the operational definition of self-determination could be measured and tested. This Final Report of more than 3 years of national evaluation will present the best currently available scientific answers to the three hypotheses above:

If we really do detect a shift in power, with reliable and valid measures, then will we actually see improved qualities of life with similarly valid measures? And if both of those things are demonstrated, then is it true that costs will be the same or less than they would have been, using reliable accounting methods?

In the following section, we rely heavily on graphics, and intentionally use non-technical language. This is to allow the broadest possible audience to have access to the history and development of self-determination.[5]

[5] We also write in the first person where appropriate, as the American Psychological Association's Publication Manual recommends.

Background and History of Self-Determination

In this section, the origins of the self-determination movement are summarized. In order for this discussion to be accessible to the widest possible audience, including self-advocates, PowerPoint slides are interspersed throughout the text. These slides have been widely used, revised, tested, re-revised, and re-tested for clarity and understandability with all kinds of audiences, and have been found useful by self-advocates, advocates, family members, and other non-technical stakeholders.

America's treatment of people with mental retardation and other developmental disabilities has included service models that resulted in people being segregated, isolated, and powerless. Because the Robert Wood Johnson's ***Self-Determination Initiative for People with Developmental Disabilities*** was conceived in part to remedy these problems, it is essential to trace the major trends in American service systems. Chief among these trends has been the growth, and the decline, of public institutions.

Changing Patterns: From Institutions to Community Support Models

The institutional model was brought to America in the 1850s, by Samuel Gridley Howe.[6] Howe had observed facilities in Europe that were designed to be self-sufficient agrarian communities, and believed that such a model might be useful in the United States.

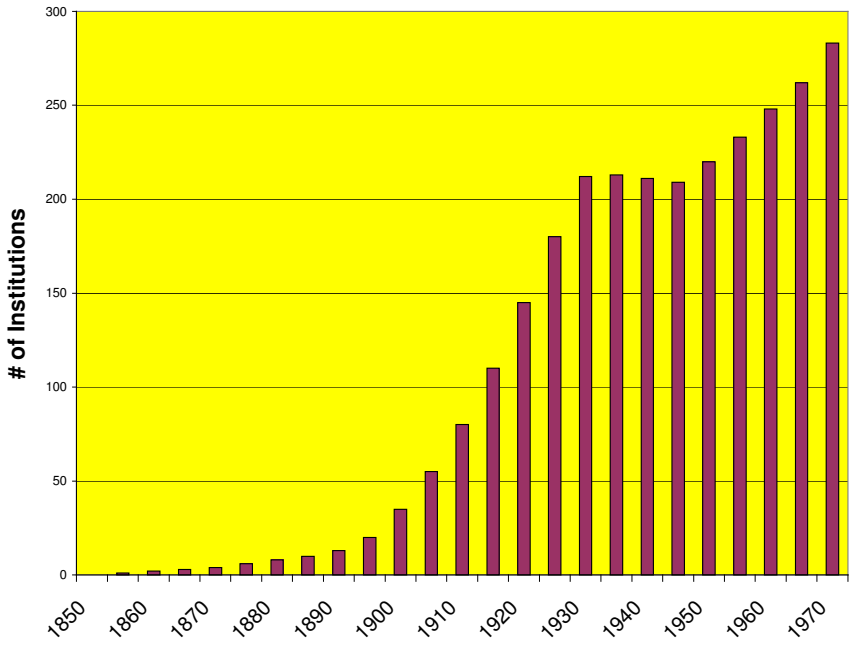
[6] Wolfensberger, W. (1975). **The origin and nature of our institutional models**. Syracuse: Human Policy Press.

Source of The Institutional Model

- Brought to the U.S. in 1850s
- By Samuel Gridley Howe
- From a "model program" in Germany
- The vision was a self-sufficient agrarian community
- Free from pressures of normal life
- Protected, safe, healthy

The institutional model grew rapidly. Some of the first public facilities were the "New Hampshire Hospital -- Brown Building" in Concord (1842), the Central State Hospital in Indianapolis (1848), and the Walter E. Fernald State School in Waltham Massachusetts (1848). The graph below shows the proliferation of these state-operated public institutions.

Number of State-Operated Public Institutions, 1840-1970



New institutions were built at an accelerating rate throughout the latter half of the 19th century, and well into the 20th. The only slowdown occurred in the 1930s and 1940s, because of the Great Depression and World War II. The number of institutions peaked in 1970, with about 280 operating in that year.

It is a strange historical fact that Samuel Gridley Howe, who brought the institutional model to the United States, turned strongly against them in rather short order. Just 14 years after he began advocating for the creation of public institutions, he began to issue compelling public statements about their very obvious flaws. The following quotes are from Dr. Howe speaking at a ceremony commemorating laying the cornerstone of a new institution in Batavia, New York in 1866:

> **"Grave errors were incorporated into the very organic principles of our institutions ... which make them already too much like asylums; which threaten to cause real asylums to grow out of them, and to engender other evils."**
>
> **"… all such institutions are unnatural, undesirable, and very liable to abuse."**
>
> **"We should have as few of them as is possible, and those few should be kept as small as possible."**
>
> **"Such persons [with disabilities] ... should be kept diffused among sound and normal persons."**

Thus, far from heeding the advice of America's greatest expert, public policy moved inexorably in the direction of isolation and segregation for the next 100-plus years. Also of historical interest is the last of the quotes above, which may be the first clear statement of the principle of inclusion in the disabilities field.

The names of these institutions often left little doubt about their purpose. For example, the Pennhurst Center (the facility's name when it closed in 1987) was originally "The Eastern Pennsylvania State Institute for the Feeble Minded and Epileptic." Its explicit purpose, defined on June 12, 1913 by the Pennsylvania Legislature, was "the **segregation** ... of epileptic, idiotic, imbecile or feeble-minded persons."

The graph below shows how many people lived in public institutions over the past 150 years.

Number of People in State-Operated Public Institutions

In keeping with the increasing number of facilities, the numbers of people housed in those facilities increased. And, just as the number of facilities reached its peak in about 1970, the peak number of American citizens in these facilities reached its highest point in about 1970 – at 187,000 individuals.

As the graph shows, a decline in the number of institutionalized people began roughly in 1970. The decline has been fairly steady over three decades. Now there are only about 43,000 people still living in public institutions. Why did this happen?

The reasons can be summarized as:

Scandals
Ideology
Litigation
Scientific Evidence on Quality
Economics

Scandals

One of the first glimpses of the severity of the scandalous conditions was provided by Burton Blatt and Fred Kaplan [7] of Syracuse University. Their photographs were compiled in 1965, using hidden cameras during tours of institutions in New York state. In their work entitled **"Christmas In Purgatory: A Photographic Essay On Mental Retardation,"** they showed the bleak horror of overcrowding and lack of stimulation. This work opened the door toward increasing national awareness of the shameful situation, and almost certainly led to the tremendous media attention that was to follow.

The parents' movement in developmental disabilities began in the 1950s, and strengthened during the 1960s. Parents were always instrumental in assisting and contributing to efforts to raise the national consciousness about institutional conditions. Organized parents sprung up all over the nation. Originally the

[7] Burton Blatt and Fred Kaplan (1974). **Christmas In Purgatory: A Photographic Essay On Mental Retardation**. Syracuse University: Human Policy Press.

organizations were called the Associations for Retarded Children, later the Associations for Retarded Citizens, and now simply the ARCs.

The earliest and best known example of media-instigated institutional scandals is Geraldo Rivera's televised exposes of conditions at Willowbrook on Staten Island in the late 1960s and early 1970s. (This was Mr. Rivera's first nationally prominent story, and he is still receiving accolades for that work.)

The institutions were horribly overcrowded and underfunded. In a 1968 televised expose of conditions at Pennhurst, it was revealed that the average cost per person at Pennhurst was $5.90 per day, while the average cost of keeping a leopard at the Philadelphia Zoo was $7.15 per day. Overcrowding had reached levels in institutions all over the country that could only be described as inhumane. Pennhurst housed more than 3,000 people in facilities designed for about 700.

State officials simply could not tolerate the media spotlights that began to be aimed at America's institutions in those years. Following Rivera's pioneering work, reporters all over America began working on their own local institutions, and found that conditions everywhere were abysmal.

Ideology

The second factor was ideology – the outcome of many years of thinking among scholars about ethics, human dignity, and disability. The overwhelming national leader in the ideological movement in developmental disabilities was Wolf Wolfensberger of Syracuse University. His works led an entire generation of human service workers to question the institutional model, [8] and later to adopt an entirely new way of looking at human services, called "normalization." [9]

Normalization "theory" is incompatible with segregation. Its central demand is:

> "The utilization of means which are as culturally normative as possible in order to establish and /or maintain behaviors and characteristics which are as culturally normative as possible."

---

[8] Wolfensberger, W. (1975). **The origin and nature of our institutional models**. Syracuse: Human Policy Press.
[9] Wolfensberger, W. (1972). **The principle of normalization in human services**. Toronto: National Institute on Mental Retardation.

This definition was broadly applicable to virtually any human service. It became most dominant in the disabilities field. It was utilized by the entire generation that began constructing community service systems in the 1970s – the very systems that became the nation's alternatives to public institutions.

An important statement of principle emerged from the normalization principle in 1979. The "Community Imperative" was a statement developed by scholars and advocates at Syracuse University in the late 1970s, and still remains a driving force in the developmental disabilities field:

The Community Imperative:
A Refutation of All Arguments In Support of Institutionalizing Anybody Because of Mental Retardation

> In the domain of Human Rights: All people have fundamental moral and constitutional rights. These rights must not be abrogated merely because a person has a mental or physical disability. Among these fundamental rights is the right to community living.
>
> In the domain of Educational Programming and Human Service: All people, as human beings, are inherently valuable. All people can grow and develop. All people are entitled to conditions which foster their development. Such conditions are optimally provided in community settings.
>
> Therefore: In fulfillment of fundamental human rights, and In securing optimum developmental opportunities, All people, regardless of the severity of their disabilities, are entitled to community living. [10]

Many of the nation's leaders in the disability movement signed their names to this statement. The Community Imperative became a rallying point for the values of inclusion, integration, and basic human rights.

Litigation

The third factor, and in hindsight perhaps the most powerful, was litigation. Public interest attorneys around the nation became interested in testing the laws of the richest society in the history of the world, to see whether the newly revealed awful institutional conditions could be remedied – and whether principles of adequate care could be given legal underpinnings from the Constitution, the Bill of Rights, and a century of federal and state laws.

[10] http://soeweb.syr.edu/thechp/community_imperative.htm

Lawsuits were filed on behalf of the people living in institutions and their relatives in a dozen states, including New York (Willowbrook), Michigan (Plymouth), Alabama (Partlow), and Pennsylvania (Pennhurst). These early lawsuits were designed to force states to improve the institutions by adequately funding them, hiring and training more staff, and providing services that would help people achieve their potential.

Led primarily by the Pennhurst case, however, these and all of the later lawsuits transformed into something unexpected. The Pennsylvania Associaton for Retarded Children (now the ARC of PA) joined a case that was already in progress, but rather than asking that Pennhurst be improved, the ARC plaintiffs claimed that no amount of money could remedy the obvious facts of isolation and segregation – which they claimed led directly to abuse and neglect. Rather than improving the institutions, the experts in these cases said, segregation should be abolished and people should be served in communities and neighborhoods just like anyone else.

In the Pennhurst case, Judge Raymond Broderick found in favor of these arguments in 1977. Every person living at Pennhurst would have to be accorded a new home and a new life in communities around Pennsylvania. Judge Broderick's decision was appealed, and was eventually argued before the United States Supreme Court three times – but after a decade of conflict, Pennhurst's last residents moved to new homes in October of 1987.

The surge of litigation also spurred the transformation of the movement for fair and humane treatment into a true civil rights movement. Shapiro (1994) [11] traced the unfolding of this latest civil rights movement in his book ***"No Pity: People with Disabilities Forging a New Civil Rights Movement."*** The inclusion of Section 504 within the Rehabilitation Act of 1973 provided the legislative foundation for later litigation – it was worded in the same way as the Civil Rights Act:

> Section 504 of the Rehabilitation Act - Nondiscrimination Under Federal Grants and Programs
> Sec. 504.(a) No otherwise qualified individual with a disability in the United States, as defined in section 7(20), shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any

[11] Shapiro, Joseph P. (1994). **No Pity: People with Disabilities Forging a New Civil Rights Movement**. New York: Random House.

program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.

Later, the passage of the Americans With Disabilities Act in 1990 furthered the movement, and was hastened and supported by a constant stream of litigation for the rights of people with disabilities to be fully included in their communities.

Because the landmark Pennhurst legal decision, and those modeled after it, were made primarily on the basis of expert opinion and principles of human rights, the most urgent question surrounding such lawsuits during the 1980s was: Will the people really be "better off" in community homes? The urgency of this question led to major research efforts, which contributed not only to the body of knowledge, but also to the movement away from segregated treatment of people with developmental disabilities.

Scientific Evidence on Quality

The urgency of the question "Are people better off" led to a series of studies in the 1980s and 1990s, the first of which was the "Pennhurst Longitudinal Study."[12] Funded by interagency agreements across several federal agencies, the Pennhurst Longitudinal Study lasted from 1979 to 1985. The study revealed that the people who moved from institution to community benefited in almost every way measured: independence, productivity, integration, choice making, perceived qualities of life, family perception of qualities of life, service intensity, meeting individual goals, freedom from abuse, access to decent health care, freedom from over-medication, and so forth.

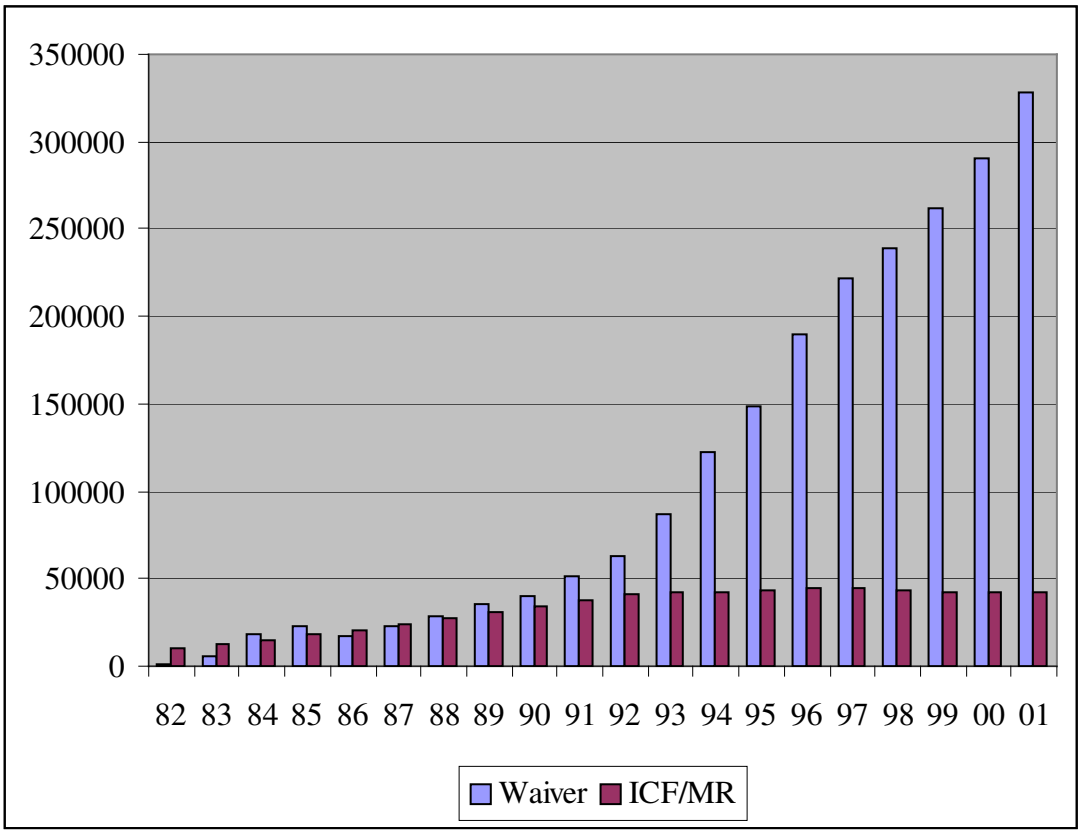
Moreover, the total public cost to support the people actually decreased. (Unfortunately, this cost decrease occurred only because the community workers' salaries and benefits [13] were far lower than the institution's state employees – and this situation continues to plague the human services today, in 2002.)

All across the nation, systems of community based homes and day activity centers sprang up. Two new funding streams were authorized within Medicaid in 1981, to encourage the growth of community services with federal financial participation: the Intermediate Care Facilities for [People Who Are] Mentally

[12] Conroy, J., & Bradley, V. (1985). **The Pennhurst Longitudinal Study: A report of five years of research and analysis**. Philadelphia: Temple University Developmental Disabilities Center. Boston: Human Services Research Institute.
[13] The community system was composed primarily of private non-profit service providers.

Retarded (Small) program, or ICF/MR program, and the Home and Community Based Services Waiver, or HCBS Waiver program. Together, these programs grew from zero in 1981 [14] to nearly 400,000 participants in 2001. The graph below shows the pattern of the trend in these two funding programs.

Numbers of People Participating in the Medicaid Home and Community Based Waiver Program, and the Intermediate Care Facilities for [People Who Are] Mentally Retarded Program, 1982-2001



The small ICF/MR program grew at about the same rate as the Waiver program in the 1980s, but the greater flexibility and non-medically dominated Waiver option began to be distinctly favored by the states throughout the 1990s and up to the present.

The Pennhurst research model, which was based entirely upon individual outcomes, was extended, refined, and applied in other states, including New

[14] Actually, a few states began to use the ICF/MR funding stream for community services before the "Interpretive Guidelines" for doing so were issued by HCFA in 1981.

Hampshire, [15] Connecticut, [16] Oklahoma, [17] and many others [18]. The results of these studies, and later of studies in other countries, strongly supported the original Pennhurst findings: people with developmental disabilities can have far better lives living and working in integrated community settings than they could ever have experienced in a large scale segregated institution – and the public cost was always less (although the reason was consistently found to be poor community worker salaries and benefits).

It was during this period of rapid and revolutionary changes in ideals, ethics, and funding that the Pennhurst Longitudinal Study and its offshoots were conducted. These studies contributed materially to the continuation and acceleration of community options for people with mental retardation and other developmental disabilities.

Policy makers could not ignore the implications of this body of knowledge. Although Medicaid (from Title XIX of the Social Security Act) became the largest funding source for services for people with developmental disabilities, and remained institutionally biased, amendments and new regulations and standards have made it easier and easier to utilize Medicaid federal funds for flexible, individualized, non-medically dominated community service systems.

It took 30 years, but the overwhelming consensus of professionals, experts, scholars, advocates, and self-advocates in the developmental disabilities field now is that the community supports model is vastly superior to the institutional model. It is likely that public institutions will cease to exist within another decade or two.

There are now only about 43,000 people in such settings, and 10 states have none at all: Alaska, District of Columbia, Hawaii, Maine, Minnesota, New Hampshire, New Mexico, Rhode Island, Vermont, West Virginia. If 10 states can

---

[15] Bradley, V., Conroy, J., Covert, S., & Feinstein, C. (1986). **Community options: The New Hampshire choice**. Concord, NH: New Hampshire Developmental Disabilities Council.

[16] Conroy, J., Lemanowicz, J., Feinstein, C., & Bernotsky, J. (1991). **1990 Results of the CARC v. Thorne Longitudinal Study**. The Connecticut Applied Research Project, Report Number 10, to the Connecticut Department of Mental Retardation. Narberth, PA: Conroy & Feinstein Associates.

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

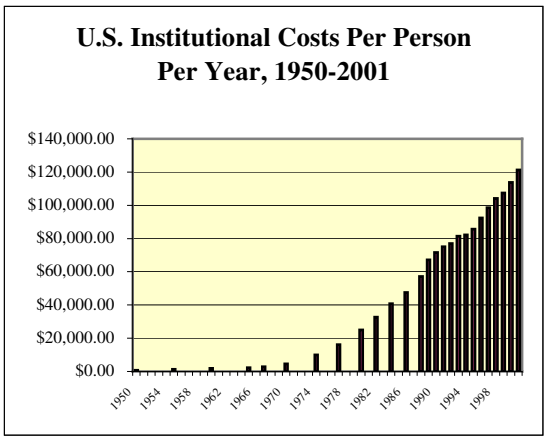
[18] We are aware of similar deinstitutionalization studies in California, Colorado, District of Columbia, Georgia, Illinois, Indiana, Kansas, Louisiana, Maine, Minnesota, New Jersey, New Mexico, New York, North Carolina, and Texas. Studies have also been conducted in Australia, Canada, England, France, Mexico, and Sweden.

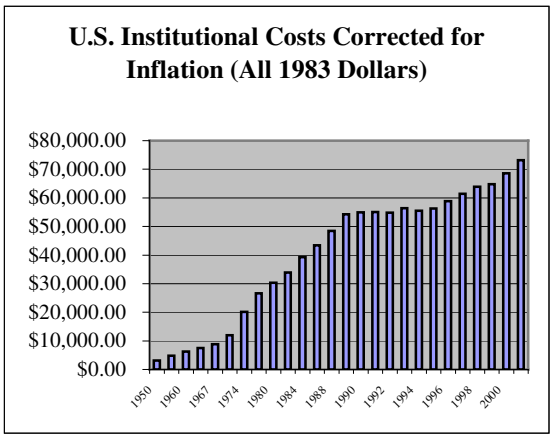
do entirely without such settings, the old argument that *"some people, because of severity of disability, behavioral issues, medical needs, or something else still have their needs met best in a public institution"* fails to be credible.

Economics

As noted above, policy makers quickly learned that community service models could be operated at less expense than public institutions. This remains true today. From 1970 to 1989, public institutional costs per person increased at an average of 15% per year. This was one of the results of scandals and lawsuits – states were pouring money into their institutions, attempting to bring on more staff, meet federal standards, refute the claims of plaintiffs in dozens of lawsuits, and bring an end to the barbaric overcrowding and lack of treatment of the 1950s and 1960s.

In raw dollars and in constant 1983 dollars, institutional costs rose dramatically during the last half of the 20th century, as shown in the graphs below.[19]





By the year 2001, the average annual cost of a public institution was $121,406 per person. This level of expenditure is by far the highest in all the human services. Obviously, this became a problem, particularly when community based systems were repeatedly being shown to be less costly and better.

Although institutional – community cost comparisons are difficult (because the institutional cost includes everything, while community costs can be scattered

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

across 10 or more funding streams), such comparisons are by no means impossible.[20] When all the community public dollars are tracked down, and then the total is compared to institutional costs, even for similar people (matched samples or pre-post methods), the community has always been found to cost less than the public institutions. Right now, the leading researchers in the field estimate the average total public cost to support a person in a small community-based group home at between $50,000 and $80,000 per person per year [21] – and that is a lot less than the current institutional average of $121,406.

However, it bears repeating that the main reason for the cost difference is that community workers, whose jobs are just as demanding as those of the institutional workers (and some would say more demanding), earn far lower salaries with grossly inferior benefit packages. This situation can be traced to the fact that the public institution workers were state employees, and most were therefore members of collective bargaining units. Their salaries and benefits rose steadily from 1950 to the present. Community workers, usually employed by small non-profit service provider companies, have always received much lower salaries than state employees, with similarly slim benefits.

Thus, although economics was one of the driving forces of the shift from institution to community, the issue of poor community worker compensation has become a crisis. Good workers are hard to recruit, and harder to retain. While it is true that most human service workers are not motivated primarily by money, it is also true that one cannot raise a family and live decently on $8.00 an hour. Many community workers have to work two jobs, and many others live in poverty.

This last impetus toward deinstitutionalization, concern about salaries, the workforce, and money in general, set the stage for the conceptualization of self-determination. Some thinkers in the field had concluded that there would never be "enough" money to serve everyone in need in the old traditional ways – hence the task became figuring out ways to use the available money differently.

---

[20] See, for example, Jones, P., Conroy, J., Feinstein, C., & Lemanowicz, J. (1985). A matched comparison of cost effectiveness: institutionalized and deinstitutionalized people. **Journal of the Association for Persons with Severe Handicaps, 9** , 304-313. Also the review article Stancliffe, R. J., & Lakin, K. C. (1998). Analysis of expenditures and outcomes of residential alternatives for persons with developmental disabilities. **American Journal on Mental Retardation, 102**, No. 6, 552-568.

[21] There are extremely wide variations in community costs across states – and even across counties within states. There is a good discussion of average community costs in Braddock, D., Hemp, R. Parish, S., & Rizzolo, M.C. (2000). **The state of the states in developmental disabilities: 2000 study summary**. Chicago: The University of Illinois at Chicago, Department of Disability and Human Development.

The Origins of Self-Determination

The Robert Wood Johnson Foundation's original demonstration of self-determination for people with developmental disabilities took place in and around Keene, New Hampshire. The regional authority for services for people with developmental disabilities was Monadnock Developmental Services, a non-profit agency with a board composed of self-advocates, family members, and concerned community members.

New Hampshire turned out to be an ideal state for this first demonstration. In the first place, New Hampshire had become the first state in the U.S. to become completely free of public institutions. The last resident left Laconia State School in 1990. From 1980 to 1990, more than 600 people moved from Laconia back to their home communities, and Laconia closed.

At that point, public officials knew that every individual with developmental disabilities was going to have to be supported in the community. The option of publicly operated segregation was gone. This spurred community service systems to seek the most progressive and successful community "best practices" and models. Secondly, New Hampshire had a record of excellence in the creation of community services, including work on integration, person-centered planning, supported employment, and very small community based group homes. The state of the art was already recognized and to a large extent implemented in New Hampshire – and Monadnock Developmental Services was a leader in that process. Third, the leadership both at the local and state level was uniquely courageous and committed to fundamental values, including dignity, human rights, freedom, and quality.

The Executive Director of Monadnock Developmental Services, Ric Crowley, had encouraged progressive thinking and service designs throughout the 1980s. After several years of working with consultant Tom Nerney, new ideas began to take shape. With the close assistance of the Director of Case Management, Ellen Cummings, these new ideas were tested slowly and carefully with a few people and their families. The new ideas centered around shifting power from professionals toward the service recipients and their allies.

While closing all institutions in New Hampshire sharply reduced segregation, and decreased medical domination, the originators of the new ideas believed that more was necessary. People's lives were being totally dominated by

paid professionals and paraprofessional, even though they lived in the community. Fundamental rights of citizenship were being abridged by the system in the name of service provision. People were still being forced into "slots" and services not designed specifically for them.

This total professional domination was parallel to the "total institution" described by Irving Goffman in his seminal treatise ***Asylums***. [22] Such places are self-contained, there is no "outside" accessible to anyone, and opportunities for individual choice are almost zero in large and small aspects – with whom to live, where to live, what to eat, what to wear, when to sleep. In the view of the originators of self-determination, our culture had brought this kind of thinking out of the institutions and into the new community homes. People had no control over their own lives, and that was viewed as intolerable.[23]

As stated by the originators of the self-determination strategy, there were a few "simple truths" that were being ignored in the traditional modes of service provision: [20]

> Simple Truth #1: All communities have as members people with disabilities. They are people of worth and value. They belong to families and neighborhoods. They are citizens, fellow workers, customers, parishioners. They are one of us.
>
> Simple Truth #2: Members of our families, our churches, our neighborhoods, people with disabilities who are our friends, our co-workers, our customers, are unwittingly being harmed.
>
> Simple Truth #3: Despite our best efforts, this harm is fundamental. It often requires individuals to live in isolation from the larger community. It requires that the funding for services and supports they require be out of their control, under the control of a system.
>
> This harm is not gentle. This harm is not benign. It precipitates active isolation from fellow citizens and the benefits of community. It means that some of "us" become "them." And "they" often go to school in different places and different ways than other neighborhood kids. "They" frequently are told where to live and with whom. "They" are not truly respected for their capabilities. Their requests and suggestions are minimized by professionals who may mean well. "They" are prevented from dreaming about what the future may hold, because "they" do not control the future.

---

[22] Goffman, E. (1961). **Asylums**. New York: Doubleday-Anchor.
[23] Nerney, T., Crowley, R., & Kappel, B. (1995). **An Affirmation of Community: A Revolution of Vision and Goals. Creating a Community to Support All People Including Those With Disabilities**. Durham, NH: University of New Hampshire Institute on Disability.

Simple Truth # 4: Not long ago, you may have used the word "consumer" rather than "they." In truth "they" are not consumers. Consumers are people who know what they want, seek out the best quality for the best price, and choose the best response to a defined need. The fact is, service systems for people with disabilities have too often acted as if people are commodities. The system is a money-generator that restricts choices and creativity. The system's "consumers" can unintentionally become exploited, victimized and stripped of their power. "They" are essentially bought and sold.

Simple Truth #5: There are people who have shown us what being one of "us" can mean. We go to school with other kids in our own neighborhoods. We (and our families) have fought for what we want and need. We have found ways to live in houses with people of our own choosing. We work at jobs that are valued and we pay taxes. We have true friendships. We've been joined in common causes by families, friends and professionals to determine our own destinies. We've taken the best we can all contribute to make a decent life within our communities.

Simple Truth #6: Let the secret be known -- without intent, we have been unwitting parties to the systematic isolation of people with disabilities and their families. We have, of course, not set out to harm. We have not plotted to keep people with disabilities from enjoying the richness of life and citizenship in community. And yet we've designed and worked within a system that has grave potential to cause hurt and isolation. The service delivery system in this country sets up barriers to full inclusion. The system is fundamentally flawed and must be restructured or completely rebuilt.

Simple Truth #7: We have assembled in files reams of paper, often authored by professionals, that purport to tell other professionals about the "person with a disability" -- paper that pretends to know the person! We now know that these voluminous written descriptions do not tell the real story. They focus on what is "wrong" with a person, their level of "dysfunction" and their need for clinical intervention. This process itself is pathological. Only people with disabilities and their intimates are able to tell the true stories in a humane and positive manner.

Simple Truth #8: We have a choice. We could let the isolation continue, but now that we know the simple truths, the harm would continue with intent. Or, we can start a revolution. A revolution to design community mutual support and common cause. A revolution for self-determination.

Led by Tom Nerney, a few of the early "stories" of what happened to individuals and their families when power shifted were put in writing. Three of those original stories will be reproduced below, because those stories were instrumental in gaining grant funding to do a full scale scientific test of the new notions.

In 1993, one of Mr. Nerney's colleagues shared with him an announcement of grant availability from RWJF entitled "Building Health Systems." The stated

purpose of this multimillion dollar grants program was to test models in which health care could be delivered differently, and better, at the same or lower cost. There was already some reason to suspect that the new ideas being tried in New Hampshire might accomplish exactly that. Hence the principals decided to prepare a proposal to RWJF for a demonstration project.

The original pre-proposal document was limited to three pages, and the three stories formed the centerpiece of that first request for funding. The pre-proposal labeled the new ideas that had been experimented with in New Hampshire as "self-determination for people with developmental disabilities." Thus the self-determination movement really began with stories – and as it has expanded and as it has been studied, individual stories have always remained at the core of knowledge and belief about self-determination.

The first story was about a man named Jack.

> **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 had similar challenging issues.
>
> Now, neither was homeless – and neither was happy. Behavioral issues and psychotic breaks continued 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.

As impressive as this brief story was, it might have been just one of those simple "service revisions" that made the difference, and perhaps signified nothing really new. The second story was about a woman name Bev, and her story led to further suspicion that something fundamental about providing supports to people with developmental disabilities was being revealed.

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, had 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 back to 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 psychiatric 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 knew 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.

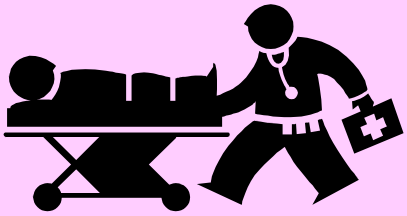
Two years later, Bev is with her circle of friends, deciding all facets of her life, no longer hurting herself or others, no longer so medicated that walking and talking were almost impossible. And the ONLY medication she takes is Synthroid for her thyroid dysfunction. Food, clothing, and shelter make 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.

This second story also implied cost-effectiveness, related once again to shifting power away from the professionals, and toward the person and the person's freely chosen and trusted allies.

The third story, and the one that has been most often told over the past decade, was about a young man named Sean. Sean's story has been cast into PowerPoint format, and is best related in that way. Sean's story is particularly instructive because Sean was comatose for the entire time of the first demonstration effort. Power shifted, not to Sean, but to his family and friends – and they made choices very different from those that paid professionals had been making.

Sean

- Just graduated from high school
- Terrible car accident, fell into a coma
- Sean's state did not have any nursing homes for head injury
- Professionals sent Sean to another state's nursing home

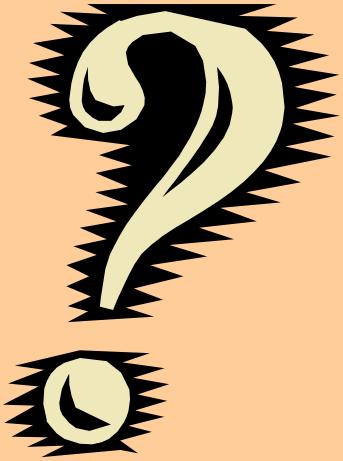


Sean Lived in a Nursing Home

- For several years
- 100 miles from his parents
- He didn't get much individual attention
- And he didn't improve
- His care was costing $120,000 per year
- No one was happy

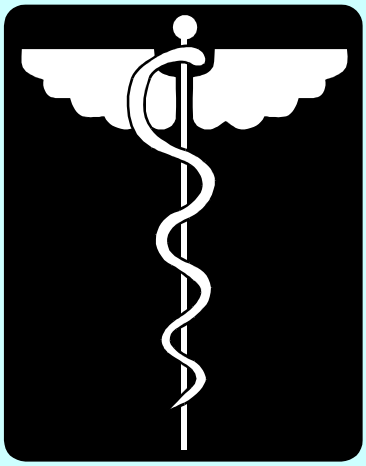
Sean's Parents Asked:

- Isn't there another way?
- How much is all this costing government?
- $120,000? Really?
- If we had control of that money, we would do things very differently.



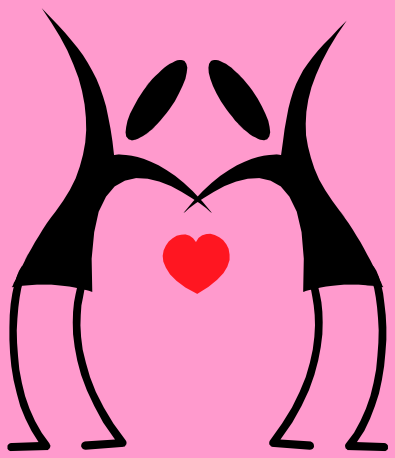
Local Authorities Asked:

- Really? What would you do differently?
- That nursing home is the only one around that specializes in head injury.
- What could you non-professionals do for Sean?



Sean's Parents Said:

- We would adapt a house for him
- 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



Local Government Thought This Just Might Make Sense

- Courageous local leaders went to state and federal officials
- Explained the situation
- Asked permission to experiment with putting family in charge of how the money was spent
- Courageous state and federal officials agreed to "look the other way" while regulations were being "bent"

Sean Came Home

- Government dollars were used to buy a house
- And to make it accessible
- And to put in special bathroom and a lift
- Friends were hired as attendants
- They took Sean into town on outings
- Family visited frequently, reading to Sean, talking in his presence, and touching him

Outcomes:

- Total dollars spent, even with the down payment on the new home and the payments on the mortgage, went down below $70,000
- (Even in the first year)
- Much lower now
- In 1996, Sean began to open his eyes and focus
- In 1997, he began to speak
- Most of Sean's allies think that would not have happened in the nursing home --- **EVER**

Much of the importance of Sean's story is that it shows that the self-determination intervention could have beneficial outcomes – even when there was

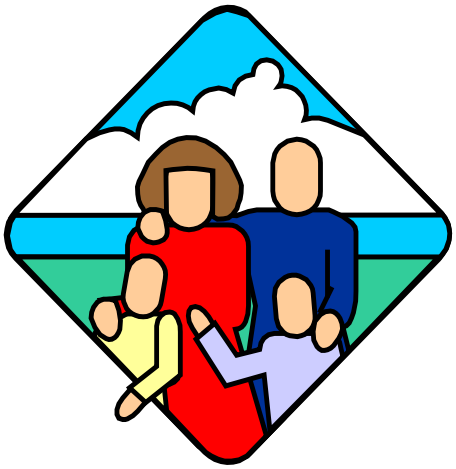
no "self" involved in the work. Sean being in a coma demonstrated that this kind of thinking, and of power sharing, could be applied with anyone, regardless of the severity of cognitive disability.

(In this context, it might be argued that **self**-determination could be seen as a misnomer. [24] Nevertheless, the term has been useful in keeping the focus on the individual, and thus striving to make life choices together, in the way closest to what the individual would be most likely to want and need.)

These three stories generated interest at RWJF. The theory behind the stories seemed to fit within the Building Health Systems framework – better care at the same or lower cost via creative redesign of systems. The new idea/theory was appealing:

New Idea / Theory:

- When families decide how to spend the public dollars
- They tend to spend more precisely according to needs
- And perhaps more wisely than professionals



RWJF therefore requested a full proposal from Monadnock Developmental Services.

[24] In fact, the original draft of the proposal used the phrase "supported self-determination" and was meant to imply that many people have very significant cognitive disabilities that prevent them from making choices in the traditional sense – yet they too could participate in self-determination, given the right supports from (usually) unpaid allies. However, that phrase was judged by the proposal team to be too long, too clumsy, and ultimately subject to just as much confusion as the shorter term.

The Professionals Who Created This Concept Wrote A Proposal

- To the largest health care foundation in the world:
- The Robert Wood Johnson Foundation
- (RWJ money came from the invention of the Band-Aid and other health products)
- They won the grant
- The first ever given in developmental disabilities field by that Foundation

The grant was awarded in late 1993. It consisted of roughly $417,000 for a 3 year demonstration, and none of that money could be used for services. The money was only for systems change via advocacy and management structure redesign.

Early in the project, skepticism was common. The idea that $140,000 per year, put into an agency with a $12 million annual budget, could really result in a massive shift in power relationships between service providers and service recipients, seemed to some to be improbable in the extreme. Even the optimists among the stakeholders believed that 3 years would prove to be far too short a time span for such sweeping and fundamental changes to occur.

Upon the award of the grant, the Foundation requested that the evaluation of the effort, to be conducted by the Center for Outcome Analysis, be separated from the implementation – in other words, to remain at "arm's length" in order to maximize objectivity. A separate grant was awarded to the Center, and through the 3 years of evaluation, independent third parties were hired and trained to conduct interviews and data collection. The evaluation design was very strong, including random assignment to self-determination or "comparison group," a very large

battery of instruments on qualities of life, power, person-centered planning, environments, friendships, and more (to be described fully in the Methods section of this report). The central idea of the independent evaluation was to find out with valid and reliable instruments whether the participants' lives improved – "Are they better off?"

The evaluators were surprised to detect significant impacts among the self-determination participants after less than 2 years. Power had indeed shifted toward the people and their "circles of friends," qualities of life (both objectively and subjectively) had improved, satisfaction was extremely high, and the total cost of supporting the participants had decreased. The table below summarizes the outcomes that were observed in New Hampshire.

New Hampshire's Self-Determination Project
Summary of Early Individual Outcomes

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

Appendix A contains the full report from the 3 year independent evaluation of the Monadnock self-determination demonstration. A version of this report has been accepted for publication in a major disabilities journal. Appendix B contains a summary of the findings in PowerPoint format, and this presentation has been given in 34 states and also Canada, England, Lithuania, and Russia.

These unexpectedly rapid quantitative changes were very encouraging. RWJF determined to fund the demonstration in other parts of New Hampshire, partly on the basis of these strong scientific findings. Then the initiative was taken to the national level at the behest of the RWJF Board of Directors. The next list

shows the chronology of critical events in the development of the self-determination movement.

- 1993 Original proposal to RWJF
- 1993 Grant awarded to Monadnock Developmental Services
- 1994 Separate contract to Center for Outcome Analysis for evaluation
- 1995 RWJF supports statewide expansion in New Hampshire
- 1996 RWJF decision to fund national grant program
- 1997 Grants awarded to 18 states, plus New Hampshire's ongoing grant
- 1998 10 more planning grants
- 1998 National evaluation begins
- 1998 13 more states join with state funds
- 1999 Michigan data show positive pre-post outcomes
- 2000 Ohio, Hawaii, Wisconsin, Maryland also show positive outcomes
- 2001 Data analyses completed
- 2002 Results come in from California under separate funding

It took only 2 years for the Foundation to decide to expand self-determination to other parts of New Hampshire, and only 1 year more to create a national grant initiative. The decision to fund the national initiative "Self-Determination for Persons with Developmental Disabilities" was made in 1996. The announcement from RWJF was distributed in late 1996.

The announcement specified that consortiums were welcome, but that the actual grantees were to be state agencies. A total of 35 states applied – reputed to be the largest number of state program applications yet seen by RWJF in any of its grant programs to states. The grants given in 1997 are detailed in the table below.

The National Self-Determination Initiative Grantees

State	Funding (1000s)	Years	Sites	# People
Arizona	200	2	2	24
Connecticut	200	2	5	125
Florida	100	2	NA	NA
Hawaii	400	3	2	125
Iowa	200	2	4	50
Kansas	400	3	2	185
Maryland	390	3	4	4 Counties
Massachusetts	100	2	MA	Unlimited
Michigan	397	3	3	370
Minnesota	400	3	1	150
Ohio	395	3	4	223
Oregon	200	2.5	1	60
Pennsylvania	100	1.5	3	105
Texas	395	3	4	240
Utah	200	2	35	700
Vermont	400	3	VT	250
Washington	100	1	2	40
Wisconsin	399	3	3	90
Totals	4976			2737+

As the table shows, states varied in grant amounts, period of performance, number of demonstration sites, and number of people participating. The largest grant amount was $400,000. Nine states received that amount, and all of them were for 3 years. Five states received $300,000, generally for 2 years of work. Four states received $100,000, for 1 or 2 years.

The interest and excitement generated by this grant program was extraordinary. By one researcher's calculation, the amount of human time spent planning in the first 6 months in one state would have eaten up the entire grant amount if their salaried time had to be paid from the grant. States, advocates, and self-advocates quickly saw self-determination become the most talked about and most desired service system reform in decades. By 1998, 10 more states had been given small ($10,000 to $20,000) grants to gather stakeholders and map out strategies for moving their systems forward. In the same year, as counted by the National Program Office on Self-Determination, 13 more states began their own attempts to implement demonstrations of self-determination.

This level of interest was unprecedented – at least in this Principal Investigator's 32 years of experience in this field. It was doubly remarkable when

the amount of money was compared to the size of the system it was intended to reform. About $5 million over a 3 year period – to reform systems into which more than $20 billion per year were flowing.

Our own evaluation of the national self-determination initiative began in 1998, in partnership with the Human Services Research Institute (HSRI). At COA, our primary intent was to find out whether people's qualities of life changed when they began participating in self-determination pilot projects – and if so, in what way(s), and how much?

By 1999, after only 1 year, the individual pre-post data from Michigan showed that participants' power relationships had changed, and quality of life indicators had improved, and public expenditures had decreased. The data were even more compelling than the 2 year results from New Hampshire.

By the following year, we had completed preliminary analyses of individual outcomes data from four more states: Hawaii, Maryland, Ohio, and Wisconsin. The patterns of changes detected among the participants in these states paralleled what had been documented already in New Hampshire and Michigan. Power did shift, lives did improve, and costs (to the extent we were able to capture them) did stay the same or decrease.

We completed our formal analyses of the individual outcome data for five states in 2001. In 2002, more data from a separately funded 3 year evaluation of California's three pilot projects became available, and is included herein. We have recently completed a 1 year evaluation in New Jersey, but those data are too recent to include here. We also completed a "post-only" analysis in Texas in 2001 – the process of negotiating the Human Subjects committees there was so prolonged that baseline data could not be collected. Instead, we visited all the participants near the end of the project, in their third year, and assessed their perceptions and recollections of how power and life qualities had changed. The Texas findings were very similar to the pre-post findings from the other states, but because of the methodological difference, they are not included here.

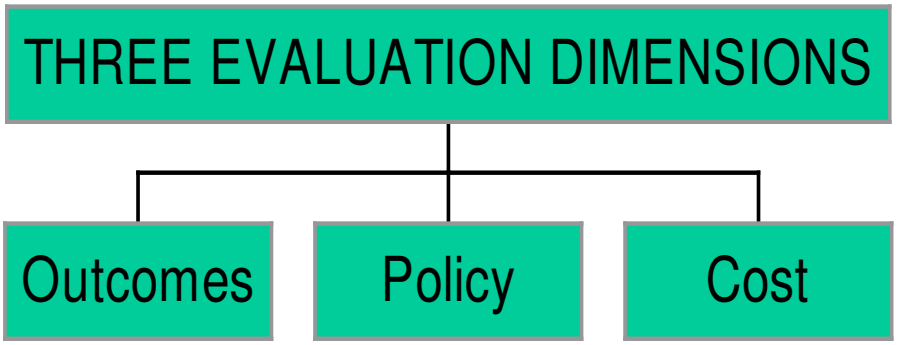
This report contains our findings from "before and after" studies of the individual lives of hundreds of self-determination participants in the RWJF (and other) initiatives. The following **Methods** section of the report details our methodology – essential so that other researchers can judge the merit of how we proceeded, and so that others could repeat our research – replication being the principal criterion of valid science. The final section of the report presents our

Results. As will be seen, the findings from the various states showed remarkable consistency in the most crucial areas of the "theory" of self-determination.

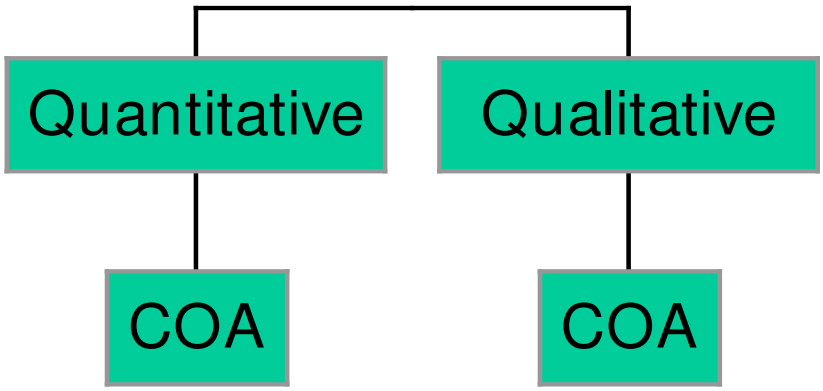
Methods

Design

Our own national evaluation began in 1998, in partnership with the Human Services Research Institute (HSRI). The design of the partnership was structured in this way:



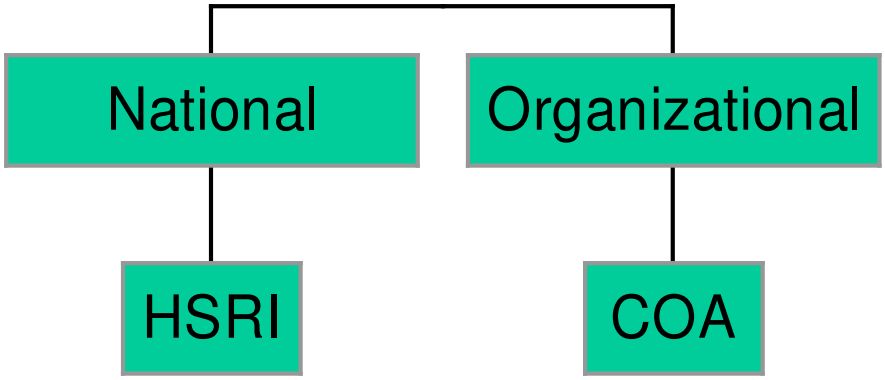
Within the outcomes dimension, COA conducted both quantitative and qualitative research:



The primary purpose of the present document is to report what was found in more than 3 years of quantitative study of the individual outcomes of self-determination. The qualitative aspects of COA's work were mainly formative, and were completed while the demonstrations were still running (e.g. case studies, focus groups, key informant interviews). That research was designed to yield insights into how the demonstrations were set up, how they differed, how individual lives were affected – and this information was fed back to states so that

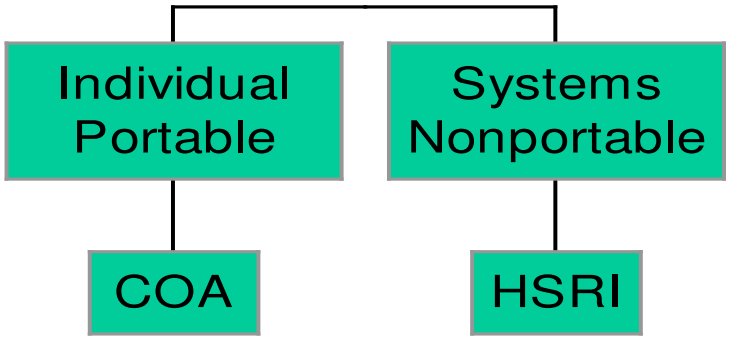
they could refine their approaches and address key issues that might have been overlooked during the conduct of the demonstrations.

In the Policy dimension, interest was directed at both the macro level, national policy, and the micro level, meaning issues confronting service provider organizations and how they could transform themselves.



HSRI considered the national policy issues related to self-determination, and COA examined some of the local problems in implementing self-determination within a context of funding and service structures that were never designed to permit or encourage self-determination.

In the costs dimension, COA attempted to obtain enough information on individual expenditures to judge whether the self-determination concept was fiscally conservative – did total public expenditures for participants go up, down, or stay the same?



At the same time, HSRI studied systems issues in the fiscal dimension. How would fixed, nonportable, administrative, and infrastructural system costs be affected by the advent of self-determination?[25]

Hypothesis and Logic Model

Researchers at COA have used these three statements as the "operational definition of self-determination" for nearly a decade.

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

An operational definition is one that can be tested by performing operations – running an experiment, collecting data, observing events. The advantage of the operational definition above is that all three elements are readily measurable.

Gaining control can be measured by our own Decision Control Inventory, which has been shown to be reliable, and definitely is sensitive to changes in power relationships. People's perceptions about their own power and control are also tapped within the COA instrument package.

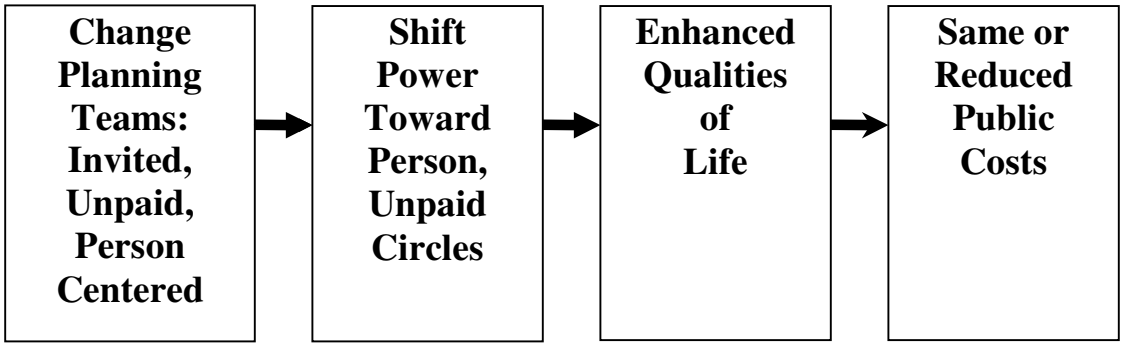
[25] Bradley, V., Agosta, J., Smith, G., Taub, S., Ashbaugh, S., Silver, J., & Heaviland, M. (2001). **The Robert Wood Johnson Foundation Self-Determination Initiative: Final Impact Assessment Report**. Cambridge: Human Services Research Institute.

Lives improving can be measured by many elements of the COA instrument package, include self-perceived quality of life in 14 areas, satisfaction, engagement, integration, achievement of goals, income, services needed, qualities of the home and work environment, and so on.

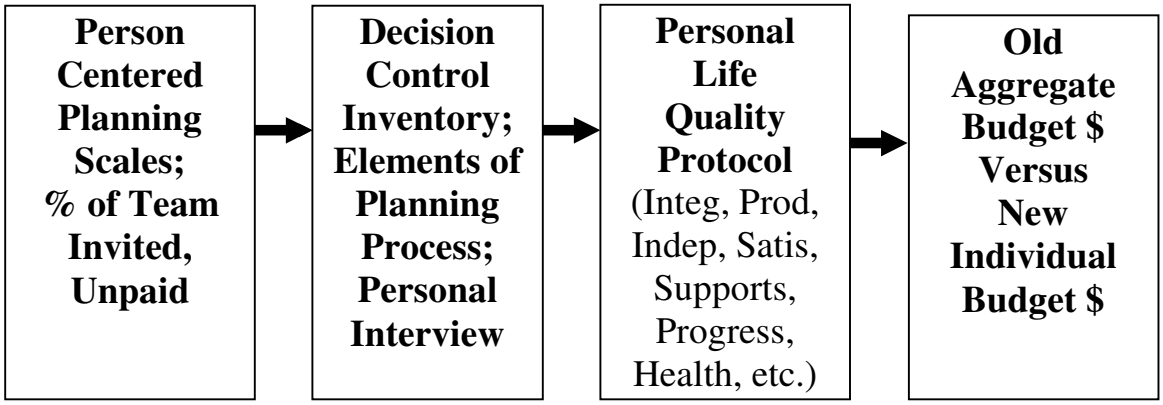
Costs can be measured by keeping track of what is in the person's individual budget – but comparing that to expenditures before the person had an individual budget is very difficult. Nonetheless, it is possible, and where it was feasible, we did so.

Shown below is a logic model of how self-determination works, and also the corresponding logic model for our evaluation.

The Model:
Theory of Self-Determination



The Evaluation:
Operationalized Measures of Self-Determination



The top graphic shows a brief "logic model" representation of the crucial features of self-determination. Originally, the starting point was to work with the individual planning team: increasing participation by unpaid folks, making sure everyone was "invited" to be there (not just as a function of regulations or professional roles), and seeing to it that the team acquired full information about the resources available to support the individual. Then power over the resources was gradually and carefully transferred from the paid members of the planning team to the individual and the individual's (usually) unpaid and freely chosen allies. The third box implies that if the first two are completed, then the individual's life quality will be enhanced. Finally, the fourth box says that if the others are in place, then the resulting cost (on the average but not necessarily in every case) will be the same or less than traditional services.

The bottom graphic shows, for each step of the logic model of self-determination, how we set out to test whether each step was actually implemented. The data were collected at the individual level, and it is at the aggregate level, or the "on the average" level, that we can make a judgment about whether the theory is borne out in empirical reality.

The next section on **Instruments** explains in detail what scales and measures are used in the four boxes in the bottom graphic.

Instruments

This section describes the background and the contents of the Personal Life Quality protocol or PLQ. This is the package of instruments that were offered to the RWJF grantee states – and each state was permitted to identify the scales from the PLQ that were most relevant or important to their unique implementation of self-determination. This made analysis far more laborious, but paid off well in terms of engagement and cooperation. Moreover, there was a common core of scales that every state elected to include – for example, the scale that measures power and control over one's own life. Hence we are able to report results from all of the most important scales across states, and thereby to compare outcomes.

The PLQ is the core of how we measured the impacts of self-determination. It is so central to our methodology that it is described at length here – and is also included here as Appendix C. Readers may refer to the Appendix, and are

encouraged to review the material here before reading the **Results** section. It is much easier to interpret results if one understands what was measured and how it was measured.

The PLQ's components are collected during an in person visit with the participant and whoever knows the participant best. The attempt is always made to complete the package with the focus person as the respondent. When that is not possible, the focus person or an ally can specify someone who knows him/her very well to help complete the PLQ.

Over the years of its development, we have consistently worked to be certain that the PLQ truly taps important dimensions of quality, things that really matter to people with disabilities and their families. In psychometric terms, these measures are also psychometrically sound, as judged by the *Standards for educational and psychological testing* of the American Psychological Association, the American Educational Research Association, and the National Council on Measurement in Education (1985).

Many of the elements of this PLQ package evolved from the Pennhurst Longitudinal Study (Conroy & Bradley, 1985). Pennhurst Class members have been visited annually since 1978. An extensive battery of quality-related data has been collected on each visit. The Pennhurst Study continues to be one of the most influential research efforts ever performed on the qualities of life of people with developmental disabilities. This is true primarily because the measures of quality utilized in that work were scientific, reliable, and valid.

Over the years, other groups have been added to the data base, such as all 600 people living in Community Living Arrangements in Philadelphia who were not members of the Pennhurst Class, more than 3,400 people receiving supports in Oklahoma, 2,400 people who moved from institution to community in California, 1,100 member of the Thomas S. class in North Carolina, more than 1,000 people involved in self-determination efforts nationwide, and 1,444 residents of Florida's Developmental Services Institutions.

"Outcomes" have sometimes been cast into the broad categories of independence, productivity, integration, and satisfaction (as specified in the Developmental Disabilities Act Amendments of 1987). Actually, these are qualities of life, not outcomes. Changes in those qualities of life over time are outcomes. Within the DD Act qualities, there are levels of detail, and there are other quality areas that are equally important, such as health. Breaking down these

areas further, these are the elements of quality of life that are touched upon by the current version of the PLQ.

- power to make one's own life choices (self-determination)
- self-care skills and skill development
- vocational skills and skill development
- psychological and emotional adjustment
- challenging behaviors and reduction of such behaviors
- stability of living and working environments
- attitudes and experience of primary caregivers
- health
- health care utilization patterns
- health care satisfaction
- use (versus overuse) of medications
- earnings
- hours per week of productive activity
- individual planning process timeliness
- individual planning process usefulness
- individual planning process degree of "person-centeredness"
- integration at the home
- integration at the workplace
- integration during leisure time
- relationships with neighbors
- friendships
- relationships with housemates
- family contacts and family relationships
- opportunities for intimate relationships
- having a financial interest in the home
- satisfaction with the home
- satisfaction with work
- satisfaction with leisure time
- satisfaction with services rendered (including case management)
- individual wishes, dreams, hopes, aspirations, and ambitions
- size of the home environment
- human characteristics of the home environment (e.g. staffing)
- physical quality of the home environment
- individualized treatment in the home environment
- normalization in the home
- costs of the service/support elements
- family/next friend opinions and satisfaction

Because COA has collected data on all of these dimensions over a 20 year period for more than 40,000 people, we are in the unique position of being able to

compare quality across service systems. Our databases on quality represent a national resource of information on outcomes. Integration, for example, can now be compared across several states as well as nationally. Changes in independent functioning over time can be compared across states. Ratings of consumer and family satisfaction can be compared state by state and nationally. No other entity can offer such analytical power for the assessment of system changes and individual outcomes.

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

The PLQ should be viewed in historical context. It is not entirely a static document. We continue to learn how to measure new aspects of life that people tell us are important to them. For example, years ago, the greatest emphasis in the package was placed on measurement of adaptive behavior. This permitted researchers to document the fact that people were growing and learning, constantly becoming more and more independent. This was very important, and still is, but in recent years, the values-driven nature of the field has demanded that we learn how to measure other dimensions of life, i.e., power, control, individual budgeting, community inclusion, friendships, and satisfaction.

Modifications made to the battery of instruments over the years have been based on the concept of "valued outcomes" (Conroy & Feinstein, 1990b; Shea, 1992). Professionals may value some outcomes most highly, such as behavioral development; parents and other relatives may value permanence, safety, and comfort more highly; and people with mental retardation may value having freedom, money, and friends most highly. The goal in our research on deinstitutionalization, and later in self-determination, has been to learn how to measure aspects of all of these "valued outcomes" reliably.

The following sections describe the major components of the PLQ. This will show what is actually measured by the modules that comprise the PLQ.

Behavior

The behavioral measures are usually shortened forms of the original AAMR Adaptive Behavior Scale (Nihira, Foster, Shellhaas, & Leland, 1974). The first part

contains 32 items on adaptive behavior, and the second, 15 items on the frequency of challenging behaviors. The measures were shortened on the basis of the mathematical criteria of factor structure and reliability. According to Arndt (1981), the best way to treat these type of data is as two simple additive scales, one reflecting adaptive behavior and the other challenging behavior. The adaptive behavior sum score has been found to be highly reliable (Isett & Spreat, 1979; Spreat, 1980; Devlin, 1989). Devlin found interrater reliability of .95 and test-retest reliability of .96. For the maladaptive behavior section, interrater reliability was .96 and test-retest was .78.

In some of our data sets (California, Florida, and New Hampshire), the California behavior scales called the Client Development Evaluation Report were used. This behavior measure is composed of 52 items. The CDER adaptive behavior measure has been reported to have excellent reliability when properly applied (Harris, 1982). Adaptive behavior is usually measured by interviewing a third party who knows the individual well.

A sampling of adaptive behavior items follows.

Behavior: CDER
Adapted from the California Development Evaluation Report

Instructions

1. This information is to be obtained BY INTERVIEW from the staff (or other) person who knows this individual best.
2. These items are generally in developmental sequence, from lowest to highest.
3. Please record the highest level of which the person is capable on each item.
4. Score only what the person DOES do, NOT what the person "can" do or "could" do or "might be able to" do. We want no speculation - only observed, actual behaviors.
5. Give credit for a "typical" behavior, that is, behavior that is performed at least 75% (three fourths) of the time during the past 4 weeks.
6. If this typical behavior is performed with VERBAL prompts, give credit (unless otherwise noted in the item).
7. Do not give credit for behaviors performed with PHYSICAL guidance (unless otherwise noted in the item).
8. On any item, a "99" can be entered if the item is not applicable (usually because the person's disabilities are too severe), or if the person is too young, or if the person has no opportunity to display the behavior. The "99" choice is specially noted on items that have most often been coded this way in the past.

ADAPTIVE BEHAVIOR

MOTOR DOMAIN

1. Rolling and Sitting

   1 Does not lift head when lying on stomach
   2 Lifts head when lying on stomach
   3 Lifts head and chest using arm support when lying on stomach
   4 Rolls from side to side
   _____ 5 Rolls from front to back only
   6 Rolls from front to back and back to front
   7 Maintains sitting position with minimal support for at least five (5) minutes
   8 Sits without support for at least five (5) minutes
   9 Assumes and maintains sitting position independently

2. Hand use (If person has use of one hand only, rate that hand)

   1 No functional use of the hand
   2 Uses raking motion or grasps with hand
   _____ 3 Uses thumb and fingers of hand in opposition
   4 Uses the fingers independently of each other

3. Arm Use (If person has one arm or use of one arm only, rate the use of that arm)

   1 No functional use of arm
   2 Moves arm from shoulder but does not extend or flex arm (i.e., does not have control of elbow joint)
   _____ 3 Partially extends arm
   4 Fully extends arm

INDEPENDENT LIVING DOMAIN

8. Food preparation

99 Person is in a service setting in which he/she is prevented from preparing food (R1)
1 Does not prepare food
_____ 2 Prepares simple foods without cooking (sandwich, cold cereal, etc.)
3 Cooks simple foods (eggs, soup, frozen dinners, etc.)
4 Cooks more complex foods and/or prepares complete meal

9. Bedmaking

99 Person is in a service setting in which he/she is prevented from bedmaking (R1)
1 Does not make bed
_____ 2 Attempts bedmaking, but does not complete
3 Makes bed completely, but not neatly (sheets and blankets appear wrinkled, bedspread crooked, etc.)
4 Completes bedmaking neatly and independently

11. Household Chores (Other than food preparation, bedmaking, washing dishes)

99 Person is in a service setting in which he/she is prevented from doing household chores (R1)
1 Does not do household chores
_____ 2 Attempts household chores but does not complete
3 Does household chores, but not neatly (leaves dirt on the floor, spills garbage, etc.)
4 Completes household chores neatly and independently

SOCIAL DOMAIN

27. One-to-One Interaction with Peers (friends, classmates, co-workers, etc.)

1 Does not enter into interaction
2 Enters into interaction only when others initiate
_____ 3 Initiates interaction in familiar or previously successful situations or settings
4 Initiates interaction in both familiar and unfamiliar situations or settings

28. One-to-One Interaction with Persons Other than Peers (store clerks, foster parents, teachers, bus drivers, etc.)

1 Does not enter into interaction
2 Enters into interaction only when others initiate
_____ 3 Initiates interaction in familiar or previously successful situation or settings
4 Initiates interaction in both familiar and unfamiliar situations or settings

29. Friendship Formation (Close social relationships)

1 Does not form friendships
_____ 2 Potential friends must initiate friendships
3 Initiates and establishes friendships

COGNITIVE DOMAIN

38. Associating Time with Events and Actions

1 Does not associate events and actions with time
2 Associates regular events with morning, noon, or night
_____ 3 Associates regular events with a specific hour (dinner is at six)
4 Associates events with specific time in past, present and future (the ball game is at six tomorrow)

40. Writing Skills (Including Braille and typing)

1 Does not copy or trace
2 Copies from model or traces
_____ 3 Prints (no model) single letters or name only
4 Prints single words only
5 Prints words and sentences legibly
6 Uses longhand for words and sentences

44. Remembering Instructions and Demonstrations

1 Does not display memory of instructions or demonstrations
_____ 2 Displays memory of instructions or demonstrations if they are repeated three or more times and the

_____ person is prompted to recall
3 Displays memory of instructions or demonstrations if they are given once and the person is prompted to recall
4 Displays memory of instructions or demonstrations without prompting if they are given once

COMMUNICATION DOMAIN

45. Word Usage
1 No use of words
2 Uses simple (one-syllable) words and associates words with appropriate objects
_____ 3 Uses complex words and associates words with appropriate objects, but has limited vocabulary
4 Has a broad vocabulary, understands meaning of words and uses them in appropriate contexts

48. Receptive Language
1 Does not understand speech
2 Understands simple words
_____ 3 Understands simple phrases or instructions
4 Understands meaning of simple conversation and combination of verbal instructions
5 Understands meaning of story plot and complex conversation

49. Expressive Language
1 Makes no sounds
2 Babbles but says no words
3 Says simple words
_____ 4 Says two-word sentences ("I go," "Give me," etc.)
5 Says sentences of three or more words
6 Carries on basic conversation
7 Carries on more complex conversation

CHALLENGING BEHAVIORS

1. Unacceptable Social Behavior (Stealing, excessive screaming, lying, teasing, etc.)
1 Unacceptable social behaviors prevent social participation
2 Unacceptable social behaviors often disrupt social participation
_____ 3 Unacceptable social behaviors seldom interfere with social participation
4 Unacceptable social behaviors do not occur or do not interfere with social participation

2. Aggression
1 Has had one or more violent episodes, causing serious physical injury within past year
_____ 2 Has had one or more violent episodes, causing minor physical injury within past year
3 Resorting to verbal abuse and threats are typical of person's behavior but person has not caused physical injury within past year
4 Episodes of displaying anger are undetected or rare and appropriate to the situation

3. Frequency of Self-Injurious Behavior (Biting, scratching, putting inappropriate objects into ear, mouth, etc.)

_____
1 Displays self-injurious behavior at least once a day and/or restraints are used as a preventative measure
2 Displays self-injurious behavior at least once a week
3 Displays self-injurious behavior at least once a month
4 Displays self-injurious behavior not more than three (3) times a year
5 Rarely or never displays self-injurious behavior

4. Severity of Self-Injurious Behavior (Biting, scratching, putting inappropriate objects into ear, mouth, etc.)

_____
1 Self-injurious behavior causes severe injury at least once per week which requires a physician's attention
2 Self-injurious behavior causes severe injury at least once a month which requires physician's attention and/or injury at least once per week which requires first aid
3 Self-injurious behavior causes severe injury at least once a year which requires physician's attention and/or minor injury at least once per month which requires first aid
4 Behavior exists but no apparent injury occurs
5 Rarely or never displays self-injurious behavior

Productivity

Productivity can be reflected by earnings, by the amount of time engaged in daytime activities that were designed to be productive (adult day activities, vocational training, workshops, supported and competitive employment), and by the amount of time reported to be engaged in developmentally oriented activities in the home. PLQ modules permit us to derive estimates of the amount of each of 17 services delivered in the preceding 4 weeks, such as dressing skills training, occupational therapy, and behavioral interventions. Following are PLQ pages that tap the productivity dimension.

Daytime Activity Program, Work, and School

1. ON THE AVERAGE WEEKDAY, WHAT TIME DOES THIS PERSON LEAVE THE HOME (COTTAGE, LIVING UNIT) TO ATTEND A DAY ACTIVITY?

   ____:____

2. HOURS PER WEEK OF DAYTIME ACTIVITIES, JOB, AND/OR SCHOOL: PLEASE ENTER THE NUMBER OF HOURS PER WEEK FOR EACH ACTIVITY. **PLEASE ENTER 0 (ZERO) IF NO HOURS ARE SPENT IN THE CATEGORY.**

2A. _____ Self-Employed: Has His/Her Own Business
2B. _____ Regular Job (Competitive Employment)
2C. _____ Supported Employment (Regular job with supportive assistance at job site)
2D. _____ Sheltered Employment (Work in a setting designed for people with disabilities)
2E. _____ Vocational Rehabilitation or Training Day Program
2F. _____ Adult Day Program - Non-Vocational Day Program
2G. _____ Senior Citizen Program, Specialized
2H. _____ Senior Citizen Program, Generic and Integrated
2I. _____ Partial Hospitalization Program - Mental Health Oriented
2J. _____ Volunteer Work
2K. _____ Public School (Regular School Building and/or classroom)
2L. _____ Public School (Separate Building or 'Center Based')
2M. _____ Private School (Regular School Building and/or classroom)
2N. _____ Private School (Separate Building or 'Center Based')
2O. _____ Adult Education - GED, Adult Ed, Trade School, etc.
2P. _____ Other _____

2Q. _____ TOTAL HOURS PER WEEK OF DAY ACTIVITIES

3. IF ZERO DAY ACTIVITY HOURS: If the total hours of day activities are zero, please explain why (such as retired, behavior problems, lost job, on waiting list, no program available, refuses, etc.).

4. EARNINGS: ABOUT HOW MUCH DOES THIS PERSON EARN IN AN AVERAGE WEEK? (Accept per hour, biweekly, per month, or annual, and make notes in the margin if necessary. Convert to dollars per week when you can.)

   _____ Dollars per week

Choice Making (Power)

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

This is the single most important scale in the evaluation of self-determination impacts. It shows whether power has shifted away from paid workers and toward the person and his/her allies.

The interrater reliability of the Inventory was reported as .86 (Conroy, 1995). The most current version of the Decision Control Inventory is shown on the following page.

Decision Control Inventory 1: For All People

Ask the respondent to say who actually makes decisions in each area as shown, from 0 to 10. If decisions are made entirely by PAID PERSONNEL (program staff, Case Manager, agency officials, doctors, etc.), enter "0" for that area. If decisions are made entirely by the PERSON AND/OR TRUSTED FRIENDS, RELATIVES, ADVOCATES, etc., enter "10." If decisions are equally shared, enter "5." UNPAID can include people who had a relationship with the person before they began receiving money for their support, such as a sibling or neighbor. Items can be left blank. Next, rate each area for "How Important" it is for the person and the person's circle to have control in each area.

WHO MAKES DECISIONS?
0---1---2---3---4---5---6---7---8---9---10
Paid Staff — **Person and/or Trusted Friends, Relatives, Advocates**

WHO		
		FOOD
_____	1P	What foods to buy for the home when shopping
_____	2P	What to have for breakfast
_____	3P	What to have for dinner
_____	4P	Choosing restaurants when eating out
		CLOTHES AND GROOMING
_____	5P	What clothes to buy in store
_____	6P	What clothes to wear on weekdays
_____	7P	What clothes to wear on weekends
_____	8P	Time and frequency of bathing or showering
		SLEEP AND WAKING
_____	9P	When to go to bed on weekdays
_____	10P	When to go to bed on weekends
_____	11IP	When to get up on weekends
_____	12IP	Taking naps in evenings and on weekends
		RECREATION
_____	13P	Choice of places to go
_____	14P	What to do with relaxation time, such as choosing TV, music, hobbies, outings, etc.
_____	15P	Visiting with friends outside the person's residence
_____	16P	Choosing to decline to take part in group activities
_____	17P	Who goes with you on outings?
_____	18P	Who you hang out with in and out of the home?
		SUPPORT AGENCIES AND STAFF
_____	19P	Choice of which service agency works with person
_____	20P	Choice of Case Manager
_____	21P	Choice of agency's support persons/staff (N/A if family)
_____	22P	Choice of support personnel: option to hire and fire support personnel
		ECONOMIC RESOURCES
_____	23P	What to do with personal funds
_____	24P	How to spend residential funds
_____	25P	How to spend day activity funds
		HOME
_____	26P	Choice of house or apartment
_____	27P	Choice of people to live with
_____	28P	Choice of furnishings and decorations in the home
		WORK OR OTHER DAY ACTIVITIES
_____	29P	Type of work or day program
_____	30P	Amount of time spent working or at day program
_____	31P	Type of transportation to and from day program or job
		OTHER
_____	32P	Express affection, including sexual
_____	33P	"Minor vices" - use of tobacco, alcohol, caffeine, explicit magazines, etc.
_____	34P	Whether to have pet(s) in the home
_____	35P	When, where, and how to worship

Integration

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

Because the scale was developed by Harris, and was used nationally with both disabled and non-disabled Americans, we have national data for comparison. This scale was also used in the National Consumer Survey of 1990 (Conroy, Feinstein, Lemanowicz, Devlin, & Metzler, 1990) with 13,075 Americans with developmental disabilities. Thus there is a very rich national basis for comparison of individual and group experiences of integrative activities.

The interrater reliability of this scale was reported to be very low when the two interviews were separated by 8 weeks, but very high when the time interval was corrected for (.97). The Integrative Activities Scale is shown on the following page.

Integrative Activities During the Past Month

ABOUT HOW MANY TIMES did this person do each of the following in the PAST MONTH? ONLY COUNT ACTIVITIES WHEN THE PERSON WAS IN THE PRESENCE OF NON-DISABLED CITIZENS. (**Rough estimates are fine.** If the past month was not typical, ask about the average month during the past year. Write DK if "Don't Know.")

_____ 1. Visit with close friends, relatives or neighbors

_____ 2. Visit a grocery store

_____ 3. Go to a restaurant

_____ 4. Go to church or synagogue

_____ 5. Go to a shopping center, mall or other retail store to shop

_____ 6. Go to bars, taverns, etc.

_____ 7. Go to a bank

_____ 8. Go to a movie

_____ 9. Go to a park or playground

_____ 10. Go to a theater or cultural event (including local school & club events)

_____ 11. Go to a post office

_____ 12. Go to a library

_____ 13. Go to a sports event

_____ 14. Go to a health or exercise club, spa, or center

_____ 15. Use public transportation (May be marked "N/A")

_____ 16. Other kinds of "getting out" not listed above

18. ACCESS TO TRANSPORTATION: If this person wanted to go somewhere on the spur of the moment (beyond walking distance), how many times out of 10 would he/she be able to? If this person does not communicate such wants, phrase the question as "If someone unpaid wanted this person to be able to go somewhere on the spur of the moment ...." Count only trips that are within 1 hour of home.

_____ times out of 10

Indicators of the Individual Planning Process

Most PLQ versions now include the "Elements of the Planning Process" scale, which is designed to reflect the degree to which planning is carried out in a "person-centered" manner. The Individual Planning section also captures aspects of how and how often planning events occurred, as well as a snapshot of the content of the plan's content. This snapshot includes the nature of the top five goals in the plan, how much of the plan is addressed with informal supports, and the perceived amount of progress made toward each individual goal in the plan.

This scale was developed in consultation with the founders of the self-determination movement in New Hampshire. It was also reviewed by John O'Brien and Michael Smull. It is far from perfect and does not capture all the aspects of person-centered planning, but it has been found to be sensitive to certain programmatic changes such as involvement in self-determination. It is one of the most important elements of the National Impact Assessment of the Self-Determination Initiative of the Robert Wood Johnson Foundation. It is presented on the following page.

Individual Planning and Supports (Past 12 Months Only)

1. Does the person have an Individual Plan?
   0 No (if No, skip this section)
   1 Yes, but no copy of it is kept here
_____ 2 Yes, and normally a copy would be here, but is not now
   3 Yes, and a copy of it is here

2. What is the plan called? If there is more than one, please name the one that is **most useful, and most familiar to the focus person and his/her support network** (relatives, staff, case managers, etc.). The Plan may be an IEP for school students.

_____

3. Elements of the Planning Process

1=Not at all 2=Somewhat 3=Half 4=Mostly 5=Completely 9=Don't know, Not applicable	
A	How were you involved in the planning process for this person? (If Not at all, skip the rest of this table.)
B	Does the planning process make strong efforts to understand the focus person's long term dreams? (As opposed to short term goals set by others.)
C	Does the planning process emphasize building a network of supports from informal, unpaid, or general community sources?
D	Are the meetings comfortable and relaxed for the focus person? (As opposed to formal and "official.")
E	Are planning sessions scheduled as needed? (As opposed to a regular set schedule, such as annually.)
F	Is the planning process defined or regulated by a set of standards, licensing requirements, rules, or laws, or regulations?
G	Does the planning process encourage creativity, new ideas, different ways of thinking?
H	Does the planning process allow for conflicts and disagreements, and try to resolve them?
I	Is the planning process flexible, allowing for changes in approach when things do not work?
J	Does the person have ultimate authority? (Could he or she overrule the entire group on an issue, within safety limits?)
K	Did the planning process emphasize cooperation among all participants? (As opposed to professional authority.)
L	Does the planning process emphasize the person's relationships? (As opposed to emphasizing skill development, or behavior, or services.)
M	Does the planning process take money into consideration? (Does the group discuss what supports cost, and what alternatives there are?)
N	Does the planning group have control over the resources (money) devoted to supporting the focus person?
O	Do the unpaid group members have the real power? (As opposed to paid staff and professionals.)
P	Do you consider this plan to be "person-centered"?

Individual Budgeting

This section is designed to collect information about the money utilized to support the person. If the person has a traditional support system, then the section captures the traditional estimates of residential and day program per diems, plus public entitlements such as SSI, plus estimates of other expenditures for transportation and other costs. If the person has an individual budget, then the section captures how that budget is being spent, as well as what kind of control(s) the person exerts over that money. In either case, getting cost information for an individual often requires a phone call to an administrative office.

The Individual Budgeting module is crucial for our evaluation of self-determination initiatives.

Connections with Family and Friends

This section collects the name and address of the person's closest relative, so that we can send a mail survey about perceptions of quality. A mail survey to all the relatives listed in this section is an inherent part of the COA quality assurance process. For every person we visit, we will send a Family Survey to whoever is noted as the person's closest relative or other contact.

Connections with Family and Friends

Who is this person's closest unpaid relative or guardian? We will send a mail survey to this individual. If there is no one we could or should send a survey to, please "x" out the address section. (Never include relatives who want no contact concerning their relative, or whom the person does not want us to contact.)

1. _____
Name(s) of Relative or Guardian

2. _____
Relationship to the Person

3. _____
Complete Mailing Address, Including Apartment #, Line 1

4. _____
Complete Mailing Address, Including Apartment #, Line 2

5. _____ 6. _____ 7. _____
City or Town State Zip Code

8. _____ 9. _____
Telephone Number Primary Language, if not English

10. **Involvement of Relative(s):** About how often do **any** relatives have the following kinds of contact with this person? (Accept times per week, or per month, and convert to approximate number of times per year.) **(Enter N/A if the person lives with a relative.)**

About how often in the past year? (Zero if none)

_____ 10a. Telephone calls (including talking with staff)

_____ 10b. Mail

_____ 10c. Relative visits person here at this home

_____ 10d. Person goes out with relative(s)

_____ 10e. Program Planning Meetings

_____ 10f. Consent for medical care

As seen above, this section of the PLQ collects the frequency of several kinds of contact with family members.

The number of friends is counted, however the person defines friends. The section concludes with the Close Friends Scale, which captures the characteristics and intensity of the person's five closest friendships. This module was added in 1997, and it emerged from the analysis of self-determination data. People frequently said that one of the most important things in their lives was to have close friends. We designed a module to capture the characteristics of close friends, and the type, duration, and frequency of the relationship.

11. **Number Of Friends**: About how many people in this person's life would you describe as friends? Do not count mere acquaintances (people one might say "Hi" to, or wave to, but with whom there is no other interaction). Friends might include housemates, co-workers, schoolmates, other people with disabilities served by the residential or day program agency, direct care workers, case managers, support coordinators, therapists, churchgoers, neighbors, merchants (workers in any commercial store), letter carriers, law officers, advocates, guardians, etc.

_____ friends

Close Friends Scale

This table is intended to get at the types and characteristics of a few of the person's closest friendships.

- A "close friend" is anyone the person (or whoever knows the person best) defines that way.
- If there are fewer than 5 close friends, just describe however many there are.
- If there are close friendships with more than 5 people, please try to count only the closest 5.
- A relative can be a friend, but contacts with relatives have already been described above, so only include a relative here if the person or the respondent feels it is important to do so.
- This scale may be left empty, if the person has no close friends; please indicate this with a large "X."

Initials or code:	**Relationship** (Present or Former) 1=Relative 2=Staff of home 3=Staff of day program, school, or job 4=Other paid (Case manager, nurse, etc.) 5=Housemate 6=Co-worker or schoolmate 7=Neighbor 8=Merchant 9=Other	Gender of this friend 1=Female 2=Male	Does this friend have a disability? 0=No 1=Yes 9=D/K	About how long has the person known this friend? (Years – use fractions and decimals if needed, as in 2.5 years, or 2 ½ years) (999=D/K)	Is this friend involved in planning meetings, PCP, or circles? 0=No 1=Yes, minor 2=Yes, moderate 3=Yes, major	About how many times has the person had contact with this friend, in the past four weeks (28 days)? For people seen several times every day, such as staff of the home, just enter 28.
1						
2						
3						
4						
5						

Perceived Quality of Life Changes

The "Quality of Life Changes" Scale asks each person to rate his/her quality of life "A Year Ago" and "Now." Ratings are given on 5 point Likert scales, and cover 13 dimensions of quality. On this scale, we permit surrogates to respond. Surrogates (usually staff persons) were "whoever knew the class member best on a day to day basis." On this scale, approximately 85% of the responses are provided by surrogates. The interrater reliability of the Quality of Life Changes Scale was found to be .76. It is shown on the following page.

Quality of Life Changes

(To Be Answered by the Person or Whoever Knows the Person Best)

Ask the person to rate the qualities of his/her own life "BEFORE" and "NOW." For the Self-Determination Project, "BEFORE" means before this person became involved in Self-Determination. If the person has not yet begun, or has just begun, involvement, use "A YEAR AGO" in place of "BEFORE." **If the person can't answer, accept answers from whoever knows the person best.**

BEFORE 1 Very Bad 2 Bad 3 OK 4 Good 5 Very Good		**NOW** 1 Very Bad 2 Bad 3 OK 4 Good 5 Very Good		
	1B		1N	1 Health
	2B		2N	2 Running my own life, making choices
	3B		3N	3 Family relationships
	4B		4N	4 Seeing friends, socializing
	5B		5N	5 Getting out and getting around
	6B		6N	6 What I do all day
	7B		7N	7 Food
	8B		8N	8 Happiness
	9B		9N	9 Comfort
	10B		10N	10 Safety
	11B		11N	11 Treatment by staff/attendants
	12B		12N	12 Health care
	13B		13N	13 Privacy
	14B		14N	14 Overall quality of life

Over many years, we have been able to compare responses on this scale over time (e.g., "Now" in 1998 compared to "Now" in 2001). We also compare each year's perceived changes in quality (i.e., "Then" as remembered, versus "Now"). The two approaches have been found to produce highly consistent results.

Personal Interview

One of the central problems in measuring quality of life among people with developmental disabilities has been that many people cannot communicate with interviewers, whether by traditional verbal, or by any non-traditional, means. Hence many researchers have permitted surrogates to "speak for" the person. We reserve the Personal Interview of the PLQ as the one section where no surrogates are permitted. This section is intended to capture the person's thoughts, and none other.

So much of the rest of the PLQ can be collected from third parties who know the person well, that it is fitting that there is one place where we who are "listening" to the data will know that this is directly from the focus person. The Personal Interview is left blank if we fail to find a way to communicate with the person. That may be unfortunate, yet it is mitigated by the fact that we still have all the dozens of other quality of life measures which can be collected by third parties. And, in the final analysis, we must have one place that is set apart, and only the focus people themselves can put their thoughts and feelings into it.

The Personal Interview is primarily designed as five point scales, which can be asked as two Either-Or questions. (For example, "How is the food here? Good? OK, would you say Good, or Very Good?") We know from the work of Sigelman et al. that Yes-No questions should be avoided when interviewing people with cognitive disabilities, because of the threats of acquiescence and nay-saying. The best overall question design for many purposes is Either-Or, because most people can answer it easily, and it is not threatened by the problems of the Yes-No format. There are also open-ended items throughout the Personal Interview, and answers to these are written down verbatim for qualitative analysis. (Example: "What things are most important for you to be happy?" and "If you had one wish, what would you wish for?")

The most widely used version of the Personal Interview is the one used in the national self-determination evaluation. A few example items are reproduced below.

Personal Interview
(To Be Answered Only by the Person)

INSTRUCTIONS

- These questions can be answered ONLY by the person, preferably in private.
- There are four situations in which the interview may be done with others present:
  1) An interpreter or other helper is needed by the person to complete this interview
  2) The person wants someone else to be there with him/her
  3) There is any strong objection from any third parties (providers, relatives, guardians)
  4) You, the Visitor, feel uncomfortable for any reason being in private with this person
- Try to interview the person, even if there is doubt about ability to respond; BUT --
- Keep it informal. Begin with the usual social niceties that you would expect from any visitor to your home. How are you, telling about yourself, comments on the home, etc.
- If the person clearly is not responding or understanding after a little while, you may make a note at the end of this section, thank the person, and terminate the interview.
- Any item with 5-point scale answers should be thought of as a "YES-NO" or "GOOD-BAD" 2-point scale, with a chance to get more detail if the person is able. Example: Ask "How do you feel about living here?" and the person answers "Good" then you probe "Would you say Good or Very Good?" If the person answers "I don't know," or "Not sure," or some indefinite answer, probe with "Do you feel on the good or bad side?" If no preference, stick with "Fair," which we will interpret to mean "In Between."
- Tell the person this interview is VOLUNTARY. Say that he/she does NOT HAVE TO talk to you. Even if he/she agrees to the interview, he/she can stop at any time, for any reason.

1. Do you want to talk to me about your home, your life, and your feelings?
   0 No (STOP)
_____ 1 Yes

2. How do you feel about living here?
   1 Very Poor
   2 Poor
_____ 3 Fair (In Between, Not Sure)
   4 Good
   5 Very Good
   9 No Answer or Not Applicable - person has no home at present

2A. What do you like about living here?
(Probe: like the best, like the most.)

2B. What do you not like about living here?
(Probe: like the least, dislike.)

8. How do you feel about the people you live with?
(NOTE: THIS QUESTION IS ABOUT ROOMMATES, NOT ABOUT STAFF, WIVES, CHILDREN, PARENTS, ETC.)

1 Very Poor
2 Poor
_____ 3 Fair (In Between, Not Sure)
4 Good
5 Very Good
9 No Answer or Not Applicable

10. Do you have enough privacy or not?

1 Definitely Not
2 Probably Not
____ 3 Maybe (In Between, Not Sure)
4 Yes, Probably
5 Yes, Definitely
9 No Answer or Not Applicable (e.g., lives alone)

11. Would you rather live somewhere else?

1 Definitely Not
2 Probably Not
_____ 3 Maybe (In Between, Not Sure)
4 Yes, Probably
5 Yes, Definitely
9 No Answer or Not Applicable (e.g., lives alone)

11A. IF YES, WHERE? _____

12. How do you feel about the people who (work with you / assist you) here (the staff)?

1 Very Poor
2 Poor
_____ 3 Fair (In Between, Not Sure)
4 Good
5 Very Good
9 No Answer or Not Applicable; no "staff" who work at the home

14. How do you feel about your [job, school, day program, workshop, etc.]?

1 Very Poor
2 Poor
_____ 3 Fair (In Between, Not Sure)
4 Good
5 Very Good
9 No Answer or Not Applicable

19. Do you ever get lonely?

1 Yes, Often
2 Yes, Sometimes
_____ 3 In Between, Not Sure
4 No or Very Rarely
5 No, Never
9 No Answer or Not Applicable

26. What things are the most important for your happiness? (Up to three things.)

26A _____

26B _____

26C _____

28. If you had one wish, what would you wish for?

Health and Health Care

The PLQ indicators of health and health care are simple and straightforward. Intensity of medical needs is rated by staff informants on a four point scale. Problems involved with getting health care for the person are rated on a three point scale (No Problems, Minor Problems, Major Problems). Number of days of restricted activity because of health problems, number of medications received daily, and percent receiving psychotropic medications, were scored as raw frequencies. The number of doctor and dentist visits, and visits to specialists, is captured. Types of health concerns are rated in 20 categories. Each medication administered to the person is recorded, along with dosage. Perception of the quality of the relationship with the primary physician is included.

Service Delivery Process

A few simple items were collected to reflect the involvement of the case manager according to records. Examples were a recording from the log book of when the case manager last visited, the presence of an up-to-date IHP at the time of the visit, and the presence of the Day Program Plan at the home.

The PLQ also contained an instrument to capture the type and amount of formal services rendered to the person. Estimates were made of the amount of each of 17 services delivered in the preceding 4 weeks, such as dressing skills training, occupational therapy, and behavioral interventions. This is shown below.

Services/Supports

INSTRUCTIONS

- Minutes per day is only a rough estimate!!!
- Most people are awake around 840 minutes per day, so be sure the minutes don't add up to more than that!
- If the service is not received every day, make notes in the margin and figure out minutes per day later.

ROUGHLY How Many Minutes Per Day of this Service Does the Person Actually Receive?

	ENTER MINUTES (0 if none)	
1.	_____	BASIC SELF-CARE SKILLS TRAINING Teaching, not just helping; include hygiene, dressing, eating, domestic skills
2.	_____	COMMUNITY SKILLS TRAINING Shopping, use of identification, transportation, handling emergencies, money management, telephone, etc.
3.	_____	APPROPRIATE SOCIAL BEHAVIOR TRAINING Manners, interpersonal skills, etc.
4.	_____	COGNITIVE SKILLS TRAINING Cognitive skills necessary for functioning in the community, including signs, numbers, etc.
5.	_____	OCCUPATIONAL THERAPY Delivered, designed, or supervised by an O.T. -- include physical & nutritional management
6.	_____	PHYSICAL THERAPY Delivered, designed, or supervised by a Physical Therapist
7.	_____	COMMUNICATION, SPEECH, & HEARING THERAPY Formal programs designed to improve communication abilities (devices included)
8.	_____	LEISURE ACTIVITIES Learning ways to use leisure time
9.	_____	MENTAL HEALTH SERVICES, PSYCHOTHERAPY, OR COUNSELING Delivered directly by a trained therapist
10.	_____	SEXUALITY EDUCATION, TRAINING, OR COUNSELING Teaching person how to make safe and rewarding choices
11.	_____	BEHAVIORAL INTERVENTIONS Systematic reinforcement programs of any kind
12.	_____	JOB SKILL TRAINING (VOCATIONAL OR EMPLOYMENT PROGRAM)

13. HOW MANY TIMES IN THE PAST YEAR (IF ANY) HAS THIS PERSON RECEIVED CRISIS INTERVENTION SUPPORTS? (N/A if not applicable; D/K if "Don't Know")

_____

Family Survey

A survey is mailed to the closest known relative or friend of every person visited. This "Family Survey" is designed to find out about the families' perceptions of the quality of the person's living and working situation. It also explores families' attitudes and concerns.

A Family Survey has been an essential part of the monitoring activities in the COA research group since the beginning of the Pennhurst Longitudinal Study in 1979. We have examined reliability for a convenient but small sample of families who filled out two survey forms, and found reliability to be very high, but we have not yet published these findings.

The National Self-Determination Family Survey instrument is included here as Appendix D.

Reliability

Professor Donald Campbell, who is credited with the founding of "program evaluation" as a science, strongly believed that "without reliability in our social measures, we have nothing." In 1990, Conroy & Feinstein agreed with this notion, and went further. Fourth in their 10 "Principles of Quality Assurance" was the contention that "reliability is essential." They wrote:

> Principle 4: Reliability is Essential
> If a monitor visits a residential setting on one day and finds deficiencies A, B, and C, and another monitor goes in two days later and finds deficiencies A, D, and E, then the provider is certain to become cynical about the quality enhancement activity. There is no "interrater reliability." The success of the provider is reduced to the "luck of the draw" of monitors. The provider comes to view this unreliable monitoring as being completely unrelated to the quality of the setting.

The modules, instruments, and scales that make up the PLQ have been consistently subjected to rigorous scientific tests of reliability since the beginnings of the Pennhurst Longitudinal Study in 1978. Reproduced below are a few of the most important reliability studies that have been done on the PLQ's components.

Conroy, J. (1995, January, Revised December). *Reliability of the Personal Life Quality Protocol. Report Number 7 of the 5 Year Coffelt Quality Tracking Project.* Submitted to the California Department of Developmental Services and California Protection & Advocacy, Inc. Ardmore, PA: The Center for Outcome Analysis.

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

Fullerton, A. Douglass, M. & Dodder, R. (1996). *A systematic study examining the reliability of quality assurance measures.* Report of the Oklahoma State University Quality Assurance Project. Stillwater, OK.

Fullerton, A. Douglass, M. & Dodder, R. (1999). A reliability study of measures assessing the impact of deinstitutionalization. *Research in Developmental Disabilities, Vol. 20, No. 6,* pp. 387-400.

Dodder, R., Foster, L., & Bolin, B. (1999). Measures to monitor developmental disabilities quality assurance: A study of reliability. *Education and Training in Mental Retardation and Developmental Disabilities, 34, 1,* 66-76.

Isett, R., & Spreat, S. (1979). Test-retest and interrater reliability of the AAMD Adaptive Behavior Scale. *American Journal of Mental Deficiency, 84,* 93-95.

Jagannathan, R., Camasso, M., Lerman, P., Hall, D., & Cook, S. (1997). *The New Jersey Client Assessment Form: An Analysis of Its Stability Over Time.* Newark, NJ: Developmental Disability Planning Institute, New Jersey Institute of Technology.

Procedures for Data Collection

Procedures for data collection were purposely kept as flexible as possible, so that the state and local participants would have the maximum freedom compatible with doing good science. In all cases, the data collectors were trained by COA directly, on site.

In each state, COA representatives met directly with project coordinators – and often also with many other stakeholders – to explain why the data would be so valuable, how they would be collected, and how they would be utilized later.

Our intent was simple – to visit and collect data face to face with as many participants as possible, as early in the self-determination project as possible. In some states, state or county employees collected data. Most often these were case managers or support coordinators. In others, COA employees collected data directly. In others, local people were hired and trained by COA. In each case, the decision about how data would be collected was left to the local implementers – rather than being imposed by the researchers, the data collection process was created by local consensus. This approach was very much in keeping with the ideals and expectations associated with self-determination. Although it would have been easier to mandate uniformity, we suspect that this kind of authoritarian approach would have failed.

Then, waiting as long as possible, we collected data for the same people again – a year or two or three later – to see whether people's qualities of life, power, and individual planning and budgeting had changed. We waited till the last possible minute to do the "post" data collection – so that there would be the maximum time interval between the two visits. The more time, the more likely that significant effects could be detected.[26]

[26] In fact, to maximize the time between the "pre" and the "post" observations, COA requested and was granted major extensions in time (but not resources) from RWJF.

Results

This section is divided into several subsections. First is a summary of the results across the six states in which we obtained good pre-post data. Second is a summary of the findings of a national survey of the relatives of self-determination participants – which we elected to perform last summer with our own resources. Third is a very brief summary of our findings on costs in two states. Collecting baseline data on costs was difficult beyond anyone's expectations – precisely because, as self-determination proponents have always claimed, traditional service systems kept money fragmented and mysterious. The data we could collect in the two states, however, were strong and compelling. The fourth section is a series of individual stories gleaned from our qualitative research work in Year Two, and from our separately funded evaluation of self-determination in California. These stories were collected in order to illustrate, or question, the quantitative findings – to put human faces on the implementation of self-determination.

The detailed findings within each state have been placed in Appendix E. The level of detail in those Appendices may be of interest to readers from specific states, but for the purpose of the overall national impact assessment, what we want to present is in the nature of a "meta-analysis." What were the outcomes of self-determination across all the states, and what were the common threads? Most of all, were the tenets of self-determination borne out by the data gathered from hundreds of people who participated?

Results 1: Summary of Pre-Post Findings in Six States

Demographics

The state applications for the Robert Wood Johnson Foundation's Self-determination had four major similarities. First and most importantly, was a core group of individuals with a fundamental respect for the civil rights of people with disabilities and their families. Second was an acknowledgment that current funding systems were generally inefficient and inequitable. Third was a belief that the principles of self-determination, as implemented in the original project in New Hampshire, offered a blueprint for large-scale improvement. The final common characteristic was a commitment to work on local systems change to support the new initiative.

The following results were obtained from Self-Determination pilot projects in six states: California, Hawaii, Maryland, Michigan, Ohio and Wisconsin. The combined number of Self-Determination participants for whom pre- and post-data was collected across the states is 441 people. The largest number of participants was in Michigan (135 Self-Determination participants).

The purpose of the first few questions in the survey is to describe the participants in various ways so that the results can be discussed with an understanding of the population and an awareness of the demographic differences across states.

Table 1.
Age, Gender, and Ethnicity

Demographics	CA	HI	MD	MI	OH	WI
Number	66	59	15	135	62	89
Average Age	25.1	32.4	38.9	44.9	36.8	30.4
Percent Male	77.3%	54.2%	53.3%	55.3%	59.7%	58.4%
Percent Minority	47.0%	71.2%	13.3%	14.4%	3.3%	6.9%

The average age of participants ranged from just over 25 years in California to about 45 years in Michigan. The majority of the participants were male. Maryland, Michigan, Ohio, and Wisconsin had low percentages of minority participants, ranging from just over 3% in Ohio to more than 14% in Michigan. In California and Hawaii, the percentage of minority participants was much higher.

California reported 47% minority participation and Hawaii reported 71.2%. "Hispanic or Latino" was the highest reported minority in California while in Hawaii it was "Asian."

The next reported characteristic of participants is their types of mental retardation labels. Many self-advocates and their friends and allies object to labels, especially if they are used to allocate resources or assign people to restrictive programs. This was certainly not the case with the self-determination initiative, in fact it is one of the basic tenets of self-determination that a person can participate regardless of level of cognitive ability or impairment. We only include this characteristic to show that self-determination is valued and utilized by people with a wide range of levels of mental retardation.

Table 2.
Level of Mental Retardation Label

Label	CA	HI	MD	MI	OH	WI
Not labeled MR	35.6%	5.1%	0.0%	3.1%	14.8%	20.2%
Mild	30.5%	28.8%	20.0%	46.6%	42.6%	27.0%
Moderate	8.5%	25.4%	13.3%	23.7%	24.1%	12.4%
Severe	13.6%	25.4%	26.7%	9.9%	13.0%	18.0%
Profound	5.1%	8.5%	20.0%	16.8%	5.6%	4.5%
MR present, no label assigned	6.8%	6.8%	0.0%	0.0%	0.0%	18.0%
Unknown	0.0%	0.0%	20.0%	0.0%	0.0%	0.0%

In five of the states the highest percentages of participants carried the labels "Mild" or "Moderate," or "Not Labeled MR." Combined total percentages for those three categories were; California 74.6%, Hawaii 59.3%, Michigan 73.4%, Ohio 81.5% and Wisconsin 59.6%. Although Maryland had only 15 Self-Determination participants, 46.7% of them were labeled with either "Severe" or "Profound" mental retardation. The other five states ranged in percentages of people labeled with "Severe" or "Profound" mental retardation from 18.6 % in Ohio to 46.7% in Maryland. It is clear that all six states included, in varying degrees, participants with significant cognitive disabilities in their Self-Determination projects.

The place where people live is often a major factor in their perceived quality of life. Community living arrangements for people with disabilities differ widely from state to state, based on State Medicaid regulations and federal reimbursement

formulas. It is therefore very important to consider the types of living arrangements for the self-determination participants.

A major related issue is the concept of developing and implementing individual budgets for people who were formerly served under the umbrella of aggregate, residential contracts or for people moving from or staying in family homes.

We found wide variations across states with regard to living arrangements. For example, in California almost two-thirds of the participants lived with their families, as did more than 52% of the Hawaii participants. The numbers for Ohio and Wisconsin were similar with approximately 34% of the participants living with family. Only 13% of the Michigan participants lived with family.

Many advocates for people with disabilities argue that group homes and other such living arrangements continue the segregation inherent in institutional care. We therefore asked all the participants to tell us how many people with disabilities lived in their homes.

The results were encouraging for advocates of integration. California reported the most participants living with zero to two other people (81%) followed by Wisconsin (77%), Michigan (68%), Hawaii (70%), Ohio (66%) and Maryland (47%). The state with the highest percentage of participants living with more than four other people with disabilities was Ohio at 14.5%. Data from both Maryland and Michigan showed that 13% of the participants lived with more than four people with disabilities while Hawaii reported 21.5%. Only 2% of the Wisconsin participants lived with more than four other people with disabilities and in California none of the participants lived with more than four people with disabilities.

A second question about living arrangements asked how many participants lived with paid staff. We do not intend to suggest that support by live-in staff is inherently negative. Rather we felt it was important to document the types of residential support chosen by participants and their allies. The results show that most self-determination participants chose not to hire live-in staff. The highest percentage of people reporting no live in staff was in Ohio at 94%, followed by Michigan at 77%, California at 69%, Wisconsin at 66%, and finally Hawaii at 55%. Too few of the Maryland participants answered this questions to consider the percentage representative.

The last question about living arrangements went to the core of self-determination. We asked participants who selected their living arrangements. Choices for this question included self, family, self and family, professionals alone, or joint decisions. For our purposes, the most telling results are the percentages of participants for whom professionals alone made the living arrangement choice. In Maryland, more than 93% of the respondents said that professionals chose their homes. The percentages were much lower for the other projects: Wisconsin and Hawaii at 18.6%, Michigan at 18%, and Ohio at 13%. The California project did not include this specific question in their data collection.

We can conclude that, with the exception of Maryland, the professionals involved with the self-determination projects relinquished power over at least one major life choice - where to live.

Legal Status

The concept of self-determination for people with cognitive disabilities is the subject of great debate. In fact, some people hold the opinion that self-determination only "works" for people who are verbal and can express their wishes and desires. This opinion could not be further removed from the original concept of self-determination. One of the great success stories from the original project in New Hampshire was a young man who was in a coma. A true description of self-determination includes decision making by families and friends who care about the person with a developmental disability.

Guardianship has always been a controversial issue in the field of developmental disabilities. Strict civil rights advocates argue against legal guardianship for all but those with the most severe cognitive impairments. Advocates of health and safety first often view guardianship as an additional level of protection for those with mild cognitive disabilities. It is unfortunate that the concepts of individual budgets and personal control of budgets has given new life to the guardianship debate. The legal status of the self-determination participants is shown below.

Table 3.
Legal Status: Percentages

Legal Status	CA	HI	MD	MI	OH	WI
Parent/Relative is Full Guardian	40.9	26.3	0.0	23.7	16.1	60.5
Parent/Relative is Limited Guardian	0.0	1.8	0.0	12.2	4.8	1.2
Non-Relative is Full Guardian	1.5	3.5	0.0	23.7	9.7	11.6
Non-Relative is Limited Guardian	0.0	1.8	100.0	2.3	0.0	1.2
Relative is Conservator	6.1	0.0	0.0	0.0	0.0	0.0
Non-Relative is Conservator	1.5	0.0	0.0	0.0	0.0	0.0
No Guardian or is Own Guardian	36.4	5.3	0.0	38.3	69.4	25.6
Parent/Relative Guardian, not court-appointed	0.0	49.1	0.0	0.0	0.0	0.0
Guardian is the Office of Public Guardianship	0.0	12.3	0.0	0.0	0.0	0.0
Unknown	13.6	0.0	0.0	0.0	0.0	0.0

Guardianship status for the self-determination participants also showed wide variations across the six states. The choices for types of guardianship listed in the table above include all the categories from all six states. All categories are not used in all states. A clear comparison of legal status can best be drawn by noting the percentages of self-guardianship. The Ohio participants reported the highest at 69%. The other five states had much lower percentages; Michigan 38%, California 36%, Wisconsin 26%, Hawaii 5.3% and lastly Maryland with no participants who were their own guardians.

The differences in these percentages only highlight the basic problem with guardianship in general. The participants in Maryland can not be so different from the participants in Ohio that the difference in self-guardianship is 69%.

Individual Budgets

Individual Budgets that are controlled by participants and their allies are what sets self-determination apart from similar values based program models such as person directed or person-centered services. Money is power in our society and the person who controls the purse strings gets a level of respect and deference that is not afforded to recipients of charity or public welfare. Fiscal conservatism is the philosophical basis for instituting individual budgets. The hypothesis is that individuals will allocate funds according to actual needs and will not spend public dollars on services that are not essential. We asked participants and their allies if they had individual budgets, the results are shown below.

Table 4.
Does this Person Have an Individual Budget?

Response Category	CA	HI	MD	MI	OH	WI
No	15.2%	41.5%	7.1%	8.3%	17.7%	37.9%
Yes	60.6%	45.3%	0.0%	84.1%	79.0%	56.3%
Don't Know	24.2%	13.2%	92.9%	7.6%	3.2%	5.7%

The responses to this question are very interesting and again show wide variation across states. The Michigan project (with 84% of respondents answering "Yes") was clearly the leader in developing individual budgets and in educating participants about their budgets. Ohio was close behind Michigan at 79%, followed by Wisconsin at 56% and Hawaii at 45.3%. The great majority of Maryland respondents did not know if they had an individual budget.

The variations in these responses are most likely due to the choices projects made about where to begin with self-determination. Some projects started right away with the difficult budget issues while others focused early efforts on individual planning, building circles of support, and developing capacity for support coordination or brokerage.

Major Secondary Disabilities

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

Table 5.
Major Secondary Disabilities

Secondary Disabilities	CA	HI	MD	MI	OH	WI
Ambulation	22.2%	15.8%	14.3%	25.6%	23.7%	31.4%
Autism	17.5%	2.6%	0.0%	4.7%	5.5%	4.7%
Behavior-Aggressive	8.1%	2.6%	14.3%	5.4%	5.3%	1.1%
Behavior-Self Abusive	1.6%	1.3%	7.7%	4.7%	3.6%	4.7%
Brain Injury	13.3%	9.2%	0.0%	3.2%	3.6%	12.8%
Cerebral Palsy	11.3%	13.2%	7.7%	17.5%	24.6%	23.5%
Communication	31.7%	26.3%	7.7%	26.4%	19.0%	30.6%
Dementia	0.0%	1.3%	0.0%	0.0%	0.0%	0.0%
Health Problems	22.6%	6.6%	14.3%	19.7%	12.3%	7.1%
Hearing	3.2%	1.3%	15.4%	5.5%	5.0%	7.1%
Mental Illness	3.2%	7.9%	21.4%	*	8.9%	2.4%
Physical Disability	11.1%	11.8%	0.0%	11.0%	5.4%	10.5%
Seizures	14.5%	3.9%	0.0%	5.5%	8.6%	15.3%
Substance Abuse	1.6%	0.0%	0.0%	0.8%	1.8%	0.0%
Inability to Swallow	3.2%	0.0%	0.0%	0.0%	0.0%	0.0%
Vision	12.7%	6.6%	7.7%	5.6%	5.2%	7.1%
Other	6.5%	11.8%	0.0%	5.2%	12.0%	13.5%

Note: Percentages add to more than 100% because some people report more than one secondary disability.
* Mental Illness was not listed as a secondary disability in Michigan.

Communication was the highest secondary disability reported by participants in California, Hawaii, and Michigan. It was reported as the second highest in Wisconsin, third in Ohio, and tied for sixth in Maryland. This result may be surprising to readers who think that behavior or health conditions are more severe disabilities than communication problems.

The second most frequently reported secondary disability across all states was ambulation. Ambulation was the highest reported secondary disability in Wisconsin, the second highest in Hawaii and Ohio, and the third highest in California and Maryland. This finding has great implications for community support with regard to developing accessible housing, transportation, and technology for mobility.

The secondary disabilities reported least were Dementia and Substance Abuse, and Self-Abusive Behavior.

Connections with Family and Friends

This section recorded the number of friends, based on the person's definition of friendship. The section concludes with the Close Friends Scale, which captures the characteristics and intensity of the person's five closest friendships.

Table 6.
Number of Friends

State	Time 1	Time 2	Change	Significance
California	20.3	13.1	-7.3	0.082
Hawaii*	6.9	15.5	8.5	0.021
Maryland*	4.3	12.4	8.1	0.003
Michigan	12.1	13.5	1.4	0.293
Ohio	10.4	15.3	4.9	0.080
Wisconsin*	8.0	15.1	7.1	0.015

* Indicates significance at the .05 level.

Number of friends decreased for California participants from about 20 friends at Time 1 to about 13 at Time 2, although this decrease was not statistically significant. The highest percentage of friends for the participants in California was reported to be in the "Other" category (26.1%), meaning not relatives, not staff, not housemates or co-workers.

The number of friends reported by the Hawaii Self-Determination participants at our first interview was an average of just under seven. At the second interview, the number of friends increased to an average of 15.5, for a change of just over eight friends. This change was found to be statistically significant from Time 1 to Time 2 using a one-tailed test. Almost 30% of the participants in Hawaii reported having relatives as their friends. Another 16.2% of the Hawaii participants reported co-workers or schoolmates as their friends. The categories, "Staff of Day Program, School, Job" and "Housemate" each accounted for about 14% of the types of friends reported by the Hawaii participants.

The number of friends reported by the Maryland Self-Determination participants increased sharply from 4.3 friends on average at the time of the first interview to 12.4 friends on average at the second interview. This increase was highly statistically significant at the .05 level. The highest category of types of friends reported at the second interview was home staff at 35%.

The number of friends reported by the Michigan participants at the first and second interviews was essentially unchanged. In Michigan, just under half (45.5%) of the total number of reported friends were paid members of the person's circle of support.

In Ohio, the increase in number of friends by almost 5 friends was not statistically significant. Top "types" of friends reported in Ohio were: Relative, Other, and Staff of Day Program/Job.

Average number of friends increased significantly in Wisconsin where unpaid friends exceeded the number of paid friends.

Behavior Changes

For many years and in many venues, people with disabilities have been assessed according to various behaviors. This method is decreasing as self-advocates and responsive professionals now view behavior as communication, especially behavior that was once thought to be inappropriate. However, for the sake of evaluation, we did measure three kinds of behavior to evaluate the possible effects of self-determination. The results for changes in adaptive, challenging, and productive behavior are shown below.

The Adaptive Behavior Scale consists of items which measure a person's skill level in several areas including self-care skills, community living skills, communication skills and cognitive skills. The scale ranges from 0 to 100, with higher scores indicating a higher skill level.

Table 7.
Changes in Adaptive Behavior

State	Time 1	Time 2	Change	Significance
California	67.4	69.5	2.1	0.074
Hawaii*	52.5	48.0	-4.5	0.002
Maryland	72.6	73.6	1.0	0.317
Michigan*	65.9	63.4	-2.5	0.032
Ohio	66.0	65.9	-0.1	0.478
Wisconsin	58.2	58.0	-0.2	0.418

* Indicates significance at the .05 level.

There were only two states that showed significant changes in Adaptive Behavior scores from Time 1 to Time 2 and those states were Hawaii (with a 4.5 point drop in the average Adaptive Behavior score) and Michigan (with a drop of 2.5 points). Decreases in Adaptive Behavior scores are unusual in the experience of this research team, and the authors can only speculate as to why these decreases occurred. Perhaps there was less emphasis placed on acquiring and reinforcing adaptive skills as skills in decision-making and social integration were being emphasized more.

The Challenging Behavior scale is composed of items intended to measure a persons ability to control occurrences of behaviors such as self-abusive behaviors, aggressive behavior toward others, running away, stealing and other types of behaviors that may be problematic to themselves, staff, or the people with whom they live. This scale also ranges from 0 to 100, with higher scores indicating an increased ability to control occurrences of challenging behaviors.

Table 8.
Changes in Challenging Behavior

State	Time 1	Time 2	Change	Significance
California	85.5	87.3	1.8	0.163
Hawaii	93.3	92.5	-0.8	0.548
Maryland	86.3	85.7	-0.6	0.426
Michigan	91.2	91.4	0.2	0.140
Ohio	89.8	88.7	-1.1	0.173
Wisconsin*	92.4	95.0	2.6	0.001

* Indicates significance at the .05 level.

In terms of Challenging Behavior scores, only Wisconsin participants showed a statistically significant change from Time 1 to Time 2 with a 2.6 point increase in the ability to control challenging behaviors. All other states showed very minor increases and decreases in overall Challenging Behavior scale scores, but none of these changes reached statistical significance.

The Productive Activities scale measures a person's orientation toward productive activities. This scale contains items which attempt to capture such information as the person's attendance at day activities, their motivation in getting up and getting to their day activity and the level of support and supervision needed at the day activity. Again, this scale ranges from 0 to 100, with higher scores meaning a greater degree of orientation toward productive activities.

Table 9.
Changes in Productive Behavior

State	Time 1	Time 2	Change	Significance
California	Data not collected in CA			
Hawaii*	47.0	39.8	-7.2	0.009
Maryland	54.9	59.8	4.9	0.123
Michigan	50.6	49.3	-1.3	0.190
Ohio*	51.2	59.5	8.3	0.000
Wisconsin	58.9	60.1	0.5	0.270

* Indicates significance at the .05 level.

Two states showed statistically significant changes in Productive Behavior, Hawaii, which lost 7.2 points on the 100-point scale from Time 1 to Time 2, and Ohio, which gained over 8 points on the 100-point scale from Time 1 to Time 2. The changes in Productive Behaviors for the other states for which data was available at both measurement intervals were not statistically significant. Again, this research team has not seen a decrease in Productive Activities scores as large as that seen in Hawaii. The finding warrants further investigation.

Individual Planning And Supports

Person Centered Planning is a term currently used to describe a philosophy and a practice that has been the foundation of good programs for people with disabilities for more than twenty years. The roots of person-centered planning can be traced to individual educational plans, individual habilitation plans, individual written rehabilitation plans, and a host of other plans, most mandated through local and federal legislation. The intent of all individualized planning was and is to create programs that meet individual needs, to acknowledge and address the unique personalities of people who are part of a larger group or population in need of service.

The historical problem with individualized planning as implemented in human services across the country is that it has been directed and certified by paid professionals. Professionals bring the advantages of education and experience to the planning table but the missing elements are personal knowledge of the person and personal commitment to the person and the plan. Person-centered Planning brings all the advantages to the table. The person with a disability, family, and friends are primary members of the planning team with the ability to access

professional advice as needed. This approach seems simple and logical but in reality, it has been difficult to implement.

Federal and state regulations mandate individual plans for most services for people with disabilities, including education, residential, and employment programs. Many of the regulations stipulate plan members such as case managers, psychologists, and teachers. The self-determination participants challenged such stipulations and reserved the right to convene planning teams of their choice. This required policy and procedure changes in some sites. As a practical matter, most people do invite their case managers to the meetings, at least to the annual meeting, which in many places is a required job responsibility for a case manager. Some project sites augmented their existing planning process with technical assistance in person-centered planning. Several sites identified staff with planning expertise to work with other case managers and families in developing their plans.

Participants and their family members report that they now know that they can request professional assistance, in the form of reports or recommendations. The difference is that final decisions are not imposed by the professionals.

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

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

Table 10.
Elements of the Planning Process

State	Time 1	Time 2	Change	Significance
California*	71.9	84.6	12.7	0.000
Hawaii*	69.7	77.6	7.8	0.034
Maryland	64.5	74.9	10.4	0.138
Michigan	Data not available for Michigan			
Ohio*	71.0	81.6	10.6	0.003
Wisconsin*	70.6	77.0	6.4	0.035

* Indicates significance at the .05 level.

The average scores for participants in California, Hawaii, Ohio and Wisconsin on the Elements of the Planning Process scale increased significantly from Time 1 to Time 2 indicating that the planning process in these states had become more "person-centered."

Table 11.
Changes in the Number of Unpaid Planning Participants

State	Time 1	Time 2	Change	Significance
California	1.4	1.2	-0.1	0.275
Hawaii	1.2	1.1	-0.2	0.272
Maryland*	0.3	0.9	0.7	0.000
Michigan	1.8	2.1	0.3	0.143
Ohio	1.6	2.0	0.3	0.304
Wisconsin	1.7	1.7	0.0	0.500

* Indicates significance at the .05 level.

The number of unpaid planning participants involved stayed relatively static in all states except for Maryland, which showed a statistically significant increase in the number of unpaid planning participants. Both of these outcomes we would expect to see in self-determination as professional dominance shifts toward a consumer and family driven system.

Table 12.
Reported Progress Toward Goals

State	Time 1	Time 2	Change	Significance
California	68.8	70.5	1.7	0.266
Hawaii	76.6	73.6	-3.0	0.112
Maryland	82.6	78.5	-4.1	0.251
Michigan*	64.4	70.0	5.6	0.002
Ohio*	69.0	61.0	-8.0	0.003
Wisconsin	66.4	71.9	5.5	0.100

* Indicates significance at the .05 level.

Two states, Michigan and Ohio, showed statistically significant changes in the reported progress toward goals from Time 1 to Time 2. However, Michigan participants were reported to have a significant increase in their progress toward goals (an increase of 5.6 points on the 100-point scale) while participants in Ohio were reported to have a significant decrease of 8 points on progress toward goals. The remaining states, California, Hawaii, Maryland and Wisconsin showed no significant changes in the reported progress toward goals from Time 1 to Time 2.

Earnings

Earnings are an important part of feeling self-sufficient for all of us. In measuring the effects of Self-Determination initiatives on the participants, we asked for the person's average weekly earnings at Time 1 and Time 2. The results are shown in the table below.

Table 13.
How Much Does this Person Earn per Week?

State	Time 1	Time 2	Change	Significance
California	$15.46	$8.40	-$7.06	0.110
Hawaii	$8.03	$11.31	$3.27	0.132
Maryland*	$9.20	$22.80	$13.60	0.035
Michigan	$26.81	$26.19	$0.63	0.429
Ohio	$50.30	$41.04	-$9.26	0.175
Wisconsin	$35.42	$38.27	$2.85	0.305

* Indicates significance at the .05 level.

Only one state, Maryland, showed statistically significant increases in the amount of money the participants earned from Time 1 to Time 2. Maryland Self-Determination participants were reported to be earning $13.60 more per week at Time 2 than they were at Time 1. Two states, California and Ohio, showed participants earning less at Time 2 than at Time 1, although these changes were not statistically significant. The remaining states, Hawaii, Michigan and Ohio showed modest increases in the amount of money the participants earned from Time 1 to Time 2, although these changes did not reach statistical significance.

An examination into the types of work being done by the California participants (for example, more community participation types of day programs and less involvement in employment settings) may explain the drop in earnings in that state. Or, as shown in the California Results appendix, it may merely be a reflection of the drop in the average number of hours worked per week by the California participants. Also worth noting in California is the fact that two people became Self-Employed from Time 1 to Time 2, and one more person got a Regular Job from Time 1 to Time 2. The number of people involved in Sheltered Employment in California remained the same from Time 1 to Time 2.

In Hawaii, the number of Day Program hours dropped from Time 1 to Time 2 by just over five hours per week (-5.4), from 22.0 to 16.6. This change was highly statistically significant using a one-tailed test. Three more people in the Hawaii Self-Determination project have secured Regular Jobs at Time 2, and two more people are participating at a Habilitative Day Training Service. While in Hawaii the number of people reported as having a Regular Job at Time 1 was more than twice the number at Time 2, the average number of hours those participants were engaged in those Regular Jobs decreased from 30.0 hours per week to 15.0.

The average number of hours spent in day program increased significantly from Time 1 to Time 2 for the participants in Maryland as well. No one in the Maryland Self-Determination project was Self-Employed at either Time 1 or Time 2. One more person was reported to have a regular job at Time 2 than at Time 1. Two people were in a supported employment situation at Time 2 who were not at Time 1. There were 4 less people attending a sheltered workshop at Time 2 than at Time 1.

The number of hours spent in a Day Program by participants in Michigan at Time 1 was just over twenty hours per week (22.4). By Time 2, however, this number had decreased to 19.8 hours per week. The change of –2.7 was statistically significant. The type of Day Program that showed the greatest increase in the

number of people participating from Time 1 to Time 2 was Self-Employment. At Time 1, only one person was Self-Employed, but at Time 2, eight people were reported to be Self-Employed.

Average day program hours were essentially unchanged in Ohio. Three people were considered to be Self-Employed both at Time 1 and at Time 2. One more person had a Regular Job at Time 2 than at Time 1. There was one more person involved in Supported Employment at Time 1 than at Time 2, while there was one more person involved in Sheltered Employment at Time 2 than at Time 1.

The amount of hours spent in Day Activities was essentially unchanged in Wisconsin as well. The biggest shifts from Time 1 to Time 2 in where Self-Determination participants in Wisconsin spend their day program hours are in Supported Employment and Regular Jobs.

Choice Making

The final principle of self-determination is the confirmation of the important leadership role that self-advocates must hold in a newly designed community support system. Because leaders need to assess information and make decisions we designed a scale to measure changes in decision making by the participants. The scale is composed of 35 ratings of how minor and major life decisions are made by paid staff or by participants and/or unpaid friends and relatives. Each rating is given on a 10 point scale, where 0 means the choice is made entirely by paid staff/professionals, 10 means the choice is made entirely by the person with a disability (and/or unpaid trusted others), and 5 means the choice is shared equally.

Table 14.
Changes in the Decision Control Inventory Scores

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

* Indicates significance at the .05 level.

All six states showed statistically significant increases in the average Decision Control Inventory scores from Time 1 to Time 2. In California, the overall scale score on the DCI increased from 80.9 at Time 1 to 88.9 at Time 2, an increase of 8 points on a 100-point scale. The top five areas of decision making which showed the greatest gains from Time 1 to Time 2 in California were in "Choice of Agency Support Personnel," "Time Spent at Work/Day Program," "Option to Hire/Fire Support Personnel," "Choice of People to Live With" and "Whether to Have Pets in the Home." All five of these areas were statistically significant.

For the participants in Hawaii, the overall scale score (DCI Scale) rose from 36.4 at Time 1 to 43.7at Time 2. This change was statistically significant and shows us that an important shift in decision-making power is taking place in Hawaii Self-Determination. The top five individual items that showed the largest increases from Time 1 to Time 2 for the participants in Hawaii were; "Whether to Have a Pet in the Home," "What to Have for Dinner," being able to engage in "Minor Vices," (like drinking coffee or smoking cigarettes) "Choice to Decline to Participate in Activities," and the choice of "What to Have for Breakfast." All five of the areas showed significant shifts in power from Time 1 to Time 2.

The overall scale score for the Self-Determination participants in Maryland on the Decision Control Inventory increased by almost 20 points on a 100-point scale, from 50.2 at Time 2 to 69.4 at Time 2. This increases in the DCI scale score was highly significant at the .05 level. When examining the DCI by changes in each item from Time 1 to Time 2, we find that 33 of the 35 items showed increases, although not all of the increases were statistically significant. The top five largest increases, or areas in which power shifted from paid staff to the person and/or their unpaid friends and allies the most were in "Choice of Work/Day Program," "When to Go to Bed on Weekdays," "Choice of Furnishings," "What to Do with Personal Funds" and "Minor Vices." All of these large increases were statistically significant except "Minor Vices."

The Michigan Self-Determination participants gained an average of 13.1 points from Time 1 to Time 2 on the Decision Control Inventory. This finding was statistically significant and suggests that the Michigan participants feel they are gaining power in the decision-making process when it comes to various aspects of their everyday lives. The greatest gains were made in "Option to Hire/Fire Support Personnel," "Choice of Agency Support Personnel," "Choice of People to Live With," "Choice of Case Manager" and "Choice of House or Apartment."

Thirty-three of the thirty-five choice making dimensions increased for the Ohio Self-Determination participants from Time 1 to Time 2, and 13 of those increases were statistically significant. The top five increases in power were in the areas of "Choice of Agency Support Person," the amount of "Time Spent at Work/Day Program," "Choice of Home or Apartment," choice of "Who You Hang Out With" and the choice of the "Type of Work/Day Program." The overall DCI scale score increased significantly from Time 1 to Time 2 for the Self-Determination participants, gaining over 7 points on a 100-point scale.

The top five changes in the items on the Decision Control Inventory show that the participants in Wisconsin are gaining fiscal power as well as more power in making choices about their service delivery arrangement. The top five DCI increases in Wisconsin were: "How to Spend Day Activity Funds," "Choice of Case Manager," "How to Spend Residential Funds," "Choice of Service Agency" and "What to do with Personal Funds," all five of these increases were highly statistically significant. Decision-making power is shifting from paid professionals to the participants and their unpaid allies as shown in the significant increase in the Decision Control Inventory scale score in all six states.

Integration

The scale used to assess integration was taken from the Harris poll of Americans with and without disabilities (Taylor, Kagay, & Leichenko, 1986). It measured how often people visit with friends, go shopping, go to a place of worship, engage in recreation, and so on, in the presence of non-disabled citizens.

The scale tapped only half of the true meaning of integration; if integration is composed of both presence and participation, then the Harris scale reflects only the first part. Presence in the community is a necessary but not sufficient condition for participation in the community. The scale simply counts the number of "outings" to places where non-disabled citizens might be present. The scale is restricted to the preceding month. The interrater reliability of this scale was reported to be very low when the two interviews were separated by 8 weeks, but when corrections were made for the time interval the reliability was high (.97).

Table 15.
Number of Integrative Activities

State	Time 1	Time 2	Change	Significance
California	43.2	47.6	4.4	0.168
Hawaii*	32.7	42.9	10.2	0.021
Maryland	22.4	32.2	9.8	0.074
Michigan*	30.5	35.9	5.4	0.012
Ohio*	39.2	37.6	-1.6	0.000
Wisconsin	41.2	38.4	-2.8	0.139

* Indicates significance at the .05 level.

California, Hawaii, Maryland and Michigan showed increases in the average number of integrative activities, although only two of those increases were statistically significant (Hawaii and Michigan). Ohio and Wisconsin showed decreases in the average number of integrative activities, although only the decrease in Ohio was statistically significant. It should be noted, however, that the average number of integrative activities per month in all participating states was relatively high at both measurement intervals, indicating that participants in these states enjoy frequent opportunities for community integration.

Access to Transportation

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

Table 16.
Access to Transportation

State	Time 1	Time 2	Change	Significance
California	7.1	6.8	-0.3	0.335
Hawaii	4.1	3.4	-0.7	0.130
Maryland	7.7	8.3	0.7	0.280
Michigan*	4.6	6.5	1.9	0.000
Ohio*	3.6	6.3	2.7	0.000
Wisconsin	6.2	5.7	-0.5	0.129

* Indicates significance at the .05 level.

Michigan and Ohio participants were reported as having significantly more access to transportation at Time 2 than at Time 1. The remaining four states, California, Hawaii, Maryland and Wisconsin showed no statistically significant changes from Time 1 to Time 2 in the amount of access to transportation reported.

Health Indicators

To determine changes in health indicators for the Self-Determination participants in the six states, we examined three questions at Time 1 and Time 2. The first question asked the respondents to rate the current health status of the participants on a 5-point scale. The other two health indicators examined in this section were the average number of all medications taken and the average number of psychiatric medications taken by the participants at Time 1 and at Time 2.

The results showed that ratings of Health increased significantly in California, and decreased significantly in Ohio. The number of medications being taken by the California participants was essentially unchanged.

The number of medications taken by the participants, both overall medications and psychiatric medications, remained essentially unchanged in all states but Ohio, in which the number of overall medications showed a statistically significant increase. This finding may perhaps be explained by the fact that the respondents in Ohio rated the participants' health significantly poorer at Time 2 than at Time 1. The average number of psychiatric medications being taken by the participants in all states also remained essentially unchanged from Time 1 to Time 2.

Quality of Work Life for Direct Care Staff

The quality of work life experienced by direct care staff can have a direct influence on the quality of care being provided to the participants. The tool used to evaluate the Self-Determination projects in these six states included a section asking the direct care staff to rate the quality of their work lives in 12 dimensions, from how well they like their jobs to the amount of rules and regulations involved in doing their job. Ratings ranged from 0 (Extremely Poor) to 10 (Extremely Good). The results of this analysis are shown in the table below.

Table 17.
Direct Care Staff's Perceived Quality of Work Life

State	Time 1	Time 2	Change	Significance
California	7.6	9.3	1.7	0.447
Hawaii*	7.7	8.4	0.7	0.042
Maryland	8.8	9.2	0.4	0.082
Michigan	8.3	8.3	0.0	0.399
Ohio*	7.5	8.0	0.6	0.004
Wisconsin*	6.3	7.8	1.6	0.015

* Indicates significance at the .05 level.

Three of the six states (Hawaii, Ohio and Wisconsin) showed statistically significant increases in the direct care staff's perceptions of the quality of their work lives. The remaining three states, California, Maryland and Michigan, showed increases in the perceptions of quality of work life, however these increases did not reach statistical significance. Again, the authors must point out that direct care staff in all six states started out with relatively high ratings for the quality of their work lives.

Perceived Changes in Quality of Life for Participants

The "Quality of Life Changes" Scale asks each participant to rate his/her quality of life "A Year Ago" and "Now." Ratings are given on 5 point, Likert scales, and cover 14 dimensions of quality. On this scale, we permit surrogates (whoever knows the participant best on a day to day basis) to respond. In our experience surrogates provide approximately 85% of responses to this scale. The interrater reliability of the Quality of Life Changes Scale was found to be .76. The changes in the Quality of Life Changes Scale for each state are shown in the table below.

Table 18.
Perceived Changes in Quality of Life

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

* Indicates significance at the .05 level.

All six states showed statistically significant increases on the Quality of Life Changes Scale from Time 1 to Time 2. The largest increase on this scale was for the California Self-Determination participants, who gained an average of over 18 points on this scale from Time 1 to Time 2. In California, the five areas that showed the greatest increases were "Running My Own Life," "Overall Quality of Life," "Getting Out and Getting Around," "Happiness" and "Treatment by Staff."

In Hawaii, every individual item, as well as the overall scale score, increased by a very highly statistically significant factor. The greatest gains were made in "Health," "Running My Own Life" and "Getting Out and Getting Around."

In Maryland, the five areas showing statistically significant changes for the quality of life items were; "Happiness," "What I Do All Day," "Running My Own Life," "Socializing," and "Food."

The greatest gains in Michigan were seen in the ability to "Running My Own Life," "Happiness," "Overall Quality of Life," "Getting Out and Getting Around" and "What I Do All Day." All five of these increases were statistically significant.

Perceptions of quality of life for the participants in the Ohio Self-Determination project increased significantly in 11 of 14 areas. The top five largest increases were in the areas; "What I Do All Day," "Overall Quality of Life," "Getting Out and Getting Around," "Socializing' and "Happiness."

As in the other five states, the areas of life quality that showed the most significant increases for the Wisconsin participants are consistent with what one

would expect to see if Self-Determination is working; "Treatment by Staff," "Overall Quality of Life," "Running My Own Life," "Happiness" and "What I Do All Day."

Personal Interview

As with any intervention or pilot program in social services, one of the most important aspects to measure is the effect the intervention or pilot program has on the individuals involved. In the case of the National Self-Determination pilot programs in the six states discussed in this report, the evaluation tool used in each of the states contained a section called the Personal Interview. This section is ONLY to be asked of the individual receiving services as respondent, no surrogate respondents are allowed.

The results of the personal interview varied widely from state to state, and the detailed analyses of this section are shown in the appendix containing the analyses for each state; however, significant findings from the Personal Interviews for the six states will be discussed briefly here.

For California participants, significant increases were found from Time 1 to Time 2 for the following questions: "How do you feel about living here?"

When we asked the California Self-Determination participants at Time 1 if they liked where they were living their average response was between "Very Bad" and "Bad." At Time 2, the responses had shifted to between "Good" and "Very Good." This change was statistically significant. People reported liking the food more at Time 2 than at Time 1 and this too was a statistically significant change. There were slight increases and decreases on the other items in the Personal Interview, but no others showed statistically significant changes from Time 1 to Time 2 except the question, "Do You Like Going Out to Those Places?" which increased from 4.8 to 5 points.

In Hawaii, positive statistically significant changes in the Personal Interview occurred for the items, "How Do You Feel About Living Here," (4.1 to 4.5) and, "How Do You Feel About Your Family?" (3.5 to 4.3). A statistically significant negative change occurred in "Do You Have Enough Privacy?" (4.7 to 4.0). There was no change from Time 1 to Time 2 in the Satisfaction scale, and a slight increase of .3 points in the Choice scale. Neither change in scale scores was statistically significant.

Ironically for the Maryland Self-Determination project participants there were significant decreases in how they feel about major elements of their lives, while at the same time there appear to have been major increases in the amount of choice they were exercising in those same areas. For example, there were statistically significant decreases in the items, "How Do You Feel About Living Here," "How Do You Feel About the Food Here," "Do You Have Enough Privacy," "Would You Rather Live Somewhere Else," "How Do You Feel About the People Who Work With You Here" and "How Do You Feel About Your Job or Day Program?" Yet there were statistically significant increases in the following items, "Did You Pick the People You Live With," "Did You Pick the People Who Work with You Here," and "Did You Pick Your Job?" In fact, the Choice subscale in Maryland increased significantly while the Satisfaction subscale decreased significantly. These are anomalous findings for this research team.

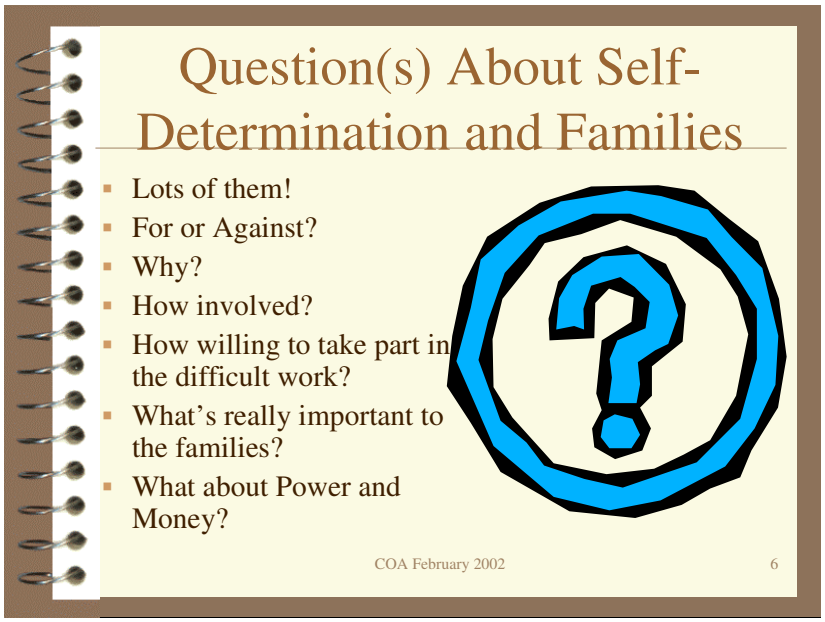
On the Personal Interview section in Michigan, only two items showed a decrease from Time 1 to Time 2, "How Do You Feel About Your Job?" and "Would You Rather Live Somewhere Else?" both decreased by .2 points. The greatest statistically significant changes were found in "Did You Pick Who You Live With?" (.7 point change) and "Did You Pick The People Who Work Here?" (.6 point change).

The average response to the question of how the Ohio participants feel about their jobs increased from a 3.6, meaning the high end of the response "In-between," to 4.0 or "Good." As mentioned before, this increase was statistically significant.

The Wisconsin participants reported they are less lonely at Time 2 than at Time 1. The Wisconsin participants also reported that they feel more positive about Self-Determination after becoming involved with it than they did before becoming involved.

Results 2: The National Self-Determination Family Survey

The purpose of the family survey was to collect and measure family opinions about the self-determination initiative.



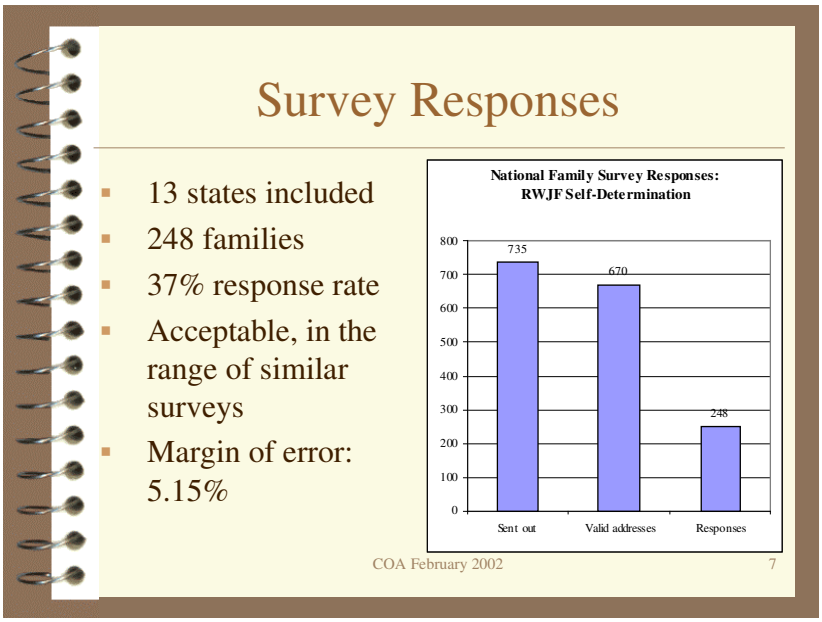
In 2001 and 2002, COA sent out paper survey forms[27] to the families of the participants described in the section on the Personal Life Quality data. These were the people we were able to visit "before" and "during" self-determination – the ones from whom we obtained the data showing that power had shifted and the participants believed their lives had improved. In the section of the PLQ about connections with family and friends, we asked:

Who is this person's closest relative or guardian? We will send a mail survey to this individual.

We extracted 825 names and addresses from the responses to this question and mailed National Self-Determination Family Survey forms to families in

[27] The National Self-Determination Family Survey is included here as Appendix D.

thirteen states. It turned out that only 760 of the addresses were valid. We received 248 completed survey forms. Thus, our response rate was 248 out of 760 possible or 32.6%. We deemed this to be an acceptable response rate. In similar Family Surveys performed over the past 20 years, we have come to expect response rates between 30 and 50 percent from a single mailing. Most of our surveys have hovered around 40%. In the simplest case, a response of 248 out of 760 would be associated with a margin of error of plus or minus 5.32%.[28] A five percent margin of error is well within the generally acceptable range for survey research.



[28] Simplest case means a simple random sample. Responses to this survey, however, were not simple random. This means the calculation of margin of error is not perfectly accurate but rather an estimate.

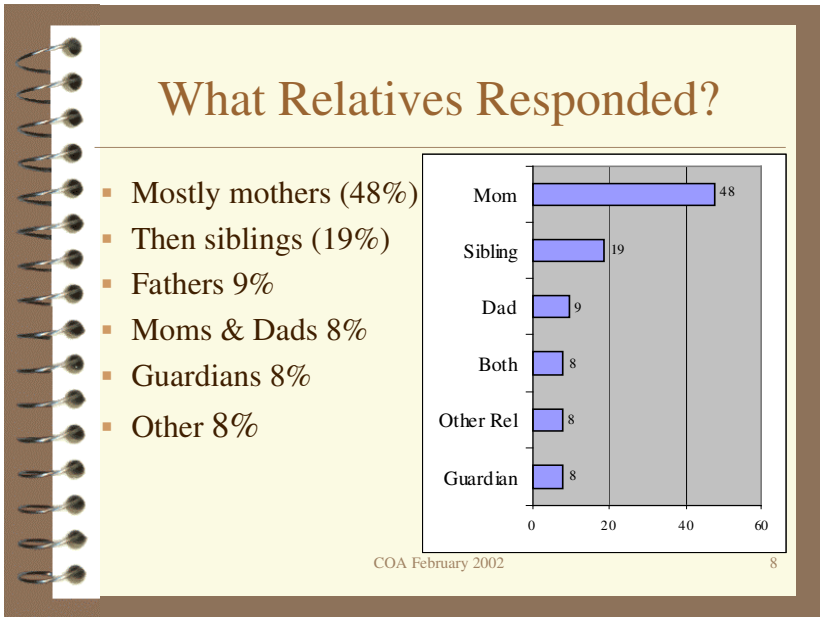
States Included in the Family Survey Analysis

State	Number	Percent
Arizona	3	1.2
California	30	12.1
Hawaii	17	6.9
Massachusetts	3	1.2
Maryland	2	0.8
Michigan	96	38.7
North Carolina	16	6.5
New Hampshire	12	4.8
New York	8	3.2
Ohio	13	5.2
Pennsylvania	14	5.6
Texas	2	0.8
Wisconsin	32	12.9
Total	248	100.0

The total number of responses is small, but the number of participants who have been involved since the beginning is small, too. This suggests that the Family Survey data should be interpreted as representative of the long-term participants. What we can learn from them, despite the small number, may be valuable for present and future participants.

What Family Members Responded?

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



The majority (65%) of the respondents were parents, 47.7% mothers, 9.3% fathers and 8% joint responses from mothers and fathers. The next highest percentage of respondents was 19.4% from sisters or brothers. The average age of the primary respondent to the Family Survey was 54 – the youngest family respondent was 21, and the oldest 92. The participants' average age was 36, with a range of 3 to 83.

We also thought it was important to measure the types and amounts of contact that the survey respondents had with their participant relatives. We asked the following question:

(13) About how often in the past year have you had contact with your relative?
(Skip this question if your relative lives with you.)

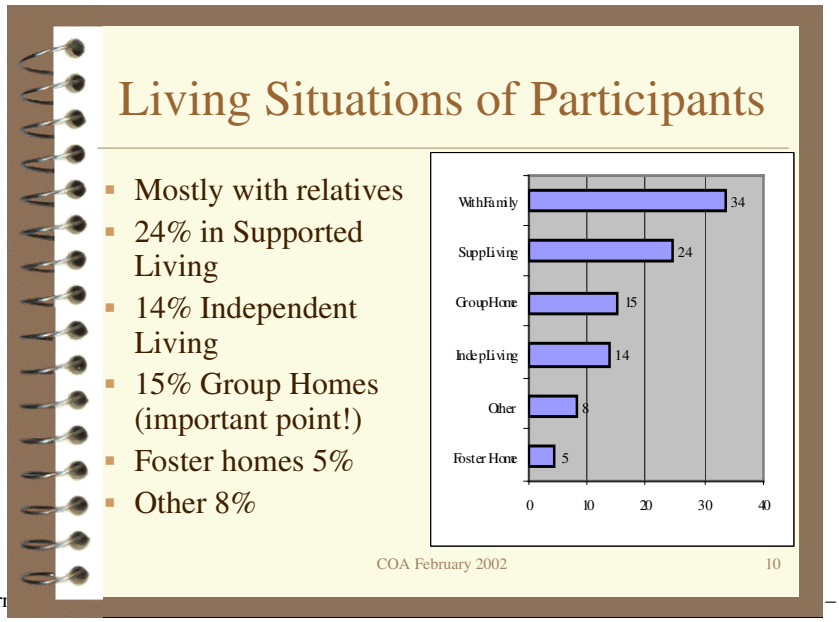
Family Contacts with Relative in Past Year

Type of Contact	Number	Average
Telephone calls (including talking with staff)	115	109.2
Mail	93	15.5
Visits at your relative's home	118	37.0
Taking your relative out or to your home	116	18.8
Person-Centered / Individual Program Planning Meetings	109	6.1
Consent for medical care	79	16.5

Family members reported telephone contact with their relative and/or support staff an average of 109.2 times in the past year, or a little over twice a week. Mail contact was reported to occur an average of 15.5 times a year, or a little over once a month. Family members reported an average of 37 visits per year at their relative's home and an average of about 19 visits per year in their own homes or somewhere else in the community. These combined visits totaled almost 56 per year for an average of more than once a week contact. Family members reported attending an average of 6.1 person-centered planning meetings a year and giving consent for medical care an average of 16.5 times a year.

Who Were the Participants?

Self-Determination participant characteristics varied from state to state. For our purposes we felt that living arrangements, and guardianship were important categories to identify.



A large percentage of the responding family participants (33.6%) were currently living with the responding family member or with other relatives. The next largest group (24.4%) of the respondents' relatives lived in a supported living situation, 15.1% lived in a group home, and 13.9% lived in an independent living situation. Less than 5% of the respondents to the National Self-Determination Family Survey had relatives currently living in a foster home. Respondents also reported that their relatives lived with an average of 4 people.

What is your relative's guardianship status?

Response category	Number	Percent
Parent or other relative is full guardian	113	49.1
Parent or other relative is limited guardian	25	10.9
Unrelated person full guardian	17	7.4
Unrelated person is limited guardian	12	5.2
Person has no guardian or is own guardian, not adjudicated	63	27.4
Total	230	100.0

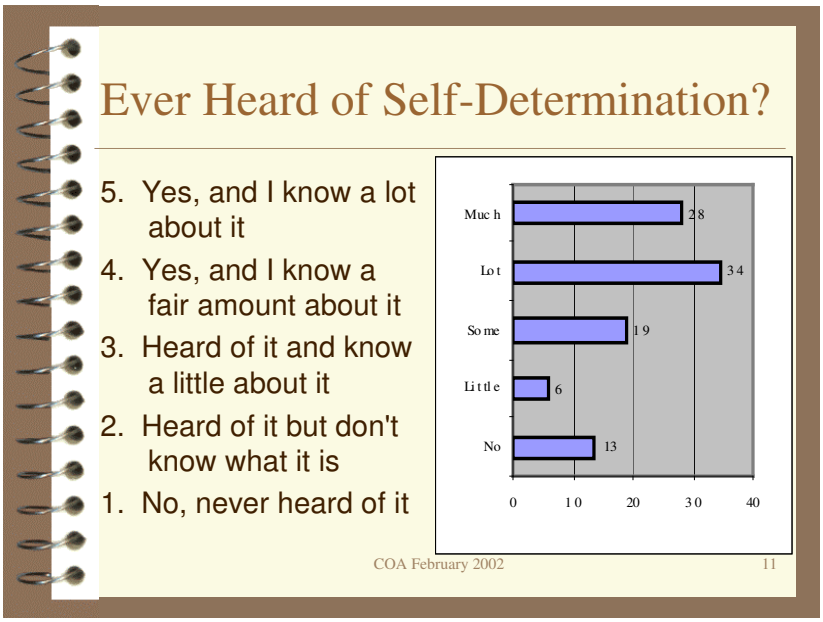
Nearly half (49.1%) of the family member respondents reported that a parent or other relative has full guardianship of the participating relative. Another 10.9% said that a parent or other relative has limited guardianship. Over 27% (27.4%) reported that their relative has no guardian or is their own guardian.

Knowledge and Involvement in Self-Determination

The original self-determination initiative emphasized the participation of families and friends in all aspects of service planning and implementation. We therefore thought it was important to measure family perceptions of their knowledge and involvement in the initiative. Question 6 in the survey was:

(6) Have you heard of Self-Determination for people with developmental disabilities?

The 241 responses to this question broke down as follows:

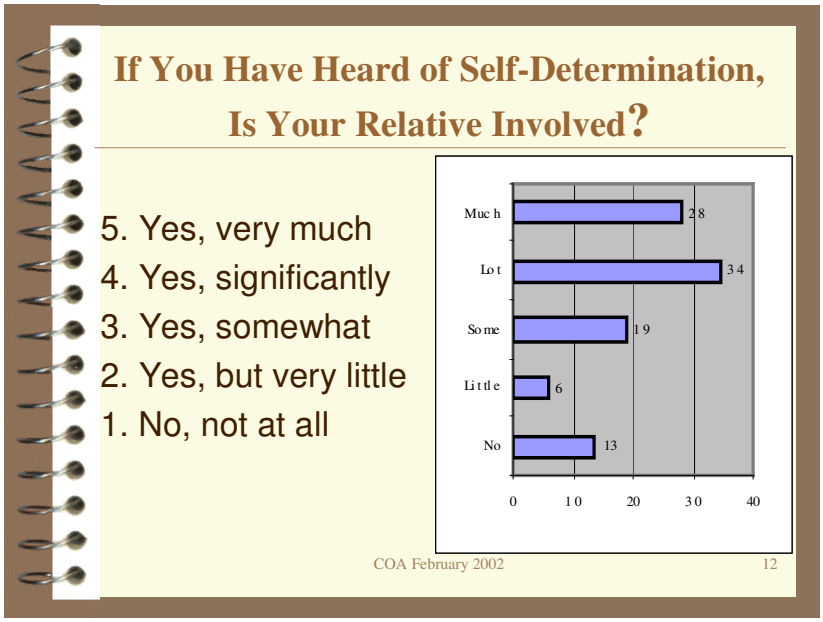


Over 86% (209) of the respondents to the National Self-Determination Family Survey had heard of Self-Determination for people with developmental disabilities. Of those that had heard of Self-Determination, 5.8% said they'd heard of it but didn't know what it was, 18.7% said they'd heard of it and knew a little about it, 34.4% said they knew a fair amount about Self-Determination, and 27.8% said they knew a lot about Self-Determination. Over 13% (32) of the respondents to this national sample of families reported that they had never heard of Self-Determination for people with developmental disabilities.

In Question 7 we asked:

(7) If you have heard of Self-Determination, has your relative been involved in it in any way?

The answers were:



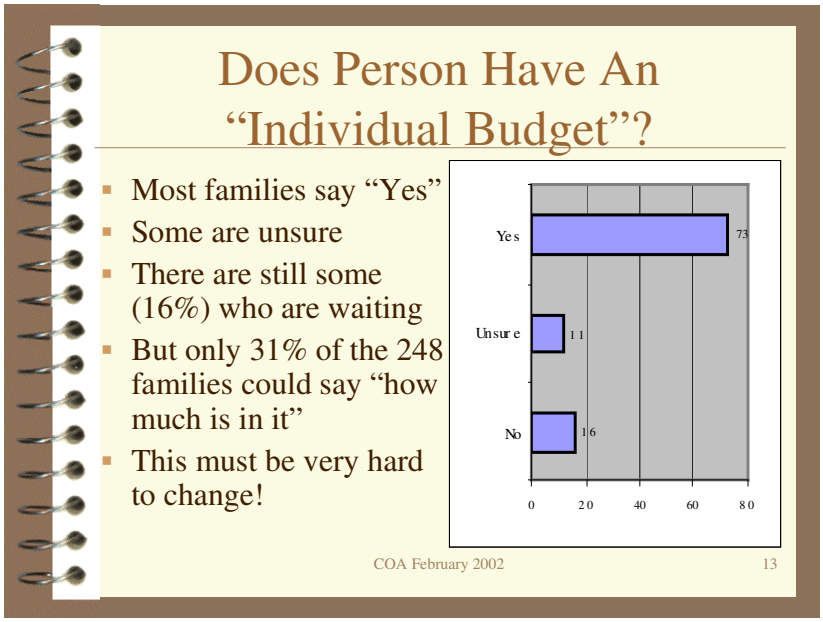
These results showed that more than half of the families (51.4%) generally perceived their relatives' level of involvement as significant or "very much." About a quarter of the family member respondents (25.7%) reported that their relative had been "somewhat" involved in Self-Determination, and 9.3% said their relative had been involved in Self-Determination "very little." Finally, just over 13% (13.6%) of the family member respondents reported that their relative had not been involved in Self-Determination at all.

Individual Budgets

The central feature of self-determination is having an individual budget. And control over that budget must be shared with the person and/or the person's closest unpaid allies. In question 8, we asked:

(8) Does your relative have an "individual budget?"
(A single unified sum of public funds that's used to support him/her for living, working, eating, transportation, and so forth.)

And the answers were:



Almost 60% (56.8%) of the respondents to the National Self-Determination Family Survey reported that their relative "positively" had an individual budget, while 16.2% answered that "maybe yes" their relative had an individual budget. Unfortunately, almost 11% (10.9%) of the family member respondents were unsure of whether or not their relative had an individual budget, 15% of the family member respondents answered in the negative, with "maybe no" and "definitely no." These responses suggested a need for more family training and participation in the concept of controlling resources.

According to the fiscal information known by respondents to the National Self-Determination Family Survey, the people represented in this sample had an average individual budget amount of $19,752.86.

Power and Control

Since control of resources is the hallmark of self-determination, it was important to find out how families perceived the control over the public funds utilized to support the participants. We asked four questions to measure this issue.
(10) Who controls the funds that are used to serve and support your relative?
The answers are shown in the tables below.

How much control over your relative's funds do you (or you with other relatives and friends) have?

Response Category	Number	Percent
Complete or nearly complete	79	35.7
More than half	9	4.1
About half	17	7.7
Less than half	21	9.5
Little or none	72	32.6
Not applicable	23	10.4
Total	221	100.0

The answers to this question were mixed. About 36% of respondents reported that they had "complete or nearly complete" control over their relative's funds, while 32.6% reported that they had "little or no" control over their relative's funds. A little over 10% of the respondents to the National Self-Determination Family Survey reported that the question was not applicable to their situation. One theory regarding these results is that changes in who controls money did not occur in any uniform way across states and programs.

How much control (over funds) does your relative have?

Response Category	Frequency	Percent
Complete or nearly complete	38	17.4
More than half	11	5.0
About half	13	6.0
Less than half	27	12.4
Little or none	79	36.2
Not applicable	50	22.9
Total	218	100.0

Somewhat surprisingly, when asked how much control over funds they felt their relative had, the majority of respondents (36.2%) reported "little or none." Only 17.4% of family members reported that their relative had "complete or nearly complete" control over their funds. Another 22.9% of the respondents felt that this question was not applicable to their relative.

How much control (over funds) do staff of the service agency (if any) have?

Response Category	Number	Percent
Complete or nearly complete	37	17.4
More than half	18	8.5
About half	26	12.2
Less than half	29	13.6
Little or none	65	30.5
Not applicable	38	17.8
Total	213	100.0

More than 30% of family members felt that the staff of the service agency had "little or no" control over their relative's funds, with only 17.4% of respondents reporting that they felt the staff of the service agency had "complete or nearly complete" control. Almost 18% of the respondents reported that the question was not applicable to their situation.

How much control (over funds) does a fiscal intermediary (if any) have?

Response Category	Number	Percent
Complete or nearly complete	30	14.9
More than half	17	8.4
About half	9	4.5
Less than half	9	4.5
Little or none	39	19.3
Not applicable	98	48.5
Total	202	100.0

Almost half (48.5%) of the family member respondents reported that this question was not applicable to their relative's situation. This indicated that most people either did not have access to a fiscal intermediary, or did not utilize fiscal intermediaries if they were available. Over 19% (19.3%) of the family member respondents reported that a fiscal intermediary had "little or no" control over their relative's funds, and only 14.9% of respondents reported that a fiscal intermediary had "complete or nearly complete control" over their relative's funds.

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

In addition to control over funds, we also wanted to find out how families felt about other control issues, such as hiring and firing staff. Had authority transferred partly or completely to the participants and their families? We asked:

(11) Who has control over hiring and firing support staff?

And the responses were captured in the following table:

How much control do you (or you with other relatives and friends) have over hiring and firing support staff for your relative?

Response Category	Number	Percent
Complete or nearly complete	56	31.3
More than half	12	6.7
About half	11	6.1
Less than half	15	8.4
Little or none	83	46.4
Not applicable	2	1.1
Total	179	100.0

The responses were mixed for this question with 31.3% answering "complete or nearly complete" and 46.4% answering "little or none." Two respondents reported that the question was not applicable to their situation.

How much control over hiring and firing support staff does your relative have?

Response Category	Number	Percent
Complete or nearly complete	53	32.9
More than half	17	10.6
About half	10	6.2
Less than half	15	9.3
Little or none	66	41.0
Total	161	100.0

The majority of respondents (50.3%) reported that their relatives had "little or none" or "less than half" of control over hiring and firing staff. However, 43.5% of respondents reported that their relatives had "complete or nearly complete" or "more than half" control over hiring and firing staff. Only 6.2%

answered "about half." In keeping with the spirit of self-determination, no respondents reported that this question was not applicable to their relative's situation.

How much control over hiring and firing staff does a provider agency have?

Response Category	Number	Percent
Complete or nearly complete	81	39.1
More than half	21	10.1
About half	14	6.8
Less than half	12	5.8
Little or none	46	22.2
Not applicable	33	15.9
Total	207	100.0

Almost 50% of the National Self-Determination Family Survey respondents reported that the provider agency had either "complete or nearly complete" or "more than half" control over hiring and firing of their relatives' support staff. In direct contrast, 28% reported that the provider agency had "little or no" or "less than half" control over hiring and firing staff. Almost 16% said that this question was not applicable to their relative's situation.

The mixed results for all the questions about who controls hiring and firing staff seem to highlight uneven implementation of this aspect of self-determination across programs. In the long run, the participants themselves should become more able and enabled to express their preferences about the people who support them.

Changes in Qualities of Life

The second main hypothesis of self-determination is that (assuming power does shift) lives will get better. We asked the question in this form:

(14) Quality of Life Changes
Please give your opinion of your relative's qualities of life "BEFORE" and "NOW."
"BEFORE" means before this person became involved in Self-Determination.

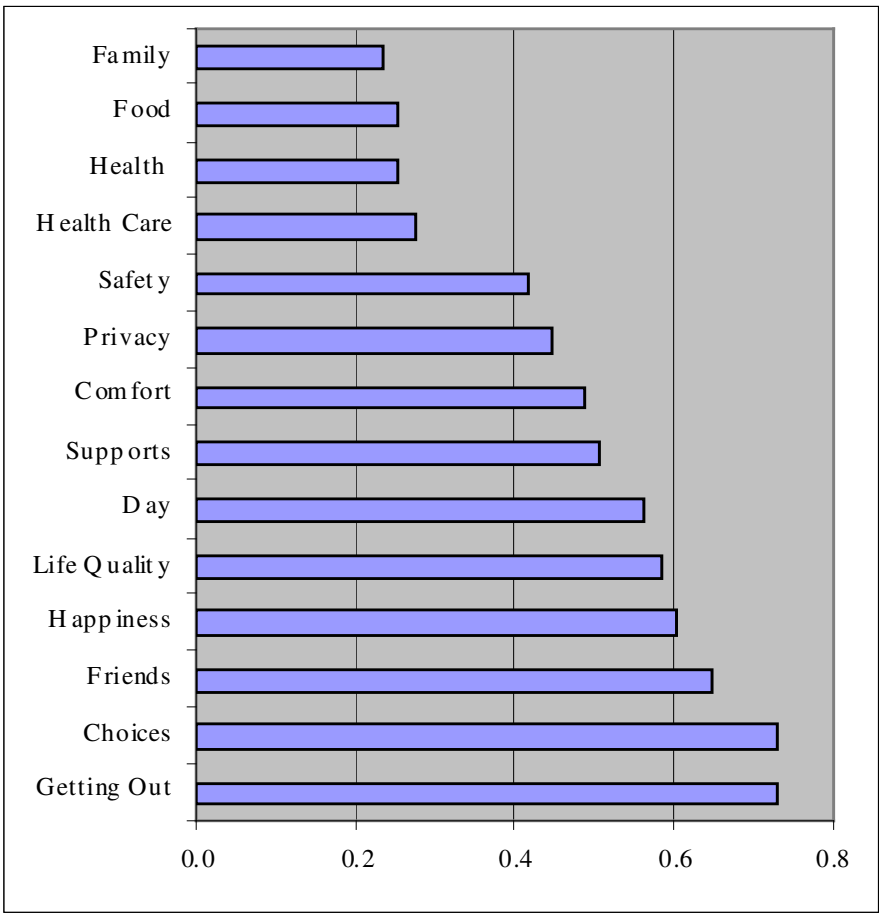
The results were as follows:

Quality of Life Changes

Life Area	Before	Now	Change	Significance
Getting out and getting around	3.3	4.0	0.7	0.000*
Running own life, making choices	2.8	3.5	0.7	0.000*
Seeing friends, socializing	3.3	3.9	0.6	0.000*
Happiness	3.6	4.2	0.6	0.000*
Overall Quality of Life	3.6	4.2	0.6	0.000*
What s/he does all day	3.3	3.9	0.6	0.000*
Treatment by staff/attendants	3.8	4.4	0.5	0.000*
Comfort	3.8	4.3	0.5	0.000*
Privacy	3.7	4.1	0.4	0.000*
Safety	3.8	4.2	0.4	0.000*
Health care including dental	3.9	4.2	0.3	0.000*
Health	3.6	3.9	0.3	0.000*
Food	3.7	4.0	0.3	0.002*
Family relationships	3.9	4.1	0.2	0.000*

* Indicates significance at the .05 level.

Family Views of Changes



This table shows the item by item breakdown for the Quality of Life Changes scale. The table is sorted by magnitude of change. All items increased in perceived quality from before Self-Determination started to Now, and all of the increases were statistically significant at the .05 level. Life Areas in which perceived quality increased the most were "getting out and getting around," "running own life and making choices," "seeing friends and socializing," "happiness" and "Overall Quality of Life." Gains in these areas were consistent with self-determination principles in so far as they reflect more attention to integration and the development of personal relationships. Life areas in which perceived quality increased the least were "safety," "health care including dental," "health," "food" and "family relationships."

We think that the smaller increases in these areas, with the exception of family relationships, are explained by the prior, traditional service system emphasis on these areas. The overall scale score for perceived Quality of Life as

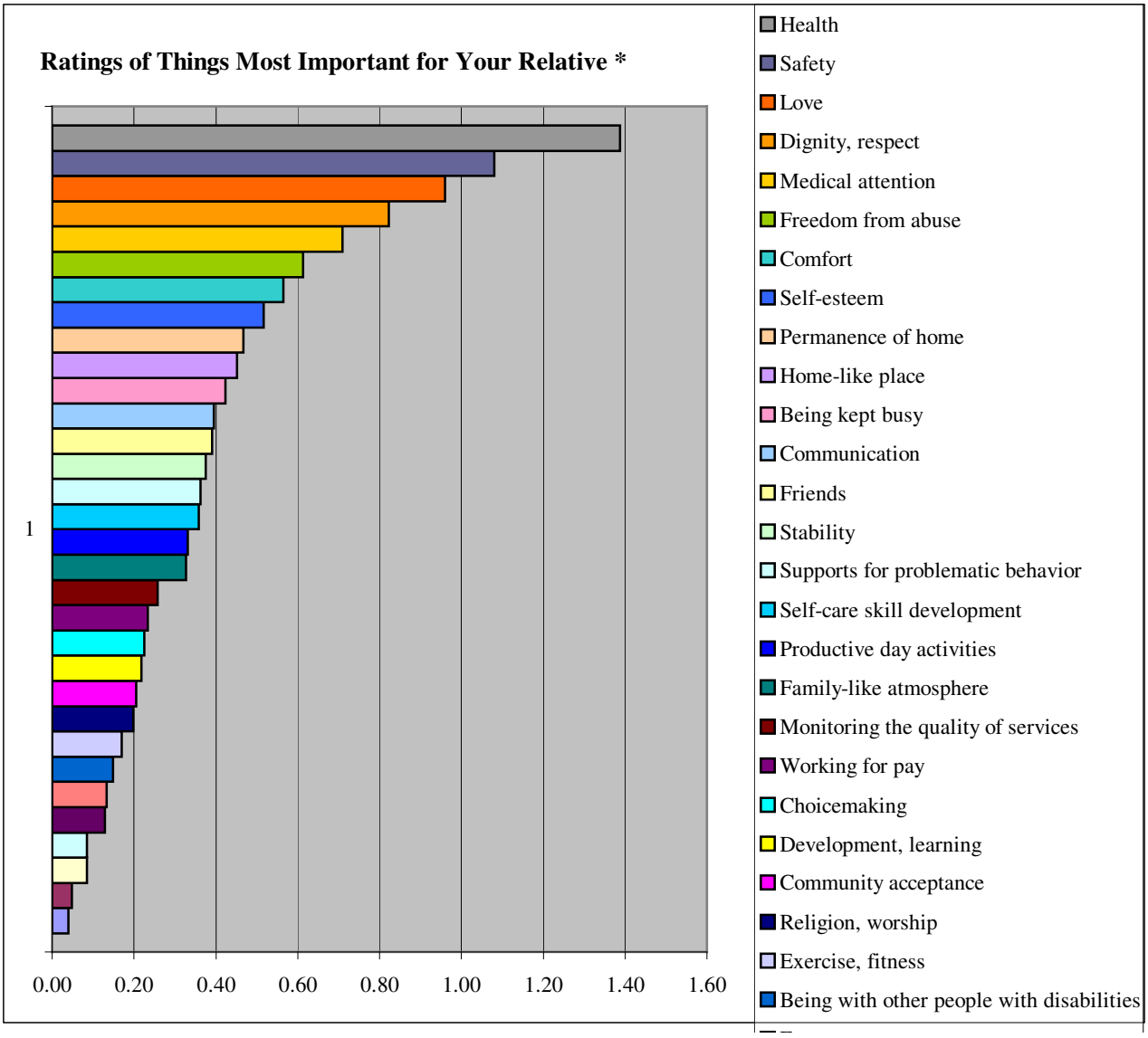
reported by family members gained 10 points from the start of Self-Determination to the date of the surveys, up from 71.9 to 81.3. This gain was statistically significant.

What's Most Important to the Families?

Because the value systems of families, participants, and professionals may be quite different, it was of great interest to find out what parents cared about the most. This question was asked in the following table, which has been sorted according to the ranked importance.

(15) FIVE MOST IMPORTANT THINGS

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



* The answers were put onto a "relative importance" scale developed for this study. The most important item was given 5 points, the second most important 4 points, and so on down to the fifth most important at 1 point. The answers were then averaged across all the respondents to produce this graph.

We think these results are very revealing. The families expressed their highest values as Health and Safety – which is not really different from the feelings of any parents. The next highest ranked values were "love," "dignity and respect" and "medical attention." The five items least valued by respondents to the National Self-Determination Family Survey were "travel/vacations," "integration/inclusion," "assistive devices," "girlfriends/boyfriends" and a "large facility to live in."

Some of the values that seem most related to self-determination, "choice-making," "community acceptance," "working for pay," were not ranked very highly by family members. What these finding might teach us is that self-determination is good, and families tend to be very happy with it. However, they may see it as secondary to their highest values such as health and safety. For the proponents of the self-determination theory, however, all of these values could and should be enhanced by the radical shifts in power implied by self-determination.

Wishes

To elicit hopes and dreams, we asked:

(17) If you had one wish for your relative, what would it be?

The responses to this question, in the personal interviews with participants and in family surveys, are always poignant. Below is a sample of family member wishes for their relatives.

- *That she will realize her dreams.*
- *That he is safe, loved and loving.*
- *It would be a blessing that my brother could walk and talk as normally as everyone else.*
- *For her to continue living a productive, happy life even after I am gone.*
- *Simply for him to be happy.*
- *For her to be able to live independently on her own in a nice apartment with good dependable staff.*
- *To live his life without being heavily medicated.*
- *He has excellent care and all his needs have been provided - but I do hope I can outlive him.*
- *My wish would be for personal staff to receive higher pay so they would likely continue in the position.*

General Comments About Self-Determination

In order to obtain details about family reactions to self-determination in their own words, we asked:

(18) Please write any comments you have about the Self-Determination Initiative.

Below is a sampling of family comments.

- Self-determination has helped us to get the medical testing and surgical help needed.
- Takes so long to even begin - things I want for him will be over by the time the budget goes through. Need more people who know things before they start the budget.
- Self-determination is an outstanding program and has given my daughter control over her life for the first time. I certainly hope it continues, as I believe she will grow to her full potential in this program. She never thought she could be independent.
- We would like a listing of counties that participate with self-determination and have individual budgets so we know what our moving options are. His life has improved 100%.
- As his guardian, I am a real advocate of the self-determination program. He and other recipients of this program have a much better quality of life. We have seen great improvement.
- Communication between staff and providing service programs for him is needed. Also follow up to make sure what was promised happened. We have been promised job placement for him. He has many fine skills and yet the only job they could find was washing dishes.
- Self-determination is a wonderful initiative. However, funding short falls prevent full implementation. Getting what we do get in the way of state funding is a constant battle. These people deserve more!

- It has provided my daughter the opportunity to socialize with her peers doing an activity that she enjoys. It also has given her the chance to meet more people in the community.
- Very glad they have control to say what is best for him. "You get to see miracles every day."
- Individual budget not yet established. Fiscal intermediary not yet established in this state. Self-determination and family support have become "buzz" words. Most staff providers or state staff don't want to give up control or way of doing business.
- The outcome is demonstrable, measurable, and positive. The process is complex. We need to develop service coordinators who know or know how to access mortgages, insurance, credit, automobile insurance and registration etc.

Family Survey Summary

This national family survey leads to several clear conclusions, and some corresponding recommendations.

First, there is strong evidence that power has shifted toward families – and to a lesser degree toward individual participants. This (in addition to the individual participant data) confirms the first tenet of self-determination – that power shifts from the traditional human service system toward the participants and their freely chosen allies. The family survey data also suggest that attention is necessary to include the participants themselves to the maximum extent possible – rather than simply shifting power from professionals to parents. This is probably the most difficult and delicate issue in the entire enterprise of self-determination. A strong and mutually respectful alliance between self-advocates and family members is urgently needed. The work already done within Project Leadership may provide a national model[29] for this important goal.

Second, there is still a significant shortage of information and knowledge about individual budgets, including the amounts of money available, and the planning team's degree of control over the funds. This leads to a simple and clear recommendation: extensive training and technical assistance is needed in the area of individual budgeting. This recommendation appears to be applicable to all states and all pilot projects.

Third, the families believe that "life has improved" significantly for the participants in 14 out of 14 life areas. To the extent that family perceptions of well-being are valued outcomes, self-determination must be very strongly recommended.

Fourth, the values of parents tend not to stress freedom, authority, support, responsibility, and self-advocacy nearly as much as their concern for health, safety, love, dignity and respect, and medical attention. These latter values appear to be parallel to the things any parent wants for any child. The finding, therefore, reveals the similarities of the values of families with and without a relative who has a disability, rather than the differences. However, one of the underlying claims of self-determination has been that the basic values of health, safety, love, dignity, respect, and attention to health issues cannot be fully realized without the systems changes inherent in self-determination. Therefore, if self-advocates and self-

[29] http://www.comop.org/leader/proleader.htm

determination promoters wish to further the long term goals, then the essential recommendation from this finding is that intensive and extensive training for families is necessary. The proposed relationship between self-determination and fundamental values must continue to be stressed and disseminated.

All in all, the family survey data show that the self-determination initiatives have been extremely well-received by family members. Redoubled training and informational efforts are needed, and monetary issues are still confusing for some, but the early initiatives have been highly successful in the opinion of family members. The family members who answered our survey would clearly not want to go back to "the old way."

Results 3: Self-Determination and Costs

The concept of self-determination in the field of developmental disabilities is simple; if people (and their freely chosen allies) gain control, their lives will improve and costs will decrease (or stay the same). The Self-Determination initiatives and demonstrations were designed in part to test the notion that movement of power and control toward service recipients would reduce expenditures.

The original Self-determination Project in New Hampshire, at Monadnock Developmental Services, must be viewed as a revolutionary attempt to implement an entirely new and different paradigm. In this new paradigm, service recipients and their significant others were the primary decision makers. Budgets were designed for individuals, not for programs. Service provider invoices were paid only after the person was satisfied with and had approved payment for the services. Case managers were personal agents and community liaisons who worked for the individual. These changes necessarily reduced professional dominance. In New Hampshire, the Center for Outcome Analysis found that cost savings through the Self-Determination model had been realized. (For full cost analysis see Appendix A). Costs were reduced by between 12.4% and 15.5%.

The Center for Outcome Analysis has measured the outcomes of self-determination pilot projects in several states. The two states for which the best fiscal data were available are discussed briefly below.

Michigan

To date, the best scientific information COA has on cost outcomes is from Michigan.

COA has data from 135 people in Michigan who participated in a self-determination project with before (1997) and after (2000-2001) quality of life data AND individual budget information in 2001. The results of this study show clearly that the concept of self-determination is working in Michigan.

The Michigan study found that costs decreased for the Michigan participants by an average of $4,022, or about 6.7%. It should be noted that some people's cost went up, but the **average** went down. Analysis also revealed that people who started with the highest costs had the largest percentage of decrease in costs through self-determination. In addition, Michigan participants were compared

with a control group on measures of power and the results suggest that having an Individual Budget has an effect on who has power.

California

Over a three year period of observation in California, purchase-of-service costs increased for the self-determination participants, but they increased less than for the comparison group of non-participants. Thus our evidence strongly suggests that the cost-neutrality part of the theory is thus far true in California. The evidence further supports the inference that self-determination has been fiscally conservative, holding back cost increases that might otherwise have occurred.

The table below shows the combined expenditures for California's three self-determination pilot sites as compared to the expenditures of the Comparison Group. This graph reveals that the costs for non-participants were rising as fast or faster than the costs for the participants.

	Start	End	Change
Self-Determination Participants	$976	$1,581	62%
Comparison Group	$632	$1,378	118%

Remarkably, the pattern of change over time appears to have favored the participants insofar as fiscal conservatism is concerned. The participants at the three pilots averaged an increase of about 60%, while the non-participants in the Comparison Group showed an increase twice as large, or about 120% up from where they started.

Although the research design was not perfect, conclusions did emerge from this analysis. It is possible that the Comparison Group members were not typical of the larger population of people who are not involved in self-determination. (We did test for demographic differences and found few.) There could be other reasons why the Comparison Group costs increased so sharply.

Nonetheless, these data lead rather inescapably to the inference that self-determination as it has evolved in California has not only been cost neutral, it has been fiscally conservative. The increases in costs that might have been expected in the absence of self-determination were slowed, perhaps even cut in half, by the

creation of explicit individual budgets and the careful transfer of power to people with disabilities and their allies.

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

However, a very large source of assistance for California's developmental services system is Federal funding via the Medicaid Waiver. For the self-determination experiments, the Federal Waiver program was consciously ignored. This was done in the belief that Waiver requirements and restrictions might have artificially limited flexibility by "disallowing" creative uses of public dollars. We found that, in fact, the self-determination participants sharply reduced their Waiver participation over the three years of the pilot projects. This situation must change if self-determination is to continue and expand. Self-determination has been applied in Waiver environments in many other states, and it can surely be done in California. Since the Federal government will pay for more than 50% of California's approved community support costs, it should be obvious that no program that exists outside the Waiver can long survive. Self-determination must be made "Waiver friendly."

Results 4: Stories of Self-Determination Participants

The following five stories are from Year 2 of the qualitative research effort sponsored by RWJF. These were our final visits with these participants.

Following those are six stories from our 3 year project in California. These were written by a professional journalist to capture the human side of self-determination.

David
Maryland

David is one of the people who have been a part of the self-determination initiative in Maryland from the first year of the project. His mother, Nancy R., learned about the initiative when it began, and immediately began talking with people about whether David would qualify; she felt that self-determination could help Dave to have the life he wanted.

After visiting with Dave last year, this researcher came to the conclusion that he is "…an extremely self determined person". However, according to those closest to Dave, he had not always been that way. Audra, his first Maryland Service Coordinator under self-determination (and currently a friend and neighbor), said that Dave had learned to say, "Everything is fine," even when he did not have what he wanted in his life. After lots of encouragement, he began to say what he really wanted. And, once he started, he didn't stop. He was very clear and very articulate.

Dave, Audra (his then Service Coordinator), Nancy (his mother) and Karen (his realtor) worked together to realize his dream of home ownership. After much planning, they overcame some daunting challenges to pull the pieces together. The result was that David bought a mobile home in a lovely, residential neighborhood, where he now lives. Dave also got a job working with a second shift work crew (after making it clear that did not want to work at a 9-5 job, and preferred evenings), and he has continued to enjoy the job and work with the crew for the last two years.

Last year, Scott, a housemate from the Maryland Waiting List, moved into David's trailer with him to help cover costs. It took over a year for Dave and Scott to get used to living together. Scott had always lived at home before, and David was used to being on his own. David tended to be the one in control. At one point, Dave discovered that Scott could read things to him, and this turned out to be good for both of them. Scott began reading to David, and they became involved in some giveaway programs that had been advertised through the mail. It was "…a bonding experience for them," after which Scott began to have a more equal role in the household.

A second issue that emerged in David's life when Scott moved into the mobile home was a systems question. How would Dave and Scott's supports work with two people living in the home? Would this become more like a group home and less like a real home?

There were some early indications that Dave's ability to make his own decisions, with the support of his team, might be challenged by the new arrangement. For example, it was decided at the agency level that it would be most practical for Dave and Scott to share support staff. The question then became how this could be done without taking away from the individualized support that each of the men should be getting.

In a December 1999 interview, Nancy informed the researcher that everything eventually worked out fine after an initial period in which everyone needed to figure out how best to support both Dave and Scott individually. Nancy also explained that she was beginning a search to locate people to serve David. The people would be hired by herself and David, since individualized budgeting allows one to hire a variety of people. They could be selected from among family, friends, and personal contacts, and might then simply need some subsequent training. The agency would not object to Nancy's search, since it would be saved the work of locating people to serve David, and it could continue be the Employer of Record. Nancy felt that this plan might work well to ensure that David and Scott would each continue to get separate, and good, support services.

During the last interview, Nancy explained that people in Maryland are beginning to raise a wider issue vis-à-vis finding and keeping good support staff (which, at the end of 1999, was still somewhat of a challenge both for the agency and for David). She noted that, "…the issue of salaries is the big push for this year. People in institutions still make a lot more."

Indeed, the state of Maryland is only one of many locations in which people are currently raising the pay issue. It is being widely discussed as one of the points that should be addressed with regard to finding and keeping good staff for people in the community. The person-centered planning that usually accompanies self-determination funding allows each person the freedom to fashion a better life, with him/herself at the center of his/her supports. Meanwhile, the self-determination initiative, on the whole, saves money that can be funneled back into supports, whether for the individual or for the whole group of people funded through self-determination. The question might be posed whether some of this money could be used to pay support staff at a better rate, so that people could hire and keep staff that are skilled and committed enough to navigate the more muddied waters that accompany the new self-determination based system. (As noted by Jackie, the mother of the other Maryland individual case study respondent, a self-determination-based system is, by nature, not as pat as a more traditional one, in which certain fixed and easy to understand rules apply. Rather, such a system must have the flexibility to change with regard to each individual, and to each situation that that individual may encounter. This may necessitate hiring a

different type of staff.) In the long run, money would still be saved, since keeping good staff longer would avoid the expense of replacing them at regular intervals.

In conclusion, after being part of the self-determination initiative in Maryland for the last two years, David continues to flourish. In the last months of the study, it will be interesting to see how hiring his own staff from outside the agency works for Dave, should this occur. It will also be informative to follow the more general discussion that is taking place in the state at this time with regard to staff salaries.

JOSHUA
Maryland

Joshua G., who is 18, lives in a home that he owns with his housemate, Joseph. Josh is a student at his local High School. Like David, he was one of the early people to become involved in the Maryland self-determination initiative. Josh's house initially belonged to his parents, who decided to modify it and sell it to Josh as the central piece in his plan for supports. Josh's parents worked with a provider and Maryland Service Coordination to develop the plan for supports and put it into action.

According to Josh's mother, Jackie, since Josh's life changed through the self-determination initiative, he has been happy for the first time in many years. Last year, this researcher noted that Josh's family has been central to his success. In addition to helping design Josh's supports, Jackie continues to be central to the process in her role as his Case Manager. She hires and manages his staff, and oversees the running of his home. She also is active in negotiating with his school vis-à-vis his program there.

In a discussion between Jackie and the researcher in December 1999, Jackie mentioned several issues that have emerged for Josh during the second year of his participation in the Robert Wood Johnson self-determination project, and discussed how they were dealt with:

1) As noted, Josh started out in self-determination with his parents working in conjunction with a provider to run his program. The provider became the Employer of Record, while Jackie, as his Case Manager, did a lot of the work of actually running the supports. By the end of 1999, Jackie and her husband were beginning to explore the possibility of setting up a "Micro Board". If this plan came to fruition, they would become the licensed provider, and would also include Joseph in their new providership. Josh's parents developed this idea in response to experiences that they had with the current provider that Jackie framed as, "the old world crashing into the new." The provider had been running supports for some years, and was sometimes having a hard time understanding that some of the things they had been doing were no longer necessary. For example, Josh and Joseph were being funded through two different types of programs. Josh's program was considered "Community Supports", or a CSLA (i.e. an unlicensed program). Meanwhile, Joseph's was considered "Residential" programming, for which more stringent requirements regarding structure and paperwork needed to be maintained. Rather than attempting to convert Joseph to "CSLA" funding, they were attempting to convert Josh to "Residential" funding. This course would put more stringent requirements into place for Josh's program, rather than easing up the

paperwork burden for Joseph's. Jackie felt that it would be more beneficial to both Josh and Joseph if Joseph's program could be converted to "CSLA" funding, so that the house could maintain the flexibility that is necessary for self-determination. After disagreeing initially, the provider eventually agreed.

Jackie cited as a second example of "the old world crashing into the new" an occasion when the Employer of Record gave the staff a three-page "Y2K Compliance Sheet" that they were required to follow in preparation for New Year's Day, 2000. It had a list of items that needed to be purchased that included flashlights, a battery-powered radio, a Coleman lantern, extra blankets, sleeping bags, and a seven days' supply of food per person. Jackie felt that it would be quite sufficient, and less institutional, if the staff simply made whatever preparations they were making in their OWN homes. The provider's response to Y2K pointed out to Jackie, once more, their old ways of looking at things. For many years, providers have always thought in terms of systems rather than in terms of individual people. After doing things in a certain way over a long period of time, it is difficult for even the best-intentioned people to change overnight. With a Micro Board, Jackie and her husband could make a fresh beginning, which might be a lot easier than taking the existing system apart and trying to rework it, piece by piece.

2) Jackie noted that self-determination allows for greater flexibility in what staff can do than was true in the old system; there are no hard and fast rules. And, since everyone is exploring new territory together, support people must be hired and trained who are able to understand and handle a greater amount of responsibility. She stressed that most of the staff that she and Josh have hired have done an excellent job. However, there was one case in which a support person took advantage of the flexibility. After trying to work things through, Jackie eventually had to fire the person. At this point, an aunt of one of the employees stepped forward and asked whether she could have the job, since she already knew Josh and was a part of his life. Jackie and her husband have "asked the staff to bring the best of themselves" to work, which may include bringing their children to work, involving Josh with their own families, etc. Jackie likes Josh's supports to be somewhat like a family. She stresses, "It's about getting a home for Josh, not just a program." Thus, due to the fact that supports were run in this unusual way, someone was waiting in the wings when staff turnover occurred.

3) With regard to school and to Josh's working future, Jackie says that the High School has made good progress during the year that he has been there. After some initial prompting, they began to understand that Josh would have a real job when he left school. For example, since Josh has an interest in collecting tickets, they are now supporting him by asking that, as kids file into the classroom, they each give Josh a ticket. While Josh is still in school, his parents have been

exploring his options for the future. One option is the idea of forming a business cooperative. Josh's parents envision investing in a movie theater- there is an empty one near Josh's house- and using it as an "empowerment zone". There could be plays as well as movies; self-advocates could come there for conferences, and so on. Josh could be the ticket-taker at the theater.

In conclusion, the leadership provided by Josh's family is one of the major factors contributing to his continuing success under self-determination. Jackie and her husband are informed, highly involved, and creative, and are ready to deal with each challenge as it arises, whether its source is the old system or simply day-to-day life. Josh is an excellent example of how well self-determination can work for a person whose family wants to take on the responsibility of participating actively in running his or her supports. While there have always been families like Josh's, who are ready and willing to structure and maintain good supports for the person whom they know and love, such families have often been denied the power and resources they need in order to do this work. For Josh's family and for some others like it, the self-determination initiative has provided the opportunity that they have long sought.

SHEA
HAWAII

Shea is a 19-year-old young man who is described by his mother as a very social and loving child who enjoys swimming and being included in things even if he doesn't always directly participate. For many years, getting to know Shea was challenging. He had numerous seizures that resulted in taking heavy medication. According to his mother Honey, "we don't know who he is or what he likes!" In the winter of 1999 Shea had been seizure free for six months. His mother believes that this came about as result of a special diet that Shea was on over the past few years as well as a decrease in his medications. These two events, according to Honey made her see that, "Shea is beginning to enjoy his surrounding and the people around him."

Honey is a strong advocate for her son, and in many ways had thought creatively about how best to provide support for Shea before becoming involved in self-determination. In the fall of 1998, as part of the self-determination initiative, Honey began to work with Easter Seals, the designated Managed Support Organization (MSO) in the State of Hawaii. Honey worked out a budget with their representative that offered more freedom to, as she said, "act as the employer in acquiring the services that Shea needs. I have freedom to embrace it now ...not to be secretive, I don't have to pretend that I don't know!"

Through the self-determination initiative Honey has been able to raise the salary she pays her support people and has hired two people with whom both she and Shea feel comfortable. Because she was able to raise salaries, she felt that the people hired were more committed not only to Shea, but to the family. Using her budget, she has been able to increase what she pays her staff as she is eliminating some of the cost she had with having to hire nurses. She believes that if the people she hires feel valued and connected to her family they may stay with them longer, thus avoiding the constant turnover they have experienced. Honey has always believed in the need for Shea's support staff to understand him and connect with her family. She feels this is especially true now as they move toward more community involvement, "he needs a network, a circle of people." As Shea has begun to be more involved with people and with his surroundings as well as to identify more clearly his likes and dislikes, Honey sees great potential to develop relationships and connections, especially if they are allotted the flexibility that comes with self-determination.

Since the summer of 1999, the focus of the family has been on other things. Honey was able to fulfill a dream when she bought some land and moved her family from the western side of the Big Island of Hawaii, to the eastern side. The

land is in a very rural area and at last contact they had no phone available. Before the move Honey talked about the difficulties of again putting a new support system in place. In preparing for the move, Honey located a new service provider who had little knowledge of, or involvement in, self-determination. There were no families on this side of the Island involved in self-determination. Honey took it upon herself to seek out an agency that she felt would support what was best for Shea. She found an agency that she felt was very open to the needs she described. In addition to the move, and the need to create a new support system, a major concern that Honey had was the uncertainty as to whether the self-determination efforts would continue in Hawaii. The uncertainty and confusion regarding the project was, according to Honey, a major obstacle. This was the overriding issue that arose in last years' report.

CHARLIE
HAWAII

At age 43, Charlie is beginning to feel comfortable in his home, in his surroundings and in his life. Charlie lives in his own home built for him by his parents, Curtis and Thelma. He currently shares his home with Mike who also provides support for Charlie. The two have become good friends. Charlie lived a good portion of his life on the mainland in a variety of states and agencies. His parents brought him back to Hawaii after they returned to retire. His mother was born on the Big Island, as was Charlie. Charlie has a brother and a sister.

Charlie has an extensive vocabulary when he chooses to use it. For many years, much of his communication had been through his behavior, but he is beginning to socialize and talk more in his home when Mike has friends over. Visiting Charlie during the summer of 1999, both at his day program and in his home it was clear that he was happier than he had been the previous year. He was eager to engage and sat in the living room with Mike and me during our whole conversation. This was an apparent change from my previous visits. Mike explained how Charlie especially loves it when Mike's friends come over. "They," he explains "have also become Charlie's friends."

Through the RWJ initiative Curt and Thelma were able to get support to create an arrangement for Charlie that provides him with a one-on-one caregiver as specified in his Essential Lifestyle Plan. It was determined that Charlie needed 24-hour care and Curt and Thelma are able to maintain and subsidize this level of support in his own home.

It wasn't, however, until the end of December 1998 that the family knew for sure that Charlie would get the necessary funds to continue the needed support. Because of the uncertainty of the status of self-determination in Hawaii, the family was prompted to try and become providers. This would allow them to continue to provide the support Charlie needed without having to start with another provider after Easter Seals lost it's contract as the Managed Service Organization (MSO). At the time of our last contact they were waiting for a final word from the Department of Health as to the status of their request.

Charlie continues to spend his days at a day program operated by a local provider agency. For now Charlie enthusiastically awaits the bus and appears very much at home doing some job tasks and some academics. While other alternatives may be pursued in the future, his family respects the change process and level of comfort Charlie is continuing to experience and they are following Charlie's lead as it relates to changes in his life.

With these individualized supports in place, and a decrease in medication (Charlie has been on psychotropic drugs for a long time and has been weaned off for the past several years,) everyone has seen positive changes in Charlie. He now sits with people and carries on a conversation and even engages people in public when out in a restaurant. These changes have brought stability to Charlie's life, something that has not been in place for quite some time. With this stability, he and his support circle are able to pursue things that they feel will add to the quality of his life, like making friends and becoming involved in things he enjoys such as basketball and swimming. His father smiles and says, "What I'm anxious to think about and try to plan for is how do we take advantage now of these new social behaviors and help him feel better about himself as a person? To get him into something more meaningful?" As Mike sees it, "Charlie is growing, let's allow him to grow as a human being." Curtis enthusiastically followed with, "It's been so good (self-determination), I'm optimistic, and it can't fail!"

While the changes in Charlie's life are positive and were supported through the self-determination initiative, the major and most imminent concern of the family continues to be the uncertainty of whether the project will continue in Hawaii. The issues of trust and recognition of the cultural needs of individuals remain critical in this state. While change has been very slow and skepticism remains high, those who have been involved in the self-determination project remain interested in its continuation.

Sheryl
Minnesota

Sheryl is a tall thin woman of 37 years who shares a small rambling home with one roommate. She immediately draws you into her home with a smile, an extension of her hand and a hug. It is clear that she is happy about having visitors. Her use of some sign language, manual and verbal gestures, and a few spoken words, draws you into the beginning of a relationship with Sheryl.

Her house is staffed 24 hours (no live-in staff) and is owned by a local agency that provides residential supports to people with disabilities. Sheryl receives one-to-one support at home. Her current living situation is the result of her desire to live in a smaller home after spending a good portion of her life in Intermediate Care Facilities (ICF). Her request to live in such a place was heard and followed up on by her guardian of seven years, Glen.

The story goes back a little. When Sheryl was three years old her parents decided that they could no longer care for her and have had little involvement in her adult life. In 1989 Sheryl met her guardian who was working in her residential program. A year later he began working for the agency that provided Sheryl support for employment. Glenn supported Sheryl in a one-to-one situation for two years while she worked at Pizza Hut and at a pet store. It was during this time that a strong relationship began between the two. As Glen describes, "she's got a great personality, I think that what endeared me (to her) was I worked with her for two years, one-to-one then I got a new job. She always has adjustment problems with new people and this (the new person) one didn't work out so the social worker decided to move her (Sheryl) to a behavioral day program. It's around that time I started thinking, this isn't right, so I sought guardianship."

In 1990 during a personal futures planning meeting, as Glen recalls, Sheryl said she wanted to live in her own house. In early 1997, after pursuing a waiver for a number of years, Sheryl received one and was able to move to her current house. In mid-1997 Glen heard of Robert Wood Johnson (RWJ) funding and immediately made an inquiry about it for Sheryl. In many ways, her participation is due to timing. Things were in place at the time the funding became available. Sheryl had a waiver and was currently moving into a supported living situation (SLS).

The first year was difficult for Sheryl. There were numerous transitions and staff turnover, which caused her a lot of stress. The two things that have been most stable is her ability to remain in the same house, and her relationship with Glen. Sheryl's day program has changed too. Last year she attended a program specifically for individuals designated as having challenging behaviors. Since that

time, and through a great deal of effort on Glen's part, Sheryl is being supported through a different agency where she has a person who works with her one-to-one. They sometimes spend part of the day at her house and other parts at a workshop setting. The idea is to get her in more steady supported employment. This remains a constant challenge for Glen who believes that the efforts being made to find Sheryl more meaningful work is limited. Though the man who provides her one-to-one support is open, Glen has not had time to orient him to the possibilities that might be available to Sheryl.

A major issue that has arisen as Glen tries to think creatively has been obstacles to enacting new ideas. For example, his current pursuit of new employment for Sheryl has been very frustrating. While he has obtained figures from several different agencies to provide one-to-one support in a work setting, the figures vary greatly and his main concern is that much of the cost includes unnecessary services. Glen provides some insight: " I think that providers are very stuck in their ways, this is the way we do business and who are you to come in here and tell me how to do my job?" This has continued to be an issue for Glen this past year. At one point he felt as though the residential provider was not providing the contracted services and he withheld payment. His argument was that if he bought something and it didn't work right he would not have to pay. This caused problems between Glen and the agency and also between him and the County.

Individuals often use more common sense ways to deal with consumer related issues and when given their own budgets, they try to use the money in the most economical way possible. In this case Glen was applying ways of doing business that are more "natural" to him as they relate to transactions in his own life. While both sides (Glen and the County) recognized the complexities of not paying the provider, both had different ways of dealing with the issues. One based on an individualized perspective and the other a systems perspective. Using tactics that might be common sense from a consumer perspective often meet with barriers when they come up against an entrenched service system.

Another issue that has remained strong for Glen and Sheryl this year relates to the security built into the existing service system. Glen seems to be moving more toward hiring folks outside of larger service providers. This is a significant change from a year ago. Because of his frustration with the services Sheryl receives, he is moving more toward doing his own hiring, though he remains reluctant to do so.

Self-determination has brought about interesting and complex questions both for individuals, families and service providers. Each new idea raises critical issues that challenge existing services and families. As families and people with disabilities get clearer and stronger with what they want, new challenges emerge and layer upon layer of the system must be re-evaluated. It is clear that as one

hurdle is overcome another emerges. Self-determination is not an end product but an emerging process.

The following six stories were written by a professional journalist, hired by COA in California for the purpose of completing the qualitative aspect of our research.

Wang Chen:
Unveiling Creativity

Wang Chen, an adult with severe disabilities, was born on February 26, 1970 and moved to the United States from the island of Taiwan in 1983 with his parents and younger sister. For this article, I interviewed Mrs. Chen, who speaks Cantonese, a dialect of Chinese. In retrospect, I understand there were likely many barriers to obtaining the information I was looking for, including my use of American slang, our different cultures, and how we each interpret life as it goes on around us. It was a wonderful experience, and an important reminder that California's developmental services system has a big responsibility in serving many people whose diversities are as much a part of their lives as their disabilities.

Wang's story, as told through his mother, illustrates how self-determination can integrate different cultures with an outcome that is respectful of individuals and their families. According to the Regional Center, Wang's supports were provided without exceeding the expense of traditional service delivery. What follows are Mrs. Chen's words through an interpreter.

Q What is Wang's disability?

A He cannot talk, and he cannot see anything. He can only see the light. Only a little bit of color.

Q What happened and when?

A In 1987, when he was in Texas. In the nighttime he was driving to a classmate's house to do homework. Someone hit him. Because of this accident he became a blind person and cannot talk. There was bleeding of a nerve in the brain. The doctor refused to do surgery. He said it could not help. I do not know why. Because my English is no good. I don't understand him.

Q How does Wang communicate?

A He uses Morse code.

Q Did you teach him Morse code?

A Yes.

Q How did you know Morse code?

A Because I am a Christian, so one day I prayed and a spirit talked to me and I learned there was such a thing I could teach him.

Q So, Wang can tell you what he wants?

A Right now we are using the computer. We put the Morse code in the computer and the computer tells me what he is saying.

Q Is he able to communicate different choices?

A He knows Mandarin, Cantonese and English.

Q **Did you teach him?**
A He learned English before the car accident.
Q **When did you move to California?**
A In March of 1988.
Q **How did you find out about the Regional Center?**
A My friend from church.
Q **Was the Regional Center helpful?**
A Yes, a lot.
Q **Tell me about Wang's day program.**
A Before self-determination, we had services but could not get speech therapy. But now he can get speech therapy because we can control the budget from self-determination.
Q. **I understand Wang has a personal aide that brings him into the community instead of a traditional day program. What do they do?**
A Wang uses a wheelchair. The aids loosen up the joints around the fingers, they feed him; they also help change his clothes when they get wet. Regarding transportation, they will make phone calls.
Q **Where do they go?**
A We have two places. {Name of Service Agency} Art Center, where he is learning to draw, and enjoys it very much.
Q **The other place?**
A Go to a movement center to train muscles and body movement, like physical therapy. If he goes swimming, the personal aide will accompany him. He doesn't swim, but exercises in the pool.
Q **Is it a public pool?**
A YMCA. There are other people there swimming. So the one who aids him will explain to the other people in the pool. Introducing them to him.
Q **I heard Wang won a contest for his painting?**
A Yes. Actually I go with him because I am helping him see around. I consider myself his eyes and I understand what he needs and I need to hold his hand. So I tell him whether it is the left or the right and then he chooses the color by himself. Then he tells me how to mix the color and then he determines by himself what he wants to draw. So actually in between we use the Morse code to communicate. The others that accompany him don't know how to interpret the Morse code.
Q **Does Wang have friends?**
A Yes. Lots of friends. From the church, from daycare, the nurses, the neighbors and also friends of his sister. And, also people from Hong Kong, Seattle and San Francisco.
Q **How does he have friends from so far away?**

A Because after they heard about our story they were so impressed they noticed he worked so hard they just wanted to write him.

Q How did they hear about him?

A Because I made testimony in the church. So we went to many churches to make testimony.

Q What was in your testimony?

A Testified to the work done by God. That we have received a lot of strength given by God and we never felt lonely and he always has hope.

Q. Has self-determination been helpful?

A Very helpful.

Q Would you ever want to go back to how it was before?

A I would like to maintain in the self-determination program.

Q Is Wang happy?

A He is very happy. Now he can choose the service he wants so I can have more free time of my own.

Q What are your hopes for Wang in the future?

A I hope he can manage to take care of himself.

Q That he can live independently?

A Right now I'm just hoping.

Q Do you think self-determination will help Wang live in his own home?

A Yes, I think so. Yes.

Q Do you think Wang has the same dream for himself?

A Yes.

Q Does he talk to you about wanting to live on his own?

A Yes.

Q Is life good?

A Very hard, very difficult. Very tired, but we have hope.

According to Wang's Regional Center service coordinator, the traditional day program limited Wang's personal growth and development. Under self-determination his individualized program has created a big change in his creativity. "We had a meeting last week and he brought to the meeting a painting he made. He won a contest for the painting, and told me he plans on becoming an artist and show his art in a gallery."

Eddie:
A Life Profoundly Changed

Eddie was diagnosed with severe mental retardation at the age of three – a little more than eighteen years ago. For most of the years to follow, Eddie got on a bus every morning at 6:15 and spent over 2-1/2 hours going to and from school. During the day he sat in a classroom located at the back of the campus where he did nothing for most of five hours. Eddie was given few opportunities to socialize with other children, and was made to eat lunch alone.

Eddie lost his motivation to learn, was lonely without any friends, wasn't known by his community, and there were no opportunities on the horizon to fill these voids in his life.

Over the years, once a pleasant and well-behaved child, Eddie transformed into an angry, self-abusive teenager. In response, the school isolated him further, identifying him as a disruption. Never did a teacher or an administrator think how Eddie might be really feeling as a fellow human being, nor was the intent behind the promise of the Individuals with Disabilities Education Act ever fulfilled.

Eddie's mother Edna was weary from fighting the school district over the years. She felt defeated. "They never really cared." Edna and Eddie's father Al pulled their son out of high school. "We made up our minds. We were just going to care for Eddie ourselves."

As for the Regional Center, there was little that could be offered to support Eddie and his family - the location of his home was too rural and remote and services were few and far between.

Even the Lanterman Act, the California law that promises Eddie the supports and services that will enable him to lead a more independent and productive life in the community, was an empty promise for this family. They were ready to give up on the idea of getting help from public sources. According to Eddie's parents, "The very systems designed to educate and support Eddie in his life, cast him aside and said there was nothing that could be done."

Two years ago, at the height of their despair, they received a phone call from the Regional Center. On the other end was a worker with news that Eddie had been selected to participate in the self-determination pilot project.

"Somehow, she actually talked me into it," said Edna.

Over the following three months, a budget was established by looking at what traditional services might be for Eddie as an adult – a day program, behavioral supports, daily living skills training, diaper service, speech and language therapy, and transportation. This same level of resources was made

available to purchase precisely the supports that would make life better for Eddie and his family.

Under self-determination the family now had the control never afforded them in all these years. They were finally empowered to help Eddie create a new life and design the programs he needed to help him learn, as they knew he could.

Today, Eddie is an integral member of his community. His individualized day program includes Pat, who has experience in teaching life skills to people with the most profound disabilities.

Pat comes to his home several times a week to help Eddie learn. After a few games of basketball or a little music on the stereo, the two go hiking at the beach, swimming at the local pool with the aquatic therapist, join the drum circle to play music, and visit the youth center where Eddie has developed the friendships he has been missing for so long.

According to Edna, "We run into some of his friends around town. He has become a part of his own community. I have lived here for 30 years, but people didn't know my son. Now they do."

Pat seizes every teaching moment even when sitting in the coffee shop. He might point out to Eddie that others are whispering, and not speaking loudly, and ask him to observe common courtesies others demonstrate to one another. Eddie's behavior has improved significantly. He's learning how to use the toilet for the first time, and his attention span has increased from 15 seconds to 20 minutes at a time.

The speech therapist discovered that Eddie knows colors, the names of shapes like "triangle" and "boat."

"I didn't know," said Edna.

For the first time, Eddie moves his head to respond "yes" or "no." He is starting to formulate sounds with his lips, uses the computer, and puts puzzles together.

Not everything is perfect, and there are disagreements with the Regional Center at times over use of the money in Eddie's budget. But they work together now, toward what Eddie specifically needs. The family now has hope that Eddie's life will never be underestimated in worth and ability again.

"It's made all of our lives better."

The life Eddie now deservedly enjoys, is not because of more money, the school system, or even the developmental services system – it's because a family now has the power and authority to build a future for their son as a contributing, included and accepted community member.

The Inclusion of Sarah and Susan

More than sixteen years ago, twins were born to a Thai family. Four months premature, both babies had enormous health issues and their disabilities would be life-long. Susan was blind from the oxygen she was given to save her life. Sarah almost died when her lungs collapsed.

Sarah and Susan's parents were both born and raised in Bangkok, Thailand where the culture includes the belief system that a child born with a disability committed a terrible sin in a previous life and the child is kept hidden at home.

The twins' birth seriously challenged their parents' heritage, culture, and values. With prayer, self-reflection, and time, the family believes they glimpsed the purpose of their daughters' lives. They saw their family's opportunity to challenge the prejudices inherent in society by making their daughters visible, and not hidden.

Unfortunately, Sarah and Susan's experience with public education has been difficult. They found the school unwilling to support their inclusion in the regular classroom because "they were too mentally retarded." Other children on campus, driven by ignorance, mocked the twins because they were different.

When Sarah and Susan were ten years old the family became aware of Regional Center services. Their mother recalls feeling like, "We had everything in the world," when the Regional Center agreed to pay for services. However, the after-school daycare had no expertise in supporting the twins' needs and provided no solution. When mainstream summer camps rejected them, a camp for kids with disabilities was the only choice.

The family had little control over the outcome of their daughters' lives. They felt that Sarah and Susan were at the mercy of programs that did not fit them, and the personalities in a system that did not want to include them.

At a time when the family was most frustrated, they were invited to participate in California's self-determination pilot project. With the proper planning, together with the family's vision, the twins now have opportunities that would not have otherwise been available. Barriers to inclusion at school still exist, but their lives outside of public education have improved dramatically.

Although it was hard at first to find the right ways to use public funds, many useful discussions ultimately clarified the family's goals. Consequently, the Regional Center service coordinator has been able to support the family in thinking creatively as they developed individualized programs of inclusion for Sarah and Susan.

The family has hired a personal assistant to accompany Susan in the community to support her participation in activities with peers, help her to improve

articulation of the English language, and facilitate her increased knowledge of American culture.

For Sarah, the family has hired a tutor who helps her with her homework. Her mother indicates, "Our English is not very good, and we aren't able to help Sarah that much."

Self-determination has allowed adaptive swimming lessons for the twins, and singing lessons intended to train their voices, teach them posture, and give them self-esteem.

"Susan sings in the Thai language and I don't understand the words. But she carries you into the spirit of the music," according to Iris, the family service coordinator.

Prior to self-determination, policy restrictions would have prevented the Regional Center from considering or funding these non-traditional services.

As the family sees it, the results of self-determination for the twins are included lives, significantly improved self-images, and a confidence in their singing talents that has widely impacted a community.

The two girls made their first public appearance at a homeless shelter as 400 people were lined up waiting for food. They sang *Amazing Grace*, and *God Bless America*. When they were done, men, women, and children shouted out their joy, calling the twins "angels," and declaring them "gifts from God."

Sarah and Susan's popularity grew, the media were alerted, and the two of them became known throughout their community. They sang for the poor, the sad, and the sick wherever they could be found. They sang everywhere, except within the Thai community.

The tragedy of September 11th left no one untouched by feelings of loss, fear and devastation. It came as a surprise when Sarah and Susan were invited to sing at the Thai Temple – the first time people with disabilities were welcomed. The two girls sang *America the Beautiful*. That day, members of the Temple donated more than $4,000 to the families in New York who lost loved-ones.

The flexibility of self-determination has lifted many barriers for Sarah and Susan in becoming accepted members of their community. However, despite laws in the Individuals with Disabilities Education Act, the school still denies services, and in complete disregard of the family values, the twins are still segregated. The attitude of the school has forced the family to spend funds in the self-determination budget to hire a personal advocate to work with the school to implement the girls' educational plan.

Sarah and Susan's continued exclusion at school hurts them deeply. They want to move somewhere different, where no one knows them and they can start over.

"There has been a lot of whispering going on in corners. It has been difficult for the family," according to service coordinator Iris.

"My girls are also learning how to forgive," said their mother.

Jose And His Family Unit

Jose was born in Mexico ten years ago. When he was one day old, his little body became wracked with seizures for reasons unknown at the time. The doctor prescribed Phenobarbital and unexpectedly Jose fell into a coma, not waking up for seventeen days.

As the days passed one by one, his mother Linda "almost went crazy" with worry. When he finally awoke, the "doctors took liquid from his spine, and did an ultrasound on his head," and neither test revealed the problem. Linda was handed her baby and told he was fine, although she sensed something was terribly wrong.

Jose was 10 months old and growing up normally – his speech was developing and he was starting to say "mom." He sat up independently in the bathtub, ate solid foods, was bearing weight and would soon be walking. Without warning, the seizures returned at a rate of 20 times per day. Every seizure left Jose crouching in a fetal position, his eyes barely open, his head limp, and his body hard.

Initially, doctors had no answers. "Jose stopped doing things normal children did," recalls Linda. He was no longer speaking or even trying, was unable to sit independently, bear weight, or eat solid food.

"I felt terrible. Everyone in the house was suffering." Soon Linda found herself caring almost exclusively for Jose and neglecting the emotional needs of her two older children. Jose's older sister, who was ten at the time, became seriously depressed and attempted suicide. Linda learned from talking to others that it is not uncommon for siblings of brothers or sisters with disabilities to feel forgotten and cast aside. Parents become overwhelmed when there is little or no support, and a sense of "family" can be easily lost.

When Jose was seven years old, his family moved to the United States. Linda doesn't speak much about her reasons for leaving Mexico. However, according to Paul, the family's Regional Center service coordinator, "In Mexico services for kids are limited. It isn't very much."

When they arrived in the United States, the family was undocumented, spoke only Spanish, and on their own in an unfamiliar country. However, it didn't take long for Linda to connect Jose and their family to the Regional Center. Soon expenses for diapers and a summer camp were covered. However, Linda would not use respite services. "I could get respite before, but I never used it because they sent the worker." Jose does not easily become accustomed to strangers.

It wasn't long after Jose was accepted as a Regional Center client that the family was notified of being randomly selected to participate in the self-determination pilot project, which was three years ago.

As I interviewed Linda through an interpreter, I got the feeling she is an uncomplicated person with good basic values and an appreciation of the family unit. I can honestly say, there isn't anything so profound about the family experiences in self-determination that point to dramatic change in their lives like many of the other families I interviewed. I looked very hard, and at first was disappointed.

However, after a closer examination of Linda's words and my interviews with the service coordinators at the Regional Center, I realized the family doesn't require much to feel supported.

The control Linda has over the use of the funds in the self-determination budget allows her to pay a family member Jose is familiar with to provide one hour of respite each day so she can attend school. Funds are also used to pay for the co-payment to the neurologist, Jose's seizure medication, and most recently a behavior specialist - Jose has become aggressive and self-abusive in recent months as a result of changes in his medication. Self-determination paid for a lawyer and fees to the Immigration and Naturalization Service so the family could apply for permanent residence.

"Before the Regional Center would just give us our services – we made no decisions about them. Now we've worked and learned to be responsible to manage our budget. For example, I wanted to get really good diapers for Jose, so our Regional Center coordinator helped me find the company."

Although Linda considers self-determination a lot of responsibility, she still prefers it to the old way.

"This is better."

Tony:
"You Don't Get Lost In The System This Way"

Anthony "Tony" has a terminal illness. He turned twenty-five years old on February 12, 2002, and has lived more than two decades longer than doctors or statistics gave him. Tony's family attributes the unexpected years of life to "the Lord and lots of love."

Tony was diagnosed with Krabbe disease when he was six, a rare, degenerative, enzyme disorder of the central nervous system. The symptoms are seizures, difficulty in feeding, paralysis, deafness, blindness, and an eventual loss of mental and motor function. Typically children do not survive beyond two years of age.

Tony breathes through a tracheotomy tube in his neck, receives his food through a j-tube placed in his small intestine, wears a permanent catheter, and uses a wheelchair. His spine has been fused to keep his trunk upright, and he lost his voice at the age of five when his larynx was removed.

Despite Tony's personal care needs, he has always been an important member of the family unit. Placing him in a group home, or institution has never been a consideration for his family.

Unfortunately, until two years ago, the only in-home support Tony and his family were authorized to receive by the Regional Center was twelve hours of respite services per month.

During most of Tony's life his aging parents and older brothers have cared for him. Seldom did the family take advantage of the respite support. The workers received a low rate of pay that the family compared to wages at a fast food restaurant. The family felt that there was no one qualified to care for Tony's complex needs and afford him the respect and dignity he deserves as a human being and an adult.

On December 28, 1998, Tony's mom Ellen had a cardiac arrest. Her heart stopped for eight minutes. She was brought back to life, but remained in a coma for four days.

During that time, nothing changed at home in the way of support. Tony and his father Ted were on their own as Ellen lay in the hospital bed not expected to live.

Four months later the family received word from the Regional Center that Tony was randomly selected to participate in the self-determination pilot project. They had just about given up on the regional center, despite the long-term support that Tony needed.

After an assessment was made to determine what traditional services would be appropriate, Tony and his parents identified goals through the person-centered planning process. "We just want a normal life."

Tony has now acquired his first communication device and for the first time in twenty years can express his needs in a way others can understand. There would be no more fights with the insurance company. A week after getting the device, he transformed into a jokester – often waiting for his parents to leave the room and then announcing, "I need." When they return he grins from ear to ear. Tony has control and power for the first time. He has waited so long.

Monday through Friday a van picks Tony up in front of his home and brings him to a day program conveniently located five blocks away. Tony likes the structure of the program, the opportunity to be around people and hearing what they have to say, and the outings in the community with his new friends. Ted said, "I don't like the program, but Tony loves to go, and that's important."

Tony and his new physical therapist share a mutual respect. Therapy is personal and Tony does not like being intimately touched and manipulated when a good relationship is absent. Prior to self-determination, there was no choice in therapists – it was a "take who you get, like it or not," situation.

Several months ago, the family found someone to provide in-home support the whole family appreciates. Self-determination allows them to pay her enough, to give Tony time away from his parents and Ted and Ellen the freedom to actually think about taking a weekend off together. "It's been a long time."

Tony now has a lift for the family van and he can easily be transferred on and off which is crucial to his self-respect. It was an embarrassment for Tony as his parents struggled to get him in and out of the van. According to Ellen, "Even when we were younger, it wasn't the easiest thing in the world to push Tony in his wheelchair up and down that aluminum ramp."

Under self-determination, Tony's new service coordinator is helping his family feel empowered and in control of their lives. "I don't have to sit inside of a box. I'm not looking at Tony and his family to see what policies they fit into. I can listen to their needs and don't have to tell them their options are limited."

The family feels very strongly about the improvements. "Let there be no doubt Tony's life has improved dramatically, giving him more freedom and participation in the every day life most of us know and take for granted." He is not isolated at home or in an institution but wakes up to the beauty of each new day he is given. As his ability to communicate on his new device grows, all the thoughts he's had over the years, and all the hopes and dreams he's been unable to express will come pouring out.

"Things are so much better now."

Julio
Living Life With Dignity And Respect

Julio is 24 years old and was born with cerebral palsy. His physical disabilities are severe, and his speech is difficult to understand. However, he has a mind of his own, and a clear view of what he wants his life to include - the dignity of choice and the respect he deserves as a fellow human being.

I interviewed Julio over the telephone using an operator from the California Speech Relay Service - a skilled interpreter of Julio's speech. At times, it would take up to five minutes to interpret a word he was communicating, but he persevered without giving way to impatience and frustration. Unfortunately, he said, he has not always been afforded the same consideration. "Because of the way I look, people think I don't know anything."

Three years ago Julio made a decision to live on his own because he felt it was time - the same decision made by most young adults of the same age. He moved from his mother's house and into a duplex. The Regional Center identified a supported living agency to supply the necessary twenty-four hour support staff to care for his personal hygiene, transfer him in and out of his wheelchair, and help him keep his house clean. "I would surely stand up and do it myself if I were able."

However, he says that it wasn't uncommon for staff members to lounge around his apartment, eating, watching television, and then put him to bed early when he wasn't tired. The dust, dishes, and laundry would pile up. There were days when Julio was left without a single clean garment to wear. Julio's only recourse was in the use of his voice, but he felt that no one listened. When he called the supported living agency to complain he was met with, "Sorry, we can't help you. We are shorthanded." This went on for more than a year, leaving Julio's quality of life out of his control.

Two years ago, Julio was informed he was selected to participate in the self-determination pilot project. After the initial planning process, his budget was established based on the expense of traditional delivery of support services. Suddenly, he says, he was no longer at the mercy of an agency unwilling or unable to hear his concerns. "They didn't care."

Today, Julio's voice is heard loud and clear. He interviews, hires and fires support staff. He invites people to be a part of his life, and expects them to value his contributions to society, respect his personal choices, and not judge his humanness because of his physical needs. If a staff member can't live up to the basic considerations Julio desires, he dismisses them from his employment and hires someone who can.

"He is extremely happy, and has good people supporting him," according to Julio's Regional Center service coordinator.

However, Julio does have concerns about the future. "I am worried that I might need some things and I can't take money from my budget because if I do it won't last for my staff, like equipment for my wheelchair in case my Medi-Cal won't pay."

He also worries that self-determination will not be in his future because someone will "mess it up for the rest of us by asking to buy swimming pools and trips." Julio is a responsible adult. He pays his bills, goes to the grocery store and buys his own food, answers his own phone, makes doctor appointments, and takes seriously his responsibility in maintaining the integrity of self-determination. "I think that before anyone goes into self-determination they should know that it's a lot of responsibility."

Not long ago, Julio had a little money left in his budget, and he bought a computer. Since he loves to talk with people, and his speech is hard to understand, he expects the computer will open up a whole new world of communication for him. Julio's physical disabilities prevent him from using a conventional keyboard, so I asked what adaptive equipment he used and he said, "That is my secret."

I left my conversation with Julio knowing he was a man in control of his own life.

Elizabeth And Her Family:
Life Is Good Once Again.

It was only six years ago that Elizabeth, born in July of 1981 with cerebral palsy, had only one option for living outside of her family home because of her fragile medical condition – a state-run institution where her spirit would die. This reality forced Liz's Regional Center case management team to develop a vision and think outside the confines of standard service delivery for people with developmental disabilities. As a result, an idea and a process slowly developed to create opportunities that would give Liz needed support in the community she knows, and allow her the freedom to live in a home of her own without feeling the fear of being cut off from the mainstream.

One of four children, Liz has always been an integral member of her family - her brothers and sister a huge part of her life. There were no family vacations or celebrations without Liz.

From the time Liz entered public education and through the 7th grade, she was mostly included in the regular classroom of her neighborhood school. She seldom saw the inside of a special education classroom – special education services supported her and her teacher. Liz was well known by her peers and her participation valued by hundreds of students on the school campus.

When she turned 13 her body started to betray her and her inclusion program at school wasn't working anymore, causing her to be isolated from friends and peers. The medical procedures were numerous, the convalescent periods long, and Liz never did regain the health she once had. In little more than a year, Liz lost her ability to swallow, and a g-tube was connected to her stomach so she could take in nutrition; her dislocated hips required surgery and confinement in a body cast for weeks; and, it took sixteen-hours to surgically place a rod in her back to straighten her spine.

Every operation begat more complications and Liz was now considered "medically fragile," requiring 24-hour care. Complex medical equipment and a hospital bed took over the teenager's room. Night after night, her parents Bruce and Louise took turns staying by Liz's bedside, ready to suction the fluid from her lungs that would easily take her life.

By this time the maximum allowable coverage under the family insurance had been reached for Liz, and although Medi-Cal agreed she was entitled to almost seven hours of nursing care per day, it was Liz's parents who were made responsible for finding the nurses to fill those hours. But there is a nursing shortage, and when nurses could be found they were unwilling to work at the Medi-Cal rates.

During their search for in-home nursing care, Liz's parents were finding Certified Nursing Assistants capable of caring for Liz's needs; however because of the severity of Liz's condition, Medi-Cal would not fund CNAs – a Catch-22 and the last straw that was about to cause the collapse of an entire family.

The burden of caring for Liz and her complex medical needs fell solely on her parents. As Louise reflects back on Christmas Day several years ago, she remembers recognizing for the first time exactly how much the overwhelming responsibility had taken a toll on their lives. "I looked up at Bruce, saw his face, and knew then he was about ready to snap."

Around the same time, self-determination was a new concept taking shape in a grassroots movement across the nation that allows people to maintain their rights as citizens and human beings in order to receive the services they need to live in their own home. Current policies, funding mechanisms and attitudes, tend to push people toward group homes, nursing homes, and institutions, and this was an unacceptable option for this family.

The Regional Center case management team started to look at what made sense to Liz and her family, developed a budget based on her medical needs, and placed the money in the hands of Liz's parents and said, "You control the money, you hire the people to support Liz, you pay the taxes, worker's compensation and insurance."

"At the time, we did not recognize this idea as cutting edge, we were just trying to find something that would work and we accidentally fell into self-determination," according to Bruce.

What took shape over the next two years developed slowly and, at times, capable nursing assistants were difficult to find. But by word of mouth Liz's parents developed a stable group of people that are loyal and love Liz. Bruce says it took a while, but at last "we got traction." If a shift problem occurs, the staff works it out amongst themselves.

More than a year ago a social worker came to Liz's family home for an interview in preparation for her move into supported living.

Bruce said, "We took the social worker into Liz's room. We told Liz this was the person helping us to get her a home of her own. The reaction on Liz's part was stunning. She understood the concept of a home of her own. She smiled more than I've ever seen her smile at a stranger. In spite of her lack of consistent communication skills, she has told us her feelings about it. We are doing the right thing."

Life is good once again.

Appendix A: Original Demonstration Outcomes

The Final Evaluation Report of the Original Self-Determination Demonstration at Monadnock Developmental Services in Keene, New Hampshire

Appendix B: PowerPoint Summary

of the Evaluation of the Original Self-Determination Demonstration at Monadnock Developmental Services in Keene, New Hampshire

Appendix C: The Personal Life Quality Protocol:

The Package of Validated Instruments from Which States Could Choose the Scales they Believed Most Important

Appendix D: The National Self-Determination Family Survey Form

Appendix E: Pre-Post Data Analyses for Each State